

ADMINISTRATION FOR CHILDREN & FAMILIES

Pediatric Cancer Trial Illuminates Pain Points in Public Benefits System

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Introduction

Children with cancer who live in low-income households have higher rates of recurrence and death than children from high-income households, even when receiving the same medical treatment (Bona et al., 2021; Tucker-Seeley et al., 2024; Umaretiya et al., 2023; Winestone et al., 2023). To evaluate whether additional financial resources provided during early treatment could positively impact health outcomes for children with cancer in low-income households, Dr. Kira Bona and the Dana-Farber Cancer Institute created the Pediatric Resource Intervention to Support Equity (“Pediatric RISE”) study.

Pediatric RISE provides unrestricted cash support during the early months of cancer treatment to families who have a child receiving chemotherapy for a newly diagnosed cancer and whose income is at or below 200% of the federal poverty level. Childhood cancer is a relatively rare disease - roughly 10,000 children are diagnosed annually across the United States - making it critical that the Pediatric RISE study be nationwide in order to provide sufficient data to determine the impact and potential of this intervention.

In order to test the impact of *additional cash support* and to prevent the medically and morally unacceptable outcome of loss of means-tested public benefits such as Medicaid, it was necessary that the cash transfers provide cumulative value to the families. In other words,

The Resilient Families Hub is an interagency effort to expand knowledge of cash transfer programs within the federal government as part of the Facing Financial Shock initiative. Developed by the Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government (EO 14058), the mission of FFS is to provide stability and smoother pathways to resilience through better benefit delivery, better benefits, and better jobs.

the Pediatric RISE team had to ensure that the cash transfers provided by the program did not negatively impact the families' abilities to obtain public benefits. Because of the national scope of the study, as well as the fact that pediatric cancer patients live in all states in the U.S., the Pediatric RISE team needed to coordinate with a host of federal, state, and local authorities charged with implementing public benefits to ensure benefits protection.

The following case study is an examination of the processes used by the Pediatric RISE team in order to highlight the difficulties and pain points in developing a program to support families facing a financial shock from their child's cancer treatment.

Cancer Treatment Creates Financial Shocks for Families

Every day, Americans across the country experience an event that strains their resources. These "financial shocks" can include medical bills, loss of income, increased rent, the end of a loan deferment or more. While all families may confront unexpected bills, it is low- and moderate-income families who are less likely to have wealth reserves to mediate such shocks, resulting in increased risks of housing instability from missed housing payments, reduced food consumption, and adverse mental and physical health outcomes (Bufe et al., 2021).

For Americans without sufficient personal resources to draw from in such a situation, the public benefits system could provide a lifeline ensuring that the family is able to recover from the shock rather than falling into debt or poverty. However, more than a quarter of people facing a financial shock receive no help from any federal program despite eligibility, leaving behind billions of dollars in unclaimed benefits and potentially failing to stabilize families. Even families that are able to access benefits spend untold hours, frequently missing work, in order to obtain the benefits for which they qualify ([Life Experience Design Charter](#)).

When a child is diagnosed with cancer, the family experiences not only a medical and psychological shock, but also a financial shock (Pelletier & Bona, 2015). Often the demands of treatment lead parents and caregivers to reduce their work hours or stop work altogether, resulting in a loss of household income. At the same time, families experience new, additional expenses such as medical bills, transportation and housing costs related to medical treatment, as well as childcare for other children in the home.

Nearly 10,000 children under the age of 15 were expected to receive a cancer diagnosed in 2024. While roughly 85% of children live five or more years after diagnosis, cancer is still the second leading cause of death in children ages one to 14 ([American Cancer Society](#)). While cancer affects children of all socioeconomic backgrounds equally, children from low-income households are more likely to experience relapse or morbidity (Aristizabal et al., 2021). Due to childhood poverty rates in the U.S., one in three children diagnosed with cancer lives in a low-income household (Dana-Farber Cancer Center, 2024). Ensuring low- and moderate-income families have sufficient economic resources during their child's cancer treatment may have long-term impacts on the child's health outcomes.

One-third of families report household material hardship, defined as "unmet basic needs including food, utilities, and[] transportation," at the moment of diagnosis (Umaretiya et al., 2021). Importantly, even families that are not in a precarious financial situation prior to their child's diagnosis may find themselves facing financial hardships that come from increased medical costs, lost work hours, and additional travel and childcare needs (Umaretiya et al., 2021).

Overall, household material hardship is associated with poorer health outcomes for children and, importantly, can be mitigated with intervention (Frank et al., 2010). Trials in primary care have demonstrated that screening for household material hardship and providing appropriate referrals to existing services can improve health outcomes (Garg et al., 2021).

About Pediatric RISE

Drawing on these research findings, Dr. Kira Bona and her team at the Dana-Farber Cancer Institute created the Pediatric RISE study to evaluate whether additional financial resources provided early in treatment could improve health outcomes for children with cancer living in low-income households (Kelly et al., 2024). Pediatric RISE provides unrestricted cash support to families with a child receiving chemotherapy for a newly diagnosed cancer and whose income is at or below 200% of the federal poverty level. Conducted as a randomized trial, Pediatric RISE will be offered to low-income families enrolling in a multi-center clinical drug trial for high-risk neuroblastoma. Over the course of four years, 84 families across eight centers will be enrolled in the study with half of the families receiving cash supports for the

first six months of their child's chemotherapy treatment and the other half receiving the usual supportive care with no cash transfer.

Direct Cash Transfers and Public Benefits Interactions

To ensure that the Pediatric RISE study is able to determine the effect of additional income supports on low-income families with a child in cancer treatment, it was necessary for the researchers to ensure that all other public benefits for which the family would be eligible without the study's payments remain in place.

As many public benefits programs are means-tested, families must meet certain income and resource (asset) limits to qualify. In addition, household income may also be used to determine a family's benefit amount. If the cash transfers provided by the Pediatric RISE program were considered part of the family's income and assets for most means-tested benefit programs, it could diminish a family's overall financial well-being by reducing or eliminating benefits. It was necessary, then, for the Pediatric RISE team to ensure that the cash transfers were excluded or exempted from consideration as income to prevent any loss of benefits.

Below is a summary of the challenges and pain points the Pediatric RISE team experienced when seeking to obtain and implement strategies to mitigate and prevent any reduction or loss of benefits.

Public Benefits Eligibility is Tied to Participants' State of Residence

Eligibility for many public benefits, including the Supplemental Nutrition Assistance Program (SNAP), Medicaid, and Temporary Assistance for Needy Families (TANF), is based on the beneficiary's state of residence. For the Pediatric RISE team, benefits protection was complicated by the fact that recruitment for the program is conducted by participating hospitals in multiple states and, because pediatric cancer is rare, many families traveled from out-of-state to receive care. To protect participant-families' benefits, the Pediatric RISE team not only had to pursue public benefit exemptions for the state in which the participating hospital was located, but also for any states in which the pediatric patients and their families reside. For example, Dana-Farber Cancer Institute in Massachusetts not only provides

treatment to patients from Massachusetts, but also frequently sees patients from New Hampshire, Rhode Island, Maine, and Vermont. This factor significantly increased the amount of outreach and communication needed to secure public benefit exemptions for participants in the Pediatric RISE study.

Due to the rarity of pediatric cancer, any research study for childhood cancer must enroll children at multiple hospitals across the country to achieve an adequate sample size to assess an intervention, further increasing the outreach needed to secure public benefit exemptions. The current Pediatric RISE study will be conducted across eight hospital centers, each located in different states. Future phases of the study are projected to be conducted nationally to gather sufficient research data and provide treatment nationwide. Under the current public benefits system, this will require public benefit exemption discussions with all 50 states – a considerable administrative and logistical hurdle.

Ability to Provide Exemptions May Require State Policy Change

In pursuing public benefit exemptions from multiple states, Pediatric RISE encountered differences regarding states' ability to provide exemptions, as well as various levels of familiarity with and willingness to approve these requests.

The TANF block grant provides an illustrative example of a state's ability to approve an exemption request. Unlike with Supplemental Security Income (SSI) and SNAP, states have broad discretion in determining TANF eligibility and benefit level. While federal law requires the assistance be provided only to "needy" families, there is no legal definition of "need." Further, each state determines what assets and sources of income are to be considered when making an eligibility determination. It is this flexibility that has ensured that direct cash payments from private funding sources have not been counted as income for TANF eligibility determinations in many states. It is also this flexibility that makes a multistate study, such as Pediatric RISE, complicated.

As there is no standardized definition of need and each state determines criteria for calculating eligibility for TANF participation within the state, the Pediatric RISE team needed to understand each state's legislative and regulatory landscape for its TANF program. In some states, the cash transfers made as part of the Pediatric RISE study are not considered income for the purposes of determining TANF eligibility per legislation or regulation. In other

states, legislation or regulation demands that the cash support be considered income when determining TANF eligibility, potentially resulting in a loss of benefits. In several states, public benefit agencies were supportive of granting an exemption for Pediatric RISE but found that they were unable to do so under their existing program regulations. In some cases, the benefit agency determined that a legislative change would be required to move forward.

Several of the mechanisms that have been identified to exclude cash transfers from income and resource limits for public benefit programs require administrative action by state benefit agencies to implement. For example, the exclusion mechanism used for SNAP ([7 CFR 273.9\(c\)\(19\)](#)) requires not only that the state exclude the income for TANF (see above) or Medicaid purposes, but that the state also opt to extend this exclusion to their SNAP program and amend their SNAP State Plan of Operation to provide description of the exemption. This highlights a second area of challenge – familiarity with and willingness to engage with cash transfer exemptions.

The Pediatric RISE team found that bandwidth and willingness were critical factors in whether states ultimately approved exemptions for the study. States that had some experience with direct cash programs and had already taken administrative actions such as updating their SNAP plan were more likely to approve the study's exemption requests.

When exemptions were already present in existing regulations and did not require additional state action to implement, the Pediatric RISE team typically requested the state's public benefit agencies review the study to confirm that the identified exemption(s) could be applied to the cash transfers. The team determined that this was necessary in most cases so that the study 1) could provide verified benefits information to families to help them make informed decisions about their participation in the study and 2) had documentation of the exemption on file if case study participants experienced negative impacts to their benefits after their receipt of cash support (see communication section below).

These program reviews required time both on the part of the benefit agencies as well as the Pediatric RISE team. Some states had set up formal processes for program reviews. In many cases, this streamlined the approval process. In another case, this ended up introducing layers of bureaucracy and extended the approval process significantly. In addition to the direct coordination with the benefit agencies, the Pediatric RISE team spent significant time consulting with experts in the field (to include a certified benefits counselor, a lawyer with the

[Harvard Center for Health Law and Policy Innovation](#), and other direct cash program administrators). The team spent further time researching the applicable laws and regulations governing potential exemptions to submit with each request, developing supporting documentation about the program, and identifying the administering benefit agencies and best points of contact to receive the request in each state. So far, the Pediatric RISE team has engaged with 13 states, including two to four benefit agencies per state, and two federal agencies regarding public benefit exemptions.

A few states, notably [California](#) and [Wisconsin](#), have issued broad administrative memos outlining exemptions that can be applied if direct cash programs meet certain criteria, eliminating the need for individual program reviews by their public benefit agencies. While this is a new approach, it holds promise in increasing efficiency.

In cases where legislation is required in order to move forward with an exemption, states may be restricted from implementing necessary legislation by the timeline imposed by the study, despite a desire to exclude the cash transfers so that families are able to participate.

The Burden of Communicating Exemptions Often Borne by Benefit Recipients

When developing Pediatric RISE, the team noted that communication of public benefit exemptions to frontline benefit eligibility workers would be critical for the successful application of these exemptions to study participant casefiles. The team anticipated that many benefit eligibility workers would not be familiar with cash support programs and the potential exemptions that may be applicable.

When state benefit agencies approved public benefit exemptions, they shared this information with their staff in a variety of ways. Some agencies issued formal memos that the Pediatric RISE team could provide to participants to share with eligibility workers; in other states or agencies, the team had to rely on email communications. This variability in approach required the development of state-specific documentation for study participants to mitigate the accidental counting of the Pediatric RISE cash support for public benefit programs. The documentation included an enrollment letter participants could use to show that the cash support came from the Pediatric RISE study and state-specific references to benefit regulations and exemption approvals for each of the applicable public benefit programs.

In addition to the time required by the Pediatric RISE team to create these state-specific documents and protocols, the onus of educating frontline staff and ensuring receipt of all benefits for which they were eligible was placed on families coping with their child's recent cancer diagnosis and chemotherapy treatment schedule.

Enrollment and Recertification Processes Vary

Public benefit programs vary with regards to how often people are required to report changes to their income. For some public benefits, such as TANF, people may be required to report any income changes in as little as 10 days from the date of the change. For other benefits, such as the Child Care and Development Block Grant (often referred to as the childcare subsidy program), income changes may only need to be reported if gross household income exceeds a certain threshold, or if benefits are being renewed. Reporting requirements may also vary within the same public benefit program. For example, some state SNAP programs have different reporting requirements based on the circumstances of a household or how the household qualifies for SNAP (McConnell et al., 2024).

Reporting requirements can also differ between states. For example, 31 states have adopted simplified reporting requirements for their SNAP program, requiring that only certain changes are reported between interim reports or recertification periods, while 19 states use a combination of change reporting and simplified reporting, and three states use unique or other combinations of these reporting systems (McConnell et al., 2024). Public benefit agencies in different states also provided differing feedback to the Pediatric RISE team as to whether Pediatric RISE cash support needed to be reported at all if they determined that it was exempt from consideration as income (non countable). This variability in reporting requirements is confusing for families to keep track of, particularly families who are new to receiving public benefits or who receive multiple public benefits that have different reporting requirements.

For states in which the Pediatric RISE cash supplements were not excluded as income or in which the payments were excluded but still needed to be reported, the team ensured that study participants understood their reporting requirements so that they did not experience any negative repercussions. Researching and confirming the reporting requirements for each public benefit program in each state of operation again involved an investment in staff time

and resources, and once more put additional requirements on families already under emotional, medical, and financial stress.

Exclusion from the Pediatric RISE Program Was Deemed Necessary for Some Benefit Recipients

Children who receive Supplemental Security Income (SSI) are excluded from the Pediatric RISE study as the program was unable to ensure that SSI benefits would continue during the time in which the family received additional income.

In 2024, the Social Security Administration released an FAQ regarding direct cash and SSI benefits. As noted in the FAQs, for the purposes of SSI, income is defined as any item an individual receives that can be used to meet their need for food and shelter. This includes earned and unearned income, and different rules apply to each category ([42 U.S.C. § 1382a](#)). As the Pediatric RISE program is privately funded and does not meet the definition of any existing income exclusions, the direct cash transfers would reduce or eliminate any SSI benefits the child receives.

Discussion and Implications of the Study

While the Pediatric RISE study's premise is simple – does providing unrestricted cash payments to low-income families with a child receiving treatment for cancer improve the health outcomes and reduce the likelihood of recurrence or death? – the ability to test the premise has been complicated by a patchwork of laws, rules, and regulations that are inconsistent across states. Given the reality that childhood cancer is a rare disease, the ability to study Pediatric RISE nationally will be a critical next step in determining the impact and potential promise of this intervention. As the Pediatric RISE program is implemented in more hospitals, it has become apparent that the current public benefits system poses significant challenges in implementing the intervention at scale. Learnings to date include:

- Families receiving Pediatric RISE cash support will experience different impacts to their public benefits depending on where they live. This means that some families who decide to participate in the study will not be able to access other financial supports that would normally be available to them as they experience a financial shock during this critical time in their lives.

- The variability in public benefit exemptions granted by states complicates the ability of the Pediatric RISE study to measure the impact of *additional cash supports* on the health outcomes of pediatric cancer patients in families with low incomes, the primary objective of the study.
- The burden placed on families receiving public benefits is significant. While participating in Pediatric RISE, families will have to calculate risks and benefits to make decisions about the potential loss of public benefits and when and how to report the cash transfers *all while caring for a child with a newly diagnosed life-threatening illness* and navigating cancer treatment. In one state, the potential risk to Medicaid coverage was so great that the Pediatric RISE team determined they could not responsibly include families who reside in that state in the study as the risk of losing Medicaid insurance while the child was receiving chemotherapy would have catastrophic financial repercussions for the household.
- The familiarity with cash transfers, bandwidth, and willingness of states to engage in discussions and implement public benefit exemptions can vary among and within states based on many factors, including other state priorities and political leadership at the local, state, and federal level. This variability is not conducive to the implementation of studies that are conducted over multiple years and across multiple sites.
- The staff time, resources, and expertise required to navigate the current public benefits system and implement a cash support study on a multi-state scale is exorbitant and may prevent the implementation of innovative studies.

Conclusion

The Pediatric RISE study highlights the need for a broad approach when considering benefits protection for clinical studies. The Pediatric RISE team proposes a solution in which any income received from an approved clinical trial, whether provided as an intervention or as compensation for participation in the trial, be exempted for the purposes of income and asset eligibility for all means-tested federal and federally assisted programs, including state and local programs receiving federal funds.

Eliminating the need for a resource intensive, state-by-state process to obtain public benefit exemptions for study participants would enable clinical trials like Pediatric RISE to scale up and conduct research at a faster rate, accelerating the development of interventions supporting the most vulnerable in our society. It may also introduce new opportunities for “agencies to streamline coordination among [public benefit] programs” and pursue cross-agency research that captures “the potential for programs to work together to meet people’s needs more holistically” - a worthy objective for any government system (Macartney & Ghertner, 2023).

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