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When Do We Lose Whom? Insights into Lost-to-Follow Up Hearing Screening Population Differences

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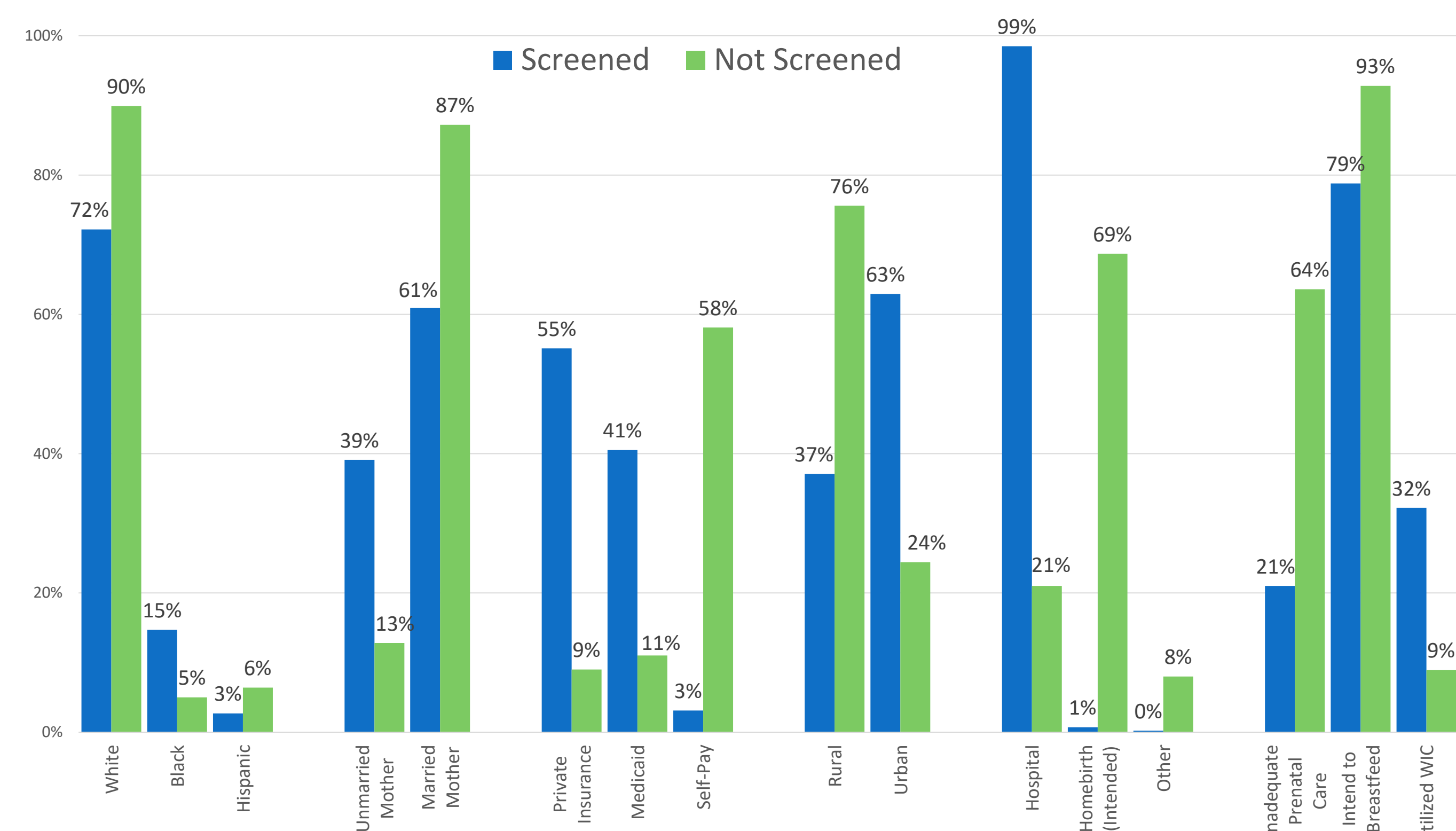
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Background and Methodology

In the United States, between two and three children out of every 1,000 are born with a detectable level of hearing loss in one or both ears.¹ Children affected by hearing loss may struggle to reach developmental milestones, particularly with speech, language, and social skills.^{2,3} Thus, unidentified hearing loss is considered a developmental emergency. For this reason, the Joint Committee on Infant Hearing (JCIH) established the 1-3-6 Benchmarks.⁴ However, despite ongoing efforts, children still do not always meet these benchmarks. This study evaluates traits of those who did not meet these first two benchmarks to try to identify areas for improving the percentage of children who successfully meet these standards.

Data from the Missouri Early Hearing Detection and Intervention (EHDI) program was supplemented with Missouri vital records data regarding the birthing mother using a deterministic linkage based upon the birth certificate state file number for the year 2020. The first group evaluated was those who did not receive a screening exam. Children were counted in this group if they were living but lacked a screening result in the Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC) system. The second population of interest was those who had been referred for diagnostic testing but had no documented diagnosis in the MOHSAIC system.

Screened vs. Not Screened



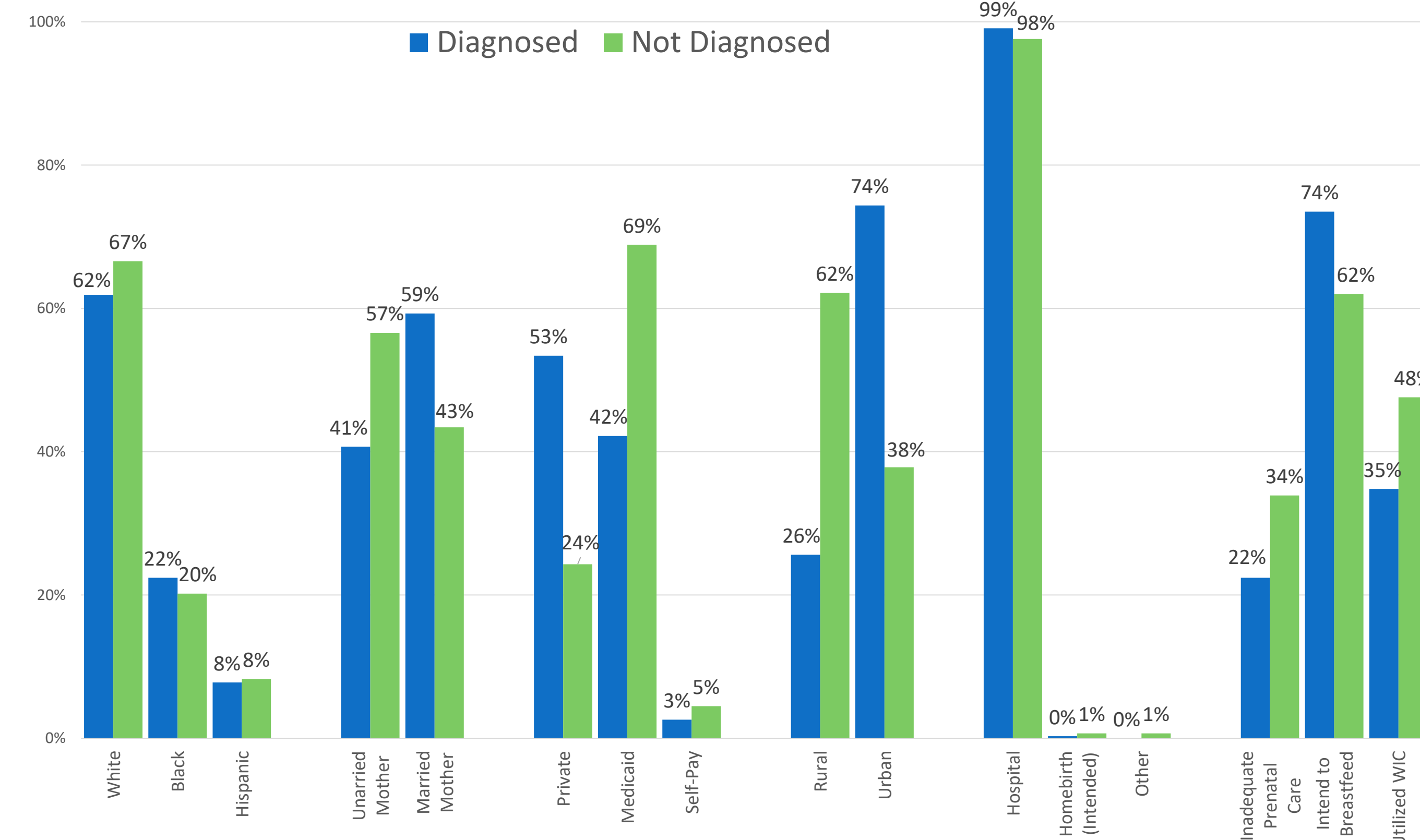
Comparing those who missed their screening with those screened:

- Overrepresentation of white babies
- A greater proportion were married
 - 87% compared with 61% of general population
- Majority were self-pay births
- Majority lived in rural counties
- Majority had intentional homebirths
 - 67% of all intentional homebirths
- Majority reported having inadequate prenatal care
- A greater proportion intended to breastfeed their newborn
- Minority utilized WIC
 - 9% compared to 32% of general population

Received Diagnosis vs. Not Diagnosed

Comparing those who did not receive a diagnosis with those who did:

- No major differences by race/ethnicity
- Majority were unmarried
 - 57% compared with 39% of general population
- Majority lived in rural counties
- No major place of birth differences
- A greater proportion utilized WIC
 - 48% compared with 32% of general population
- A lower proportion intended to breastfeed their newborn
- A greater proportion had inadequate prenatal care.
 - 34% compared with 22% of general population



Two Different Populations

Race/Ethnicity

- Those lost at screening showed an oversampling of white babies.
- Those lost at diagnostic were somewhat more racially diverse than the general population.

Marital Status

- The majority of those lost at screening were married.
- The majority of those lost at diagnostic were unmarried.

Insurance at Time of Birth

- The majority of those lost at screening were self-pay.
- The majority of those lost at diagnostic utilized Medicaid.

Rurality

- The majority for each group resided in rural counties.
- A greater proportion of those lost at diagnostic were urban than those lost at screening.

Location of Birth

- Homebirths made up the majority of those who were lost at screening.

WIC Utilization

- A larger proportion of those lost at diagnostic utilized WIC.
- A smaller proportion than the general population utilized WIC when lost at screening.

Intention to Breastfeed

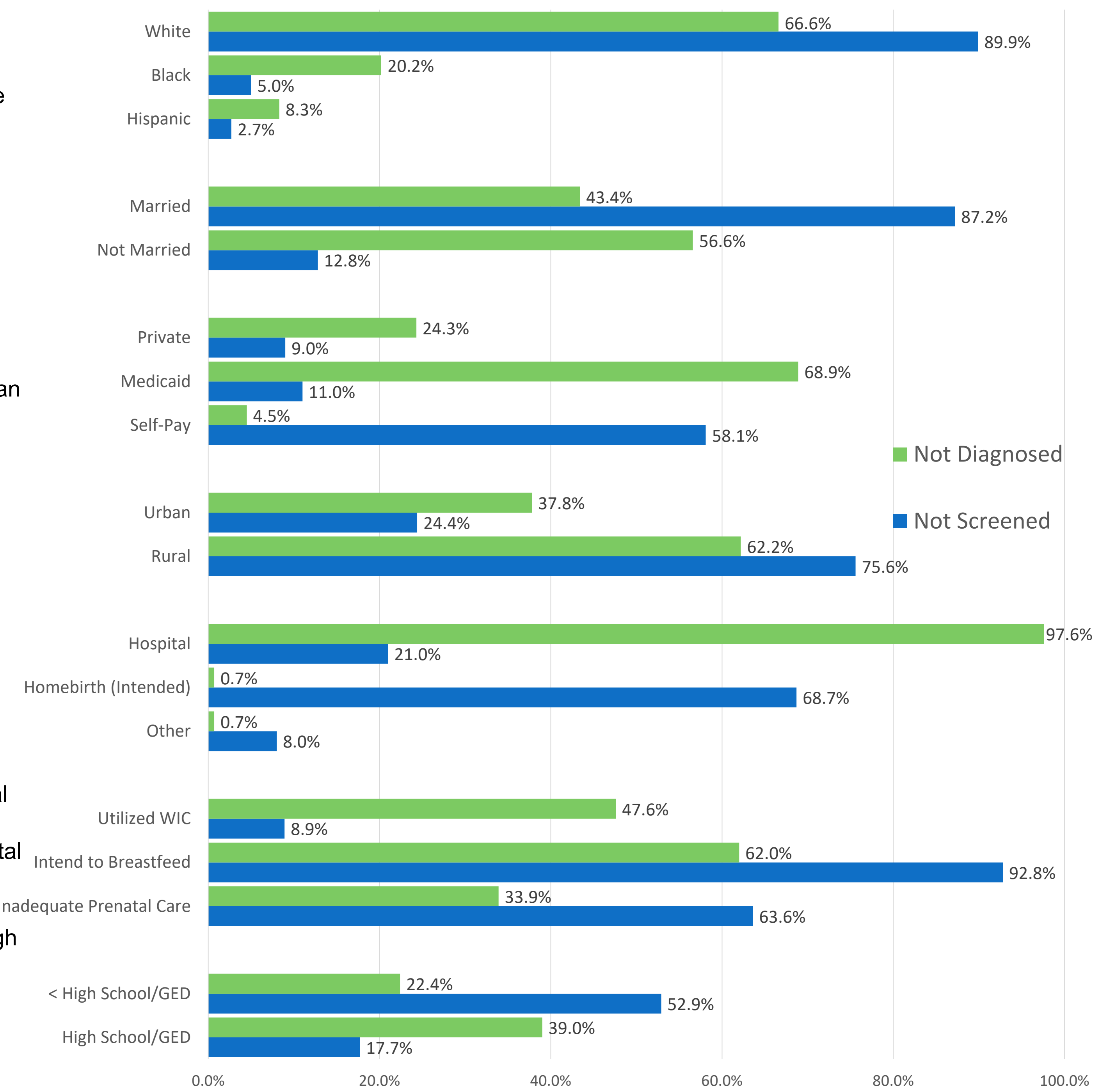
- The majority intended to breastfeed for each group.
- A greater proportion intended to breastfeed when lost at screening than lost at diagnostic.

Prenatal Care Adequacy

- The majority of those lost at diagnostic had adequate prenatal care.
- The majority of those lost at screening had inadequate prenatal care.

Education

- Maternal education when lost at screening was majority < High School or GED (51%).
- The greatest proportion of maternal education when lost at diagnostic was High School graduate or GED (39%).
- The greatest proportion of maternal education in the general population was an Associates degree or higher (41%).



Conclusions

The data supports the hypothesis that there are significant differences between these populations. As such, a more tailored approach is necessary in attempting to reach those who are lost-to-follow up at different stages. These populations differ in where they are born, the services they utilize, and their social support structures. Insights from this research, such as the need to target efforts to improve hearing screening within the home birth population, will guide the Missouri EHDI program as they work to develop new partnerships and enhance existing ones, seeking to meet these families where they are and to help them obtain the care they need.

Public Health Implications

Enhancing the information available for those who are considered lost-to-follow-up helps provide a better understanding of who the Missouri EHDI system is losing and when the system loses them. By focusing messaging to reach those who are at higher risk of becoming lost-to-follow-up, the Missouri EHDI program anticipates a reduction in those numbers, thus improving outcomes for the deaf and hard of hearing population in Missouri.

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