

Report Summary

Social Security Administration Office of the Inspector General

November 2011



Objective

To evaluate the collection, use, and disclosure of Social Security numbers (SSN) in States' newborn screening programs.

Background

Each year, State Departments of Health (DoH) screen millions of newborns for disorders that require early detection and treatment to prevent serious illness or death. To assist in this process, many hospitals and birthing facilities collect mother and infant demographic information, including the mother's SSN, on the State's newborn screening form. Although no single Federal law regulates overall use and disclosure of SSNs, the *Social Security Act* and the *Privacy Act of 1974* contain provisions that govern disclosure and use of SSNs.

To view the full report, visit <http://oig.ssa.gov/audits-and-investigations/audit-reports/A-08-11-11181>

Collection, Use, and Disclosure of Social Security Numbers in States' Newborn Screening Programs (A-08-11-11181)

Our Findings

Our review of State DoHs' newborn screening programs disclosed that many routinely collected and used mothers' SSNs as identifiers, despite the continuing rise in identity theft. We believe such practices increase the risk of SSN misuse and unnecessarily subject mothers to the possibility of identity theft.

Our review also disclosed that privacy issues or identity theft concerns have led several DoHs to eliminate SSN collection and use in their newborn screening programs. One DoH eliminated SSN collection because of State law. Low compliance rates in providing SSNs, driven by concerns over privacy, led another DoH to eliminate the collection of mothers' SSNs in its newborn screening program.

We recognize that the Social Security Administration (SSA) has conducted outreach efforts to educate such entities as State and local governments. We also believe SSA is well-positioned to encourage DoHs that use SSNs in their newborn screening programs to eliminate this practice and adopt alternate identifiers in their record systems.

Our Recommendations

We recommended that SSA encourage State DoHs to eliminate the collection and use of mothers' SSNs in their newborn screening programs.

SSA agreed with this recommendation.