



HFS

**Illinois Department of
Healthcare and Family Services**

JB Pritzker, Governor
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To the Honorable Members of the Illinois General Assembly:

In compliance with the requirements set forth in the Data Governance and Organization to Support Equity and Racial Justice Act (20 ILCS 65 et. al) (the “Act”), the Department of Healthcare and Family Services hereby submits a progress report detailing the programs and data that have been cataloged for which the demographic categories described in Section 20-15 of the Act have been standardized and, to the extent possible, the data sets and programs that are planned for the coming year.

The Act requires the Department of Healthcare and Family Services (HFS) to report statistical data regarding demographics of program participants for each major program administered by the Department.

While “major program” is not defined in the statute, the agency has adopted the following definition provided by the Governor’s Office of Management and Budget: a major program is a program with an enacted appropriation of greater than \$1 million in a fiscal year; direct services provided to individuals and/or a reasonable expectation that demographic information can be aggregated via proxy data without substantial cost or disruption to program delivery.

Using these definitions, the Department has identified the following programs and program participant populations for analysis:

Medical Assistance
Child Support Services

Since the July 2024 statistical report, the Department has taken the following actions to assess the changes needed to catalog demographic data for each of the aforementioned programs.

- While additional effort may be necessary to define and standardize some demographic data across the programs, the Department already collects many demographic disposition statistics from our customers on a voluntary basis. Following its initial progress report, the Department has determined that age, sex, disability status, and primary or preferred language have been defined and standardized for the Medical Assistance and Child Support Services programs. This data is consistently used to inform Department decision-making

and has served as a major input to several recent equity-driven projects such as long-term care reform, healthcare transformation, managed care pay for performance metric reporting, and child support interest payment elimination.

- The Department is working to develop collection of required demographic data not currently received such as sexual orientation and certain race and ethnicity categories. Please note, while most race and ethnicity data are already collected for each major program, further standardization of specific race and ethnicity categories across the major programs is needed.
- In the coming year, the agency will utilize the Office of Equity's guidance to further refine and standardize definitions for the remaining demographic categories and ensure standardization exists across all programs identified in this report. The Department will work with the Department of Innovation and Technology and the Governor's Office of Management and Budget in the coming months to streamline its data collection and collect the relevant data from major program participants.

Since the initial progress report, the Department has outlined the following technical and paper process changes required to streamline data collection and reporting on major program participants. This multi-year project will impact various areas of the agency.

- HFS continues to work with system development contractors to identify contractual costs associated with the implementation of new collection processes for the enhanced demographic dispositions required by the Act, such as programming and training needs, data collection forms, data management staffing needs, modifications to program structure, and new database or interface changes.
 - The new Child Support EPIC system is estimated to be operational in June 2026. The new ERJA demographics and dispositions have been added to current EPIC project reporting and information-gathering requirements. Absent further changes to ERJA data capture requirements, EPIC contract deliverables currently allow these changes to be added at a minimal cost.
 - For the Medical Assistance Program, the Integrated Eligibility (IES) and the Illinois Medicaid Program Advanced Cloud Technology (IMPACT) systems may require additional program contractual costs to collect enhanced demographic disposition data. Modifications to program structure will be needed. HFS continues to work with system development contractors to identify the contractual costs associated with modifications to IES and IMPACT. Please note, IMPACT is not yet

operational and, therefore, making the changes only to the new system will result in data not being captured until the go-live date.

As the State works to implement the Act, Department data stewards, information and technology staff, and diversity, equity, and inclusion leaders will work with the Department of Innovation and Technology and the Governor's Office of Management and Budget to analyze currently cataloged data, identify data gaps, and determine how to collect demographic information. While the Department may request specific demographic disposition data from clients in order to comply with the requirements of the Act, in some instances responses will be voluntary since submission of certain information is not federally required for eligibility determination. Ultimately, we hope to provide valuable data and analysis that will be meaningful and inform program design and policy-making endeavors.

Very Sincerely and Respectfully,

A handwritten signature in cursive script that reads "Elizabeth M. Whitehorn, M.D.C.". The signature is written in black ink and is positioned above the printed name.

Elizabeth M. Whitehorn

Director

Illinois Department of Healthcare and Family Services