

Chapter 31

EHDI Information Management

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Overview

Background

According to the [Joint Committee on Infant Hearing](#) (JCIH, 2007), information management is used to improve services to infants and their families; assess the quality and timeliness of screening, evaluation, and enrollment into intervention; and facilitate collection of demographic data on neonatal and infant hearing loss. Within that broad context, however, there are many systems with varying degrees of effectiveness. [The Centers for Disease Control and Prevention](#) (CDC) have outlined national goals, program objectives, and performance measures for Early Hearing Detection and Intervention (EHDI) tracking and surveillance systems. Goal 6 of the CDC list states that “every state will have a complete EHDI tracking and surveillance system that will minimize loss to follow-up.” *Program Objectives 6.1. Comprehensive System* recommends that each state have a computerized system that maintains current information on hearing screening for every infant, evaluation for

all infants and children who do not pass the screening, and interventions for every infant from birth through 5 years of age with hearing loss.

The number of babies lost to follow-up or lost to documentation has been, and continues to be, a significant concern. The summary of 2007 national CDC EHDI data indicates that 44.8% of babies who did not pass the hearing screening were lost to follow-up or lost to documentation prior to diagnosis. Of the babies with identified hearing loss, 35.7% had no documented enrollment in early intervention programs (CDC, 2007). While some states do better than these figures would indicate, there is still considerable room for improvement in our tracking and surveillance efforts. Babies lost to documentation due to an inadequate system are no less lost than those who do not follow-up for other reasons. Loss to follow-up or documentation has been a continuing concern of both the CDC and [Maternal and Child Health Bureau/Health Resources and Services Administration](#) (MCHB/HRSA). Both agencies have provided federal assistance for states

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and territories to improve their EHDI programs and reduce the percentage of babies lost to more manageable numbers.

In an effort to encourage states to develop effective EHDI tracking and surveillance systems and integrate the EHDI system with other state/territorial screening, tracking, and surveillance programs that identify children with special healthcare needs, the CDC offered a funding opportunity that was outlined in the January 4, 2005, Federal Register. States and territories were encouraged to apply for grants to help develop and strengthen information management systems (IMs) that would report and manage standardized, unduplicated, individually identifiable data on infants in the EHDI programs. States whose systems were only able to report aggregate data lacked the capacity necessary to effectively track individual babies. The guidance for these grants stressed individual, identifiable

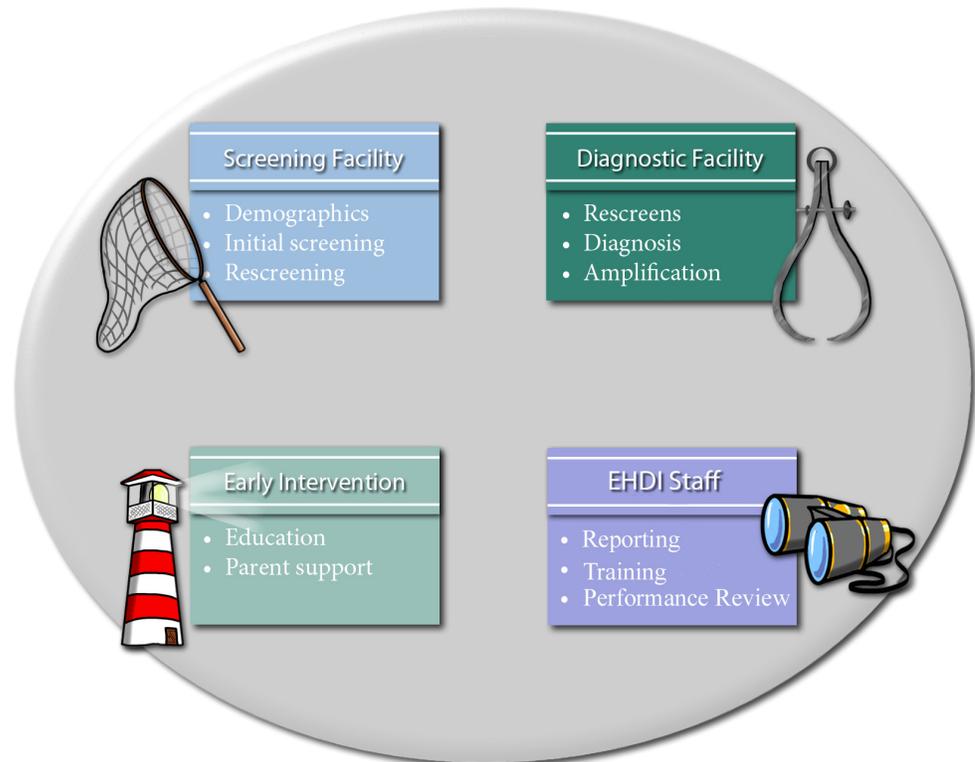
data and the integration of multiple information sources and integration of the EHDI data with other state databases (Federal Register, 2005). As a result of these CDC grants, many state IMs have been significantly strengthened and improved. Continued federal, state, and local support has provided additional funding for further refinement of IMs.

EHDI Program Design

EHDI program design varies considerably, depending on federal and state requirements, resources, and the size and diversity of the population served.

Participating programs. A typical EHDI program consists of three main types of information management activities: (1) screening, (2) diagnostic evaluation, and (3) early intervention services (see *Figure 1*). These activities are conducted by hospitals, local health departments,

Figure 1
 Single-Source Program Design



One of the most challenging aspects of operating a successful EHDI program is information management.

and state health departments to different degrees in different states. Information flow between these groups is important to understand and accommodate, because each participant has different data to collect and varied reporting needs.

The EHDI program design process should include feedback from these and other potential participants from the start. Coordination meetings, video conferencing, electronic mailing lists, and social media technology can all be used to build feedback processes.

Screening technology and devices.

Selecting screening technology and equipment is another essential design decision. This guide does not compare the advantages of the different types of screening technology [e.g., otoacoustic emissions (OAEs), distortion product otoacoustic emissions (DPOAEs), and automated auditory brainstem response (AABR)]. However, screening programs are typically one stage (screening is completed when baby is an inpatient) or two stage (initial screening is done as an inpatient, and for those who do not pass, screening is completed as an outpatient). Within a one- or two-stage program, there may be different test protocols (e.g., OAE followed by AABR and diagnostic ABR for those who refer or OAE, AABR with diagnostic ABR after discharge, or several OAEs with OAE-AABR after discharge, etc.). Your specifications should include provisions for any unanticipated changes in the design of your program due to procedural or technical advances.

The collection and transmission of screening results is important to the quality of data in your program. Program designers should select technology from equipment manufacturers that provides electronic methods of transmitting screening results to IMSs whenever possible.

IMS. One of the most challenging aspects of operating a successful EHDI program is information management. If the task was only to count and report the total number

of births, number screened, number who passed, and number of non-passes, program design would be very easy. When all the other information necessary to follow-up and track babies is added in, program design becomes considerably more complex. Even the smallest of programs generate an astounding amount of data that can quickly overwhelm the capacity of a poorly conceived IMS.

The following information will help you build an effective IMS by assisting you in the process of defining your needs and then selecting an implementation that fits those requirements.

Requirements for Your Program

Data Requirements

The required data collection and tracking features vary depending on the scope of the program. Three common scopes are (1) hospital, (2) region, and (3) state. Although each scope has slightly differing goals and contributions for successful newborn hearing screening implementation, there are basic requirements shared among them.

Basic data. Your data should include items as shown in *Table 1*.

Hospital-specific data requirements.

Hospitals may have additional data collection requirements related to billing and local quality assurance practices. Data elements related to insurance coverage and nursery location may also be useful to hospital EHDI programs.

The hospital EHDI program may also choose to report performance measures on their screening staff members.

State-specific data requirements. State EHDI programs may be required to report statistics to the CDC. When this is the case, additional demographic variables, such as mother's age, race, and ethnicity, should be made available. To more

Table 1

Data Items Basic to EHDI Programs

Demographics	Inpatient Screening Results	Outpatient Screening Results
<p>Name, birth date, medical ID, sex, hospital name, nursery type, parent/contact name, address, telephone, and medical home or primary healthcare provider (PHCP) identification. Demographic data may also include insurance carrier information, language preference of the family, transfer hospital, etc. Many EHDI programs have found that collecting additional points of contact (relatives, friends, etc.) is extremely valuable in reducing the number of infants lost to follow-up.</p>	<p>Date, type of test, results for each ear, reasons (if not screened), screener identification, and unit identification.</p>	<p>Date, type of test, results for each ear, and screener identification.</p>
Risk Factors	Diagnostic Results	Amplification Information
<p>Information on any of the JCIH or locally determined risk factors present.</p>	<p>Date, type of test, results for each ear, test data for each ear, recommendations, and diagnostician identification information. Multiple tests are included in a diagnostic battery, so it is desirable to have the capability to handle historical test data in a system. For tracking progressive or late-onset hearing losses, the system must be able to accommodate multiple sets of diagnostic results.</p>	<p>Date, specifications, test results, recommendations, and dispenser information. This can, and probably should, include sufficient data to track multiple amplification systems (i.e., hearing aids, cochlear implants, etc.).</p>
Early Intervention	Tracking Data	
<p>Date of enrollment, program identification, service provider, and recommendations.</p>	<p>Recommendations, schedules, changes, updates, and reminders.</p>	

Photo courtesy of Octicon A/S

closely monitor the effectiveness of EHDI programs, the CDC is requesting more specific information regarding many facets of the EHDI system. It is vitally important to be able to update the system's reporting capabilities to stay in tandem with CDC's reporting requirement revisions.

Region-specific data requirements.

Regional EHDI programs need to provide system access to off-site users and produce aggregate reports. This may be done by using county of residence or some other geographic marker from patient records.

In addition to the basic data described above, many programs choose to include considerably more information related to management of the infant and family. It is always best to assume you will think of additional data that should be included in the IMS and provide for expansion in the initial design.

Required Information Management Features

When considering an IMS, it is wise to start with broad feature requirements; then look at specifics that are necessary for your EHDI program. Whether you are considering a commercial package or designing your own system, looking at existing software may save you from "reinventing the wheel." Often, programs developing a list of specifications find that some items are not essential and add substantially to the cost and complexity of program design. Adding non-essential items and features may not add much value or functionality to your overall system.

Collecting patient information. You need a record of each live birth. This information may be obtained from birth records and entered into your system manually or may be transferred electronically from some other database, such as an electronic birth registry system or hospital patient IMS. Your system should provide not only for babies actually tested, but those who refuse, are transferred, missed, or not screened for

some other reason. However the database is populated, it is important to be able to identify all live births and ensure their participation in your EHDI program.

Accuracy of data is a huge consideration, and your system must have some means of checking data for completeness and accuracy as it is collected. Obstacles to clean data collection should be identified during your design process. Repeated data entry, manual system lookups, and other difficult tasks should be reduced, wherever possible, because they greatly overload staff responsibilities and increase the likelihood of erroneous data.

Collecting screening outcomes. Ideally, your program design will include screening devices that collect and export data that is compatible with your IMS. Depending on the device, basic demographic information may also be collected at the time of screening through the screening device software. Collecting this type of information "upfront" at the time of screening is often the best time, because it is available there in the nursery.

Basic features. For hospital-based screening programs, your IMS should have the following broad capabilities:

- Record user information (hospitals, screeners, screening equipment used).
- Record infant demographics and birth information.
- Record parent, contact, and provider information.
- Identify the screening status of any child registered on the local system.
- Capture/record newborn hearing screening and rescreening results from designated equipment.
- Record information on babies not screened and the reason not screened.
- Record scheduled appointments for screening or follow-up services.
- Allow new patient-related data to be defined, recorded, and retrieved.
- Document appointment and provider information related to referral for rescreening, diagnostic assessment, or early intervention services.

Your system should provide not only for babies actually tested, but those who refuse, are transferred, missed, or not screened for some other reason.

- Document information related to scheduled follow-up dates for outpatient rescreening or diagnostic services.
- Document information related to results of assessment and diagnostic services. The following minimum data should be available for each ear:
 - Air- and bone-conduction click threshold
 - Tone pip ABR (at least 4 frequencies)
 - SSEP thresholds (at least 4 frequencies)
 - Tympanometry—probe frequency and results
 - OAE results (TEOAE and/or DPOAE)
 - Behavioral hearing thresholds at multiple frequencies
 - Dates and types of tests carried out
- Include an area assigned to free text entry for comments, progress notes, and information not specified in other screens.
- Include provisions for confidential transfer of data from all service sites to a central database.
- Contain provisions to identify and suitably deal with duplicate records.
- Support the use of context-sensitive help facilities.
- Use matching algorithms to prevent unmanageable amounts of duplicate records.
- Use ranking algorithms to identify which screening outcomes are the most conclusive, given several attempts.

Reporting Requirements

While you expect to be able to monitor the number of births, number screened, number passed, and number of non-passes, few programs (and even fewer funding sources) would be happy to receive only this limited amount of information. Quality assurance efforts dictate that you be able to monitor program efficiency and effectiveness by hospital and, in many cases, by individual screener. The CDC has identified a number of data elements that are collected from programs in the United States to help determine effectiveness of our EHDI efforts:

- Hearing aid fitting: left, right ear, type of aid, specifications.
- Hearing aid verification measures (DSL, etc.).
- Early intervention details (i.e., date enrolled, type of program).
- Generate letters to parents and providers related to results, referrals, scheduled follow-up, failure to keep appointments, risk monitoring, and other related activities.
- Alert EHDI staff when information related to follow-up services has not been received and recorded.
- Generate and archive routine and user-configured reports.
- Archive and retrieve individual infant records and event information.
- Support controlled levels of access for individual and groups of users.
- Enable groups of users to have appropriate access to data and system functions.
- Provide backup and recovery functions to ensure that no infant's information is lost or compromised.
- Validate all data on entry and prompt users to correct inappropriate or erroneous data.
- Provide for security and privacy of individual patient data.
- Number of live births.
- Number screened prior to discharge.
- Number screened after discharge but before 1 month of age.
- Number referred for audiological evaluation.
- Number who received audiologic evaluation by 3 months of age.
- Number with permanent childhood hearing loss (PCHL), aged 0-7 years, by birth year.
- Number with PCHL by classification.
- Average/median age of diagnosis.
- Number of infants enrolled in early intervention by 6 months of age.

Predefined reports providing CDC data elements may help serve as a good basis for quality assurance efforts. As mentioned

The ability to tailor reports to the requirements of your program greatly simplifies your follow-up and tracking efforts.

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Assessing the effectiveness of an EHDI program depends on results and reports collected over a long period of time (i.e., comparing hearing screening information from kindergarten testing to newborn hearing screening results to find hearing losses that may have been missed in the initial screening). This involves not only the aggregate information presently supplied but child-specific information, so individual babies can be tracked through the EHDI process. Including capability to add and compare additional information to that already contained in the system will significantly increase its usefulness.

Migrating Existing Data

Since most EHDI programs have been in existence for at least several years, a considerable amount of existing data may need to be integrated into any new or updated system. It may be unrealistic to expect program personnel to operate more than one IMS to accommodate the needs of new versus existing data. Ideally, any IMS being replaced will have the capability to export data to a new system. Similarly, the new system must provide a clear path for integrating existing with newly generated data. Often, however, this is not the case, and data may be lost or rendered ineffective by poor program planning or selection. It is imperative that the need for integration of existing data be clearly understood by EHDI program staff as well as software designers and suppliers.

Providing Access to EHDI Participants

Information is the lifeblood of any EHDI program, and it is vital that timely and accurate information reach those involved if the 1-3-6 month goals are to be achieved for every baby. All EHDI program participants, screening sites, diagnostic centers, and early intervention programs may need some degree of access to the IMS. This access can be provided in different methods and at varying levels.

Privacy and security of records must be addressed in manageable ways. Be prepared to address legal or practical limitations on data sharing. Each state seems to interpret privacy laws somewhat differently. Many states have passed legislation authorizing the sharing of EHDI data specifically for purposes of tracking and follow-up. Other states and regions may not be as inclusive in their data-sharing policies and require specific releases for information to be shared at multiple points in the tracking and follow-up process.

Technical Specifications

The technical specifications for an EHDI IMS are often beyond the scope of layperson or department of health staff technical expertise. However, at a minimum, it is important to have a high-level knowledge of the topics shown in *Table 2*.

Selecting or Building an IMS

Overview

After you have defined your data elements, reporting, and information management features, you will be well prepared to select or build an EHDI IMS.

Most of the software designed by hearing screening device manufacturers for use with a specific piece of screening equipment is adequate for screening in a single facility but not designed for the tracking and follow-up needs of a full EHDI program across multiple locations. When using a device-specific system, one also locks the program into using equipment from only that manufacturer, unless the system is designed to operate with more types of hardware.

The implementation of an IMS is a complex undertaking that requires an unusual mixture of expertise and experience in healthcare delivery systems, implementation of newborn hearing screening and follow-up systems, and

Table 2 EHDI IMS Technical Specifications

Centralized Database

A centralized database is one database that is shared and accessed by all participants (e.g., hospital, audiologists, and pediatricians) in your state or region's EHDI program. In most cases, this is implemented using web-based technologies.

Advantages	Considerations
<ul style="list-style-type: none"> • Access to the most recent copy of the records is available. • Centralized information technology (IT) resources may be easier to manage, because they may fall under a single IT department. 	<ul style="list-style-type: none"> • Computing resources (e.g., servers, network connections) must be shared among all logged-in users. • Increased risk of having incomplete or unfinished data entry. • Legal ownership of and access to the centralized data must be considered. • System downtime affects the entire state or regional program.

Distributed Database

Distributed databases are made up of separate databases at different locations across your program. The central state or regional copy of the data is electronically synchronized on a schedule.

Advantages	Considerations
<ul style="list-style-type: none"> • Database computing is distributed across all data systems separately and independently. • Data entry processes can be completed prior to transmission to the upper-level state or regional database. • Data is owned and maintained at local sites. This allows for independent data usage activities that may only be related to local sites. • Database redundancy provides backup copies of the records. • System downtime only affects local staff. 	<ul style="list-style-type: none"> • Updates to data come incrementally, and depending on the system, the lower (source) databases may not be updated with subsequent changes from upper levels. • More cumulative IT effort is required to support separate systems.

Table 2 (continued)

Thick Client Access

The type of client—or user program—available for access is also an important technical specification. Thick clients are computer programs that run directly from the hard drive of user computers. They have access to all of the user computer memory and processing strength. They also take advantage of advanced components, special drivers, and installed frameworks to improve the user experience.

Advantages	Considerations
<ul style="list-style-type: none"> • Functionality is responsive and feature-rich, because advanced components can be utilized. • Processing is distributed across all computers in the system. In other words, each computer assists in the processing required to make the system work. 	<ul style="list-style-type: none"> • Installation is required. (“Microsoft’s .Net Framework” and other software frameworks are available to simplify installation for newer software). • Individual computer updates are required to get new features, although some systems include automatic updates.

Thin Client Access

Thin client access is provided by a centralized application or web server. This type of user experience may be restricted, because the software runs within the limitations of a web browser or application delivery service. The resources and advanced components of each user computer are usually not available to the thin client software.

Advantages	Considerations
<ul style="list-style-type: none"> • Only minimal installation required for user computers. • Access may be available from any computer with network access. 	<ul style="list-style-type: none"> • Usability tied more directly to the network (speed, availability, security). • Software features may be limited due to delivery method. • Lack of technology or network connections may prevent some remote sites from connecting.



Photo courtesy of Octicon A/S

Understanding the needs of all the program participants and responding to those needs makes system implementation a relatively smooth process.

software development and support. Far too often, EHDI is added as an afterthought to some other IMS, with little understanding of the unique requirements for the tracking and follow-up an effective program requires. Implementation of an IMS must be a collaborative endeavor that responds effectively to the needs of all stakeholders. Understanding the needs of all the program participants and responding to those needs makes system implementation a relatively smooth process. Often, minor modifications of the IMS can make significant differences in reducing the implementation timeline.

Implementing an effective IMS involves much more than just building or purchasing a piece of software and distributing it to users. A systematic and comprehensive implementation plan is required. In addition to providing the actual software, the supplier (or designer) must be prepared to accommodate the needs of all users for training and ongoing support. Each user must be prepared to work with the supplier's project manager to ensure implementation at every site is designed to meet their needs and functions exactly as specified. As part of the implementation plan, provisions must be made for maintenance and periodic upgrading of the software and hardware, as necessary.

Support to the end user must be readily available at the time it is needed. A local help desk or support specialist can be a considerable help to users, particularly during the initial implementation stages of any IMS. Suppliers are often willing to train local support staff as a routine part of system implementation. Most system suppliers have personnel available to provide help to local support specialists and end users, but the quality and availability of that support varies widely among suppliers. Placing several calls to gauge the adequacy of support services is always a wise practice prior to committing to final purchase of any system.

The system should be easily expanded to accommodate more users and heavier processing demands. Performance

with both light and heavy processing loads should be sufficient, so no users experience undue delays in their ability to use the system. It goes without saying that the software should provide sufficient redundancy so as to provide maximum reliability. Security must be robust and flexible—most easily provided in multilayered systems. Program managers must be able to access all areas of the system, while restricting users to only those portions for which they are responsible.

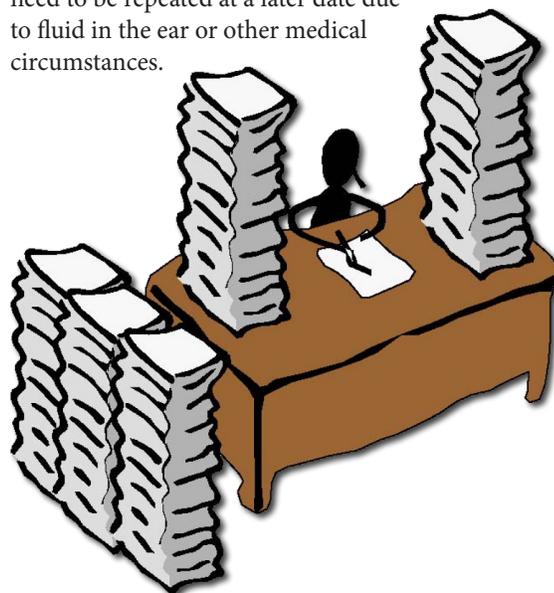
EHDI IMSs can either be built in-house or purchased from a vendor.

Built In-House

When a system is developed in-house, it is usually either piggybacked on an existing system or built as a separate system specifically for EHDI data.

Piggybacked on an existing system.

One route some states have taken is to incorporate EHDI tracking variables into an existing data system, such as metabolic or birth certificate systems. Two advantages to this approach are that it removes the need for building a new system and, in some cases, may require less training. However, the data collected from these systems is often too shallow and reduced to a simple pass/fail field. This approach is often inadequate, because screenings may need to be repeated at a later date due to fluid in the ear or other medical circumstances.



Pencil-and-paper systems are, by definition, very labor intensive; there must be adequate personnel to deal with the anticipated volume of paper forms received.

Historical information about repeated tests, including the date, screener, and technology used, is lost in a simple pass/fail implementation. Another challenge to this method is that EHDI data may have to conform to data entry restrictions and availability of another data system.

Separate custom-built system. Many programs—lacking the funding to purchase or develop a computerized system—have started with pencil-and-paper reporting systems that adequately served their purpose. Pencil-and-paper systems are, by definition, very labor intensive—there must be adequate personnel to deal with the anticipated volume of paper forms received.

Some have adapted software products, such as Microsoft Excel or Access databases, to serve the purposes of their EHDI programs. A few EHDI programs have custom written software—taking into account their own needs and capabilities. For small numbers of births and limited tracking needs, home-grown systems are often initially quite adequate.

The danger, of course, is making the home-grown system too limited for expanding numbers of births and reporting requirements. Increasing the capacity and capability of such systems is often very difficult and labor intensive. Another danger of home-grown systems is that they almost always become obsolete due to improvements in operating systems and programming languages. Programs written in unconventional languages or dependent on dated software may be faced with the prospect of depending on obsolete hardware to function. It is critical that any home-grown system be designed with the future in mind—often an exceedingly difficult task for those without the proper background and experience.

Another important consideration for in-house systems is the availability of technical support. Verify that your EHDI staff will have adequate access to technicians and information specialists

who built the system. Provisions should be made to extend the technical support of your system in the event of departmental reorganization or job reassignment of your staff.

Purchased from Vendor

Buying an IMS software package is often a better option. Some EHDI programs go this route to avoid reinventing the wheel; that is, to capitalize on information management and IMS experience of specialists. Several software systems are available on the market.

Selecting a vendor. Referring to your list of system requirements when reviewing commercial system software will help you locate a vendor and product. When faced with a whiz-bang demonstration of the things an IMS will do, the question must be asked, “How will using this system make our program more efficient and effective?” Often, there are many flashy capabilities and extra options that have absolutely nothing to do with how your program is conducted. We have all seen the systems that will give us volumes of information but have no provision to generate the follow-up letters that we need to send daily. Be equally skeptical when capabilities are described but not demonstrated. Purchasing “vaporware” (the term applied to software capability that does not exist) can be avoided by careful examination and verification of claims that seem doubtful.

Things to look for in vendor-provided software include:

- Meets all of your data and functional requirements.
- Has a consistent “look and feel” across all major functional areas.
- Provides software fixes, upgrades, new releases, and enhancements on a regular basis.
- Ensures data compatibility and integrity of the database for future releases and upgrades.
- Has a good track record of customer satisfaction.

Successful track record. Implementing an IMS for a hospital, regional, or statewide EHDI program is a significant investment of both financial and personnel resources. For that reason, it is important to ensure that the IMS is being purchased from a supplier or designed by an organization that has a successful track record and will be available in the future for support and system improvement. Obtain references from any potential supplier and take the time to check those references carefully. Information gained from present users of systems can be very helpful in making the very best decision for your IMS supplier or designer.

Technical support. Technical support always provokes a lively discussion between program suppliers and consumers. Anyone who has purchased computer software from one of the large, multinational companies can tell horror stories of trying to obtain effective technical support while waiting for hours on hold listening to mediocre music. A supplier who offers technical support during normal business hours may not be much help to a hospital screener faced with a problem that prevents her from doing her job at midnight. On the other hand, off-hour technical support is often prohibitively expensive, so the needs of your program must be balanced with the budget you have available for information management. Technical support is crucial if your system is to function as intended—it is not a matter of *if* problems will occur, but only a matter of *when*. Careful training of staff can go a long way toward eliminating mundane problems, but technical support is essential when more complex problems appear. Screening and professional staff are rarely computer-savvy enough to be able to solve complex IMS issues on their own, so your EHDI program will be heavily dependent on technical support availability and effectiveness.

Software updates. In regards to software updates, some important questions to ask a vendor include:

- Can your system be easily updated to take advantage of new hardware capabilities?
- How will changing some of the parameters of your program affect the overall system?
- Will your present data be compatible with any hardware or software updates?
- Are there provisions for protection of your database during updating operations?

While software must be expected to serve the needs of users in the short-term, it must also establish a foundation that enables flexibility, extensibility, and scalability for the future.

“It is quite apparent that the screening and information management portion of EHDI programs is at the crossroads of two rapidly changing fields: (1) EHDI and (2) information technology. It is certain that changes in these two fields over the next few years will impact the way hearing screening is done, how data is recorded, and how information is used to provide better services to children and families”
 (White, 2003).

Hosted database offerings. Some IMS suppliers offer to host your database and software on their servers at a location remote to your program. Users access the system via the Internet, and all maintenance operations are conducted at the remote site. In practice, where servers are located matters little to the end users. There are some advantages to this type of arrangement:

- More elaborate servers may be provided.
- Data processing professionals will be responsible for server operation, maintenance, and updating.
- Data can be regularly archived and stored securely off site.
- Software updates are easier for the supplier to implement.

Potential disadvantages to remote hosting include:

Technical support is crucial if your system is to function as intended—it is not a matter of *if* problems will occur, but only a matter of *when*.

The goal of data integration is to link patient records electronically across all participating data systems, including birth registries, immunization systems, early intervention systems, and hearing screening systems.

- Your whole program is out of operation if the servers or Internet connections are not functioning.
- You have no control over when backup and archiving are done for your data.
- Security issues may be easier to resolve on a local level.
- The number of users on the system at any time may significantly affect the speed of your operations.
- Your program may not be assigned high priority for technical support or problem resolution.
- Ownership issues regarding your data may surface if you decide to change systems or suppliers.
- Bankruptcy, ownership changes, or other business problems of the supplier will have an adverse effect on the continued operation of your IMS.

Integration with Other IMSs

Overview

The goal of data integration is to link patient records electronically across all participating data systems, including birth registries, immunization systems, early intervention systems, and hearing screening systems. While databases that have been piggybacked onto another system already provide a certain level of data integration, vendor-provided databases can also be integrated with other IMSs.

The primary characteristic of an integrated system is the use of a common database among several distinctively different, but related, applications. A few states are integrating electronic birth certificate, metabolic screening, hearing screening, diagnostic results, early intervention, and immunization information into a single database. In a recent self-survey, one state department of health found they were maintaining 28 separate databases on children! The possibility of combining or integrating all those databases into one has certainly been the subject of much discussion and planning.

Integrating information into one database that can serve the needs of many programs can be efficient and cost effective. For example, initially populating a database from the electronic birth registry and then later having each participant add their specific information to the existing record. This eliminates a great deal of data entry effort and reduces the opportunity for error. However, in practice, meeting the diverse needs of a multitude of users can be difficult for software designers and administrators. The considerable tracking and follow-up requirements of an effective EHDI system are often foreign to designers of integrated systems, resulting in steep learning curves and lengthy delays in implementation.

Rather than attempt to group all patient health information into one single database, electronic linking allows each data system the freedom to specialize, grow, and do what it does best. As with an integrated database, linking provides the ability for participating programs to see a comprehensive ad hoc medical record showing everything known about a child. Linking also allows programs to alert other programs of important patient data-related conditions, such as scenarios requiring urgent attention.

Implementation

Budgets, privacy issues, and resource constraints are all potential obstacles to effective integration. Integrating shouldn't be seen as an all or nothing effort. States can make deliberate long-term plans to implement data integration, starting at the most basic levels and then progressively improve as time and budgets allow. Several facets of the continuum of data integration are illustrated in *Table 3*.

Direction. The three directions of data integration describe how a participating system will exchange data with other participating systems. Each system may send data, receive data, or do both.

Data mutability. Data mutability describes to what extent participating systems are allowed to change data in

Table 3
Facets of the Continuum of Data Integration

Facet of Integration	Complexity Continuum		
	Basic	Moderate	Advanced
Direction	One way: Receive only or send only	Two way: Receive and send	
Data mutability	View only	View and append	View, update, and append
Access method	<ul style="list-style-type: none"> File exchange (XML, flat file, etc.) 	<ul style="list-style-type: none"> Stored procedures SOAP web service 	<ul style="list-style-type: none"> Electronic messaging (e.g. HL7)
Central coordination	None	None	Communication broker
Record matching	<ul style="list-style-type: none"> Manual Reporting tool identifies duplicates. 	<ul style="list-style-type: none"> Automated but decentralized (relies on end-point data systems to match incoming data) Deferred match resolution 	<ul style="list-style-type: none"> Automated and centralized (part of broker) Record linking Deferred match resolution
Notifications	None	Pull method	Push method
Coding	<ul style="list-style-type: none"> Standardized code schemes Code scheme translation 		

The most advanced mutability allows a system to change existing data in another system.

other systems. Basic mutability is when systems are only allowed to view data from other systems. Moderate mutability allows a system to append or add new data to other systems. The most advanced mutability allows a system to change existing data in another system. Advanced mutability will be dependent on other facets of integration, such as record matching and access method.

Access method. Access method describes how data is shared between participating systems. Possible levels of access are: (1) file exchange, (2) direct communication,

and (3) the utilization of a communication broker middleware.

- File exchange is the most basic method. A formatted data file is either written or read by the participating system. The files must be formatted to be compatible for the participating systems. Common formats are XML and flat delimited files. Although this approach is often simple, it is also directly dependent on the data structure of each participant. This means that when one participant changes its structure, it may adversely affect other participants.

Record-specific notifications about healthcare conditions, including hearing screening and related conditions, can be a compelling advantage of data integration.

- Moderate access methods for systems to exchange data directly include stored procedures and web services.
 - Database stored procedures allow a sending system to directly add patient data into another system. A receiving system can query another system's patient data. This is accomplished by specially coding each system to send or receive system-specific parameters. This method is limited, because, in most cases, the programming is specific to each participant. Thus, changes to one participant's database structure may affect other systems.
 - SOAP (Simple Object Access Protocol) web services (<http://en.wikipedia.org/wiki/SOAP>) can also be used for direct communication between participants. This method is similar to using stored procedure methods, except that it uses Internet technology to communicate across broader networks.
- Electronic messaging is an example of advanced direct communication. In some ways, it is similar to email. Using this technology, systems are configured to either broadcast or listen for data messages on computer networks. Data from these messages is extracted and used to populate patient records. HL7 (www.hl7.org) is an example of a standardized message format that is commonly used in healthcare data systems. Using a standardized message format provides data structure independence between participants—unlike file exchanges and direct procedure calls.

Central coordination. Advanced integration access can be accomplished by utilizing the preceding methods and incorporating a central data communications middleware system. This

type of system routes communication between participants and manages a system-wide patient index. This index is built and maintained by a matching module within the middleware system and provides a centralized method for linking records across participant data systems.

Record matching. Manual matching is the most basic level on the continuum of record matching. With manual matching, no records are automatically checked or flagged for possible duplicates. In this case, duplicates must be identified after being added to the system. Software tools will likely be utilized by data managers to identify and resolve these duplicates.

A moderate level of record matching is automated but decentralized. At this level, each receiving data system acts as the gatekeeper for data coming in from other systems. Each system will check incoming data against their current data to look for possible matches. Well-designed data systems will be able to provide users with tools to review candidate matches for records from other data systems. Primitive participating systems should, at a minimum, merge high-confidence matches together without user interaction, while keeping questionable matches separate.

Advanced record matching offers all the capabilities of moderate matching, with the added advantage of record linking made possible by a centralized middleware system. The central system maintains a system-wide master patient index. As data is exchanged between participating systems, this master index is updated when matching records are found.

Notifications. Record-specific notifications about healthcare conditions, including hearing screening and related conditions, can be a compelling advantage of data integration. Notifications aren't necessarily required for the most basic integration, but they are often the reason that managers of participating systems seek to integrate their databases. For example, a mother can be notified by the birth

certificate data manager when she comes in to request a certificate that a follow-up hearing screening is recommended.

The simplest notification system is a “pull” system, where the user of a specific system can query data from other integrated systems. Following the previous example, the birth certificate data manager would need to click on a “Hearing Screening” button within their birth certificate system to see if the child needs further screening.

Advanced notification systems are able to “push” out notices when certain healthcare conditions exist across the integrated systems. In the birth certificate manager example, the manager will see a pop-up reminder for hearing screening when accessing the baby’s birth certificate record. Other examples of push notifications are instant messages, SMS text messages, or emails when conditions occur.

Coding. Coding is a significant aspect of data integration. For any access method, data elements must be coded in standard ways. A few general purpose data elements, such as names and addresses, rarely need coding, but the vast majority of healthcare and EHDI data are coded in proprietary schemes. For example, “P” and “R” codes may indicate “Screening Pass” or “Screening Refer” in one data system, but other systems may use different codes to indicate the same outcomes. Even simple elements, such as maternal language, race, education level, and screening type, will be coded in different ways across different systems.

To achieve data integration, systems must either agree to use standardized coding schemes, such as LOINC (<http://loinc.org/>) and SNOMED CT (<http://www.ihtsdo.org/snomed-ct/>), or build in active translation mechanisms to adapt coding schemes between systems.

In Summary

With proper planning and design, data integration is an achievable goal at a variety of implementation levels. Although a high degree of integration is always

desirable, limited resources, vendor cooperation, data complexity, software limitations, and other factors may prohibit that goal. Understanding the advantages and disadvantages of the various levels and facets of integration can help you make effective use of the resources available to you and your organization.

Using an IMS in an Actual EHDI Program

NOTE: *The next section will describe how the Illinois EHDI program has assimilated an IMS into its daily operation. Dr. Tanner is intimately familiar with the Illinois system and offers some insights into effective tracking and surveillance.*

Administering an EHDI program requires storage and easy access to a considerable amount of information. Whether operating from the hospital perspective or from a state or regional operation, information management is key to effective screening, reporting, tracking, and management. Data must flow in a smooth process that can account for all babies born, screening results, parent/guardian, and primary care physician contact information, along with the ability to add outpatient follow-up data, diagnostic data, and early intervention information to original records.

While no system will provide for seamless, humanless information management, automation is essential to timely reporting, tracking, and follow-up. Ease of use is also important, as hospital reporters, data entry clerks, and even administrators are not necessarily database-savvy.

HI*TRACK has been used in Illinois prior to the effective mandate of the Hearing Screening for Newborns Act on December 31, 2002. Illinois law for EHDI requires that hospitals report all births, along with screening results or other status data, as appropriate (e.g., babies that expire, are transferred, are missed, etc.), to the department on a weekly basis. The files are submitted by emailing to the department

With proper planning and design, data integration is an achievable goal at a variety of implementation levels.

an encrypted email attachment. The department then “de-crypts” the file, checks for missing data or data errors, and merges the files into the centralized database. Through the database, letters are automatically generated for those children who do not pass the screening in both ears. Exceptions to these generated letters would be children who have transferred to another facility and those infants who have expired.

For infants transferred to other facilities, the birth hospital reports the name of the hospital to which the baby was transferred. This allows the department to run a report asking for the identifying data for all babies transferred to any given hospital. The staff can then check the database for duplicate records (in the event that the transferred *to* hospital has also submitted a report

on the same child), combine duplicate records, and contact the transferred *to* hospital for the status/screening data for any child for whom screening information has not been received. In this way, infants who transfer and who may not be ready for testing due to other medical issues can be effectively tracked through screening. Letters will be automatically generated for those who do not pass the screening (see *Examples 1 and 2*).

Once non-pass letters are generated, they are mailed to the parents and primary care physician, along with automatically generated forms containing the child’s identifying information. Primary care physician offices, audiologists, and other sites that do outpatient screening are required by law to submit outpatient testing results to the department. This can be done through the submission of the forms or electronically, in the case of hospitals who have HI*TRACK. Manual data entry is required for those reports that are submitted on paper through mail or fax. Children’s records in HI*TRACK will automatically update to include additional screening or diagnostic data.

For those children for whom follow-up testing information is not received, letters can be generated to the local health authority for a home visit by a public health nurse to assist families in obtaining follow-up screening or diagnostic testing. A “Notes” section within HI*TRACK allows for documentation of each contact made regarding a child with automatic documentation, by whom the entry was made, and a date/time stamp of the entry (see *Example 3*).

HI*TRACK includes a “scheduled” field, whereby a child’s scheduled appointment, date, and location can be entered into the data system. From this field, a report can be run by date and location of appointment, so department staff can effectively make contacts with those offices to obtain test results—in the event they were not submitted—or to identify those infants who had broken appointments. Upon identifying a broken

Example 1 . . .

Baby Boy Doe, born at ABC Hospital, passes screening in both ears. Hospital notifies parents and primary care physician. Data is entered into HI*TRACK (either by electronic transfer from screening machine or manually) and submitted to the department. The department previews and downloads into the centralized database. No further action required.

Example 2 . . .

Baby Boy Doe, born at ABC Hospital, passes/right and refers/left on first and second screening. Hospital notifies parents and primary care physician by letters generated through HI*TRACK. Data, including parents’ contact information and name of primary care physician, is entered into HI*TRACK (either by electronic transfer from screening machine or manually) and submitted to the department. The department checks and downloads into the centralized database. Parent and primary care physician letters, along with appropriate forms with identifying information entered, are automatically generated by HI*TRACK.

Example 3 . . .

Outpatient testing results for Baby Boy Doe have not been received 30 days post-screening. A letter to a local health authority can be generated through use of HI*TRACK. This letter, as well as other letters, is logged in the “Letters” section of HI*TRACK for tracking purposes. The contact can also be entered into “Notes” to keep a running log of activities.

appointment, the “broken appointment” field is completed in HI*TRACK, which automatically generates a “broken appointment” letter to both the parent/guardian and the child’s primary care physician (see *Example 4*).

To assure that all infants are reported to the department, a quarterly audit is done, with hospitals comparing their birth log/birth certificate log numbers to the numbers of infants reported in HI*TRACK for each month. HI*TRACK offers a feature whereby a date of birth range of files and/or files that were modified on a specific date can be submitted independently of resending an entire month’s worth of data.

This allows specific data to be sent to the department and centralized HI*TRACK without the need to review all records and reduce the possibility of resending duplicate records that the department has already eliminated.

HI*TRACK allows for combining records by viewing pertinent data in a side-by-side fashion, assuring that all data is transferred from one record to another, and that only one record exists for each child.

Audiologists who have access to HI*TRACK can enter diagnostic data directly into HI*TRACK, which downloads to the department when a transmission is made. While this is an excellent way of submitting diagnostic information, there is no “pop up” or means of the department knowing when a report has been submitted that indicates a confirmed hearing loss without viewing individual files, which is time consuming. For this reason, diagnostic reports are reported on paper and reviewed by a department audiologist before being manually entered into HI*TRACK. This allows for consistency in how the diagnostic data is entered and provides a cross-check to determine if a hearing loss has been diagnosed prior to referrals for intervention being made. This data-entry process also allows creation of a “tickler file” on those children for whom diagnostics have been completed but a diagnosis is not yet confirmed.

When children are confirmed with hearing loss, documents for making referrals to early intervention can be generated directly from HI*TRACK. Documentation is kept within the HI*TRACK file and allows entering the date of early intervention enrollment to assure intervention has begun.

HI*TRACK features also assist in completing annual reports to NCHAM and the CDC. Specifics about degree of hearing loss, type of hearing loss, and age of both diagnosis and intervention can be obtained in aggregate form through the use of HI*TRACK reports.

Example 4 . . .

Baby Boy Doe is scheduled for an outpatient appointment. A list of “scheduled” appointments for a specified time period is generated in HI*TRACK. This list includes the child’s identifying information, mother’s information, date, and location of scheduled appointment. Department personnel make phone calls to confirm that the child kept the appointment and to obtain results of appointment.

Outcome 1

Outpatient screening or diagnostic testing is done, and hardcopy report submitted to the department, or if done at a birthing hospital, data is submitted by HI*TRACK transfer. If not submitted via HI*TRACK, screening/diagnostic data is manually entered into HI*TRACK.

If child passes, no further action is taken.

If child refers and another appointment is indicated, the appointment is entered into HI*TRACK as “scheduled” for a specific date and location.

If no follow-up appointment date is specified, the file is tagged for local public health department notification, if further information is not received within 1 month.

Outcome 2

Child does not return for scheduled outpatient appointment. The department is notified either by hardcopy or data entry into HI*TRACK, which is submitted to the department with next transfer file. A “broken appointment” letter is automatically generated and sent to parent/guardian and primary care physician.

The file is tagged for local public health department notification, if further information is not received within 1 month.

While no data system is going to be perfect for both the hospital and a centralized system, HI*TRACK adequately meets the needs of our EHDI system.

While no data system is going to be perfect for both the hospital and a centralized system, HI*TRACK adequately meets the needs of our EHDI system. The program allows for processing of necessary data at the hospital level and additional capabilities that are used at the state level. One of the best attributes of HI*TRACK is the customer support, which is available to hospitals and the centralized state program. The “help desk” provides assistance and training, including fine-tuning some aspects

of the system to better serve the needs of all participants in our EHDI system.

Further Information Regarding EHDI IMSs

Helpful articles, contact information for state EHDI and information management coordinators, and links to IMS suppliers may be found on the NCHAM website: www.infanthearing.org

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