IMMUNIZATION INFORMATION SYSTEMS
NVAC PROGRESS REPORT
FEBRUARY 2007

Immunization Information Systems
NVAC Progress Report
February 2007

Background

In 1997, NVAC undertook an Initiative on Immunization Registries by forming a workgroup made up of NVAC members and others. The workgroup was charged with identifying barriers to developing and implementing immunization registries, and defining milestones for the development and implementation of a comprehensive plan for the implementation of universal state-based and community-based immunization registries. The workgroup held four public meetings attended by more than 400 persons and received testimony from 104 persons. At the request of the workgroup, the National Immunization Program (NIP)[*] of the Centers for Disease Control and Prevention (CDC) conducted a series of 20 focus groups around the country to obtain views of parents. The result of this activity was the report "Development of Community- and State-Based Immunization Registries" approved by NVAC January 12, 1999.[1]

The report defined immunization registries as "confidential, computerized information systems that contain information about immunizations and children." A Healthy People 2010 goal has been established to increase to 95% the proportion of children <6 years of age who participate in fully operational population-based immunization registries.[2] Many immunization registries have expanded and contain information about persons of all ages. Registries have become known as "Immunization Information Systems" (IIS) and will be so called during the remainder of this report.

The NVAC report identified the vision guiding its recommendations as "a nation with all children appropriately protected against vaccine-preventable diseases" and enunciated the goal of a "nationwide network of community/state population-based registries that are capable of sharing information while maintaining privacy and confidentiality." Four primary objectives were identified and recommendations and action steps were developed for each:
- Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.
- Ensure participation of all immunization providers and recipients.
- Ensure appropriate functioning of registries.
- Ensure sustainable funding for registries.

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[*] In 2006, NIP became a part of the National Center for Immunization and Respiratory Diseases (NCIRD) at CDC. It will be referred to as NIP throughout the body of this report (reflecting past activities) and NCIRD in the recommendations (reflecting future activities).

CDC/NIP published a response to this report in 2001.[3] In January, 2001, NVAC approved a report on the substantial progress that had been made in the nearly-two year period since issuance of the original report.[4] It made a series of recommendations relating to each of the four objectives (Table 1). The remainder of this report will describe progress since 2000 in each of the four areas.

Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.

A great deal of attention has been paid to issues of privacy, confidentiality, and security - to the extent that these have not been major barriers to implementation of IIS. CDC led a team including representatives from the National Vaccine Program Office, state health departments, and the All Kids Count program that developed minimum specifications for protecting the privacy of registry participants and the confidentiality of registry data. After review by privacy consultants and other stakeholders, the report was approved by NVAC in February 2000.[5] Technical assistance has been provided to states to facilitate compliance with minimum specifications and to ensure that IIS that are regulated by HIPAA comply with requirements. CDC has issued guidance on HIPAA and public health[6] and the American Immunization Registry Association (AIRA) has issued a resource document to help IIS be in compliance with HIPAA security standards.[7] Every Child By Two (ECBT), in collaboration with George Washington University, developed a model immunization information sharing statute.[8]

CDC provides support for immunization activities (including IIS) to 64 grantees (all 50 states, DC, Chicago, Houston, New York City, Philadelphia, San Antonio, Puerto Rico, Virgin Islands, and six Pacific island countries or territories) through Section 317 of the Public Health Service Act. According to the 2005 Immunization Registry Annual Report (IRAR), as of December 31, 2005, 50 state or city grantees have written confidentiality policies (47 have been reviewed and found to be in compliance with federal, state, and local legislation) and 52 state or city grantees have written security policies (47 reviewed and in compliance)(Gary Urquhart, CDC, unpublished data, August 23, 2006). Privacy developments at the national level and their implications for IIS are being monitored by CDC.

One area in which there have been difficulties has been in the exchange of information with schools. The Family Educational Rights and Privacy Act (FERPA) provides that "Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions….appropriate officials in cases of health and safety emergencies."[9] Interpretation of FERPA varies among the states but, in general, interpretations have meant that the exchange of health-related information has been one way, with schools receiving health information about students from the public health and health care systems but not providing health information to those systems without prior parental consent.

It is unclear whether records of school clinics maintained separately from the school system and not funded by the Department of Education would be considered part of the "educational record" and therefore subject to the provisions of FERPA.[10]

Ensure participation of all immunization providers and recipients.

Progress in state or city grantee participation is shown below:

	2000	**Dec 31, 2005**
Children <6 participating	21%	56%
Public provider sites participating	38%	75%
Private provider sites participating	19%	44%

As of December 31, 2005, only one state (NH) reported having no efforts to develop and implement an IIS. Nine states, Philadelphia, and New York City reported >95% of children <6 participating in IIS (Figure 1); 23 states and New York City reported >95% of public immunization provider sites participating; and five states and the District of Columbia reported >95% of private immunization provider sites participating in IIS (Figure 2).[11]

In 2005, America's Health Insurance Plans (AHIP) surveyed members about a variety of immunization related activities, including participation in IIS. Of 140 plans surveyed, 61 (44%) responded. 85% of HMOs and PPOs reported that they were currently sharing information with an existing immunization registry in their service area/state.[12] Collaboration among AIRA, ECBT, and CDC promoting data exchange between IIS and health plans resulted in an increase in the number of IIS who exchange data with health plans from 15 in 2002 to 35 in 2004. In addition, 40 IIS provide data to health plans for HEDIS reporting. AIRA and ECBT have developed a practical guide to partnering with health plans.[13]

In 2004, Glazner *et al* conducted a survey of two rural family practices, two rural community health centers, three urban pediatric practices and two rural public health departments to measure labor costs and time for immunization-related activities during both pre- and post-IIS implementation periods.[14] They found that, for private practices and community health centers, total time spent by nurses in all immunization activities (including time spent on IIS activities) decreased from pre-IIS implementation to post-IIS implementation. These findings suggest that participation in an IIS can provide a net benefit by improving the efficiency of the immunization delivery process.

A 2001 national survey of pediatricians and public health clinics found that, although 38% of pediatricians were conducting regular assessments of immunization coverage in their practices, only 16% were currently using routine reminder or recall messages.[15] Among public health clinics, 85% were conducting regular assessment and 51% were

using reminder or recall notices. IIS can readily generate reminder/recall messages although this functionality is not yet being used by many providers at the local level.

In 2002, Clark *et al* conducted a survey of 264 private practices identified as registry non-participants and 971 practices identified as registry participants in 15 states with population-based statewide IIS.[16] Overall response rate was 62%. Participants primarily used the registry to input data on vaccines administered, to review immunizations records of individual patients, and to print immunization records for patients. Few reported using the registry to assess immunization coverage for the practice or generate reminder/recall notices. Few reported any significant problems in using the registry. Nearly half (48%) interacted with the registry via internet, 36% submitted hard-copy data by mail or fax; 19% used modem connections; 10% reported more than one mode of interaction.

Among non-participants in the Clark survey, the most frequently cited reasons for non-participation were: too much cost/staff time to participate (38%), practice has its own system for recording and monitoring immunizations (37%), practice has not yet been recruited for or told about the registry (22%), and registry not compatible with practice's computer system (21%). Factors most frequently cited by non-participants as being essential to participation included compatibility of registry technology and office computers (48%), automated data entry (46%), and on-site technical assistance from registry staff (33%).

In 2004-2005, AIRA surveyed IIS around the country to identify barriers to provider participation in IIS and strategies that had been successful in overcoming the barriers. The results were published in "Turning Barriers into Opportunities: Survey and Best Practice Report."[17] Of a list of 32 previously identified challenges to provider participation, more than 50% of the 55 respondents listed nine barriers as either highly or somewhat significant. These challenges were consolidated into a roster of six for purposes of displaying best strategies to overcome them (Table 2).

The American Academy of Pediatrics has recently issued a new policy statement on IIS that, in summary, states:
> "The American Academy of Pediatrics continues to support the development and implementation of immunization information systems….Pediatricians and others must be aware of the value that immunization information systems have for society, the potential fiscal influences on their practice, the costs and benefits, and areas for future improvement."[18]

In its new "General Recommendations on Immunization," the Advisory Committee on Immunization Practices (ACIP) states, in part:
"IIS are a critical tool that can increase and sustain increased vaccination coverage by consolidating vaccination records of children from multiple providers, generating reminder and recall vaccination notices for each child, and providing official vaccination forms and vaccination coverage assessments. A fully operational IIS also can prevent

duplicate vaccinations, limit missed appointments, reduce vaccine waste, and reduce staff time required to produce or locate vaccination records or certificates."[19]

Ensure appropriate functioning of registries.

Minimum functional standards for immunization registries were developed by a Technical Working Group in 1997 and adopted, in slightly amended form, by NIP in 2001 (Table 3).[20] These standards have been used as the basis for further development and implementation of IIS. As IIS have matured and evolved to meet new public health needs, functionality has been increased and the tracking of immunizations for older age groups has been included. To address these new uses of IIS, it may be necessary to expand the core data set endorsed by NVAC in 1995.[21] Modifying elements in the core data set will empower IIS to capture information more uniformly and exchange it consistently with clinical systems and other IIS. Modifications to the IIS core data set could ensure better support for coverage assessment studies (such as the National Immunization Survey), measure disparities for key demographic groups, and increase tracking effectiveness in IIS operations such as reminder/recall, outbreak control, and vaccine inventory control.

In late 2001-early 2002, the NIP Immunization Registry Support Branch went through an extensive strategic planning effort involving approximately 50 stakeholders. The effort resulted in enunciation of ten focus areas, 13 goals, and 22 objectives (Appendix 1) to be achieved by 2007. The plan is currently guiding ISRB activities.

To stimulate improved performance and functionality of IIS, CDC/NIP required a detailed business plan in 2006 applications for IIS funding through Section 317. The plans summarized operational and financial objectives and indicated how the objectives were to be achieved. The plans will also assist CDC in monitoring IIS project activities and providing additional technical assistance to those requiring it, with priority placed on those with very low IIS child participation rates.[22]

In response to earlier NVAC recommendations, NIP established a Technical Work Group to develop approaches to objectively measure IIS performance against the twelve registry functional standards as a step toward certification of IIS. The Work Group developed a set of proposed evaluation criteria[23] and pilot tested them in three volunteer sites. These results identified concerns in the area of message processing through the use of the Health Level Seven (HL7) protocol and in data quality tracking and monitoring. Since the pilot testing, ongoing efforts including large-scale roll out and implementation of IIS certification have been delayed.

Reflecting the emphasis on adopting HL7 as a standard for exchanging information, the number of IIS that can receive and process HL7 query messages or vaccination records has increased from 7-8 in 2000 to 25 in 2005. The use of the HL7 standard promoted the exchange of several thousand record exchanges following Hurricane Katrina (see below).

Since 2003, NIP has provided supplemental support to relatively advanced IIS to achieve higher standards of data quality and to routinely analyze IIS data for programmatic decision-making. Michigan and Arizona are the two IIS Sentinel Sites receiving continuing support to monitor real-time trends in immunization; determine how events have affected immunization acceptance; answer questions concerning specific vaccines; and monitor data quality in child and adolescent populations. Four other grantees are funded to conduct similar Sentinel Site activities in children <6 years of age.

An important aspect of ensuring appropriate functioning of registries has been the activities of AIRA. AIRA is a membership organization to promote the development and implementation of immunization registries as an important tool in preventing and controlling vaccine preventable diseases. The Association provides a forum through which registry programs, interested organizations and individuals and communities combine efforts and share knowledge that promotes registry activities as a resource for IIS and immunization programs. AIRA goals are:

- To promote and advocate for universal population-based registry standards.

- To contribute to the development and maintenance of immunization registries.

- To advocate for immunization registries through legislation, policy development and public information.

- To build stronger partnerships with and between public and private registries, vendors, providers and federal agencies.

- To collaborate with agencies and organizations, both domestic and international, on issues of concern to immunization registries.

In conjunction with the Association of Immunization Managers (AIM) and CDC/NIP, AIRA formed a Programmatic Registry Operations Workgroup (PROW), which reviewed ways in which IIS can and should support immunization program activities. PROW published a "Standards of Excellence" report, which was endorsed by NVAC in February, 2003.[24][†]

[†] "The NVAC believes the growing maturity and functionality of immunization registries demonstrates they can play an increasingly important and critical role with immunization programs. In particular, the recent joint efforts of the Association of Immunization Managers, the American Immunization Registry Association, and the National Immunization Program have highlighted ways in which registries can provide important support to other core program strategies, such as assessment, vaccine management, reminder-recall, and provider quality assurance. The NVAC believes the CDC should continue working with its partners to identify and disseminate best practices for registry support of an immunization program, such as those found in the Registry Standards of Excellence in Support of an Immunization Program."

Implementation of the Standards of Excellence began in October 2003 with the initiation of a national demonstration project of 13 IIS projects. The experiences of the demonstration sites have been summarized in the document "Centers of Excellence: Lessons Learned from the Programmatic Registry Operations Workgroup (PROW) Demonstration Sites.[25] The standards of excellence have been implemented in 24 immunization programs.

AIRA, in partnership with CDC/NIP, formed a Modeling of Immunization Registry Operations Workgroup (MIROW) to develop a guidebook of best practices for IIS. As a result of a survey of IIS, the first topic selected was to examine how IIS should manage persons who had moved or gone elsewhere (MOGE). Through a facilitated face-to-face meeting and multiple teleconferences, current practices were analyzed and consensus recommendations developed. These recommendations are presented as the first chapter of the emerging "Best Practice" guidebook. The chapter title is "Management of Moved or Gone Elsewhere (MOGE) Status and Other Patient Designations in Immunization Information Systems."[26]

Other useful AIRA products available at www.immregistries.org are:

- IIS-VAERS Collaboration for Vaccine Adverse Events Reporting
- Healthy People 2010 Countdown / IIS Meeting the challenge
- A Perspective on the Next Generation of Connecting for Health
- Do You Have a Fundraising Plan? A Resource Guide for Immunization Registries
- How Immunization Registries Can Make a difference: Advocacy at Your State and Local Level
- Registries and Physicians: Creating a Partnership that Works!

In 2005, CDC partnered with AIRA to conduct a survey to guide development of a research and evaluation agenda for IIS.[27] Thirteen research categories were identified and ranked in order of importance:

1. Provider perspectives and needs
2. Data quality
3. Technical data exchange
4. Increasing provider participation
5. IIS cost and cost savings
6. Benefits of IIS
7. Accuracy of data
8. IIS impact on coverage rates
9. IIS use
10. Non-technical data exchange
11. Real-time data access and input
12. Data sharing between states
13. Factors affecting IIS population-based measurements

In 2005-2006, of the 62 CDC grantees with (or developing) IIS, 19 are using software developed by the grantees themselves. The State of Wisconsin contracted with Electronic Data Systems (EDS) for the applications development of the Wisconsin Immunization Registry (WIR). The Wisconsin Immunization Program has provided the WIR software to 12 entities. Scientific Technologies Corporation (STC) provides software to nine. Envision Technology provides software to seven grantees (KS, NV, and five island grantees). AMCI and HLN Consulting each provide software to three IIS. Altarum (based on MI IIS), and Avanza/Humansoft each provide software to two IIS. Consilience, EDS, the Indian Health Service, TCI, and TRW each provide software to a single IIS, and for two grantees, the vendor is unknown. Thus 21/62 IIS are using software based upon the WIR product or STC.

As documented in the 2001 NVAC report, IIS have demonstrated their utility in improving immunization coverage, supporting vaccine safety, increasing timeliness of immunization, helping providers reach coverage goals, studying effectiveness and efficiency, and keeping managed care records up to date. Since then, many other articles have been published regarding the strengths (and weaknesses) of IIS. A list of published articles about IIS 2001-2006 is found in Appendix 2. Appendix 2 includes the MMWR articles on national progress with IIS published each year by CDC.

Ensure sustainable funding for registries.

The level of federal support for IIS declined in the late 1990s and reached a low of approximately $12 million in 2000 (Figure 3). Estimated funding in FY 2005 was approximately $40.6 million, about the same as in 1997. This total includes funding from Section 317 and from VFC operational funds (~29% of the total).   Although overall Section 317 funds have been increasing, they are having to cover substantially greater increases in funding needs as new vaccines are introduced and other unexpected immunization program demands arise (e.g., Hurricane Katrina, planning for pandemic influenza).

VFC operational funding is being used to support IIS activities but not to as great an extent as initially envisioned by NVAC. As is true with Section 317 funding, VFC operational funding is subject to annual appropriations, and is not an entitlement as is VFC vaccine purchase.

Funding sources for the 56 state or city grantees in 2005 are shown below.

Funding source	Number
Section 317	50
State/local	27
CMS	10
Other federal	11
Emergency preparedness	7

Private	7
Nonprofit	3
Other	2

Medicaid funding to support the development of IIS became available during 2000, but despite strong efforts to promote the development of applications for funding, only 10 immunization program grantees have been successful in receiving funds during FY 2005. These efforts have not been successful primarily for the following reasons:

- Lack of support at state or regional CMS offices;
- Concerns about data ownership and infrastructure;
- A difficult application process.

The 2001 NVAC report called for intensification of discussions with insurers/health plans urging them to provide support for IIS. Financial support for IIS from health plans and insurers has had limited success probably because few IIS were mature enough to meet the data quality and quantity demands of HEDIS. With recent state or city grantee data from 2005 indicating that more than 13 million children (or 56%) <6 years of age with two or more immunizations are participating in an IIS, the situation now looks more promising. Almost 40% (22 of 56 state or city grantees) now report child participation levels of 80% or more and some health plans have started paying providers incentives of up to $250 for each child with a completed immunization history in an IIS. If this practice can be promoted further, health plans get their HEDIS reports for much less cost; immunization coverage increases; providers get incentives to submit data; and completeness of immunization histories in an IIS improves. As noted earlier, 85% of HMOs and PPOs responding to an AHIP survey report they are currently sharing information with IIS.

Cost studies of IIS carried out before the 2001 NVAC report suggested an annual cost of $4-5/child. Since that time, registries have matured and are increasingly web-based, so operational costs may be lower than originally estimated. A recent study assessed the costs in a sample of 24 IIS around the country, stratified by functional status, number of children enrolled, and whether the IIS had been developed as an independent system or was integrated into a larger system.[28] The estimated annual cost per patient record (CPR) ranged from $0.09 - $10.30 in operating IIS. About 20% of IIS had between 2.9-3.2 million records and showed CPR estimates of $0.09. Overall, CPR was highly sensitive to local providers' participation. The authors estimated that an additional $75.6 million would need to be allocated nationwide over the next five years in order to achieve the HP 2010 goal of 95% participation in IIS.

A recently published study found a significant and meaningful association between the level of Section 317 funding and vaccination coverage. One of the important uses of Section 317 funding is to support development and operation of IIS.[29]

There has not been a specific IIS grant program enacted, as recommended by NVAC in 2001.

Newer uses of IIS

IIS and adolescent/adult immunization

Increasing emphasis is being placed on immunization of adolescents, an age group that does not regularly seek preventive care. IIS represent an important tool to identify adolescents due/overdue for immunizations and to generate reminder/recall notices. In 2005, 87% (49/56) of grantees report containing information on adolescents in their IIS. 75% (42/56) report containing information on persons >50 years of age, and approximately 23% of persons in this age group are enrolled in IIS.

IIS and Preparedness

In March, 2006, CDC/NIP surveyed IIS grantees to assess the readiness of IIS to respond to a pandemic flu outbreak. Of 35 respondents, 29 (83%) answered that their IIS will be used for collecting individual vaccine doses administered for pandemic flu. 34/35 indicated that the IIS currently has the capability to collect vaccine doses for all ages. 22/35 indicated that using the IIS to collect flu vaccine data is part of their state pandemic flu preparedness plan.[30]

A dramatic example of the use of IIS in preparedness/disaster response was the experience of the Louisiana Immunization Network for Kids Statewide (LINKS), the Louisiana state IIS. Hurricane Katrina resulted in the flooding of the central office of the state immunization program and IIS in New Orleans. The back-up server in Baton Rouge was up and running within 24 hours. Scientific Technologies Corporation (STC), the software vendor, established a mechanism for allowing other authorized IIS to query LINKS and access information about Louisiana children who had been displaced. In the aftermath of hurricanes Katrina and Rita, LINKS was accessed by IIS in every state in the nation (and five other countries) and provided information in response to more than 55,000 out-of-state queries for records, which were then used for vaccination and school entry. Within Louisiana, there were more than 100,000 successful queries for internally displaced children.[31] Estimates are currently being made of the dollar value of vaccines that did not have to be purchased and administered because there was accurate information available about the immunization status of displaced children.

Although the use of IIS following Hurricane Katrina provides a dramatic example of the utility of IIS, it also underscores the difficulties of interstate data sharing. Grantee IIS are developed using CDC-recommended HL7 guidelines but despite the technical capability for interstate data sharing, individual state laws regarding confidentiality or re-disclosure of data may prevent data sharing in an efficient manner. To address this issue, immunization projects need to enter into individual memorandums of agreement (MOA) with other states in order to allow the efficient transfer of data. Federal approaches to allow the states the ability to share immunization and birth data without having to enter into individual MOAs with other states might rectify this problem.

IIS and vaccine shortages

IIS can be used to evaluate the impact of vaccine shortages, monitor compliance of providers with amended recommendations, and recall children for vaccination once the shortage is over. For example, Allred *et al* used data from the Michigan Child Immunization Registry (MCIR) to assess the impact of the 2004 pneumococcal conjugate vaccine (PCV7) shortage.[32] During the shortage, CDC recommended that providers delay administration of the third and fourth doses of PCV7 to healthy children, in order to allow initiation of the vaccine series in all children.   Data from MCIR showed that PCV7 coverage for both the third and fourth doses fell significantly in the month following the recommendation, even though coverage for the third dose of DTaP and first dose of MMR (which are administered at about the same time and remained in good supply) remained constant. Data also showed that coverage returned close to pre-shortage levels shortly after recommendations to resume the normal schedule.

IIS and interoperability with other health information systems/health information exchanges (HIE)

IIS are among the most mature public health information systems that bridge the public health/clinical care divide. However, as long as they serve the single purpose of monitoring immunizations, their utility will be limited. Since 1999-2000, efforts have been supported by the Robert Wood Johnson Foundation, the Genetics Services Branch (Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Services Administration [HRSA/MCHB]) to integrate IIS with other child information systems, notably vital registration, newborn dried bloodspot screening (NDBS), and early hearing detection and intervention (EHDI). These programmatic areas were selected because they are universally recommended (even mandated), begin shortly after birth, involve both the public and private sectors, and are time sensitive (i.e., poor outcomes may be associated with delays).[33,34] Twenty-one states have been funded and are at varying stages of integration. In this arena, integration refers to the integration of information as it is presented to the user, not to the background hardware or software. A variety of different approaches is being used to accomplish the integration.

At the national level a Framework for Strategic Action in delivering consumer-centric and information-rich health care has been published by the Office of the National Coordinator for Health Information Technology.[35] The President has stated (in 2004) that "Within 10 years, every American must have a personal electronic medical record."[36] Health Information Exchanges (HIE) are being established around the country to provide a means of sharing health information among health care providers, healthcare institutions, and health departments.[37] IIS should play major roles in the design and implementation of these exchanges.

Conclusions and recommendations

Considerable progress has been made since NVAC's 2001 IIS progress report. IIS have demonstrated their effectiveness in improving immunization services and immunization coverage. They have also demonstrated their worth in dealing with

vaccine shortages and coping with disasters. They will be important components of addressing pandemic influenza or other threats and should play major roles in the emerging Health Information Exchanges. Most IIS now have the ability to accept information on persons of all ages.

More than one-half of the nation's children are now participating in population-based IIS and it appears possible to achieve the 2010 objective. However, significant challenges remain, including assuring sustainable funding for IIS and assuring that IIS will be able to communicate with each other and with other information systems, including electronic medical records and health information exchanges.

Recommendations and Action Steps

1. **Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.**

NVAC Recommendations:
1. Continue to ensure that IIS comply with HIPAA and other applicable laws/regulations governing privacy, confidentiality, and security, e.g., PHIN standards.
2. DHHS should work with the Department of Education to ensure that FERPA does not impede the sharing of immunization information among schools, healthcare providers, health departments, and IIS.
3. Federal legislation to establish a minimum set of standards and regulations for inter-state sharing of immunization data would be very helpful.

Action Steps:
1.1. CDC should continue to monitor privacy and confidentiality developments (including legislation) at state and local levels to identify new issues and to resolve existing issues.
1.2 CDC should fund and implement the certification protocol developed by the TWG to ensure that an IIS has implemented written confidentiality policies and procedures, including administrative and technical practices to protect health care information. The policies and procedures should be consistent with applicable federal (e.g. HIPAA), state and local laws and regulations as recommended in the updated "*Community Immunization Registries Manual: Chapter II: Confidentiality,"* except where these specifications conflict with applicable law.
1.3 CDC should develop high-level guidelines to address all privacy, confidentiality, and security concerns regarding IIS release of information.
1.4 IIS partners should establish a working group to determine the feasibility of using the Model Interstate Immunization Information Sharing Statute developed by the George Washington University Department of Health Policy and Every Child By Two as a basis for Federal legislation for inter-state sharing of immunization data.

2. Ensure participation of all immunization providers and recipients

NVAC Recommendations:

1. IIS Research and evaluation activities should be conducted to incorporate health care providers' perspectives and needs into IIS development.

2. Ensure appropriate IIS' that are useful to all providers, both public and private. Providers and interested community groups should be involved throughout registry development and implementation.

3. IIS performance measurements should be developed that demonstrate IIS value to all providers, both public and private.

4. Continue to pursue partnership opportunities with professional organizations and other key stakeholder groups for collaboration on strategies to bring IIS into provider practices, to include incentives for participation.

5. Ensure recipients/parents have easy access to their IIS immunization information.

   Action Steps:
   2.1   NCIRD should continue to collaborate with partner organizations to conduct research on: factors that affect provider participation in and use of an IIS; the effects of legislative and other approaches to increase participation; the illustration of provider use of IIS; and provider outreach as well as IIS evaluation studies.

   2.2   NCIRD should use focus groups of public and private immunization providers or other methods to gather crucial information about attitudes and thoughts related to IIS.

   2.3   NCIRD should promote the use of assessments of private practice needs in developing or enhancing an IIS to ensure that IIS are easy-to-use and convenient systems. These may include added value components such as alternatives to manual data entry and the ability to accept batch data and EMR interfaces.

   2.4   NCIRD should work with IIS stakeholders to design and implement a training plan to include a variety of venues and options for IIS training of providers and other IIS users.

   2.5   NCIRD should work with IIS stakeholders to develop performance indicators that will demonstrate the value of IIS to all providers.

   2.6 NVPO should convene a meeting of representatives of state/local health departments, health insurers, health plans, CMS, professional organizations, and others to deliberate the pros and cons of legislative and other approaches to increase provider participation in an IIS.

3. Ensure appropriate functioning of registries

NVAC Recommendations:

1. Finalize and implement the approach to certification of IIS by promoting third party evaluation of IIS functionality, performance, and data quality assessment.

2. Resolve remaining issues on exchange of information between IIS.

3. Promote integration of IIS with electronic medical records, other health information systems, and Health Information Exchanges.

4. Promote the expansion and utility of IIS. One such expansion might be to include persons of all ages in an IIS.

5. Promote the continued development, implementation, and maintenance of standards pertaining to immunization registries

6. Promote the central role of IIS in response to pandemic influenza or other public health emergencies.

7. Encourage further evaluation and feasibility studies that use IIS data to support national vaccination coverage data needs.

8. Promote enhanced immunization program management by analysis and use of IIS data for program evaluation, quality control, and assessment to meet state and local needs (e.g., outbreak control, VFC functions, up-to-date analyses, new vaccine uptake, identifying pockets of need, vaccine management and inventory functions, school assessments).

9. Collaborate with Office of the National Coordinator on Health Information Technology (ONC) to ensure Immunization Information System reporting standards are incorporated into Electronic Medical Records that receive federal funds or that are certified by the ONC.

Action steps
3.1 NCIRD should further develop IIS certification protocols as program needs or technology evolves; resources should be made available to sponsor, support, and conduct IIS certification.
3.2 NCIRD should support technical and analytic staff at the state and national level to promote the adoption of information exchange standards and technology for immunization needs with medical records systems. As necessary it should encourage vendors for billing systems, patient management systems, and EMRs to negotiate for the development of discount rates for interactions between EMR and IIS interfaces.
3.3 NCIRD should expand the functional growth in IIS in a variety of areas and develop a clear rationale for providers why each new data element is important:
- Include persons of all ages for enrollment and reporting to the system.
- Change the following data variables from optional to required status:
  - patient race/ethnicity;
  - patient birth order for multiple births.
  Add new optional data variables:

- historical vaccination flag indicator;
- VFC eligibility;
- history of varicella disease indicator;
- patient status indicators that include active, inactive, MOGE, and other classifications.

3.4   Promote the adoption of a guidebook and best practices for IIS as started by the CDC/NIP and AIRA/MIROW workgroup to adopt uniform operational guidance and quality control procedures that ensure good data quality.

3.5   Further define essential registry system functions and attributes to support program needs.

3.6   Enable intra- and inter-registry record exchange with standard (e.g., HL7) messages.

3.7   Adopt system security standards to address both technical and administrative issues and to ensure that access is limited to authorized persons

3.8   NCIRD and partners should create IIS educational materials such as guidebooks, and/or training courses to assist IIS programs and program managers with operations promotion, use and management of the IIS

3.9   NCIRD should encourage the adaptation of existing IIS, to ensure that they can provide required information for CDC-developed systems for tracking of persons receiving medical countermeasures during immunization related public health emergencies such as outbreaks of pandemic influenza and smallpox. Specifically, NCIRD should encourage IIS use for appropriate roles in preparedness exercises and drills.

3.10   NCIRD should assess and expand the role of IIS in supporting national immunization coverage methods such as the National Immunization Survey and IIS Sentinel Site projects.

3.11   NCIRD should encourage the use of IIS in support of the Vaccine Adverse Event Reporting System or other adverse event monitoring approaches

3.12   NCIRD should require immunization program grantees to provide an annual report that documents the role of the IIS in support of program functions, such as coverage estimations, role in outbreak control, surveillance, adverse events, VFC functional requirements, and completeness of immunization information on participants in the IIS.. Grantees should use the AIRA PROW document to assist in utilizing IIS data to assist with Immunization program operations.

3.13   NVPO and CDC should convene a meeting with the Office of the National Coordinator on Health Information Technology (ONC) to ensure Immunization Information System reporting standards are incorporated into Electronic Medical Records that receive federal funds or that are certified by the ONC.

3.14   DHHS should pursue approaches that would allow states (and territories) to share immunization and birth data without having to enter into individual Memorandums of Agreement with other states.

4.   Ensure sustainable funding for registries:

NVAC Recommendations:
1. Assure sustaining funding for IIS:
   - Continue and increase support for IIS through the 317 program
   - Increase use of VFC operational funds
   - Increase support from CMS
   - Intensify discussions with insurers/health plans urging them to provide support for IIS (e.g., $5/year/person covered)
   - Develop a 5-year $60 million/year grant program to support further development and initial operation of IIS (this could be handled through a targeted increase in 317 funding).
2. Continue to update and expand studies of costs and benefits of IIS.

Action steps
   4.1   NVPO should convene a meeting of representatives of state/local health departments, health insurers, health plans, CMS, professional organizations, etc., to deliberate the pros and cons of provider performance incentives based on the completeness of immunization data available in an IIS.
   4.2   NVPO should convene a meeting of representatives of health insurers and health plans to develop a statement noting the value of IIS and urging financial support for IIS.
   4.3   NVPO should convene a meeting with CMS to develop and implement guidance for immunization program grantees on how to access CMS funds for IIS development and operations.
   4.4   CDC should expand the sponsorship of research and evaluation studies of costs and benefits of IIS.
   4.5   Congress should assure that CDC has adequate funds and staff to continue to provide leadership and technical support.

Glossary of acronyms

AHIP – America's Health Insurance Plans
AIM – Association of Immunization Managers
AIRA – American Immunization Registry Association
CDC – Centers for Disease Control and Prevention
DTaP – Diphtheria and Tetanus toxoids and acellular Pertussis vaccine
ECBT – Every Child By Two
EDS – Electronic Data Systems
EHDI – Early Hearing Detection and Intervention
FERPA – Family Educational Rights and Privacy Act
HEDIS – Health Plan Employer Data and Information Set
HIPAA – Health Insurance Portability and Accountability Act
HL7 – Health Level 7
HMO – Health Maintenance Organization
HP 2010 – Healthy People 2010
IIS – Immunization Information Systems
IRAR – Immunization Registry Annual Report
LINKS – Louisiana Immunization Network for Kids Statewide
MCIR – Michigan Childhood Immunization Registry
MIROW – Modeling of Immunization Registry Operations Workgroup
MMR – Measles, Mumps, Rubella vaccine
MOGE – Moved Or Gone Elsewhere
NCIRD – National Center for Immunization and Respiratory Diseases
NDBS – Newborn Dried Bloodspot Screening
NIP – National Immunization Program
NVAC – National Vaccine Advisory Committee
ONCHIT – Office of the National Coordinator on Health Information Technology
PCV7 – Pneumococcal Conjugate Vaccine – 7 valent
PHIN - Public Health Information Network
PPO – Preferred Provider Organization
PROW – Programmatic Registry Operations Workgroup
STC – Scientific Technologies Corporation
TWG - Technical Working Group
VAERS – Vaccine Adverse Event Reporting System
VFC – Vaccines for Children
WIR – Wisconsin Immunization Registry

Table 1
Recommendations from December 2000 Report

1. Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.
    a. Continue efforts to ensure that all registries implement policies and procedures that meet minimum specifications for protecting privacy and confidentiality.
    b. Monitor implementation of minimum specifications.
    c. Further explore and develop privacy and confidentiality guidelines for interstate exchange of information.
    d. Continue to ensure that privacy and confidentiality specifications are consistent with evolving HIPAA regulations.
2. Ensure participation of all immunization providers and recipients.
    a. Intensify efforts with major payers and plans to go beyond mere endorsement and obtain commitment to participation.
    b. Continue dissemination of information about the utility of registries.
    c. Continue demonstration of registries' decision support functions at the provider level.
    d. Additional research on the impact of registry use on workflow in providers' offices.
    e. Additional research on the impact of registry use on parents/families.
3. Ensure appropriate functioning of registries.
    a. Continue advocacy and dissemination of the HL7 standards and the ACIP algorithm (perhaps making them required conditions for continued 317 funding).
    b. Finalize and implement approach to certification of registries.
    c. Disseminate information about how registries are being used to improve immunization coverage and immunization practices (this also serves as an important means of recruiting providers).
    d. Continue to provide technical assistance.
    e. Assure quality of data in registries.
    f. Resolve remaining issues on exchange of information between registries.
4. Ensure sustainable funding for registries.
    a. Continue and increase support for registries through the 317 program.
    b. widely promote use of Medicaid funds for registries and monitor implementation; explore possible use of CHIP/S-CHIP administrative funds.
    c. Obtain approval to use VFC operational funds for registries.
    d. Intensify discussions with insurers/health plans urging them to provide support for registries (i.e., $5/year/child covered)
    e. Develop a 5-year $60 million/year grant program to support further development and initial operation of registries (this could be handled through a targeted increase in 317 funding). This is justified by the cost-effectiveness of registries.
    f. Continue to update and expand studies of costs and benefits of registries

Table 2
Summary of Best Practices and Successful Strategies by Barrier

Barrier #1: Cost and/or time of data entry and retrieval
- Include assessment of private practice needs in requirements analysis before development of registry and periodically thereafter.
- Use focus groups representing target participants to gather crucial information about attitudes and thoughts related to immunization registries.
- Design an easy-to-use, web-based system with the added value components that practitioners want.
- Provide alternatives to manual data entry, such as the ability to accept batch data and EMR interfaces.

Barrier #2: Practices are too busy to consider a new procedure and anticipate difficulty integrating registry use into business processes
- Build relationship with key person in practice, communicate consistently and regularly to identify the practice's needs and how the registry can help.
- Work with key person in practice to develop process improvements and office procedures that integrate the registry and allow its use to be a time-savings activity.
- Cultivate trust and partnership with health care community to understand their needs and concerns, building relationships with professional associations, such as AAP, and recruiting influential practices early.
- Develop a communication plan that includes newsletters and other tools that feature providers who have successfully integrated the on-line registry into their work flow.
- Conduct user group meetings that are interactive and encourage sharing information among practices about strategies to integrate the registry.

Barrier #3: Cost and/or time to train staff to participate in registry, including clinic staff turnover
- Provide variety of venues and options for training: onsite/in-person, group/regional trainings, video training on the web or CDs, Webex, on-line manuals, etc.
- Plan for staff turnover in the practices—be ready to provide training to new staff.
- Have CD-ROM or on-line video that educates staff about value of using the registry.
- Provide toll-free *Help Desk* service to assist with specific questions and provide phone training as needed.
- Design training in modules, i.e., view-only, basic, advanced, to fit the needs and time-availability of staff.

Barrier #4: Concerns about privacy, confidentiality, and HIPAA
- Design a parent notification system to inform parents about the registry and their child's inclusion (depending on state law).
- Analyze the HIPAA Privacy Rule in relation to the registry's HIPAA status, having explanatory handouts available to practices.

- Include references to HIPAA and other state and federal laws in registry's provider information sharing agreements.

Barrier #5: Provider does not see any value to their practice
- Ensure stakeholder and user involvement in developing the technical requirements as well as the marketing approach and messages.
- Use focus groups representing target participants to gather crucial information about attitudes and thoughts related to immunization registries.
- Promote registry as a data tool that helps practices save time by reducing number of reports to submit to state, retrieve information quickly, run reminder-recall, etc.

Barrier #6: Issues relating to interfacing with other systems, including working with vendors and cost to providers
- Work with billing/PMS/EMR vendors on behalf of a group of clinics to negotiate for development of export or interface and to get discounted rates.
- Provide funding to cover vendor charges to practices.
- Provide registry staff liaison as point person with vendors and providers.
- Ensure a supportive IT staff backing the registry program, with the skills to deal with the technical side of importing and exporting data.

Table 3
Minimum functional standards for IIS

1) Electronically store data on all NVAC-approved core data elements.
2) Establish a registry record within 6 weeks of birth for each newborn child born in the catchment area.
3) Enable access to and retrieval of immunization information in the registry at the time of encounter.
4) Receive and process immunization information within 1 month of vaccine administration.
5) Protect the confidentiality of health care information.
6) Ensure the security of health care information.
7) Exchange immunization records using Health Level Seven (HL7) standards.
8) Automatically determine the routine childhood immunization(s) needed, in compliance with current ACIP recommendations, when an individual presents for a scheduled immunization.
9) Automatically identify individuals due/late for immunizations(s) to enable the production of reminder/recall notifications.
10) Automatically produce immunization coverage reports by providers, age groups, and geographic areas.
11) Produce official immunization records.
12) Promote accuracy and completeness of registry data.

Table 4
Support for Immunization Information Systems
June 2000

Formal Resolutions:
- AAP (American Academy of Pediatrics)
- AMA (American Medical Association)
- APHA (American Public Health Association)
- AOA (American Osteopathic Association)
- National Medical Association

Letters of Support or Endorsement:
- AAHP (American Association of Health Plans)
- ACPM (American College of Preventive Medicine)
- ASHA (American School Health Association)
- ASTHO (Association of State and Territorial Health Officers)
- IPAVAPP (Informed Parents Against Vaccine Associated Paralytic Polio)
- NACCHO (National Association of County and City Health Officials)
- NAPNAP (National Association of Pediatric Nurse Associates and Practitioners)
- NASN (National Association of School Nurses)
- NSBA (National School Boards Association)
- USDoE (US Department of Education)

Organizations Collaborating With or Supporting Registries:
- Aetna/US Healthcare
- AKC (All Kids Count)
- AMIA (American Medical Informatics Association)
- CIRSET (Committee on Immunization Registry Standards for Electronic Transmission)
- CPRI (Computerized Patient Record Institute)
- ECBT (Every Child by Two)
- Epic Systems
- HCFA/Medicaid (Health Care Financing Administration)
- HL7 (Health Level 7 Standards Setting Organization)
- Kaiser Permanente
- NVAC (National Vaccine Advisory Committee)
- SMS (Shared Medical Systems)

Appendix 1
Immunization Registry Strategic Plan 2002-2007

- Focus Area 1 - Partnerships
  - Goal - Forge new, and strengthen existing, partnerships with IIS stakeholders to implement the plan
    - Objective - Identify all stakeholder organizations and elicit their commitment to work toward Healthy People 2010 IIS objective
- Focus Area 2 - Provider Participation
  - Goal - Promote the use of IIS as a standard practice in the delivery of health services
    - Objective - Identify, develop, and promote strategies to support recruitment and retention of immunization providers participating in IIS
- Focus Area 3 - Education
  - Goal - Educate stakeholders about the use and benefits of IIS
    - Objective - Develop and implement specific strategies for stakeholder education, including developing a central mechanism for sharing educational materials and best practices
    - Objective - Develop and implement specific strategies for internal NIP staff education, including developing a central mechanism for sharing educational materials for ISRB staff
- Focus Area 4 - Data Quality
  - Goal - Have IIS data be the "gold standard" for all stakeholders
    - Objective - Ensure quality data by identifying, developing, implementing, and promoting standardized data quality methodologies
- Focus Area 5 - Data use
  - Goal - Use IIS data for decision making
    - Objective - Identify and promote effective uses of IIS data
- Focus Area 6 - Privacy & Confidentiality
  - Goal - Provide support in the formulation of responses to applicable law
    - Objective - Identify and share laws applicable to IIS
    - Objective - Monitor current federal legislative and rule-making activity that could impact IIS
    - Objective - Assess the extent to which IIS meets privacy and confidentiality guidelines
    - Objective - Identify and address legal barriers to enable inter- and intra-state IIS data exchange
- Focus Area 7 - Technical Capabilities
  - Goal - Promote integrated, secure, easy-to-use immunization information systems that contain timely and quality data

- Objective - Monitor, evaluate, and report emerging industry trends that will influence IIS operations
- Objective - Monitor, evaluate, develop, and share IIS progress and best practices
- Objective - Provide technical assistance to promote the advancement of IIS projects in the US
- Objective - Maintain a set of standards for functioning and using IIS and communicate changes

- Focus Area 8 - Integration
  - Goal - Promote appropriate integration and linkages of IIS in health information systems
    - Objective - Promote active collaboration with all appropriate federal information technology-related projects that can help to advance IIS operations

- Focus Area 9 - Immunization Registry Support Branch Staff
  - Goal - Obtain sufficient staff and accompanying resources to support all objectives of the strategic plan
    - Objective - Assess current staff responsibilities and reorganize to maximize strategic plan support
  - Goal - ensure staff has appropriate skills knowledge, and opportunity to support the objective of the strategic plan
    - Objective - Provide timely training to ensure all staff have technical and programmatic skills needed to support strategic plan objectives
    - Objective - Create an environment that encourages openness and innovation and facilitates sharing of experience and knowledge among branch members

- Focus Area 10 - Funding
  - Goal - Assist projects in obtaining diverse, sustainable sources of funding for IIS
    - Objective - Identify existing and potential funding sources and the processes required to get the funding
    - Objective - Participate in 317-grant review process to affect funding decisions regarding IIS
  - Goal - ensure efficient use of NIP IIS funds
    - Objective - Hold projects accou9ntable for NIP IIS funds awarded
  - Goal - Obtain sufficient funding for ISRB to support goals of the strategic plan
    - Objective - Obtain CDC management support in the budgetary process to ensure sufficient branch funding

Appendix 2
IIS Publications 2001-2007

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Figure 1
Percentage of children <6 participating in IIS
December 31, 2005

FIGURE 1. Percentage of children aged < 6 years participating* in a grantee†
immunization information system-- United States and six cities §, 2005

*Participation is defined as a child having two or more vaccinations recorded in an immunization information system.

†Grantees include 50 states, five cities and the District of Columbia, funded under section 317b of the Public Health Service Act.

§Chicago, Illinois (34%- 66%); District of Columbia (67%–94%); Houston, Texas (34%–66%); New York City, New York (95%–100%); Philadelphia, Pennsylvania (95%–100%); San Antonio, Texas (67%– 94%).

No Report
0-33%
34-66%
67-94%
95-100%

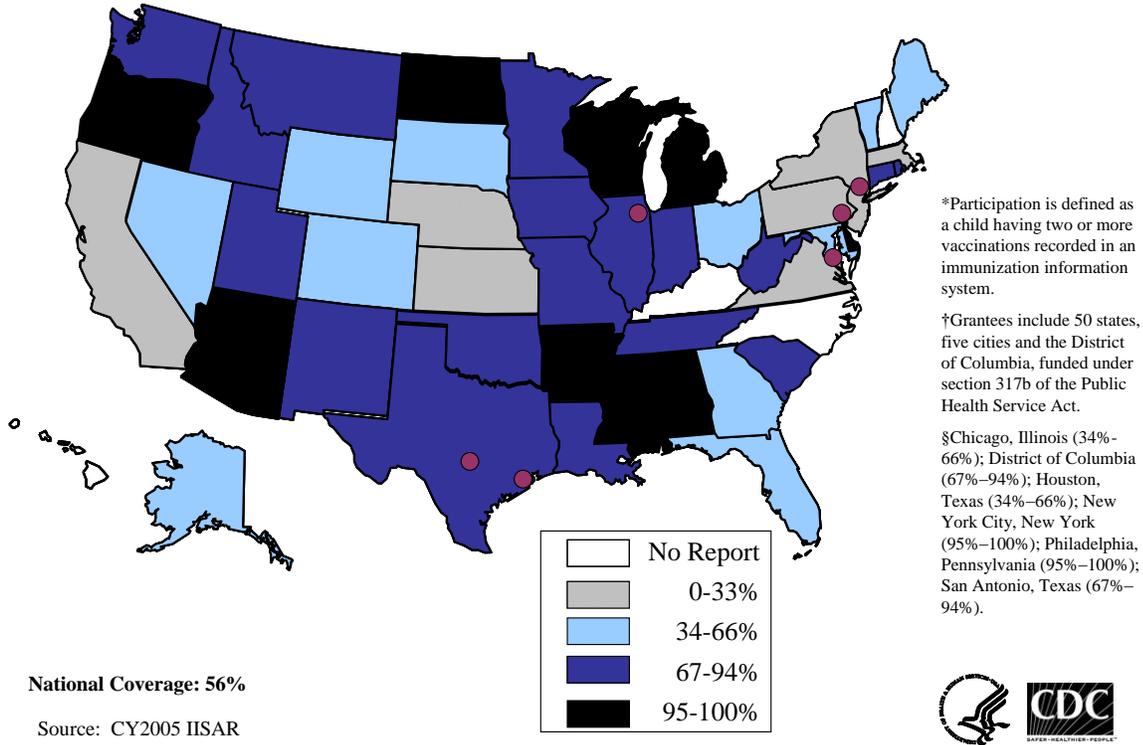**National Coverage: 56%**

Source: CY2005 IISAR

Figure 2
Percentage of private provider sites participating in IIS
December 31, 2005

**FIGURE 3. Percentage of private provider sites participating in a grantee[†]
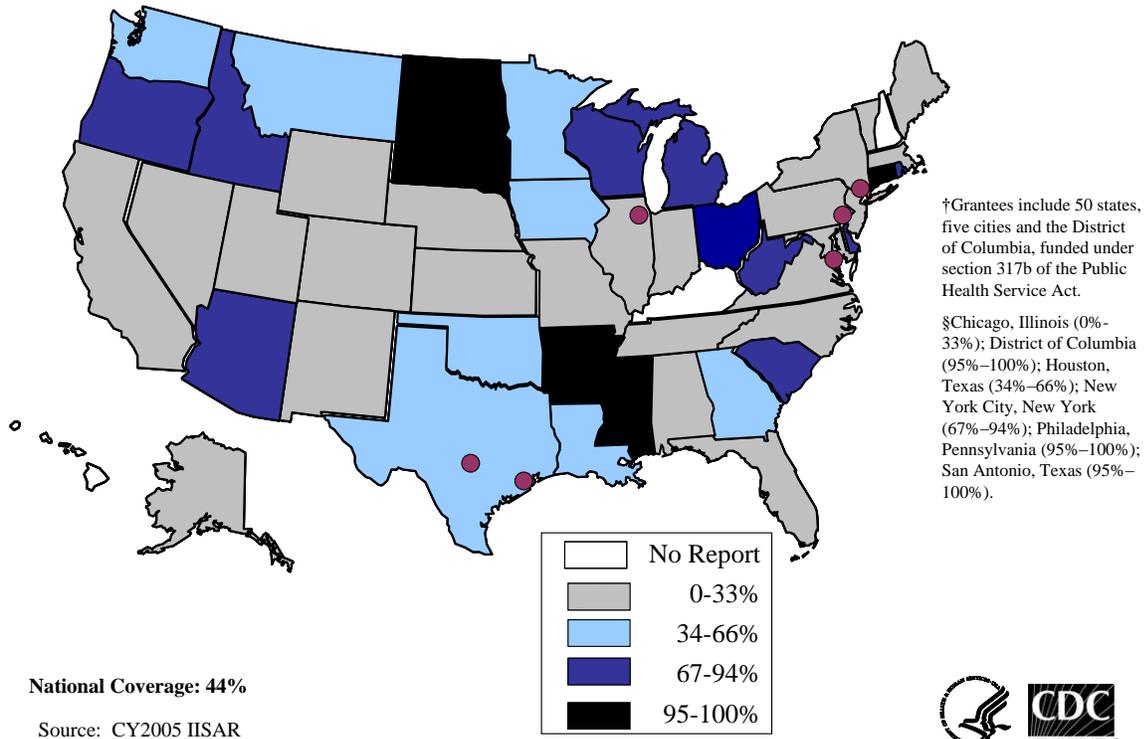immunization information system-- United States and six cities [§], 2005**

†Grantees include 50 states, five cities and the District of Columbia, funded under section 317b of the Public Health Service Act.

§Chicago, Illinois (0%-33%); District of Columbia (95%−100%); Houston, Texas (34%−66%); New York City, New York (67%−94%); Philadelphia, Pennsylvania (95%−100%); San Antonio, Texas (95%−100%).

	No Report
	0-33%
	34-66%
	67-94%
	95-100%

National Coverage: 44%

Source: CY2005 IISAR

Figure 3
CDC funding for IIS, 1995-2005

Estimated 317 and VFC Grant Awards for Immunization Information Systems
1995 - 2005
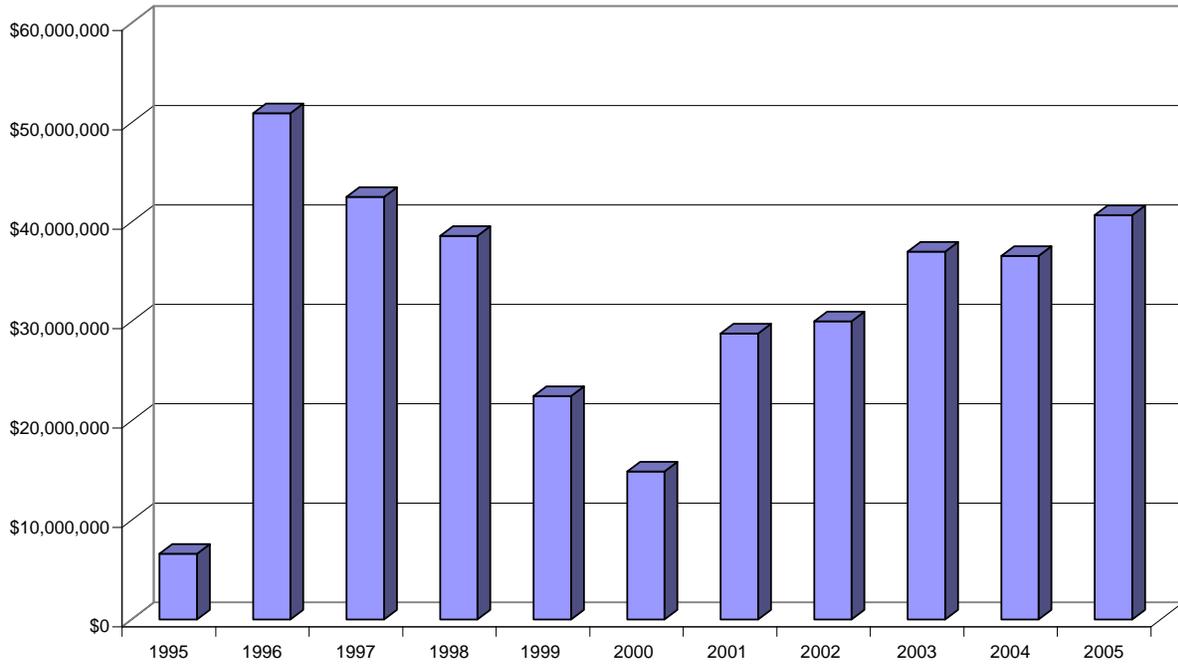
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