



HFS

Illinois Department of
Healthcare and Family Services

JB Pritzker, Governor
Elizabeth M. Whitehorn, Director

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Date: June 28, 2024

To: Honorable Members of the Illinois General Assembly

From: Elizabeth M. Whitehorn, Director
Illinois Department of Healthcare and Family Services

Re: Data Governance and Organization to Support Equity and Racial Justice Act
Section 20-15(a) Report

This report is issued pursuant to the provisions of Section 20-15(a) of the Data Governance and Organization to Support Equity and Racial Justice Act (“the Act”) (20 ILCS 65/20-1). The Act requires the Department of Healthcare and Family Services (“the Department”) to report statistical data on the racial, ethnic, age, sex, disability status, sexual orientation, gender identity, and primary or preferred language demographics of program participants for each major program the Department administers.

Introduction

In the first annual March Data Governance and Organization to Support Equity and Racial Justice Act Report, the Department identified the following major programs and corresponding participant populations for analysis:

Medical Assistance

Child Support Services.

For each major program, this report will provide statistical data where available for each of the demographic dispositions enumerated in the Act: race, age, sex, disability status, sexual orientation, gender identity and primary or preferred language.

Section 20-15(e) of the Act states “if the Board or Department is unable to begin reporting the data required by subsection (a) by July 1, 2022, the Board or the Department shall state the reasons for the delay under the reporting requirements.” As of the date of this report the Department is unable to begin reporting the following data: indigeneity, gender identity, sexual orientation, and specific race and ethnicity categories identified in the Statistical Data section.

The Department has taken steps to assess currently catalogued demographic data for each of the aforementioned programs. Following its initial assessment, the Department has determined that additional work needs to be done to define and standardize the demographic categories enumerated in the statute.

While additional effort may be necessary to define and standardize some demographic data across the Department's programs, the Department already collects many race, ethnicity, and other equity 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.

Change Management Efforts and Potential Challenges

The Department is working to develop collection of required demographic data not currently received. These ongoing efforts include continued work to develop collection of indigeneity, gender identity, 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. The Department will also 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 and 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.

Moreover, the Department has identified other areas that will help to streamline data collection and reporting on major program participants. They include:

- A new Senior Public Service Administrator position charged with directing all aspects of the ERJA change management process; assisting with information gathering on technology and non-technology changes necessary to fully implement the collection of enhanced demographic categories and dispositions; and serving as the HFS liaison to the Governor's Office of Equity in connection with the ERJA.
- Continued 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 Child Support Enforcement and Paternity for Illinois Children (EPIC) system is estimated to be operational in 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. Please note, EPIC 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.
 - Regarding 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 catalogued 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, the Department will work to provide valuable data and analysis that will be meaningful and inform program design and policy-making endeavors.

Methodology

The information contained in this report is based solely on the data provided by program participants and collected by programming personnel for the various major programs. The data provided by program participants has not been audited for completeness and quality, therefore, no baseline for comparison has been established.

For the purpose of this report, the Department has adopted the following definition of "major program" 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. Programs with anonymous reporting of violations, those which utilize tele-help lines, and regulatory/licensure programs have been excluded from this definition.

The program participants count is the number of distinct individuals that have been identified as program participants regardless of demographic category. For Medical Assistance program participants, available demographic disposition data was obtained from the Medicaid Management Information System (MMIS) for May 31, 2024. The MMIS data was collected from the Department's Electronic Data Warehouse (EDW).

For Child Support Services participants, available demographic disposition data was obtained from the Key Information Delivery System (KIDS) for May 31, 2024.

Statistical Data

The following tables detail statistical data for each demographic disposition, organized by program.

- "x" is used to indicate when a demographic disposition has 10 or fewer people.
- A blank space is used to indicate that data for a demographic disposition is not collected.
- "0" is used to indicate that data for a demographic disposition is collected, but no program participants have selected that category as of when the report was pulled.

Age

Program Name	Program Participants	18 and under	19-24	25-34	35-44	45-54	55-64	65+
Child Support Services	1,002,174	309,440	83,185	179,172	232,783	129,585	49,211	18,798
Medical Assistance	3,492,407	1,483,394	269,291	456,111	365,196	288,638	292,343	337,434

Sex

Program Name	Program Participants	Female	Male	Unknown	Other Category
Child Support Services	1,002,174	509,580	491,115	1,479	
Medical Assistance	3,492,407	1,877,519	1,614,888		

Race

Race	Child Support Services	Medical Assistance
Amer. Indian/Alaska Native	4,415	33,060
Asian/Asian American	6,201	143,363
African American/Black	408,588	827,215
Native Hawaiian/ Other Pacific Islander	0	
Middle Eastern/North African	0	
White/European American	362,098	1,508,720
Hispanic	88,445	7,868
Some Other Race Alone	21,190	183
Two or More Races	0	
No Race Specified	111,237	971,998
Program Participants	1,002,174	3,492,407

Ethnicity

Ethnicity	Child Support Services	Medical Assistance
Latina/Latino/Latinx/Hispanic	88,445	361,953
NOT Latina/Latino/Latinx/Hispanic		1,797,330
Asian/Asian American	6,201	
White/ European American	362,098	
African American/Black	408,588	
Other	21,190	
Unknown/Not Specified	111,237	1,333,124
Indigenous	4,415	
Program Participants	1,002,174	3,492,407

Disability Status

Program Name	Program Participants	Disability Status	
		Disabled Yes	Disabled No
Child Support Services	1,002,174	35,497	966,677
Medical Assistance	3,492,407	569,502	2,922,905

Primary or Preferred Language

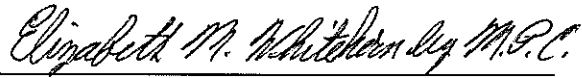
Program Name	Child Support Services	Medical Assistance
Non-English		
Spanish	2,537	218,565
Polish	49	5,884
Chinese (including Mandarin, Cantonese)	X	4,377
Tagalog (Including Filipino)		
Hindi		
Arabic	x	5,668
English		2,136,168
Urdu		1,953
French	X	
Romanian	0	
Russian	X	
Vietnamese	X	
Other	11	3,768
Unknown	999,559	1,116,024
Total Program Participants	1,002,174	3,492,024

*May not add due to use of "x" to indicate 10 or fewer clients

Conclusion

This report is transmitted on behalf of Director Elizabeth M. Whitehorn. For additional copies of this report or more specific information, please contact Michael Casey, Chief Financial Officer, michael.p.casey@illinois.gov, and 217-524-7480.

Very Sincerely and Respectfully,

A handwritten signature in cursive script that reads "Elizabeth M. Whitehorn by M.P.C." The signature is written in black ink and is positioned above a horizontal line.

Elizabeth M. Whitehorn

Director

Illinois Department of Healthcare and Family Services