TOWARD TRANSPLANT EQUITY IN NEW YORK STATE

THEY CAN DONATE, BUT THEY CAN’T RECEIVE

NYLP I
JUSTICE THROUGH COMMUNITY POWER

NYIC
35 YEARS OF BUILDING IMMIGRANT POWER
ABOUT NYLPI

For more than 45 years, New York Lawyers for the Public Interest has combined the power of law, organizing, and the private bar to fight for civil rights and make lasting change where it’s needed most. Our Health Justice program brings a racial equity and immigrant justice focus to health care advocacy in New York City and State. Our Undocucare program provide holistic wrap-around services, comprehensive immigration and health screenings, legal representation, and organ transplant advocacy to connect seriously ill immigrant New Yorkers to comprehensive healthcare that meets their needs.

For more information, please visit us at nylpi.org and on twitter @nylpi.

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EXECUTIVE SUMMARY

End-Stage Renal Disease (ESRD) is a potentially deadly diagnosis given to patients whose kidneys can no longer filter toxins from their blood.

The only permanent treatment for ESRD is kidney transplantation. But for approximately 245,000 low-income undocumented and underinsured immigrants, including members and clients of Make the Road NY, the New York Immigration Coalition, and New York Lawyers for the Public Interest, this cure is virtually inaccessible.

Currently, undocumented immigrants are barred from federal health programs including Medicare, Children’s Health Insurance Program, the Affordable Care Act, and most Medicaid programs. Although undocumented and uninsured immigrants can and often do donate kidneys and other organs both as living and deceased donors, New York State prevents its Emergency Medicaid program from reimbursing hospitals for lifesaving kidney transplants. This means that many immigrant New Yorkers with serious kidney disease must rely solely on far more costly and debilitating long-term dialysis treatments.

While federal health programs exclude immigrants who are not citizens or lawful permanent residents, New York State provides some, but not all, with comprehensive health coverage through state-funded
Medicaid, Child Health Plus and Essential Plan programs. But even for those eligible for comprehensive health coverage, immigrant New Yorkers often face additional barriers to receiving an organ transplant or even a preliminary evaluation to be placed on the waiting list. Health providers at transplant centers often lack accurate information and cultural competency when working with these patients; may dissuade immigrants from seeking transplant care by asking for unnecessary information like Social Security numbers; and may make incorrect assumptions about the likelihood that these patients will lose insurance coverage or lack family and social support.

Legislators in New York State and City government and decision makers in health care systems can work in concert to save lives and save money by taking immediate, concrete steps to improve access to transplant evaluations, operations, and post-transplant medical care. To accomplish this goal, they should:

- Expand access to comprehensive health insurance for all low-income New Yorkers regardless of immigration status through the state’s Essential Plan or Medicaid programs.
- Expand the state’s Emergency Medicaid program to explicitly cover transplant surgeries and related care.
- Hire specially trained transplant coordinators and advocates to help immigrant and Medicaid patients with referrals to transplant centers, accessibility needs, and follow up for evaluations and care.
- Create and disseminate accurate and up-to-date educational materials for medical providers and patients on obtaining health insurance and transplants and overcoming biases within the healthcare system.
- Collect and publish data on the number of patients referred to New York transplant centers, the number on transplant waiting lists, and the number successfully transplanted, broken down by citizenship and insurance status.
END STAGE RENAL DISEASE: A DEADLY DISEASE THAT IS BEST TREATED THROUGH ORGAN TRANSPLANTATION

End stage renal disease (ESRD) is a condition in which one's kidneys can no longer function on their own. Patients with ESRD must receive dialysis treatment or a kidney transplant to survive. Nearly 786,000 people in the United States are living with ESRD. Seventy-one percent are on dialysis, and each year, the number of people waiting for a kidney transplant far exceeds the number of available organs. Of the approximately 8,569 people waiting for a transplant in New York, 84 percent need a kidney.
DIALYSIS IS NOT ENOUGH

Dialysis treatment uses a machine that acts as an “artificial kidney” to filter a patient’s blood, which keeps them alive while they wait for a healthy kidney to become available for transplantation. Patients typically visit an outpatient dialysis center approximately three times per week, where they undergo three to five hours of treatment per session. This treatment can impose serious, cascading costs on patients and their families. Common medical complications include changes in blood pressure, muscle cramps, itching, heart disease (the leading cause of death for people on dialysis), sleep problems, anemia, bone disease, fluid accumulation in the lungs, heart inflammation, high potassium levels, various infections, joint pain and stiffness, nerve damage, and related mental health issues like depression or anxiety. Once a patient is stabilized on dialysis treatment, the best practice is to try to find a transplant as soon as possible. Dialysis is ineffective as a long-term solution, with an approximately 40 percent survival rate five years after treatment begins.

NYLPI has represented numerous clients whose ability to work, spend time with loved ones, and engage meaningfully in their communities is severely limited by long-term dialysis treatment. For example, a client with diabetes was no longer able to work because of her dialysis schedule. Because she was unable to work, she could not afford to pay for blood glucose test strips. To access one form of care, she gave up the ability to support herself or pay for other healthcare and necessities. Another client waited nine years to be placed on a kidney transplant waiting list. During that time, he continued lengthy dialysis treatments and forwent economic opportunities, including the ability to attend accounting school, a necessity for his professional growth.
ESRD PATIENTS NEED KIDNEY TRANSPLANTS

Medical literature has established that kidney transplants improve the length and quality of life of ESRD patients. A kidney from a living donor functions for an average of 12 to 20 years, and a kidney from a deceased donor functions for an average of eight to 12 years. Studies also show major improvements in measures of health and quality of life after a successful transplant, including increased energy, a more varied diet, and fewer health complications, with sharp increases in physical and emotional health, and the ability to return to work.
IMMIGRATION STATUS AND INSURANCE ELIGIBILITY IN NEW YORK STATE

While non-citizen immigrants can be organ donors — one of the most altruistic human acts — they face potentially lethal barriers to receiving transplanted organs. New York’s large and diverse immigrant communities make invaluable contributions to our state’s economy and civic life.\(^\text{17}\) Despite paying billions of dollars in taxes, serving disproportionately as essential workers,\(^\text{18}\) and making up nearly a quarter of the labor force in our state,\(^\text{19}\) many non-citizens cannot receive comprehensive healthcare simply because of their immigration status.\(^\text{20}\)

In New York, residents who meet financial eligibility requirements may access comprehensive health benefits through the state’s Medicaid or Essential Plan health insurance programs. But many undocumented immigrants do not qualify and as a result must rely solely on Emergency Medicaid, a limited stopgap program that only covers care considered
necessary for a medical emergency.\textsuperscript{21} This leaves many non-citizen immigrants without the ability to see a primary care doctor or to treat chronic illnesses.\textsuperscript{22} Because of the severity of ESRD, New York rightly recognizes regularly scheduled dialysis as emergency care and allows otherwise uninsured immigrants to access this treatment,\textsuperscript{23} but the state’s care for most immigrants without legal immigration status stops there.

\textbf{Even though transplants are the only effective long-term treatment for ESRD, New York explicitly prohibits Emergency Medicaid from covering kidney transplants.}\textsuperscript{24} These exclusions are inconsistent with both state and federal governments’ emphasis that ESRD is a severe public health issue and runs counter to the prioritization of health coverage for ESRD via a special Medicare program (from which undocumented immigrants are also excluded).\textsuperscript{25} New York can become a national public health leader by allowing all immigrants to access comprehensive health coverage through the state-funded Essential Plan program, and by authorizing the Emergency Medicaid program to cover transplants as an immediate, interim step.
EVEN IF ELIGIBLE FOR HEALTH INSURANCE, IMMIGRANT NEW YORKERS FACE BARRIERS TO TRANSPLANT CARE

In New York, some non-citizen immigrants are eligible for public insurance via Medicaid or the Essential Plan. They must meet income requirements, live in New York State, and reside in the United States as a “qualified” or “lawfully present” non-citizen or be “permanently residing under the color of law (PRUCOL).” However, patients covered by Medicaid are much less likely to receive kidney transplants in the state’s transplant centers than those with private insurance or Medicare.
In 2019, only 13 percent of the 1,664 kidney transplants performed in New York State hospitals were for Medicaid patients, even though those patients on average made up 26 percent of the total patient discharges at those same hospitals.27

The experiences of our members and clients illustrate the barriers to receiving transplants that many fully insured non-citizen immigrant patients face:

1. **Medical staff at transplant centers often lack a nuanced understanding of how non-citizens can obtain health insurance, which creates significant practical barriers to accessing organ transplants.** Staff, including financial coordinators, social workers, nurses, and doctors, often do not know that patients or potential candidates might be eligible for comprehensive health insurance under the PRUCOL public benefits category. For example, while a Social Security number is not required to enroll in Medicaid or the Essential Plan,28 many transplant centers improperly ask for patients’ Social Security numbers and immigration status during transplant evaluations or initial telephone intakes. Some go as far as requiring a Social Security number on file before the initial transplant evaluation — a major barrier to care given that only U.S. citizens, permanent residents, and eligible non-immigrant workers can apply for a Social Security Number.29 Lastly, some providers will erroneously require a “PRUCOL letter” from an immigration practitioner as proof of insurance eligibility, even after such eligibility has been established by the appropriate public benefits administration. Not all practitioners have knowledge of PRUCOL and a large majority of undocumented people do not have access to practitioners who could write such letters. Denying a patient a consultation and transplant on any of these grounds may constitute unlawful discrimination based on national origin.30 Thus, there is an immediate need for clear and consistent education on the PRUCOL eligibility category for all hospital staff and administrators involved in transplant referral and evaluation processes.
2. **Hospital systems receive lower reimbursements for transplant procedures from insurance programs covering non-citizen immigrant New Yorkers.** Insurers’ reimbursement rates from hospitals for transplant-related care, including surgery, pre-operative care, and post-operative care, vary widely in the United States. In 2020, hospitals caring for Medicaid patients were reimbursed on average only 88 cents for every dollar spent on their treatment. As a result of underpayment, hospitals must make difficult choices about what services to provide — an especially critical issue at safety-net hospitals where close to half of patients are Medicaid enrollees or are uninsured. When insurance does not adequately pay for transplant care or related medications, some patients are forced to pay out-of-pocket for transplant procedures, or to apply for hospital “charity care” funds to cover an operation. With high poverty rates among immigrants in New York, extremely few can afford to pay out-of-pocket for a transplant.

3. **Racial and ethnic bias, whether explicit or implicit, may influence decisions to reject immigrant and low-income New Yorkers as transplant candidates.** Striking racial disparities persist in rates of transplantation. White and Asian patients undergoing dialysis are much more likely to receive transplants than Black, Hispanic, or Native American patients, and while Black patients are four times more likely than white patients to develop kidney disease, they are half as likely to receive a kidney transplant. Likewise, Latinx and Indigenous people are 1.3 and 3.5 times more likely to suffer from kidney failure, respectively, than white people. In addition to systemic disparities in access to insurance and health care, bias and misunderstanding are significant contributors to poor health outcomes for people of color.

Biases at various stages of the transplant referral and intake process also create barriers to transplant care for immigrant patients:
a. Transplant providers often consider whether a patient has ample social support to aid in their recovery when determining eligibility for a transplant. Providers often assume that non-citizen patients lack social support, which will lead to poor outcomes and possible organ rejection. However, medical evidence does not support this view: in one study that analyzed a cohort of over 10,000 patients with Medicaid who received a kidney transplant between 1990 and 2011, the small number (346) of nonresident non-citizen transplant recipients who received transplants (presumed to be undocumented) had similar outcomes to U.S. citizens, even though the former group had been on dialysis longer. Similarly, another study showed that the very small number of undocumented patients who receive liver transplants have comparable three-year survival rates to U.S. citizens, even though there is a misperception that immigrants that are “undocumented” face higher risks of transplant failure. When transplants do fail in immigrants, the more likely reason is because they cannot afford immunosuppressant medications without Medicaid or another source of funding.

b. Providers may incorrectly assume that most non-citizen immigrant patients are at imminent risk of deportation and therefore not likely to remain in New York long enough to receive necessary care. Another common manifestation of racial/ethnic bias includes questions about the immigration status of potential caregivers, with the suggestion being that they too could be at imminent risk of removal.

c. Questioning the validity or stability of a non-citizen’s insurance coverage unnecessarily duplicates and undermines the rigorous means-testing and enrollment processes already in place for Medicaid and Essential Plan programs and may further discourage immigrant patients from seeking transplants.
Other barriers to successful transplantation for immigrant patients include inadequate interpretation services, unavailability of patient education materials in patients’ preferred languages, and a general fear of interactions with the medical establishment and public services because of rising anti-immigrant sentiment and policies in the United States.

Finally, many immigrant and low-income patients who receive care at public and safety-net community hospital systems and private dialysis clinics must be referred to large private hospital centers for transplant care, as most public safety-net hospitals in New York State do not perform transplant surgeries. Each private transplant center has its own policies and procedures for intake and screening, making the referral process difficult to navigate, especially for individuals who are not U.S. citizens. Additionally, some private transplant centers incorrectly instruct front-line staff to ask patients for Social Security numbers before beginning intake and evaluations.

One client’s story illustrates these barriers.

Ms G. called NYLPI seeking assistance in obtaining health insurance in 2022, and was able to enroll in New York’s Essential Plan after qualifying for the PRUCOL eligibility category.

She called to secure an appointment for a kidney transplant evaluation at a large New York City transplant center. She voluntarily disclosed that she did not have a Social Security number during a follow-up call, and the hospital cancelled her appointment — a devastating blow after months of working to obtain full insurance coverage. Ms. G was only able to obtain an appointment weeks later after a senior NYLPI Advocate intervened on her behalf.

During communications with the hospital about this case, instances of institutionalized bias against non-citizen patients occurred at nearly every administrative level, even though this patient was fully insured.
- While the transplant center allowed Ms. G to schedule her initial appointment and verified her health coverage, the facility sent her a printed form letter stating that her appointment would be cancelled if she did not provide a Social Security number. On Ms. G’s copy, this section was highlighted. The letter also requested proof of immigration status.

- The transplant center’s schedulers incorrectly believed that Social Security numbers were required by law to get onto the transplant waiting list. These staff were unaware that this system provides unique identifiers on demand for transplant candidates.

- The department supervisor expressed disbelief when NYLPI’s advocate told them that providing a transplant to a person without a Social Security number is lawful.

- An administrator confirmed that the transplant center conducts secondary insurance eligibility checks outside of the customary insurance benefits verification. The administrator stated the department only conducted these checks for non-citizen immigrants enrolled in state Medicaid or Essential Plans. In addition to conducting these checks, the department requires some patients to procure “PRUCOL letters” from an immigration practitioner to get care.

- Hospital staff claimed these requirements were necessary to ensure that patients have “stable” insurance coverage. This is rationalized by a belief that non-citizen immigrants are likely to lose coverage at any moment and that they are likely to not recertify their insurance eligibility as a result of lack of their immigration status.

- A hospital staffer stated that patients with private, employment-based health insurance would be given several assistance options if they change insurance plans or lose coverage. These options did not appear to be extended to Medicaid or Essential Plan patients.

While Ms. G ultimately continued her care at this facility, she tearfully expressed that the incident felt humiliating and dehumanizing.
INVESTMENT IN AN EQUITABLE TRANSPLANT SYSTEM IS COST EFFICIENT

Because requiring patients with ESRD to remain on long-term dialysis is expensive, New York could save millions of dollars by improving transplant access.\(^47\) The average cost of a kidney transplant in the United States is $442,500, including organ procurement, surgery, hospitalization, and post-operative medications,\(^48\) while the total cost of dialysis per patient per year has been estimated at about $121,000.\(^49\) While kidney transplants have a higher up-front cost, numerous studies find that transplants are a more cost-effective in the long-term than ongoing dialysis.\(^50\) Patients are more likely to be able to return to work, participate more fully in the economy, and pay taxes after a successful transplant.\(^51\) For many patients, this also means financially supporting U.S. citizen and documented family members in mixed-status households.\(^52\)

Finally, expanded insurance coverage for transplantation can increase the supply of available kidneys, as many uninsured ESRD patients have family members willing to donate a kidney, but lack financial resources or insurance to pay for surgery and postoperative care.\(^53\)
DENIAL OF TRANSPLANT CARE IS UNJUST, INEQUITABLE, AND UNETHICAL

The inaccessibility of organ transplants for non-citizen immigrant patients is a troubling moral problem. The National Organ Transplant Act of 1984 clearly requires that only medical criteria be used in organ allocation decisions; under the law, citizenship status does not preclude eligibility for a transplant.54 Similarly, the American Transplant Foundation states that “Severity of illness, time spent waiting, blood type, and match potential are the factors that determine [a patient’s] place on the waiting list. A patient’s income, race, or social status are never considered in the allocation process.”55
Even while facing barriers to transplant services, immigrants can and often do become living and deceased organ donors. In some areas of the country, undocumented people donate up to ten percent of available organs, even though they receive less than one percent of them. Bioethicists Aaron Wightman and Douglas Diekema have concluded, “Any system that uses the organs of individuals who would themselves not be considered eligible for a transplant because of inability to pay is clearly unjust.”

In New York City, the number of immigrant donors may be even larger following the widespread implementation of the IDNYC program, which allows all New York City residents to obtain a free municipal identification card and register as organ donors, regardless of immigration status. Although the precise number of residents that are considered undocumented is unknown, many foreign-born residents applied for an ID card within the program’s first year, and many IDNYC cardholders indicated a willingness to contribute to the donor pool. At the state level, the 2019 Driver’s License Access and Privacy Act (The Green Light Law) allows New Yorkers aged 16 and older to apply for a standard, non-commercial driver’s license or learner’s permit regardless of their citizenship or immigration status. Similarly, California’s Transplant and Donor Network reported a thirty percent increase in the number of new organ donors after the state made driver’s licenses available to all. Illinois also permits this and in 2014, approximately 45 percent of immigrants who received driver’s licenses registered as organ donors.
RECOMMENDATIONS TO IMPROVE ACCESS TO TRANSPLANTS FOR IMMIGRANT NEW YORKERS

New York’s legislators, regulators, and health care systems can and should take immediate steps to advance equity in transplant care. Below are our recommendations, each of which can be implemented in the short and medium term.

STATE POLICY RECOMMENDATIONS:

New York State can make lifesaving care at its 13 transplant centers accessible to the approximately 4.4 million immigrants who live in the state.⁶⁴
- **Pass legislation ensuring access to comprehensive health insurance for low-income New Yorkers regardless of immigration status.** This can be achieved by expanding eligibility for the state’s Essential Plan or Medicaid programs to every New Yorker earning up to 250% of the Federal Poverty Level.

- As an interim step, the Legislature and Governor should **authorize New York’s Emergency Medicaid program to reimburse hospitals for kidney transplant surgery and postoperative care.** Along with Coverage For All, this measure would immediately save and improve lives and would complement the state’s Living Donor Support Act, which aims to increase the number of living kidney donors and available organs and reduce costs of long-term dialysis.  

- **Establish a dedicated transplant fund** to cover costs associated with organ transplantation for recipients enrolled in Medicaid and Essential Plans and those who remain uninsured. This could include travel expenses, lodging, meals, or other accommodations and fees in connection with organ transplant surgery.

- **Provide funding** to help hospitals hire specially trained transplant care coordinators to help immigrant and Medicaid patients receive access to organ transplants.

To reduce the impacts of bias and misinformation, the New York State Department of Health (DOH) should:

- **Create and disseminate educational modules for healthcare providers on PRUCOL-based public insurance eligibility for immigrant non-citizens and on how to end racial/ethnic bias in medical care.** These materials should be targeted to doctors, medical students, nurses, case managers, financial service coordinators, and social workers at transplant centers and referring medical offices and clinics. These materials must include clear guidance prohibiting hospitals and health centers from conducting secondary insurance eligibility checks for patients who are enrolled in Medicaid and Essential Plans.
- Distribute “know your rights” information materials both physically and online translated into multiple languages for non-citizen patients on pathways to obtaining insurance and transplant center access.

To provide transparency and track progress, New York State should:

- Update hospital reporting and data collection systems (including SPARCS and Institutional Cost Reports) so that policymakers and the public can better track disparities across our healthcare system. For example, the state should publish regular summaries of each hospital’s “payor mix” for each health service and specialty area. This should include the number of patients insured by Medicaid, Essential Plans, and other insurers and the number of uninsured patients.

- Ensure that all Essential Plan and Medicaid insurance contracts and summary plan descriptions clearly affirm that organ transplant care is covered.

CITY POLICY RECOMMENDATIONS:

New York City has a long and commendable history of providing care to all regardless of ability to pay: it operates the largest public hospital system in the nation and has several programs to help New Yorkers to obtain health insurance. To further ensure equal access to transplant care and track progress, the City should:

- Publish data on the number of NYC Health & Hospitals (H&H) Patients, Metro Plus members, and NYC Care members receiving dialysis, transplant referrals, and transplants each year broken down by race, insurance status, citizenship status, and borough.

- Establish a transplant ombudsman office to support low-income New Yorkers in need of organ transplantation. This program should provide accessible information and client-focused case management and advocacy to patients across the City’s safety net healthcare system. Services should include assisting with transplant center referrals and connections, addressing, evaluating
and investigating patient grievances, liaising with city and state regulators, helping H&H track data and making recommendations to relevant agencies and elected officials.

- Expand the benefits offered by the City’s NYC Care program\textsuperscript{57} to include pre-transplant referrals, care coordination, and post-transplant medications and medical care. This funding could cover costs in the event of a gap in coverage for people enrolled in state Medicaid and Essential plans at NYC H&H facilities.

**TRANSPANT CENTER RECOMMENDATIONS:**

Many patients are referred to a private hospital transplant center without sufficient information, support, or follow-up from a trained health advocate. For others, these hospitals may be the first point of contact when attempting to access care. Under federal, state, and city law, nonprofit hospitals must treat patients without respect for real or perceived race, national origin, or immigration status.\textsuperscript{68} To improve equity and fairness for their patients and communities, transplant centers should be required to:

- Employ dedicated Immigrant Health Coordinators and Advocates trained in insurance eligibility categories for non-citizens and cultural competency. This program can provide non-citizen transplant candidates with appropriate guidance; assist patients and providers with referrals to transplant centers; create clear and consistent pathways for referrals and coordination of care between transplant centers, primary care medical homes, and safety-net hospitals; and refer patients in dialysis treatment to legal support to determine eligibility for insurance enrollment. By helping patients obtain insurance enabling hospitals to perform additional reimbursable transplants, health systems can generate revenue to help fund these new positions.
- Remove administrative barriers to the intake process for potential transplant candidates, including questions about Social Security numbers (other than to verify whether a unique identifier will need to be requested from UNOS before listing), immigration status, request of superfluous immigration related documents, “PRUCOL Letters,” secondary insurance eligibility checks (outside of insurance benefits verifications), and pre-authorization processes.

- Implement mandatory and regular provider education on PRUCOL-based public insurance eligibility and other financial assistance options for immigrant non-citizens and on ending racial and ethnic bias in medical decision-making. These modules should be consistent across New York transplant centers and should be targeted to all doctors, medical students, nurses, case managers, financial service coordinators, and social workers involved in transplant care, intake, and referrals.
ACKNOWLEDGMENTS

Thank you to our partners at Community Service Society of New York for their supportive research and review of this report, and to staff at the NYS Department of Health, NYC Health and Hospitals Corporation, and SUNY Downstate Medical Center who have helped to illuminate this topic. Special thanks to Kelly Folkers of NYLPI and the CUNY School of Law for drafting and editing this report. Finally, this report would not be possible without the dedication and expertise of NYLPI’s Health Justice staff, past and present.

ABOUT NYLPI

NYLPI pursues equality and justice for all New Yorkers. Our Health Justice program brings a racial equity and immigrant justice focus to health care advocacy in New York City and State. Our Undocucare program provide holistic wrap-around services, comprehensive immigration and health screenings, legal representation, and organ transplant advocacy to connect seriously ill immigrant New Yorkers to comprehensive healthcare that meets their needs. Please find our resource guide “Health Care is for You” at https://welcometocup.org/assets/images/Healthcare_is_for_you_WEB.pdf or visit https://www.nylpi.org/resource/health-insurance-and-immigration-status-in-new-york/ for information on immigration status and health coverage in New York.

ABOUT MAKE THE ROAD

Make the Road New York (MRNY) builds the power of immigrant and working class communities to achieve dignity and justice through organizing, policy innovation, transformative education, and survival services. MRNY has over 25,000 members and operates five community centers in Brooklyn, Queens, Staten Island, Long Island and Westchester.
ABOUT NEW YORK IMMIGRATION COALITION

The New York Immigration Coalition (NYIC) is an umbrella policy & advocacy organization that represents over 200 immigrant and refugee rights groups throughout New York. The NYIC Health program is dedicated to improving immigrant health by increasing access to health coverage and care and strengthening capacity within immigrant-serving community organizations to help overcome barriers to care.

APPENDICES

A. Health Insurance and Immigration Status Chart for New York State

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<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>Medicaid</td>
<td>Medicaid is funded jointly by the federal and individual state governments and provides health coverage to eligible low-income adults (up to 138 percent of the federal poverty level) between the ages of 18 and 64, children, pregnant women, elderly adults, and people with disabilities. Medicaid coverage includes regular check-ups, doctor and clinic visits, hospital stays, lab tests, and organ transplants. Medicaid recipients do not have a deductible, nor do they pay monthly premiums; for many doctors’ visits, there are no co-pays. Effective in 2023, otherwise eligible individuals over the age of 65 will qualify for state-funded Medicaid. As of September 2022, over 7.6 million New Yorkers receive their health coverage through Medicaid. While federal funds cannot be used to cover undocumented immigrants, New York has opted to cover otherwise eligible immigrants using state funds only.</td>
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<tr>
<td>Essential Plan</td>
<td>Unlike Medicaid, cost sharing varies for Essential Plan recipients depending on their income level.72</td>
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<tr>
<td>Emergency Medicaid</td>
<td>Emergency Medicaid provides for “care and services necessary for the treatment of an emergency medical condition, to certain temporary non-immigrants (e.g., certain foreign students, visitors/tourists) who are otherwise eligible and undocumented non-citizens.” Services meet the definition of “emergency medical condition” if they: 1) place the patient’s health in serious jeopardy; 2) cause serious impairment to bodily function; or 3) cause serious dysfunction to any bodily organ or part. “New York’s policy states that care and services related to an organ transplant procedure are not included in this definition.”73</td>
</tr>
<tr>
<td>PRUCOL (“permanently residing under color of law”)</td>
<td>PRUCOL is a designation used for certain immigrants so that they can receive public benefits.74 It does not describe a person’s immigration status and is not used by any federal immigration authorities.75 In New York, a person can obtain PRUCOL status by demonstrating that the federal government knows about the person’s presence in the United States and is not contemplating their removal.76 Additionally, immigrants who have applied for certain forms of relief (e.g., asylum, cancellation of removal, or temporary protected status, among others) and are awaiting decisions are considered PRUCOL.77</td>
</tr>
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B. The Costs & Impacts of Long-Term Dialysis Treatments

Dialysis, the only alternative to transplants, is ineffective as a long-term solution, with an approximately 40 percent survival rate five years after treatment begins.\textsuperscript{78} The COVID-19 pandemic has only made it more essential for people with ESRD to get prompt care, as chronic kidney disease is a risk factor for more serious illness for those who contract the virus.\textsuperscript{79} Undergoing hours of sometimes painful dialysis treatment can also profoundly disrupt and limit the lives of ESRD patients and their families.\textsuperscript{80} Some experience fear and confusion because of the daunting amount of time, money, and logistical planning dialysis requires, particularly as the treatment limits the ability to see family and friends and live independently.\textsuperscript{81} Though dialysis can mimic some of the kidney’s blood filtering functions, it is not able to produce the hormones and enzymes that a healthy kidney would.\textsuperscript{82} As a result, patients must take many medications, and receive frequent injections and intravenous iron infusions, all of which may have negative side effects.\textsuperscript{83} For the duration of dialysis treatment — often the remainder of a patients’ life — they are instructed to restrict liquid intake to as little as four cups a day and limit sodium, phosphorus, and calcium intake as well.\textsuperscript{84}
ENDNOTES


3 End-Stage Renal Disease (ESRD), JOHNS HOPKINS MEDICINE, available at: https://www.hopkinsmedicine.org/health/conditions-and-diseases/end-stage-renal-failure.

4 Id.


6 Id.


8 See Appendix B for more information on the costs and impacts of long-term dialysis.

9 This type of dialysis is called hemodialysis. A second type of dialysis treatment is called peritoneal dialysis and involves filtering the blood through a catheter at home. See Hemodialysis, NAT’L KIDNEY FOUNDATION, available at: https://www.kidney.org/atoz/content/hemodialysis.

10 Hemodialysis may “acutely induce regional left ventricular (LV) systolic dysfunction, which is associated with increased mortality and progressive heart failure.” See Solmaz Assa, et al., Hemodialysis-Induced Regional Left Ventricular Systolic Dysfunction and Inflammation: A Cross-sectional Study, 64 AM. J. KID. Dis. 265, available at: http://www.ajkd.org/article/S0272-6386(13)01471-6/fulltext.

11 Bone disease is common among dialysis patients and can lead to joint pain, bone pain and fractures. See Renal Osteodystrophy (Bone Disease), THE KIDNEY SCHOOL, available at: http://kidneyschool.org/m16/13/.

12 “2022 Annual Report, Chapter 6: Mortality, Figure 6.7” US Renal Data System. Available at: https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/6-mortality.


16 A study in 1985 found that “79.1 per cent of the transplant recipients were able to function at nearly normal levels, as compared with between 47.5 and 59.1 per cent of patients treated with dialysis (depending on the type). Nearly 75 per cent of the transplant recipients were able to work, as compared with between 24.7 and 59.3 per cent of the patients undergoing dialysis.” Roger W. Evans, Diane L., Manninen, Louis P. Garrison, et al., The Quality of Life of Patients with End-Stage Renal Disease, 312 NEW ENGL. J. OF MED., 553 (1985), available at: http://www.nejm.org/doi/full/10.1056/NEJM198502223125530. Life satisfaction, well-being, and psychological affect were all rated higher for transplant recipients than patients on dialysis. Id. Finally, “the quality of life of transplant recipients compared well with that of the general population” while that of dialysis patients did not. Id. A study demonstrated that “transplantation improved longevity in all groups of recipients, including patients who were 60 to 74 years old at the time of transplantation.” Robert A. Wolfe,


21 In New York, this program only covers treatment in circumstances where, if left untreated, the medical issue would: 1) place the patient’s health in serious jeopardy; 2) lead to serious impairment to bodily function; or 3) lead to serious dysfunction of any bodily organ or part. *Medicaid for the Treatment of an Emergency Medical Condition Fact Sheet*, NEW YORK STATE DEPT. OF HEALTH, available at: https://www.health.ny.gov/health_care/medicaid/emergency_medical_condition_faq.htm. See also Appendix B.


23 In 1972, the federal government passed a law that guaranteed access to renal replacement therapy (RRT) to all patients with ESRD in the United States without mention of citizenship status. However, by 1986, the Consolidated Omnibus Budget Reconciliation Act (COBRA) explicitly prohibited “the use of federal funds to cover undocumented immigrants for non-emergency services such as dialysis or transplants.” In 1996, the Personal Responsibility and Work Opportunity Reconciliation Act re-wrote immigration eligibility for means-tested federal public benefits. States may now choose to use state funds to cover certain excluded populations. New York State has chosen to cover regularly scheduled outpatient dialysis for undocumented immigrants, but not kidney transplants. See also Nina R. O’Connor, et al., *Survival after Dialysis Discontinuation and Hospice Enrollment for ESRD*, 8 CLIN. J. AM. SOC. NEPHROL. 2117 (Dec. 6, 2013), available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3848402/ (“Without dialysis, ESRD patients’ bodies accrue potassium levels high enough to stop their hearts from beating in a median of eight days.”)

24 McKinney’s Social Services Law § 122.


27 ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, Data Reports. We compared UNOS data on kidney transplants by transplant center and primary payer for 2019 with patient discharge data for the same set of hospitals from the most recent available New York State Institutional Cost Reports for the year 2019. UNOS data is available at: https://optn.transplant.hrsa.gov/data/view-data-reports/. NYS Institutional Cost Reports are...

28 “A person residing under PRUCOL status cannot directly apply for U.S. citizenship or sponsor family members to obtain U.S. Citizenship. Though some of these individuals do not have SSNs, if financially eligible, PRUCOL individuals can get Medicaid, Child Health Plus, or Essential Plan in New York State.” See Immigrants: Qualified Aliens/PRUCOL Aliens, New York City, available at: https://www1.nyc.gov/assets/ochia/downloads/pdf/prucol_information.pdf.


33 The New York Safety Net Hospital Coalition, of which NYLPI is a member, is currently advocating for “budget focused on structural reimbursement reform for safety net hospitals serving 45 percent or more Medicaid and uninsured patients. The proposal should be developed in partnership with the Centers for Medicare and Medicaid Services (CMS) and focused on recognizing the role of safety net hospitals as anchor institutions in their communities.” For more information on the New York Safety Net Hospital Coalition, see: https://www.nysafetynets.org/.

34 New York City Health & Hospitals, the city’s public safety net hospital system, has a program called NYC Care (https://www.nycare.nyc), which provides limited medical care for patients that are otherwise unable to enroll in state-funded health insurance. However, that program does not cover all medications needed for post-transplant care. Should more funding be allocated to NYC Care to cover pre- and post-operative care costs for ESRD patients, New York City's private medical centers may have more funding available to cover the cost of kidney transplant procedures, without having to allocate funding for immunosuppressive medications and other ancillary costs.

35 Median annual earnings for undocumented immigrants who live in New York City in 2017 was $25,300, which was significantly lower than median annual earnings for U.S. citizens ($45,500). See also An Economic Profile of Immigrants in New York, 2017, The Mayor's Office for Economic Opportunity, available at: https://www1.nyc.gov/site/opportunity/reports/immigrant-economic-profile.page.

36 US Renal Data System, 2022 Annual Data Report, Chapter 7: Transplantation, p. 31. Available at: https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/7-transplantation


40 Transplant centers often use social support to determine transplant eligibility despite lack of an evidence base and vague regulatory guidance on what “social support” means. A majority of transplant providers surveyed about social support believed that the concept disproportionately impacted patients of low socioeconomic status. See Keren Ladin, Joanna Emerson, Kelsey Berry, et al., Excluding patients from
transplant due to social support: Results from a national survey of transplant providers, 19 AM. J. TRANSPLANT 193 (Jan. 2019).

41 This study reviewed records from 10,495 patients for which Medicaid was the primary payer. 82.4 percent were U.S. citizens, 14.2 percent were legal permanent residents, and 3.3 percent for non-resident, non-citizens presumed to be undocumented. See Jenny I. Shen, Daniel Hercz, Lilly M. Barba, et al., Association of Citizenship Status with Kidney Transplantation in Medicaid Patients, 71 AM. J. KIDNEY DIS. 182 (Feb. 2018).

42 See Brian P. Lee & Norah A. Terrault, Liver Transplantation in Unauthorized Immigrants in the United States, 71 HEPATOLOGY 1802 (Sept. 2019).


44 Kidney transplant candidates who live in ZIP codes with a greater number of non-English speakers are less likely to be placed on the kidney transplant wait list and wait longer for a transplant evaluation, if they receive one at all. See Efrain Talamantes, Keith C. Norris, Carol M. Mangione, et al., Linguistic Isolation and Access to the Active Kidney Transplant Waiting List in the United States, 12 CI. J. AM. SOC. NECR. 383 (Mar. 2017).

45 https://nylpi1-my.sharepoint.com/:w/r/personal/jwood_nylpi_org/_layouts/15/Doc.aspx?source=%7B47599ed6-35eb-4eb3-a8f2-9e7836c591ce%7D&action=edit&wdPid=65fbee1f

46 There are thirteen renal transplant centers in New York state: Albany Medical Center, SUNY Downstate Medical Center, Erie County Medical Center, Montefiore Hospital & Medical Center, Mt. Sinai Medical Center, N.Y. Presbyterian Hospital/Columbia, N.Y. Presbyterian Hospital/Weill Cornell, New York University Langone Health, North Shore University Hospital Manhasset, Strong Memorial Hospital at University of Rochester, SUNY Health Science Center at Syracuse University Hospital, University Hospital Transplant Services, and Westchester Medical Center. See New York State Transplant Referral Guide, available at: https://esrd.ipro.org/wp-content/uploads/2015/02/NW2-Transplant-Guide-English.pdf.


52 See NYC Mayor’s Office of Immigrant Affairs Releases Fourth Annual Report, Empowering Immigrant Communities and Building an Equitable Recovery for All, April 19, 2021, available at: https://www.nyc.gov/site/immigrants/about/press-releases/nyc-moia-releases-fourth-annual-report-2021-04-19.page#:~:text=Nearly%2062%20percent%20of%20New,%20mixed%20status%20families%20(nearly%2062%20percent%20of%20New%20Yorkers%20live%20in%20family%20households%20with%20at%20least%20one%20immigrant%3B%20about%2012%20percent%20of%20New%20Yorkers%20living%20in%20mixed-status%20households%2C%20in%20which%20at%20least%20one%20undocumented%20person%20lives%20with%20other%20persons%20who%20have

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legal status; about 14 percent of all children or 240,000 live in mixed-status families).

53 Ackah et al., supra note 51.

54 42 U.S.C. § 274.


58 About IDNYC, CITY OF NEW YORK, available at: https://www.nyc.gov/site/idnyc/about/about.page. (“Immigration status does not matter.”)

59 “By the end of last year, 732,630 people had applied for the ID, with a high ratio of enrollment coming from immigrant-rich communities across the five boroughs. In Queens, 25,366 identity cards were issued in Corona, another 28,707 in Flushing and 13,654 in Jackson Heights. In Sunset Park, Brooklyn, 22,139 people were issued IDNYC. In Manhattan, 10,142 Chinatown residents and 27,213 people from Washington Heights enrolled in the program. In providing further indication of interest from immigrant New Yorkers, MOIA reported that 52 percent of IDNYC inquiries to the city’s 311 helpline were from non-English speakers. Of these, 88 percent spoke Spanish, 4.6 percent spoke Mandarin, followed in turn by Cantonese, Russian, Korean, and at least nine other languages.” Samar Khurshid, New Data Indicates IDNYC Popularity Among Immigrants, GOTHAM GAZETTE, Jan. 14. 2016, available at: http://www.gothamgazette.com/index.php/government/6085-new-data-indicates-idnyc-popularity-among-immigrants.

60 Only six months after the launch of IDNYC, 50,000 cardholders had agreed to be organ donors. “Six Months After Launch Mayor de Blasio and Speaker Mark-Viverito Announce Over 400,000 New Yorkers Have IDNYC Cards,” NYC.GOV, available at: http://www1.nyc.gov/office-of-the-mayor/news/518-15/six-months-after-launch-mayor-de-blasio-speaker-mark-viverito-over-400-000-new#/0.


64 Supra note 24.

65 Currently, five other states cover kidney transplantation for undocumented patients through Medicaid, Emergency Medicaid, or special transplant funds. See Katherine Rizzolo et al, Access to Kidney Care for Undocumented Immigrants Across the United States. 176 ANNALS OF INTERNAL MEDICINE, April, 2023. Legislation making kidney transplant costs eligible for emergency Medicaid reimbursement has been introducedin the state legislature senate: https://www.nysenate.gov/legislation/bills/2023/S3577.

For more on the New York State Living Donor Support Act see: https://www.nysenate.gov/legislation/bills/2021/s1594.

66 There are few published studies on the impact of trained immigrant health coordinators for ESRD patients moving through referrals and steps toward transplantation; there are some controlled studies of trained peer navigators for ESRD transplant candidates. See Rachel Patzer & Christian Larsen, Patient Navigators in Transplantation - Where Do We Go From Here? 103 TRANSPLANTATION 1076-7 (2019). Studies on navigators and in transplant and dialysis center settings include: Catherine Sullivan, et al., Impact of Navigators on Completion
of Steps in the Kidney Transplant Process: A Randomized, Controlled Trial, 7 CLIN. J. AM. SOC. NEPHROL. 1639 (2012); Mohua Basu et al., Transplant Center Patient Navigator And Access to Transplantation among High-Risk Population: A Randomized, Controlled Trial, 13 CLIN. J. AM. SOC. NEPHROL. 620 (Mar. 2018).

67 NYC Care, NEW YORK CITY HEALTH + HOSPITALS, available at: https://www.nyccare.nyc.


69 The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PWRORA) excludes undocumented immigrants from receiving federal funding for public benefits, including Medicaid and health insurance offered on federal ACA marketplace exchanges. Thus, all health coverage funding for undocumented immigrants must come from individual states. See also August 2022 Medicaid & CHIP Enrollment Data Highlights, CENTERS FOR MEDICAID & MEDICARE SERVICES, available at: https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html.


75 Id.

76 Supra note 32. Examples of types of immigration statuses that confer PRUCOL status in New York are: individuals with a pending or approved I-130 family petition, DACA recipients and applicants, and non-citizens residing in the U.S. with the knowledge and permission or acquiescence of USCIS/ICE.

77 Id.

78 Supra note 12.


81 Id.


They can donate, but they can’t receive