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Supporting Mothers with Mental Illness: Postpartum Mental Health Service Linkage as a Matter of Public Health and Child Welfare Policy

Jesse Krohn, MSEd, JD
Drexel University

Meredith Matone, DrPH, MHS
Children’s Hospital of Philadelphia

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SUPPORTING MOTHERS WITH MENTAL ILLNESS: POSTPARTUM MENTAL HEALTH SERVICE LINKAGE AS A MATTER OF PUBLIC HEALTH AND CHILD WELFARE POLICY

JESSE KROHN, MSEd, JD, AND MEREDITH MATONE, DrPH, MHS

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About the Article

Through our work in youth advocacy as, respectively, legal and public health professionals, we are all too aware of the high levels of health care fragmentation experienced during pregnancy and postpartum by poor, young mothers of color. Meredith Matone’s research highlights the heightened risk of fragmentation for girls with histories of child welfare involvement. For example, she found that 66.7% of young mothers who had resided in out-of-home placements and who had taken antipsychotic medication prior to becoming pregnant failed to fill prescriptions for antipsychotics in their first postpartum year. Put another way, two-thirds of these vulnerable young mothers—a far higher proportion than young mothers without histories of child welfare involvement—were not getting the treatment that they needed to care for themselves and their children. The very real consequences of this phenomenon can be seen in the experiences of Jesse Krohn’s clients, several of whom have their stories told here.

Treatment discontinuity, particularly during the transition to parenthood, places mothers at risk for poor health outcomes and maladaptive parenting approaches; threatens the health and safety of infants; and triggers child welfare involvement. This article explores the negative consequences and root causes of treatment discontinuity, as well as particularized population vulnerabilities for treatment discontinuity including, as noted, involvement with child welfare. It will also provide public health and child welfare policy solutions for reducing treatment discontinuity and improving mental and physical health outcomes for new mothers and infants.

The population of mothers at highest risk for postpartum treatment gaps is not small: more than 40% of Medicaid-financed births to young women aged 15 to 24 occurred in mothers who had a childhood relationship to the child welfare system. It is unacceptable to be aware of the pervasiveness of this problem, particularly among intersectionally vulnerable women, and not deploy a targeted and evidence-based preventative and remedial response.

About the Authors

Jesse Krohn has a BA from Harvard College and an MSEd and JD from the University of Pennsylvania. She clerked in the District of Maryland and, beginning as
a Skadden Fellow, worked at Philadelphia Legal Assistance, where she served indigent teen parents, most of whom were survivors of sexual, intimate partner, or family violence. She recently came to Drexel University, where she continues her work in the field of sexual and relationship violence.

(215) 571-3839 | jkrohn@drexel.edu | 3141 Chestnut St., 55G, Philadelphia, PA 19104

Meredith Matone is the Deputy Director of PolicyLab at the Children’s Hospital of Philadelphia. Her research interests include child maltreatment prevention and maternal health. Her recent work includes a statewide evaluation of home visitation programs for families of young children and an assessment of the health service needs of adolescent mothers with involvement in the child welfare system. She received her Doctor of Public Health from Johns Hopkins University.

(267) 426-5300 | matonem@email.chop.edu | 2716 South Street, 10th Floor, Philadelphia, PA 19104
I. Introduction

Jalisa\(^1\) was diagnosed with schizophrenia when she was nineteen. Her condition was well-managed by antipsychotic medications, and with the help of Supplemental Security Income ("SSI"), she was able to live independently and maintain a clean one-bedroom apartment. This all changed when she became pregnant. Although research increasingly demonstrates that antipsychotics are safe during pregnancy,\(^2\) due to overlapping physical health challenges (preexisting hypertension and pregnancy-related elevated blood sugar levels), Jalisa’s doctor recommended that she taper off of her medication for the duration of her pregnancy.

Although at first Jalisa attended all of her prenatal appointments and appeared to be doing well, during her third trimester, she began missing appointments and her condition deteriorated quickly. Neighbors contacted Jalisa’s mother after they smelled smoke coming from the apartment and pushed their way in. They found that Jalisa had set the curtains on fire, and was sitting quietly, not reacting. They put out the fire and tried to speak to her, but she was experiencing auditory hallucinations and her speech was disorganized. Jalisa’s mother was not helpful in arranging care for her daughter. She also had schizophrenia, and although she and Jalisa were tightly bonded, Jalisa had spent much of her youth in out-of-home placements.

Jalisa was hospitalized for several weeks, during which time she delivered a healthy baby boy. Although Jalisa’s condition improved markedly once she was again receiving antipsychotic medication, she had no recollection of setting the fire. Child welfare authorities placed the child with the father, with the social worker advising the father not to permit Jalisa any access to the child once she was released. Jalisa was released just weeks after the delivery. Deeply depressed and discharged without a feasible plan to bridge services from her inpatient placement to her return to the

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\(^1\) Name and minor details of all patient/client stories contained herein changed to protect privacy.

\(^2\) Simone N. Vigod et al., Antipsychotic Drug Use in Pregnancy: High Dimensional, Propensity Matched, Population Based Cohort Study, BRIT. MED. J. 1, 9 (May 13, 2015) ("Women requiring antipsychotic medications are at higher absolute risk for certain adverse maternal and perinatal outcomes compared with the general population. As such, it is prudent to closely monitor the medical health of these women before and during pregnancy, with particular attention to issues related to diabetes, hypertension, preterm birth, and fetal growth. However, antipsychotic medications themselves do not seem to have an extensive negative impact on important measures of maternal medical and short term perinatal wellbeing. This is reassuring, at least in the short term, for a woman with serious mental illness who requires an antipsychotic medication to achieve and maintain psychiatric stability during and after pregnancy.")
smoke-stained apartment, Jalisa stopped taking her medication. She had to be hospitalized again, further jeopardizing her chances of reunifying with her infant son. Evidence suggests that the perinatal and postpartum periods feature high levels of health care fragmentation, particularly for low-income mothers of color like Jalisa. For mothers with mental health conditions, this can result in treatment discontinuity in the postpartum period. This treatment discontinuity places mothers at risk for poor health outcomes and maladaptive parenting approaches; threatens the health and safety of infants; and triggers often costly and stressful child welfare involvement. This article will explore the negative consequences and root causes of treatment discontinuity, as well as particularized population vulnerabilities for treatment discontinuity, including mothers who, like Jalisa, have had involvement with child welfare as parents and also when they were children. This article will also explore the manner in which patient protection policies may aggravate the experience of treatment discontinuities, and provide public health and child welfare policy solutions for reducing treatment discontinuity and improving mental and physical health outcomes for new mothers and infants.

II. CONSEQUENCES OF TREATMENT DISCONTINUITY

While treatment discontinuity in pregnancy is medically necessary under some circumstances, it is not without risks and may occur at a rate that exceeds medical necessity due to maternal safety concerns. Furthermore, treatment discontinuity that begins or extends into the postpartum period presents significant challenges for maternal health and parenting outcomes. For example, for mothers with schizophrenia, the duration of untreated psychosis has been found to be, among a broad range of factors, the strongest predictor of symptom severity after treatment is resumed, even controlling for the baseline severity of symptoms. Mothers with depression who experience treatment interruptions during pregnancy present a variety of adverse

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3 Pennsylvania law requires that discharge planning “shall be an integral part of the hospitalization of each patient and shall commence as soon as possible after admission.” See 28 Pa. C.S. §105.22(a). However, despite the fact that all hospitals must maintain “written policies governing discharge planning,” 28 Pa. C.S. §105.22(b), there is often little oversight to ensure that such discharge planning be reasonably achievable by the individual patient. For example, patients are routinely discharged into homelessness, or with contact information for service providers who do not have appointments immediately available.

4 See generally Ian M. Bennett et al., Pregnancy-Related Discontinuation of Antidepressants and Depression Care Visits Among Medicaid Recipients, 61 PSYCHIATRIC SERVICES 386 (2010).

5 Id. See also, generally Amy Dworsky & Jan DeCoursey, Pregnant and Parenting Foster Youth: Their Needs, Their Experiences, UNIV. OF CHICAGO (2009).


health outcomes, including, unsurprisingly, substantially higher rates of relapse. Similarly, disruption of treatment with lithium or other mood stabilizers for mothers with bipolar disorder is associated with a high risk of early relapse and suicide; putting them at further risk, pregnant women actually experience a higher proportion of depressive or mixed episodes after discontinuing lithium than nonpregnant comparators, even after controlling for differences in factors such as the age of onset, duration of illness, and number of prior episodes. Mothers with untreated mental illness are also more likely to engage in risky behavior such as engaging in substance abuse or self-harm.

Compounding the problem of mothers with mental illness being harmed by not receiving treatment during pregnancy or in the postpartum period is the coinciding problem of missed or delayed diagnosis. Pregnant women are less likely than other women to have symptoms of mental illness identified as such; they are also less likely to receive treatment than other women once diagnosed, with pregnant women from already-marginalized groups (young mothers, mothers of color) being particularly poorly served.

Of course, when pregnant women and mothers with mental illness go without treatment it is not only the mothers, but also the children, who are at risk of poor health outcomes. Mothers who self-medicate with drugs and alcohol during pregnancy deliver infants presenting with a host of related physical health issues, including low birth weight; fetal alcohol syndrome; withdrawal; neurobehavior abnormalities; hyperactivity, and other behavioral issues. The health of the mother directly affects the health of the fetus, but the risk to children does not end at birth, as treatment discontinuity places mothers at risk of adopting a host of maladaptive parenting practices. The consequences for children whose mothers have experienced untreated mental illness are long-lasting and significant, affecting not only their current health outcomes, but also their future development and well-being.

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8 See generally Lori Bonari et al., Risks of Untreated Depression During Pregnancy, 60 CANADIAN FAM. PHYSICIAN 242 (Jan. 2004) (summarizing health effects of untreated depression on mothers and children, pre- and postpartum).


10 Viguera et al., supra note 6, at 180-2. It should be noted that a higher proportion of pregnant women studied had discontinued lithium rapidly in response to the potentially harmful effects of taking such medication during pregnancy. Id. at 182.


12 See Michelle L. Geier et al., Detection and Treatment Rates for Perinatal Depression in a State Medicaid Population, CNS SPECTRUMS 18 (2015) (concluding that “pregnant women suffering from depression are less likely to be diagnosed or treated than nonpregnant [sic] controls,” that “[e]ven when depression is diagnosed, less than half of those afflicted receive any treatment for their illness,” and that there are “significant disparities in the delivery of healthcare services to certain subpopulations of pregnant women, including those of Hispanic descent, younger age, or living in an urban environment”).

Approaches. Mothers with depression in the postpartum period are less likely to engage with their children, adversely affecting development, and are less likely to follow daily routines. Mothers with psychiatric disorders are more likely than other mothers to engage in poor home safety practices, and commit acts of physical abuse and neglect. With respect to poor home safety practices, mothers with depression are, for example, less likely to lay their children down in the back sleeping position, to consistently use a car seat, and to supplement an infant’s diet with water, juice, or cereal inappropriately early; they are more likely to rely on the emergency room for their children’s health care. With respect to physical abuse, anecdotal evidence from child fatality review suggests that treatment discontinuity has played a role in infant deaths.

Consider the case of Toccara, a young, low-income, African American mother with bipolar disorder and a chaotic family history. Toccara was found wandering nude in the frigid February air in the area surrounding Temple University, nearly six miles from her home in the impoverished Point Breeze neighborhood of Philadelphia. Less than a year postpartum with her third child in as many years, Toccara was off her medication. She was hospitalized, and a social worker and police officer were dispatched to her home, where she had left her three children alone with two older cousins. One of Toccara’s children was dead, his body placed on the stairs. The oldest child present, just eight years old, described how Toccara had been “hugging” the boy for hours, crying, then left the house. When the police confronted Toccara in the hospital, it became apparent that she had not even realized the child was dead, and that her “hugging” had smothered him.

While this is an extreme example, it highlights not only the severe consequences of maternal treatment discontinuity on children, but also the important complicating factors of poverty and race. The relationship of mental health and poverty is bidirectional. Mental health problems are known to increase the probability of poverty, while at the same time, mothers in poverty are more likely to experience mental health problems, including depression. This is most severe for non-Hispanic black mothers

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17 Balbierz et al., supra note 15, at 1217-18.

18 This includes children who die due to abuse, but also due to neglect. There is abundant evidence linking instances of infanticide by mothers to poor maternal mental health, if not treatment discontinuity specifically. See, e.g., Susan Hatters Friedman & Phillip J. Resnick, Child Murder by Mothers: Patterns and Prevention, 6 WORLD PSYCHIATRY 137 (Oct. 2007).

like Toccara, among whom disproportionately high rates of depression and co-occurring financial adversity are coupled with low rates of mental health service receipt.\footnote{Karen A. Ertel, Janet W. Rich-Edwards & Karestan C. Koenen, \textit{Maternal Depression in the United States: Nationally Representative Rates and Risks}, 201 J. OF WOMEN’ S HEALTH 1609, 1611-14 (Nov. 2011) (observing that women with depression were more likely to experience adversities, including those related to employment, personal relationships, and financial security, than other women, with non-Hispanic black mothers exhibiting elevated rates of adversities and decreased rates of receipt of services for their mood disorders).}

Treatment discontinuity imposes tremendous costs. The health and safety of mothers is threatened, as well as that of their children, due to heightened risk of harm \textit{in utero}, and their mothers exhibiting maladaptive parenting characteristics after birth, including neglect (medical and otherwise), abuse, and inability to cope with grinding poverty. There are also social costs, in terms of expenditures on anti-poverty programs and already over-burdened child welfare infrastructure, which will be discussed further, \textit{infra}.

\section*{III. Mothers \textit{at heightened risk of treatment discontinuity}}

Not all mothers with mental illness are at equal risk of treatment discontinuity. Low-income women like Toccara are more likely to experience treatment discontinuity than better resourced women.\footnote{Bennett et al., \textit{supra} note 4 at 386.} This of course results in a racial disparity: due to the relatively weak economic position of women of color, they are more likely than white women to experience treatment discontinuity due to lack of resources.\footnote{\textit{Id.} at 390.} Exacerbating the problem, low-income women of color are more likely than white women to experience postpartum depression to begin with.\footnote{See generally Linda H. Chaudron et al., \textit{Accuracy of Depression Screening Tools for Identifying Postpartum Depression Among Urban Mothers}, 125 PEDIATRICS 609 (Mar. 2010).} However, even within the population of low-income mothers of color, there are subsets of women with particularized vulnerabilities.

Young women are less likely than older women to be receiving stable treatment for serious mental illness.\footnote{Ronald C. Kessler et al., \textit{The Prevalence and Correlates of Untreated Serious Mental Illness}, 36 HEALTH SERVICES RES. 987, 997 (Dec. 2001).} Young women are more likely to believe they can resolve mental health problems without intervention, and to deny that they need treatment.\footnote{\textit{Id.}} Young women from urban areas are more likely than their rural counterparts to report feeling stigmatized due to mental illness.\footnote{\textit{Id.} at 999.} Youth without family support are particularly hard-hit. This array of factors points to a specific population: young women with histories of involvement with child welfare. Indeed, data demonstrates that mothers involved with child welfare during their own childhoods are at higher risk than their other young, low-income peers for treatment discontinuity in the
postpartum period for chronic health conditions, especially mental and behavioral health conditions. It should not have been difficult to see, before she began missing appointments and set fire to her home, how the risk factors for treatment discontinuity were all aligned against Jalisa.

Mental and behavioral health conditions are exceptionally common in mothers who were child welfare involved as children and adolescents. In one recent Philadelphia study of low-income mothers between the ages of 15 and 24, researchers confirmed that mothers who were child welfare involved as children and adolescents were more likely than non-involved mothers to have diagnoses for mental or behavioral health conditions.27 Mothers whose involvement with child welfare included out-of-home dependent or delinquent placements, as opposed to mothers receiving in-home services only, were more likely to be diagnosed with conduct disorders (22.1% v. 9.5%) and substance abuse (29.1% v. 14.0%).28 More than one in four of these mothers (28.8%) had filled a prescription for psychotropic medication, representing use of antipsychotics three times higher than studied mothers without child welfare involvement, or who were not placed.29

Yet, despite these high rates of diagnosis and receipt of treatment during the preconception period, including taking psychotropic drugs, these mothers were more likely to experience treatment discontinuity than their peers: 61.7% of mothers who had been in dependent or delinquent placement and who had received psychotropic medications in the preconception period did not fill any prescription for psychotropic medication in the postpartum period, compared to 48.9% of non-involved mothers.30 The gap widens further for mothers diagnosed with schizophrenia or bipolar disorder, with 66.7% of mothers with out-of-home placements who had taken antipsychotics preconception failing to fill a prescription for antipsychotic medication postpartum, compared to 51.4% of non-involved mothers.31 The treatment discontinuity gap exists across physical health conditions as well, and as with mental health conditions, treatment discontinuity may be exacerbated for young mothers with the most serious physical health conditions, like HIV.32

27 Meredith Matone et al., Chronic Disease Burden and Discontinuation of Medications Among Young Mothers with a Relationship to the Child Welfare System, CHILD & YOUTH SERVICES REV. 64, 66-72 (2016).

28 Id. at 70.

29 Id. See also Catherine Roller White et al., Depression Among Alumni of Foster Care: Decreasing Rates Through Improvement of Experiences in Care, 17 J. EMOTIONAL & BEHAV. DISORDERS 38, 44 (2009) (Finding that depression over presents in youth in foster care, during placement and lifelong—41.1% compared to 19.8% among the general population; White, et al. also observed that youth in care were 2.8 times more likely than their peers (26.8% v. 11.4%) to have considered suicide, and were four times more likely to have made suicide attempts (15.3% v. .2%).)

30 Matone et al., supra note 27, at 70.

31 Id.

32 Mothers who had been in dependent or delinquent placement experienced discontinuity at a rate of 69.2% in the aggregate across physical health conditions, significantly higher than mothers whose families had received in-home child welfare services during the mother’s own childhood (53.0%), and 52.4% of mothers with no previous child welfare involvement. Id. Alarmingly, of the 257 HIV positive young mothers included in the Philadelphia study, 208 of
In light of these findings linking a history of child welfare involvement (and, more specifically, out-of-home placement) with an increased prevalence of diagnosed but untreated mental health conditions in teen and young adult mothers, treatment discontinuity in this population of vulnerable girls can quite squarely be identified as a child welfare issue. Yet again, it is not only the mothers (regardless of age) who are at risk, but also the children, as mothers with past dependency or delinquency involvement are at increased risk of child welfare involvement with their own children.33 This second tier of child welfare involvement may further feed the cycle of treatment discontinuity in this vulnerable subset of women, as follows.

Children born to adolescent mothers who have experienced abuse are more likely than other children to experience abuse or neglect, triggering child welfare involvement.34 This may in part be linked to the fact that mothers with untreated mental illness are more likely to exhibit maladaptive parenting behaviors and commit acts of child abuse or neglect, as discussed, supra. These mothers are also more likely to be poor, and poverty in itself increases a family’s risk of interaction with the child welfare system,35 often due to utility shut-offs, unstable housing, or food insecurity;36 indeed, distinguishing poverty from abuse and neglect can prove challenging.37 Yet, the situation is bidirectional: living in poverty can heighten preexisting stress or depression, further undermining the parent’s ability to appropriately care for children,38 including increased likelihood of corporal punishment.39 Furthermore,

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33 Emily Putnam-Hornstein et al., A Population-Level and Longitudinal Study of Adolescent Mothers and Intergenerational Maltreatment, 181 AM. J. OF EPIDEMIOLOGY 496 (Apr. 2015) (“a parental history of maltreatment has consequences for children, with heightened rates of abuse and neglect often being observed among the offspring of maltreated parents”) (internal citation omitted).

34 Id. See also Patricia Flanagan et al., Predicting Maltreatment of Children of Teenage Mothers, 149 ARCHIVES OF PEDIATRIC & ADOLESCENT MED. 454 (Apr. 1995).

35 Mothers who have been in dependent care placements are substantially higher risk of poverty than other mothers: they are less likely to have completed high school or college, and more likely to be unemployed and experience periods of homelessness. See White, supra note 29, at 38.

36 Cancian et al., supra note 19, at 3 (internal citations omitted).

37 Generally speaking, “child maltreatment risk is associated with various indicators of economic hardship, including welfare receipt; unemployment; and single-parent family structure,” and “child maltreatment has been shown to correlate with community- or state-level poverty rates; unemployment rates; and welfare receipt rates and benefit levels.” Id. (internal citations omitted).


39 Kristen Shook Slack et al., Understanding the Risks of Child Neglect: An Exploration of Poverty and Parenting Characteristics, 9 CHILD MALTREATMENT 395, 396 (2004) (internal citations omitted). These parents “tend to employ harsher discipline, spank and punish their children more often, reason less with them, [and] become more easily frustrated” while having “more difficulty managing parenting stress.” Id. (internal citations omitted).
mothers may be unwilling to seek help for mental health conditions if they fear alerting child welfare, resulting in a treatment discontinuity.

The heightened prevalence of child welfare involvement of mothers who were dependency- or delinquency-involved when they were themselves children may in this way be directly and causatively linked to the prior involvement, rather than simply demographically or correlatively linked. These mothers are already known to child welfare authorities and may come under scrutiny other mothers would escape. It has been suggested, in a parallel context, that parents who receive welfare are more likely to become child welfare involved than other parents not merely because of poverty or the associated problems of mental health and maladaptive parenting behaviors, but because welfare recipients interact with potential mandatory maltreatment reporters in the process of accessing these benefits, exposing them to heightened scrutiny. Mothers in care are routinely investigated and subject to removal of children for engaging in such behaviors as co-sleeping or choosing not to vaccinate, behaviors in which many non-involved mothers engage without triggering scrutiny by child welfare authorities. This has critical consequences for the matter of treatment discontinuity. Based on past experience, these mothers may so fear the involvement of child welfare authorities with their own children that they are discouraged from seeking care for mental health or substance abuse issues. Of course, this coping behavior merely squeezes the balloon, with other problems related to the lack of treatment bulging out to take their place.

IV. ROOT CAUSES OF TREATMENT DISCONTINUITY

In the previous section, we started to pick apart the causes of treatment discontinuity particular to mothers with child welfare involvement during their own childhoods. Yet moving beyond this specific subset of particularly at-risk women and girls, there is a much broader landscape to explore when it comes to identifying and addressing the root causes of treatment discontinuity in mothers.

Of course, a fundamental cause of treatment discontinuity for mental illness in mothers is mental illness itself. As noted, pregnancy often requires that women taper off of or otherwise alter their treatment with psychotropic medications. Mental health symptomatology increases the chance that mothers will fall off the radar and fail to follow through on medical treatment that would bring them back to stability, such as physician-supervised reintroduction/titration of medication and/or therapy.

Insurance coverage is another key cause of treatment discontinuity in mothers. Insurance status may change for many mothers in the postpartum period, or at a minimum, require reauthorization following pregnancy. Medicaid plays an important role, as it is the primary source of health coverage for low-income women, and for births nationally: Medicaid is the principal payment source for the delivery of nearly half of all infants born in the United States each year. Under federal law, low-income pregnant women can receive Medicaid throughout pregnancy and until they are sixty days postpartum, regardless of any increase in income; after the sixty day period, they

40 Slack, Lee, & Berger, supra note 38, at 208.

must demonstrate continuing eligibility.\textsuperscript{42} For example, in Pennsylvania, where Medicaid is the principal payment source for the delivery of nearly a third of all infants born each year,\textsuperscript{43} pregnant women whose household income is within 220% of the federal poverty limit, including the unborn child in the mother’s household size, are presumptively eligible to receive Medicaid through the sixty day postpartum period.\textsuperscript{44} Medicaid also covers all children in dependent care,\textsuperscript{45} as well as all children formerly in care, even if they have “aged out,” through the age of twenty-six,\textsuperscript{46} an important component of the Affordable Care Act intended to serve as an analogue to the provision permitting parents to keep their children on their own health coverage until those children are twenty-six.\textsuperscript{47}

The expiration of the sixty-day period triggers problems for many mothers. They may be unaware that they must reauthorize coverage and let their coverage lapse; be aware of the different eligibility requirements but unaware of how to demonstrate continuing eligibility; or, if coverage is maintained, simply misperceive their health coverage and fail to take advantage of services they could access. These effects may be particularly heightened for former foster youths, as systems serving them may not yet have caught up to the new continuing eligibility boon, and as they may “graduate” from care without having secured coverage, or even having been informed of their right to receive such coverage during their dependent care transition planning. Studies have shown that states with automatic enrollment and redetermination processes keep the largest number of youth “aging out” on Medicaid, whereas states that require action on the part of the individual young adult have lower levels of enrollment.\textsuperscript{48}

In addition to frequently prompting child welfare involvement, as discussed, \textit{supra}, poverty also frequently in and of itself prompts treatment discontinuity. Low-income mothers face barriers to seeking medical care for themselves. They may find themselves paralyzed by stress, unable to make and keep appointments or act as self-advocates navigating an often complex health care system. Although it seems almost too obvious to remark upon, simply scheduling clinical preventative services appointments is a key determinant of services receipt, but even that step may be beyond many mentally ill mothers.\textsuperscript{49} Currently or formerly child welfare involved


\textsuperscript{43} Bill Toland \textit{Medicaid Covers Nearly Half of Births}, \textit{Pittsburgh Post-Gazette} (Sept. 5, 2013).

\textsuperscript{44} \textit{Medical Assistance Eligibility Manual}, \textit{Pennsylvania Health Law Project} (Feb. 2015), at 13.

\textsuperscript{45} \textit{Id.} at 4.

\textsuperscript{46} \textit{Id.} at 15.


\textsuperscript{48} \textit{Id.} at 5 (citation omitted).

\textsuperscript{49} Lisa B. Sinclair et al., \textit{Tools for Improving Clinical Preventive Services Receipt Among Women with Disabilities of Childbearing Ages and Beyond}, \textit{19 Maternal Child Health J.} 1189 (2015) (internal citation omitted).
mothers in particular may lack the positive social support necessary to focus on maintaining positive self-care behaviors.

Consider the case of Liliana, a young mother who had aged out of foster care and had no family or friend network support to speak of. She had a child with a man who, unbeknownst to her, had spent many years in prison for committing sexual offenses against teen girls. They separated during Liliana’s pregnancy when he became abusive, and he went back to prison shortly thereafter for committing an aggravated assault on another man during a brawl. Liliana had a lifelong history of anxiety and depression, and her depression symptomology was greatly impacted in the postpartum period. She acknowledged that she needed mental health treatment, but faced a number of barriers. Her primary care physician, who Liliana saw regularly for treatment for a blood clotting disorder, prescribed her anti-depressants, but she was put on a long waiting list for an appointment with a therapist. When she finally received an appointment, she canceled twice due to an inability to secure childcare. Her only reliable source of childcare was the child’s paternal grandmother, who Liliana disliked depending on because she had assisted the father in concealing his criminal history from Liliana; did not assist Liliana when she revealed the physical abuse; and constantly threatened to report Liliana to child welfare and/or take custody of the child due to Liliana’s physical and mental health conditions and her poor-quality housing.

Liliana’s case illustrates how poor mothers bear the brunt of the poorest models of service delivery. They have more paltry coverage, and less freedom to seek additional services outside their coverage; with the scarcity of behavioral health providers for low-income women, they may face long appointment delays. This effect is heightened for mothers who require more specialized care, such as young mothers requiring care from child psychiatrists, mothers who require treatment for co-presenting mental health and substance abuse issues, and mothers who, like Liliana, present with both physical and mental health conditions.

Here the often fragmented relationship between behavioral health insurers and providers, and physical health care providers and insurers, plays a key role. Rather than providing integrated care to mothers with overlapping health concerns, behavioral and physical health care providers coordinate poorly and frequently fail to share critical information. Adults with severe mental health conditions have higher rates of chronic general medical conditions than people without such mental health conditions, likely due to a number of factors including higher rates of poverty and substance abuse, medication side effects, and “unhealthy behavior and neglect of self-care.” Yet, “[e]vidence suggests that people with severe mental illnesses have difficulties obtaining general health care.” They frequently report that providers “dismiss their somatic complaints,” and studies have confirmed that “the quality of general health care is poorer for people with severe mental illnesses than for less impaired people,” including preventative services and treatment for chronic conditions like diabetes and heart disease.

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50 Id.


52 Id.

53 Id. (citation omitted).
Although this is likely attributable to a number of overlapping factors, “the lack of clinical integration in the care of people with severe mental illnesses plays a key role.” 54 For example, mental and physical health providers are rarely co-located and may not be treated by insurance coverage in an equivalent manner, and such providers rarely commit to screening for issues outside the provider’s service area; this all thwarts the exchange of information and the development and implementation of integrated treatment plans, leading to an increased prevalence of treatment discontinuity. 55

V. CONCLUSION: POLICY PROBLEMS, POLICY SOLUTIONS

The problem of treatment discontinuity for mothers with mental illness in the perinatal and postpartum periods is aggravated by a public health policy landscape that may be harming patients it intended to protect, and a child welfare policy landscape that fails to recognize the problem and/or is unequipped to remediate it.

The Health Insurance Portability and Accountability Act (“HIPAA”) Privacy Rule (the “Privacy Rule”) 56 prohibits covered entities (broadly construed to include health insurers and medical service providers, including independent contractors thereof) from disclosing Protected Health Information (“PHI”). 57 PHI is any information concerning a patient’s health status and health history; receipt of health-related services, including medications and other treatment; and history of payment for health care. 58 With the exception of mandatory reporting to child welfare agencies and compliance with law enforcement or valid court order, disclosures of PHI can only occur with a patient’s express written authorization, typically in order to facilitate parallel treatment or resolve a payment issue. 59

However, although HIPAA “is often cited as a barrier to sharing information between primary care and mental health practitioners,” the sharing of information “for the purposes of care coordination is a permitted activity under HIPAA, not requiring formal consents.” 60 States may have mental health laws that are more restrictive, and such statutes should be re-examined for the purposes of ensuring patient privacy does not override the ability of patients to receive appropriate care. 61 Even in the absence of such statutory barriers, however, concern about liability for HIPAA Privacy Rule violations has caused providers to become overly-cautious about information sharing,

54 Id.
55 Id. at 662-64. See also, generally, Chris Collins et al., Evolving Models of Behavioral Health Integration in Primary Care, MILLBANK MEMORIAL FUND (2010).
57 Id.
58 Id.
59 Id.
60 Collins et al., supra note 55, at 4.
61 Id.
even when it would improve behavioral health service linkage for patients who are at risk of treatment discontinuity. 62

The answer is, of course, not to compromise patient privacy, or to put providers at risk of liability. Rather, as a balanced solution, providers need to screen patients for risk of treatment discontinuity and include preventing discontinuity in the individual patient’s treatment plan, including ensuring that the patient will not experience gaps in insurance coverage. This includes executing written authorization or Data Use Agreements for information sharing between mental and physical health care providers if necessary. In the context of postpartum treatment discontinuity among under resourced mothers, obstetricians providing prenatal care may be the sole health care providers for pregnant mothers, and could thus serve as critical facilitators of behavioral health service linkage, provided they were equipped with appropriate patient information and perceived information sharing to be permissible.

In addition to facilitating information sharing as a first step, a superior system must be established for identifying mothers experiencing treatment discontinuity. As discussed, Philadelphia researchers learned that 61.7% of mothers who had been in dependent or delinquent placement stopped receiving psychotropic medications in the postpartum period, including 66.7% that stopped filling prescriptions for antipsychotics. 63 Non-child welfare-involved mothers faced lower, yet still unacceptably high rates of discontinuity, with nearly half of Medicaid-recipient mothers studied, ceasing treatment for mental health conditions in the postpartum period. 64 It is unacceptable that all of these mothers—like Toccara, the mother who inadvertently smothered her small son—were diagnosed and treated, on the radar of a medical professional, then promptly lost contact after delivery. Accordingly, systems must be designed to support health care providers in identifying and responding to treatment discontinuity.

Electronic health records offer a venue for embedding alerts and screeners for physicians to identify treatment gaps among high-risk patients. While a helpful first step, this solution works only when mothers return for care with the same provider or within the same health care system, if they seek continued care at all. Yet, the health information exchanges established under the Health Information Technology for Economic and Clinical Health Act of 2009 (“HITECH”) 65 offer an opportunity to

62 See, e.g., Meredith Kapushion, Hungry, Hungry HIPPA: When Privacy Regulations Go Too Far, 31 FORDHAM URB. L. J. 1483 (2003). See also Ryan Gray, How HIPAA Is Harming Patient Care, MD MAGAZINE (Feb. 10, 2016) (“HIPAA, although well-intentioned, has created a culture of paranoia”); Dan Orenstein, It’s Time To Modernize The HIPAA Privacy Rule, FORBESBRANDVOICE (AETNAHEALTH) (Jul. 28, 2015) (“Rather than enabling information exchange, many in health care perceive the HIPAA privacy and security rules as barriers to the free flow of health information.”); Jane Gross, Keeping Patients’ Details Private, Even From Kin, N.Y. TIMES (July 3, 2007) (“Hipaa [sic] was designed to allow Americans to take their health insurance coverage with them when they changed jobs, with provisions to keep medical information confidential. But new studies have found that some health care providers apply Hipaa [sic] regulations overzealously, leaving family members, caretakers, public health and law enforcement authorities stymied in their efforts to get information.”).

63 Matone et al., supra note 27, at 70.

64 Id.

65 HITECH ACT ENFORCEMENT INTERIM FINAL RULE, U.S. DEP’T OF HEALTH & HUMAN SERVICES.
share medical record and health service utilization information across providers and health systems. They may ultimately be capable hosting a similar function in identifying patients with adverse health care utilization profiles across a broader capture of health systems. To date, health information exchanges have not achieved their highest levels of engagement with public payers and ambulatory clinical data has not always been a priority for users of exchange information. But, given the substantial prevalence of mental health morbidity and the high cost services associated with poor maintenance of mental health treatment, including residential facilities, emergency department visits, and injuries, it is justifiable to prioritize functionality and user engagement around ambulatory behavioral health information within health information exchanges.

There is also potential for reaching mothers through their children. Although many mothers do not return for their own care after birth, many do attend health care visits in the postpartum period for their infants. Liliana, whose story is told above, may have twice canceled appointments with a therapist for herself, but she never missed a well-child visit for her son. A May 2016 informational bulletin issued by the Centers for Medicare and Medicaid Services allows for reimbursement of maternal depression screening and select treatment in the postpartum period under a child’s Medicaid Early Periodic Screening Diagnosis and Treatment benefit. While this guidance does not address treatment gaps specifically, as state Medicaid programs and individual health care practices and providers respond and create systems to support the identification of maternal depression, there is an important opportunity to identify treatment discontinuity and build enhanced referral and service coordination. More time would help: expanding the period during which mothers are presumptively eligible to receive Medicaid, currently sixty days postpartum, would offer additional opportunities for contact, as infants are supposed to see a pediatrician for well-baby checkups and vaccinations no less than five times during their first nine months. These visits all provide critical footholds to screen mothers, connect them to resources, and provide them important information, including about the continuation of their insurance coverage.

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66 See generally Julia Adler-Milstein, Sunny C. Lin & Ashish K. Jha, The Number of Health Information Exchange Efforts is Declining, Leaving the Viability of Broad Clinical Data Exchange Uncertain, 35 HEALTH AFFAIRS 1278 (July 2016).

67 Rhode Island has seen some success using CurrentCare, Rhode Island’s health information exchange, to integrate “behavioral health into the exchange between primary care physicians and other clinical specialists”; this permits providers to effectively monitor medications dispensed and picked up at pharmacies throughout the state, coordinate appropriate follow-up care after hospitalizations, and track lab results....” Charlie Hewitt & Michael Lardiere, Health Information Exchange: IT Gets Real in the Field, eSOLUTIONS NEWSLETTER (SAMHSA-HRSA CTR. FOR INTEGRATED HEALTH SOLUTIONS).

68 Id.

69 Vikki Wachino, Maternal Depression Screening and Treatment: A Critical Role for Medicaid in the Care of Mothers and Children, CRS. FOR MEDICARE & MEDICAID SERVS., DEP’T OF HEALTH & HUMAN SERVICES.

70 Id. These visits then greatly decrease in frequency, with toddlers seeing a pediatrician only every six months, and older children only yearly.
Effective data systems and service coordination within the health care system is critical, but even more is needed. For young, under-resourced mothers, the health system must also provide services in a trauma-informed, culturally competent, and youth-friendly manner. As noted, mothers at risk for postpartum treatment discontinuity are more likely to be low-income, women of color, and coping with trauma exposure—a profile that may differ distinctly from the provider him/herself. Microaggressions on the part of providers, or simply a perceived lack of understanding, may contribute to feelings of stigma among mentally ill young mothers, and may discourage them from committing to the receipt of treatment. Providers should also consider the individual patient’s risk factors for treatment discontinuity as decisions are made about any medication reduction during pregnancy and weigh the potentially deleterious effects of discontinuity on both mother and child against any risk factors associated with continuing medication during pregnancy and/or nursing.

Finally, considering the large role scheduling appointments plays in treatment discontinuity, providers should endeavor to be more accessible to patients. This means having reserved “slots” for emergency appointments and new patient appointments built into the provider’s schedule, in order to blunt the impact of long appointment delays. This also means moving beyond the phone and mail: today’s youth are loathe to communicate by speaking over the phone, and low-income people frequently change addresses. Mental and physical health providers should do as many other

71 Geier et al., supra note 12.

72 See Jennifer M. Gómez, Microaggressions and the Enduring Mental Health Disparity: Black Americans at Risk for Institutional Betrayal, 41 J. OF BLACK PSYCH. 121, 130 (2015) (noting that microaggressions “contribute[e] to mental health disparities by engendering decreased levels of trust in mental health care providers and decreased receptiveness to treatment” and providing suggestions for improved care) (citations omitted); Cultural Respect, NATIONAL INSTITUTES OF HEALTH (July 29, 2016) (“The concept of cultural respect has a positive effect on patient care delivery by enabling providers to deliver services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients.”). See also Tamarah Moss, Barriers to Health Care for Youth of Color, ADVOCATES FOR YOUTH (providing suggestions for culturally appropriate service delivery to youth, in the context of sexual and reproductive health); Characteristics of Youth-Friendly Health Care Services, HEALTHY TEEN NETWORK (same).

73 The risk factors associated with continuing medication during pregnancy and/or nursing are discussed in Vigod et al., supra note 2.

74 Lisa Brandenburg et al., Innovation and Best Practices in Health Care Scheduling, INST. OF MED. OF THE NAT’L ACADEMIES OF SCI. 1, 3 (Feb. 2015) (noting that “patients with nonurgent needs who experience prolonged wait times have been shown to have a higher rate of noncompliance and appointment no-shows.”).

75 NEIL HOWE, WHY MILLENNIALS ARE TEXTING MORE AND TALKING LESS, FORBES (JULY 15, 2015) (“Text messages now out rank phone calls as the dominant form of communication among Millennials”); TETDY WAYNE, AT THE TONE, LEAVE A WHAT? MILLENNIALS SHY AWAY FROM VOICEMAIL, N.Y. TIMES (JUNE 13, 2014) (describing speaking over the phone and leaving voicemails as a “source of anxiety” for millennials).

providers of services to low-income people have done, including legal aid providers, and make scheduling by text and email accessible, including the use of automated appointment reminders.77

Coordination with community programming is another strategy for engaging with hard to reach families. Community public health and social programs, including maternal-infant home visiting programs and Women, Infants, and Children ("WIC") programs, are often more accessible and less intimidating than traditional health care services. Health care partnerships with such programs allow for bidirectional referral, improved screening and identification opportunities, and increased reach of the highest-risk families.78 Such programs have already achieved success in the treatment of depression in adolescents;79 importantly, these programs are replicable and evidence based.80

Major reforms are also necessary on the child welfare side. Investment in child welfare systems is critical so that children and families experiencing extreme poverty or a mental health crisis, rather than actual abuse or neglect, do not fear child welfare involvement, but rather welcome services it can connect them to. Rather than simply removing a child from a parent who is unable to secure adequate housing, child welfare systems should help that parent secure adequate housing. Rather than simply removing a child from a parent who is unable to provide appropriate care and control for that child due to her own acute mental health condition, child welfare systems should assist the parent in securing treatment.

Of course, this is a proposal of large-scale, macro mission-shaping. But, there are immediate, concrete steps that can be taken to improve the treatment of young parents still in care. Strong coordination of child welfare systems with health systems and other public systems is essential. The Fostering Connections to Success and Increasing Adoptions Act of 200881 requires the creation of a health oversight and coordination plan within a child’s case plan, including facilitating linkages to a medical care and oversight of psychotropic medications.82 For youth who become pregnant in care, revisiting health oversight plans provides an opportunity to proactively establish a plan

77 Kat Aaron, Don’t Forget Your Court Date: How Text Messages and Other Technology Can Give Legal Support to the Poor, Slate (Dec. 07, 2012) (describing how indigent legal services providers are “using new tools to deliver information to clients, support volunteer lawyers, and improve their own systems,” including “using text messaging, automated call-backs, Web chats, and computer-assisted mapping.”).

78 Id.


80 The Department of Health and Human Services even maintains a site dedicated to the Home Visiting Evidence of Effectiveness ("HomVEE") review, which “conduct[s] a thorough and transparent review of the home visiting research literature” in order to provide “an assessment of the evidence of effectiveness for home visiting program models that target families with pregnant women and children[.].” See Home Visiting Evidence of Effectiveness, Dep’t of Health & Human Services.


82 Id.
for health care continuity during the transition to the postpartum period. This should be an expectation for all case managers working with youth who become pregnant. The law also requires transition plans for youth aging out of care that include a plan for health insurance coverage and access to relevant health care providers. Ensuring continuity of health insurance coverage must, accordingly, be a part of transition planning for youth aging out of care, but all youth in care should discuss ensuring continuity of coverage in the event they leave care prematurely (colloquially known as “going AWOL”). Again, this should be an expectation for all case managers working with older youth.

Additionally, all congregate care placements serving older youth must integrate parent-baby beds, rather than relying on segregated facilities equipped for parent-baby pairings, as this segregation of parent-baby beds necessitates a disruptive transfer of the expecting parent at a particularly vulnerable time. In many states, efforts are ongoing to increase placements of dependent children in kinship care, rather than congregate care or foster care. Although these efforts have met with some success, many adolescents, especially those who have histories of poor performance in school; delinquency; and oppositional, defiant, or otherwise negative or challenging behaviors and attitudes may not find relatives willing to take them in. Instead, they end up in congregate care where, if they get pregnant and their facility cannot accommodate them with an infant, they currently have limited options. Coveted supervised independent living placements are limited, as are beds in facilities that serve mother-baby pairings, prompting transfer into an appropriate facility or a foster care, if a home that will accommodate the teen and the infant can be located. Due to the resulting stress on all parties, further transfers are essentially inevitable, resulting in the teen going AWOL and disconnecting from services vital to both parent and child.

Finally, there is a public benefits dimension to addressing the problem of treatment discontinuity, separate from the issue of medical benefits. In recognition of the fact that having reliable childcare is an essential component in parents making it to medical

83 Id.

84 For example, kinship care placements have increased 24% in Pennsylvania since 2012. Laurie Mason Schroeder, More Foster Kids Finding Homes with Kin, Thanks to Shift in Courts, THE MORNING CALL (Jan. 2, 2016).

85 According to the Center for Law and Social Policy, only 6% of children in kinship care run away, compared with 16% in foster care and 35% in group homes; along the same lines, only 63% of children in kinship care have to change schools, compared with 80% in foster care and 93% in group homes. Id.

86 It is a general principle of child welfare placement that “younger children are more likely to be living with families and older children more likely to be living in group homes or institutions.” 33% of children aged one to five are placed with relatives, with only 1% living in group homes or institutions; for children 16 and older, the numbers are flipped, with just 11% living with relatives and 36% living in group homes or institutions. Data Snapshot on Foster Care Placement, ANNIE E. CASEY FOUNDATION (May 2011).

87 The utter non-existence of father-baby facilities must be here remarked upon.

88 See Michael R. Pergamit & Michelle Ernst, Running Away from Foster Care: Youths’ Knowledge and Access of Services, NATIONAL RUNAWAY SWITCHBOARD, at 24-29 (Apr. 9, 2011) (exploring the reasons foster youths give for going AWOL, including frustration with rules and structure, pregnancy, and the desire to be with a romantic partner, among others).
appointments and setting aside time for mental health treatment, including counseling, subsidized childcare should be available, even if on a per diem basis, to low-income parents with disabilities, not just those who require childcare in order to work or go to school. Pervasive work or educational requirements attached to state subsidized childcare programs deny the reality that even parents serving as full-time caregivers to children occasionally require childcare assistance, and not all parents have access to appropriate caregivers through friend or kinship networks; this principle may be exacerbated in currently or formerly child welfare-involved mothers.

In Pennsylvania, a mother must work at least twenty hours a week or be enrolled in school in order to qualify for subsidized childcare;\(^99\) similar requirements attach to most of our neighboring states, including Maryland,\(^90\) New Jersey,\(^91\) and New York.\(^92\) Delaware is unique in that families are eligible for subsidized childcare if the parent, “because of a special need, is unable on his/her own to care for children” for some portion of the day, if a doctor or other professional so verifies.\(^93\) This more flexible definition of eligibility is desirable, as it is not predicated merely on facilitating employment or education in order to minimize ultimate dependence on state resources, but rather on an understanding that parents with disabilities precluding them from employment or educational opportunities may still require assistance in order to address the scope of their disabilities.

In light of the serious negative effects treatment discontinuity has on mothers and children, and the burden these effects ultimately impose on already stressed state resources, a coordinated reaction is required. The population of mothers at highest risk for postpartum treatment gaps is not small: more than 40% of Medicaid-financed births to young women aged 15 to 24 occurred to mothers who had a childhood relationship to the child welfare system.\(^94\) It is unacceptable to be aware of the pervasiveness of this problem, particularly among intersectionally vulnerable women, and not deploy a targeted and evidence-based preventative and remedial response.

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\(^89\) See 55 Pa. C.S. Sec. 3041.43.


\(^91\) New Jersey Cares for Kids (NJCK) Voucher Information, PROGRAM FOR PARENTS (2016).

\(^92\) Child Care Subsidies, NEW YORK OFFICE OF TEMPORARY AND DISABILITY ASSISTANCE (2016).

\(^93\) 11000 Child Care Subsidy Program, STATE OF DELAWARE.

\(^94\) Matone et al., supra note 27, at 70.