The Personal Stories of Those Affected by Indiana's § 1115 Waiver

By Mara Youdelman

In 2007, Indiana applied for a waiver project to expand health coverage to certain adults who, at the time, were not eligible for coverage under the Medicaid Act. In approving the Healthy Indiana Plan (HIP) project, HHS allowed Indiana to impose limits on coverage for this not-otherwise-eligible group, including charging monthly premiums and terminating coverage for failure to pay, imposing lockout penalties for noncompliance with certain features of the project, and eliminating the retroactive coverage required by the statute. Indiana began implementing the project in 2008.

In 2015, the Secretary authorized Indiana to modify HIP to include populations that were otherwise eligible for the Medicaid program, including parents/caretaker relatives and the entire Medicaid expansion population. The State rebranded the project "HIP 2.0." In 2017, Indiana requested yet another extension of the HIP 2.0 project, this time for three years, despite the fact that the State had been "testing" the key features of the project on low-income individuals for nearly a decade. As part of that request, Indiana also asked to impose a new, unprecedented restriction on coverage – conditioning Medicaid eligibility on compliance with mandatory work and community engagement requirements. On February 1, 2018, CMS approved the HIP 2.0 extension application, allowing Indiana to impose work requirements as a condition of Medicaid eligibility beginning in 2019. The approval also permitted the State to maintain the other existing restrictions on coverage and to add an additional lockout period for failure to complete the eligibility renewal process on time.

Indiana began implementing the work requirements on January 1, 2019. It will begin suspending the coverage of individuals who have not met the work requirements on December 31, 2019. Indiana estimated that once fully implemented, the work requirements would result in roughly 24,000 individuals losing Medicaid coverage each year for failing to comply. Because Healthy Indiana 2.0 violates numerous provisions of federal law and will gravely harm tens of

thousands of Indiana residents, the National Health Law Program (NHeLP) and co-counsel Indiana Legal Services filed a lawsuit challenging the approval on September 20, 2019.[1]

The lawsuit was filed on behalf of four individuals who currently obtain their health care through Medicaid and will suffer serious harms as a result of the HIP 2.0 extension. Below are descriptions of how HIP 2.0 has and will continue to affect the named plaintiffs:

- Monte A. Rose, Jr. is 48 years old and lives alone in Bloomington, Indiana. He completed high school and took some college courses. In the past he has collected scrap metal, worked as a research assistant at Indiana University, and written columns for local newspapers. Mr. Rose is not currently working and does not have any income. He receives a housing subsidy from the Bloomington Housing Authority to pay for his rent. Mr. Rose goes to his local food pantry for food, and he eats organic vegetables that he grows himself. Mr. Rose does not have internet in his home. He goes to the library to access the internet. He does not have a driver's license or a car. To get around he rides his bike, asks for rides, or takes public transportation. He has Meniere's disease, an inner ear condition that periodically causes migraines, dizzy spells, and headaches. He applied for disability in 2007 or 2008, but was denied. Mr. Rose has been enrolled in Medicaid for approximately two years. During that time, he has used his coverage to obtain new glasses. He believes it is important to keep his Medicaid coverage in case his health declines and he needs to see a doctor or he has a medical emergency.

  Under the HIP 2.0 extension, he is required to pay a premium of $1 per month. In the past, he has been able to rely on the kindness of others to pay the premium. He does not know where he will be able to get the money to pay his premiums in the future. Mr. Rose has received a notice indicating that he would be required to participate in Gateway to Work to keep his Medicaid. Mr. Rose has not yet reported any work hours. Given his interest in gardening, Mr. Rose is thinking about a gardening invention. He is not sure if he can count the time he has spent planning inventions or helping his 82-year-old neighbor read his mail and do housecleaning. While he has asked both Indiana and his Medicaid health plan whether or not those activities qualify as work or community engagement activities, he has not gotten an answer. Mr. Rose finds the reporting process confusing. He does not have internet access at home, which will make it more difficult for him to report hours. Mr. Rose is concerned that he will lose his health insurance at the end of the year because he has not met the work requirement.

[1] For more information on the lawsuit, see *Summary of Lawsuit Against HHS Approval of Indiana's "Healthy Indiana 2.0" Waiver,* https://healthlaw.org/resource/summary-of-lawsuit-filed-against-hhs-approval-of-indianas-healthy-indiana-plan-2-0-waiver/.

- Rhonda Cree is 61 years old and lives with her husband in Logansport, Indiana. In the past, Ms. Cree worked in retail management and previously owned a bar and restaurant. Currently she is not able to work outside her home because of significant vision impairment, a complication of diabetes. She is the caregiver for her husband. Her husband receives $1,548 per month in Social Security Disability Income. Their annual income is approximately $18,576, which is roughly 110% of FPL for a family of two ($16,910). After they pay their bills each month, there is only enough money left over for food. Ms. Cree must maintain a strict diet to manage her diabetes. As a result, her grocery bills are high. In addition to diabetes, which has led to vision loss in both eyes, she has high blood pressure and high cholesterol. To treat these conditions, she takes three prescription medications. She also gets monthly injections that keep her eyes strong and prevent hemorrhaging. The longer she goes without these injections, the weaker her eyes become.

  Ms. Cree enrolled in Medicaid in April 2017. Since then, she has had serious problems with the HIP premium requirement. Due to her vision loss, she has trouble reading the premium notices and her husband must read them to her. She is required to pay a monthly premium of $20. She can only pay the premium after her husband receives his disability check. In the past, her premium invoice has come on different days of the month and was due on different days of the month, which made it impossible to plan or set money aside to pay the premium. Sometimes, she paid a few days late. In 2018, Ms. Cree paid what she could afford every month, usually the full $20. In August 2018, the invoice she received indicated that she owed $68.96. In November 2018, she received a bill for $60. She was not able to determine why she owed that much, and she was not able to pay more than her required $20. On December 1, 2018, Indiana terminated her Medicaid coverage for failure to pay the premium. After she lost coverage, she was locked out of Medicaid until May 31, 2019.

  While she was locked out, she was not able to get the injections that keep her eyes strong. She only went to the doctor once, and she had to borrow $100 from friends to pay for that visit. She also had to pay out-of-pocket for her regular prescriptions. Because Indiana eliminated retroactive coverage, any medical bills she incurred during that time would not have been covered. Her health has suffered as a result of this gap in coverage. She experienced a hemorrhage in her right eye, causing significant additional vision loss. She is concerned that her doctor will recommend surgery due to the severity of the vision loss. She has had this surgery before, and it was a serious and frightening procedure. Ms. Cree re-applied for Medicaid coverage in June 2019 when the lockout penalty ended. In July, she received an invoice for $10 from her previous Medicaid

health plan, which she paid. In August, she received another bill asking for $50. She was told this was for her July, August, and September premiums. Fearing that she would lose coverage again, she took money out of her food budget to pay the $50. Despite having paid $60 in premiums, Ms. Cree has yet to receive a notice from Indiana informing her that she is enrolled in Medicaid again. Her health plan did tell her that she could go to the doctor. This is critical, as she needs to resume the eye injections. At this point, she has not had an injection since October 2018. Ms. Cree is worried that the requirements in the HIP 2.0 project, including monthly premiums, will once again make her unable to maintain Medicaid coverage.

- Mary Holbrock is 54 years old and lives in Fort Wayne, Indiana. She has a Ph.D. in Linguistics and taught at the university level until 2010, when she lost her job in the recession. She was not able to find another job in academia. Ms. Holbrock now works part-time grading standardized tests, and her hours fluctuate significantly. Some weeks she works 20 to 30 hours, and some weeks she does not work at all. She has no control over and little advance notice of her schedule. At the beginning of the month, she submits her availability to the testing company, and the company assigns shifts to her. In August 2019, for example, Ms. Holbrock indicated that she could work eight hours per ***day***, and the company assigned her 8 hours for the entire ***month***. In addition, the company can cancel most assigned shifts at any time, even after they have started. On average, Ms. Holbrock earns $400 per month. Her annual income is about $4,800, which is approximately 38% of the FPL for a single person ($12,490). She also receives $180 in SNAP benefits. All of her income goes to covering her basic needs. She has no money left over at the end of the month.

  Ms. Holbrock enrolled in Medicaid in 2011 or 2012 after she lost her job. She has Lyme disease, which has caused a number of health problems, including memory loss, muscular weakness, and chronic pain. Ms. Holbrock also has post-traumatic stress disorder, anxiety, and depression. She uses her Medicaid coverage to get regular treatment for these conditions. Medicaid covers her lab tests, multiple prescription medications, and doctors' visits. Ms. Holbrock is currently classified as medically frail yet her health plan has revoked her medically frail status twice without explanation, even though her health conditions had not improved. Ms. Holbrock frequently receives notices that the health plan is evaluating her status. Yet Ms. Holbrock also received a letter informing her that she is exempt from the HIP work requirements. The letter did not contain an explanation why. She believes this is because she is medically frail. If she loses her exemption, she will ultimately have to work at least 20 hours per week to maintain Medicaid coverage. She is concerned that she will not be able to meet that requirement given her fluctuating work assignments. Because her hours and income

change every month and sometimes without any prior notice, reporting those changes would be difficult. Ms. Holbrock is concerned that she could lose her Medicaid coverage and end up with medical bills that would not be covered due to the elimination of retroactive coverage.

Currently, Ms. Holbrock is required to pay a $5.00 monthly premium. While she has been able to pay that amount, she has had ongoing issues with her managed care plan over the processing of her premiums. Around 2015, she paid too much in premiums and was not reimbursed. On multiple occasions she has received multiple billing statements in the same envelope, with each one showing a different amount owed. Given how confusing the billing process has been, she does not even look at the bills now. Instead, she has her bank mail a check for $5.00 every month. However, several times the bank has mailed a check, and her managed care organization has said that it did not receive it. When the managed care plan makes this kind of mistake, she is required to pay a copay to visit the doctor or fill a prescription. If the plan makes a mistake at a time when she is not considered medically frail, she will also lose coverage for dental, vision, and chiropractic services. Ms. Holbrock has used non-emergency medical transportation (NEMT) to get to medical appointments in the past. If she needs transportation when her medically frail status has been revoked, Medicaid will not cover NEMT.

- Erin Nicole Tomlinson is 25 years old and lives alone in Evansville, Indiana. Ms. Tomlinson studied Media Arts, Animation, and Fashion Design for a year at the Art Institute of Indianapolis. She has worked in retail for most of her adult life. Currently, she works as a cashier, fabric cutter, and stock person at JoAnn Fabrics. As a retail employee, she has no control over her hours, which fluctuate constantly. In a given week, she may work as few as 8 hours or as many as 23. She usually only finds out when she will work about two weeks in advance. Occasionally, her employer will ask an employee to go home early from a shift if business is slow. On average, she works roughly 17 hours per week. Ms. Tomlinson earns approximately $7,956 per year, which is 64% of the federal poverty level for a single person ($12,490). She lives in her grandmother's house and does not pay rent. Still, after she has paid her bills, she has no money left at the end of the month.

  She has been enrolled in Medicaid since 2014 or 2015, when she needed health insurance to pay for an inhaler to treat her asthma. Currently, she uses her Medicaid coverage to pay for two inhalers and a breathing machine. When her asthma is not under control, it can affect her ability to work. Ms. Tomlinson has several other medical conditions, including scoliosis and poor vision. Additionally, Ms. Tomlinson is transgender. She experiences gender dysphoria and depression, and access to gender-

affirming care is keeping her alive. Medicaid coverage has allowed her to receive hormone replacement therapy and will allow her to receive gender-affirming surgeries. These health care services are a matter of life and death for her.

Ms. Tomlinson was not aware of the work requirement until it had already been in effect for some time. She has yet to receive any mail or other communication from the State regarding the work requirement. To the extent that her health plan noted her compliance with the work requirement on her account statement, she was not aware of it. On September 12, 2019, Indiana Legal Services helped her call her health plan to determine whether or not the work requirement applied to her. She learned that her work requirement status is "Reporting Met," meaning that the State knows how many hours she works, and she does not need to report her hours every month. However, given how frequently her work hours fluctuate, she is concerned that if she loses hours, she will need to start reporting her hours to the State. In addition, she is not certain that she would be able to pick up additional hours to meet the work requirement. While she could look for additional work, she is not certain that she would be able to land another retail job depending on the season. Ms. Tomlinson is required to pay a monthly premiums to maintain her coverage. Sometimes she has had to pay her premium bill after its due date in order to pay other pressing bills.

In addition to these individuals, the HIP 2.0 extension will harm tens of thousands of Hoosiers across the state. All of these individuals need primary, preventive and potentially emergency care including check-ups, diabetes treatment, mental health services, blood pressure monitoring and treatment, and vision and dental services.