

Business Case
Model 2.0

**Developing and using a Business Case
Model to calculate the specific benefits and
costs of integrating child health information
systems**

Technical Report

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Key Abbreviations and Definitions

BCM	Business Case Model
Business case	A business case sets out the information needed to enable a manager to decide whether to support a proposed project, before significant resources are committed to its development. The core of the business case is an assessment of the costs and benefits of proceeding with a project.
Discount rate	The interest rate used in the calculation of the present value of expected future costs and benefits
EHDI	Early Hearing, Detection and Intervention
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
ICHIS	Integration of child health information systems
Integration	Combining information systems to provide timely and electronic sharing of child-level information among authorized users of different child health programs
Marginal benefit	A term in economics that denotes the extra value accrued (e.g., the value of an immunization registry increases when it is linked with other information systems).
NDBS	Newborn Dried Blood Spot Program
Present value (PV)	The current, discounted value of future costs or benefits.
WIC	Women, Infants and Children Program

I. Introduction

Children are falling through cracks in the systems designed to provide preventive health care services. Throughout the United States, these children do not receive the timely immunizations, screenings, or follow-up care that should be available. Research shows that such failures may lead to illness(es) or even life-long disabilities, which are potentially preventable. Through the cracks in these systems these children, their families, and society pay the price. The efforts of families, health care providers, and public health programs to close the gaps in coverage and to optimize health care and health outcomes for children are often limited by the lack of timely, complete, and accurate health information.

Integrated child health information systems (ICHIS) create the potential to fill the holes in the delivery of child health preventive services. The Business Case Model (BCM), which is available to state public health departments, researchers and others interested in the business case for ICHIS, was developed by the Public Health Informatics Institute (PHII), with funding from the Robert Wood Johnson Foundation and the Maternal Child Health Bureau, Health Resources and Services Administration. This report documents the methods, data, and assumptions underlying this modeling tool, and is intended to supplement the BCM User's Guide. Each state differs in terms of its current status with ICHIS, the nature of the programs and services provided newborn and child demographic, and ICHIS goals. In recognition of this diversity, we developed the BCM so that Users can customize the tool to the needs and circumstances of their respective states. There are many components to the costs and benefits of ICHIS; as such, data is collected from many different sources. The BCM comes preloaded with much of the data necessary for analysis, from a collection of literature and other sources, so that the tool is instantly useable, and reduces the burden of data collection and validation for users. The sources for this information are documented in the BCM and in this report to allow Users to better draw conclusions on the accuracy of data inputs for their state. The BCM allows Users to easily change most of the underlying data and assumptions in the model.

While data on child health program participants and other BCM inputs are readily available, there is a paucity of information on inputs that are key components in building the business case. For example, very little research has been conducted on the impact of ICHIS on healthcare delivery patterns (e.g., screening rates, referral patterns, and follow-up care) and public health program processes (e.g., work processes, program organization, and informing public health decisions).

In the remainder of this report we describe the major components of the BCM. Methods, data, and assumptions are discussed for each component. Also, we discuss research gaps that, if filled, could help to provide complete and precise estimates of the benefits and costs of ICHIS.

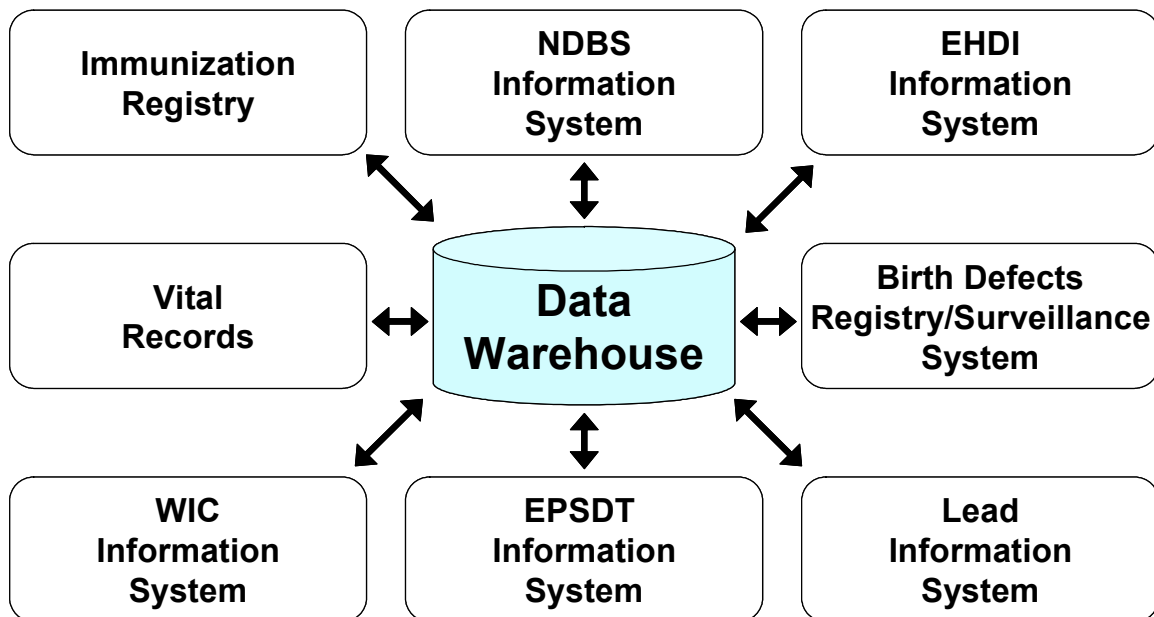
II. Child Health Information Systems Modeled

The BCM allows Users to choose among the following child health programs in developing a business case scenario: Immunizations; Newborn Dried Blood Spot (NDBS); Early Hearing, Detection and Intervention (EHDI); Vital Records; Women, Infants and Children (WIC); Early and Periodic Screening, Diagnostic, and Treatment (EPSDT); Lead; and Birth Defects.

Integration is defined as the timely and electronic sharing of child-level information among authorized users of different child health programs. While the characteristics of integrated systems will differ by state, the main categories of ICHIS are a decentralized system (Exhibit 1), a centralized system (Exhibit 2), or a hybrid system with both centralized and decentralized components.

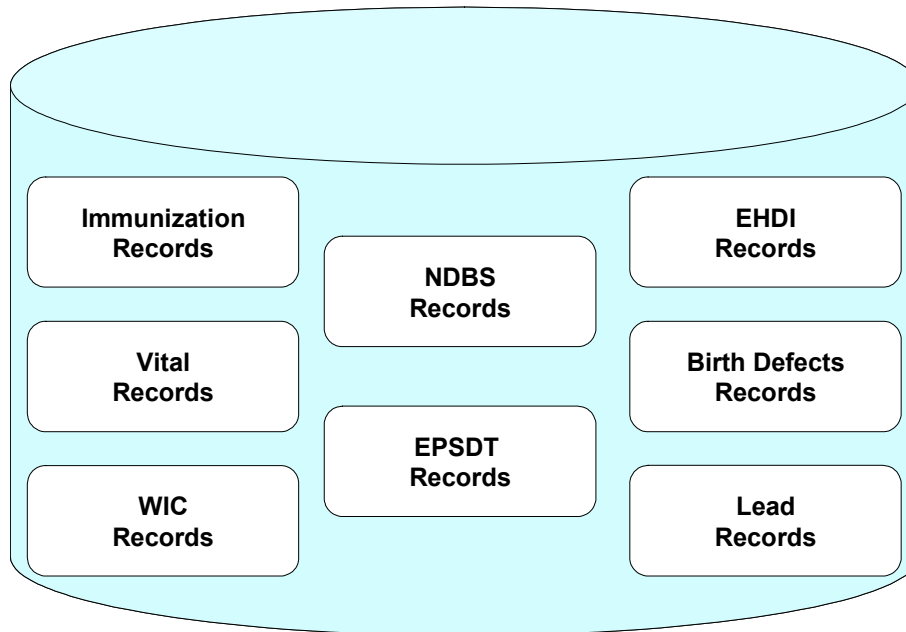
In a decentralized system, child health programs maintain their own information systems and collect their own data. These information systems share data in different ways, for example, a data warehouse. To share data, a unique identification code is needed for each child, and a process must be put in place to merge and “de-duplicate” the data when information on the same child comes from multiple sources.

Exhibit 1: Decentralized, Integrated System



With a centralized system, the same information system is used by all child health programs. Thus, when information on a child is input into the system by staff in one program, it is automatically available to staff in other programs (who are authorized to view that information). A centralized system has the potential to be more efficient than a decentralized system for items such as reduced data entry and deduplication.

Exhibit 2: Centralized, Integrated System



We discuss the integration benefit data and assumptions for each of the child health information systems.

A. Vital Records

Integrating vital records with other child health information systems creates the potential for benefits in three major areas:

- First, complete records of 100 percent of the children born in a given state helps to identify newborns and children who might be eligible for select health programs, track screening and program participation, and reach out to non-participants. Infants born outside hospitals (e.g., at home with a midwife) and infants in need of critical medical attention at birth are examples of children who are sometimes neglected in terms of screening and immunizations that occur shortly after birth.
- Second, information from vital records (e.g., demographics) can be linked with information from other sources to help identify trends in program participation and timely receipt of healthcare services. This information can inform public health policies at both the state and program level.
- Third, there exists the potential for improved program efficiency through reduced data collection and entry costs, to the extent that other programs collect information already present in vital record collection.

Some benefits of vital record integration, such as tracking NDBS screening, are realized only when the child health program (e.g., NDBS) receives information from vital records in a timely manner (e.g., within a few days of child birth). Because children move over time and some information collected through vital records changes over time, the

potential value of integrating vital records is greatest for health programs that target newborns and young children.

The BCM is pre-populated with state-level information derived from vital records, such as size and demographics of the birth cohort and child mortality rates.

B. Immunization Registries

1. Overview

While almost all children are vaccinated prior to starting school (at approximately age 5), many still fail to receive timely vaccination. Some are vaccinated too early, which reduces vaccine effectiveness and requires revaccination; some receive unnecessary, duplicate doses (i.e., extra-immunization); and many children are vaccinated late, which lengthens the time they are under-immunized, increasing their risk of disease.

Creation of immunization registries has improved the timeliness of vaccinations and reduced the likelihood of invalid and/or duplicate doses, but the potential for improvement remains. The business case argument for integrating immunization registries with other child health information systems is predicated on the benefits of improved vaccination timeliness when other child health programs have access to immunization information and can refer children for vaccination. In addition, information in immunization registries (e.g., child/parent contact information) can be useful in the provision of outreach services for other child health services. The BCM estimates the benefits of improved vaccination timeliness under different referral and follow-up assumptions (Exhibit 3).

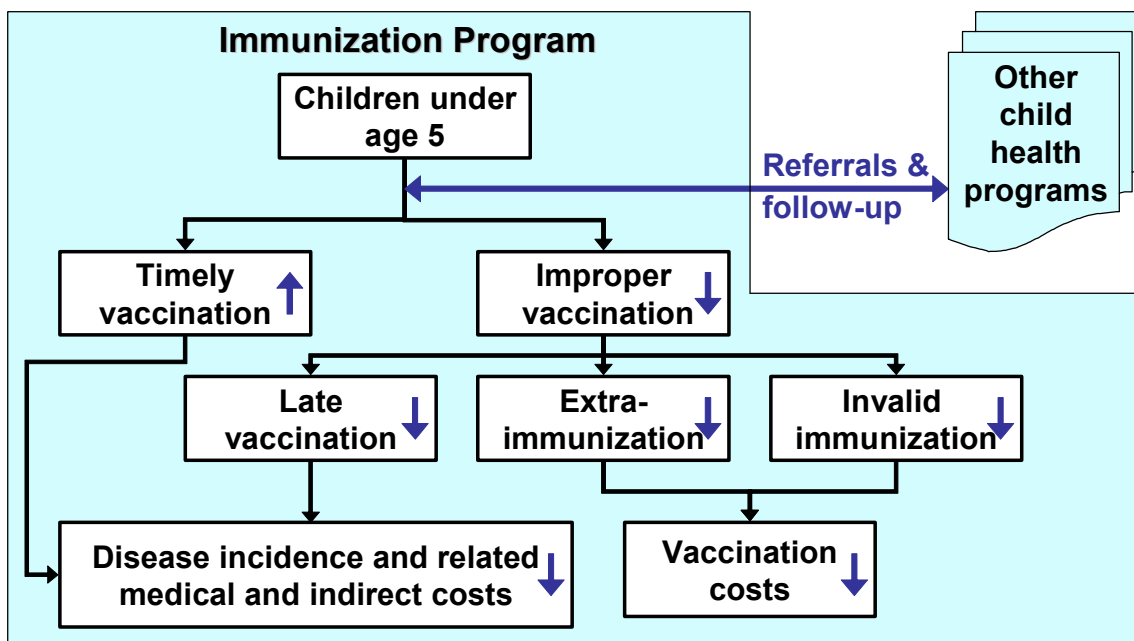


Exhibit 3: The Immunization Component of the BCM

The benefits of integrating immunization registries with other information systems include benefits related to vaccination and benefits related to other child health needs. If, for example, a child participating in WIC is due for vaccination, an integrated system could alert the WIC case manager, who could then refer the child for vaccination or, if available, provide a vaccination during the WIC visit. Other programs can also benefit from integration with immunization registries because such registries can provide information on young children currently living in the state. For example, children in an area at high risk for lead exposure can be identified through the immunization registry and encouraged to receive lead screening.

2. Data

The BCM is pre-populated with some state-specific data (e.g., immunization rates), as well as national estimates which have been converted to state estimates (e.g., disease risk and cost per disease case). Some estimates are based on state-specific data; other estimates are based on national studies; some estimates are provided based on expert opinion in the absence of empirically-based estimates.

Table 1 summarizes the default information on vaccination rates and average delay (if under-vaccinated) in the BCM. Table 2 contains estimates of the increased disease risk due to under-vaccination. These estimates are calculated by dividing the national, average number of child disease cases (annual average from 2001 through 2003) by the estimated national, annual number of days of under-vaccination (as calculated through the BCM).

Estimates of health care utilization, as well as the medical and indirect costs per disease case are based on findings reported in the literature (Table 3). The BCM converts national cost per case estimates to state-specific estimates using both medical and overall cost of living indices.

Table 1. Vaccination and Childhood Disease Data

Vaccination Schedule	Vaccination Rate	If under-vaccinated, average delay (in days) until proper vaccination
@ 3 months for: DTP, Polio, Hib, HepB, PCV	BCM contains state-specific estimates by vaccine and month (a)	10*
@ 5 months for: DTP, Polio, Hib, HepB, PCV		20*
@ at 7 months for: DTP, Polio, Hib, HepB, PCV		30*
@ 13 months for: DTP, Polio, Hib, HepB, PCV, VAR, MMR		40*
@ 19 months for: DTP, Polio, Hib, HepB, PCV, VAR, MMR		60*
@ 24 months for: DTP, Polio, Hib, HepB, PCV, VAR, MMR		60*
@ 25-60 months for: DTP, Polio, Hib, HepB, PCV, VAR, MMR	*	DTP: 193.7 Polio: 168.4 Hib: 168.7 HepB: 208.2 PCV: 200.0 VAR: 132.6 MMR: 144.4 (b)

Source: * Placeholder estimate pending more precise data. (a) US, National Immunization Survey, 2004. <http://www.cdc.gov/nip/coverage/NIS/04/toc-04.htm>; (b) Timeliness of Childhood Vaccinations in the United States: Days Undervaccinated and Number of Vaccines Delayed. *JAMA* 293(10): 1204-1211. Table 2

Table 2. Disease Cases per 1,000 Child Years of Under Vaccination

Disease	Rate
Diphtheria	< 0.01
Tetanus	< 0.01
Pertussis	8.32
Polio	< 0.01
Hib	0.84
Hepatitis B	0.03
Streptococcus pneumoniae	837.30
Varicella	18.36
Measles	0.04
Mumps	0.08
Rubella	< 0.01

Source: Estimates calculated by dividing national, annual disease cases by estimated national, annual child-years of late-vaccination. Estimate for streptococcus pneumoniae assumes 75% vaccine effectiveness.

Table 3. Average Healthcare Utilization and Medical Cost per Disease Case

	Healthcare Utilization				Indirect Costs		Cost per Case (c) (US Average, 2006 dollars)		
	Hospital ICU days	Non-ICU Hospital Days	Physician Office Visits	Other	Mortality Risk	Parent lost work days	Medical	Lost Productivity (parents)	Total
Diphtheria (a)	10	4			7.5%	14	\$30,589	\$2,129	\$32,717
Tetanus (a)	0.9	2.1	1.4		11%	4.4	\$5,246	\$669	\$5,915
Pertussis (a)		1.05	2	Culture and antibiotics 65% of cases @ \$155 per case	0.14%	3.05	\$1,692	\$464	\$2,155
Polio (a)	0.45		2	Physical therapy 6.3 days	2.5%	8.75	\$11,043	\$1,330	\$12,374
Hib (a)		0.4	1		0.55%	1.4	\$623	\$213	\$836
Hepatitis B (a)		0.165	0.055		10.6%	0.22	\$232	\$33	\$265
Streptococcus pneumoniae (b)	0.0004	0.05	1.02		0.02%	1.07	\$143	\$163	\$306
Varicella (a)		0.0045	0.15225		0.001%	2.7	\$17	\$411	\$428
Measles (a)		0.75	1.75		0.015%	2.5	\$1,159	\$380	\$1,539
Mumps (a)		0.35	1		0.34%	1.35	\$554	\$205	\$759
Rubella (non CRS) (a)			1		0.8%	1	\$71	\$152	\$223

Sources: (a) Health care utilization and indirect cost assumptions from Albee et al. (2000). (b) Health care utilization and indirect cost assumptions from IOM (1999). Streptococcus pneumoniae definition includes bacteremia and sepsis, pneumonia, otitis media/sinusitis/bronchitis, and meningitis. (c) Medical and indirect cost estimates calculated in the BCM are based on state-specific estimates of the average cost per hospital day, office visit, etc.

The integration of immunization registries with other child health information systems has the potential to significantly reduce the number of cases of extra-immunization as well as invalid vaccinations. Estimates of the percent of extra-immunized children (Feikema et al., 2000) and the percent of children with invalid doses (requiring revaccination) (Stokley et al., 2004), might overstate waste due to unnecessary vaccinations, as recent modifications and updates in immunization registries have already caused these numbers to improve.

The default administration cost for each unnecessary vaccination given in the BCM is \$6.09 (national estimate, in 2006 dollars). Vaccine type and public/private sector price differentiation causes variations in cost per dose (Table 4). The BCM allows the User to specify the proportion of vaccinations that are provided at the private sector price; the default setting is 50%, an even split between public and private sector pricing.

Table 4. Average Healthcare Utilization and Medical Costs per Disease Case

Vaccine	Cost per Dose (a)		Percent of children extra-immunized at 25-60 months (b)	Percent of children with invalid doses at 25-60 months (c)
	Public sector	Private sector		
DTP	\$12.25	\$21.40	4.3%	2.0%
Polio	\$10.42	\$21.80	5.0%	0.4%
Hib	\$10.22	\$22.77	3.8%	1.0%
HepB	\$9.00	\$21.37	5.8%	5.4%
PCV	\$54.12	\$65.95	1.0%	1.0%
VAR	\$52.25	\$66.81	1.0%	1.6%
MMR	\$16.67	\$40.37	2.8%	1.3%

Sources: (a) http://www.cdc.gov/nip/vfc/cdc_vac_price_list.htm (b) Feikema et al. (2000). (c) Stokley et al. (2004).

C. Newborn Dried Blood Spot Screening

1. Overview

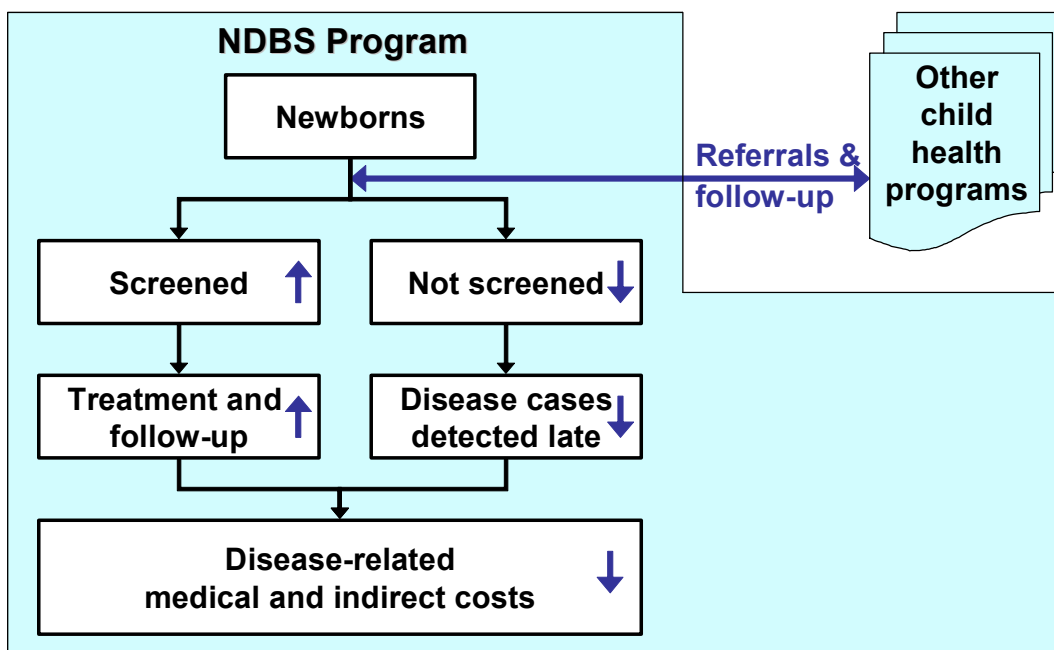
NDBS screening and follow-up rates in most states is close to 100 percent; consequently, integrating the NDBS information system with other child health information systems will have a limited impact on the reduction of diseases that can be prevented or mitigated by early detection and treatment. Still, a small percentage of children slip through these cracks in the public health system, resulting in disease cases that could have been prevented or mitigated.

Because the NDBS system collects data on close to 100 percent of newborns, this system contains data (e.g., medical home information) that could be useful to other newborn-focused public health programs.

The BCM uses state data on number of newborns and estimated screening and follow-

up rates to estimate the number of children who fall through cracks in the system, as well as the number of children with a disease who do not receive timely treatment. Under different sets of assumptions regarding the change in screening and treatment follow-up rates under alternative integration scenarios, the User can calculate the projected number of child disease cases prevented by ICHIS and the associated medical and indirect costs (Exhibit 4).

Exhibit 4: The NDBS Component of the BCM



2. Data

The BCM combines disease prevalence rates, state-specific NDBS screening and follow-up rates, and Census Bureau estimates of the number of newborns in each state in order to model the total number of newborns that are screened, receive follow-up care, and are diagnosed with one or more of the 28 diseases modeled. The probability and severity of sequelae associated with each disease can vary by whether timely treatment is received. Estimates of the medical and other costs (e.g., long term care, lost productivity, special education) associated with each disease case are either obtained from the literature or calculated in the model. We discuss these various data needs and sources in turn.

- Screening rates:** Precise estimates of the percent of newborns in a state receiving blood spot screening are difficult to obtain because most states do not report unduplicated number of screenings. The default screening rates used in the BCM are state-reported rates of the percentage of newborns receiving an initial PKU screening. For states that do not report initial screenings independent of subsequent screenings, the default estimate is the calculated average (99%) across all states that do report this information (Table 5). Combining screening rates with Census Bureau data on number of newborns

provides an estimate of the number of newborns screened in each state in the current and future years.

- **Disease incidence rates:** The BCM uses national estimates of disease incidence because state-specific estimates are based on small populations that are not sufficiently large to provide reliable incidence rates for rare diseases. Combining these incidence rates with number of newborns produces estimates of the expected number of disease cases in a particular state in a given year.
- **Follow-up rates for children whose initial screening result is abnormal.** The default estimates of follow-up rates in the BCM are national estimates. For diseases where follow-up rates are unavailable, we use a follow-up rate of 98% (a conservative estimate).
- **Number of disease cases detected early and late:** Based on the screening and follow-up rates, the BCM estimates the total number of disease cases detected early, detected late due both to missed screening(s) and missed follow-up after an abnormal initial screening results. The number of disease cases is reported in fractions (e.g., a small state might have 0.5 cases of a particular disease), which reflects the rarity of these diseases and the use of probabilities in estimating the number of cases.
- **Disease case sequelae probability and severity:** Early detection and treatment can often prevent and/or mitigate the mortality and physical and mental disabilities associated with these newborn diseases. Estimates of the probability and severity of sequelae (Table 6) and estimates of the effectiveness of early treatment in preventing or mitigating sequelae (Table 7) come from the literature (e.g., Carroll and Downs, 2006; UTHSCSA National Newborn Screening Report, 2000).
- **Cost per disease case:** The medical and indirect costs per disease case come either from the literature or from internal BCM calculations. The data and methods to calculate these cost estimates are described later, but they include medical costs directly attributed to the disease, higher long term care and special education costs, and lost earning potential due to reduced earning capacity and/or premature mortality.

Table 5. NDBS Screening and Follow-up

Disease (a)	Birth Cohort Screened		Disease Incidence Rate (c)	Follow-up Rate if 1 st Screening Returns Abnormal Result (c)
	% (b)	#		
3-Methylcrotonyl-CoA carboxylase deficiency	Estimates are reported percentage of newborns receiving initial PKU screening, 2002.	U.S. Census Bureau data on number of newborns multiplied by estimated screening rate.	1.3	98%*
Argininosuccinic academia			1	98%*
Biotinidase deficiency			1.6 (d)	96.5%
β-Ketothiolase deficiency			1	98%*
Congenital adrenal hyperplasia			5.3 (d)	98%
Methylmalonic acidemia (CbIA and ClbB forms)			1	98%*
Cystic fibrosis			25.5 (d)	98.4%
Congenital hypothyroidism			32.9 (d)	97.4%
Citrullinemia			1	98%*
Carnitine uptake defect			1	98%*
Glutaric acidemia type I			1.3	98%*
Classical galactosemia			1.9 (d)	97.1%
Hb S/C disease			13.5 (d)	97.7%
Hb S/β-thalassemia			2	98.1%
Homocystinuria (due to CBS deficiency)			0.3 (d)	98.7%
3-OH 3-CH3 glutaric aciduria			1	98%*
Isovaleric acidemia			1	98%*
Long-chain L-3-OH acyl-CoA dehydrogenase deficiency			1.3	98%*
Multiple carboxylase deficiency			1	98%*
Medium/short-chain L-3-OH acyl-CoA dehydrogenase deficiency			1.3	98%*
Maple syrup disease			0.4 (d)	97.6%
Methylmalonic acidemia (mutase deficiency)			1	98%*
Phenylketonuria			7.2 (d)	95.6%
Propionic acidemia			1.3	98%*
Sickle cell anemia (Hb SS disease) Hb			26.9 (d)	98.4%
Trifunctional protein deficiency			1	98%*
Tyrosinemia type I	1	100%		
Very long-chain acyl-CoA dehydrogenase deficiency	1.3	98%*		

Sources: *Placeholder estimate pending more precise data. (a) Diseases included in BCM based on <http://www.mchb.hrsa.gov/screening/> (b) <http://www2.uthscsa.edu/nnsis/> (c) unless otherwise noted, estimate from National Newborn Screening Report--2000. <http://genes-r-us.uthscsa.edu/resources/newborn/00/2000report.pdf> (d) Estimates provided by Donna Williams, National Newborn Screening & Genetics Resource Center (based on data from 1990-1999).

Table 6. Risk of Sequelae if no Treatment

Disease	Death by Age 5	Physical Disabilities			Developmental Delay		
		Severe	Moderate	Mild	Severe	Moderate	Mild
3-Methylcrotonyl-CoA carboxylase deficiency							
Argininosuccinic acidemia							
Biotinidase deficiency		76%			50%		
β -Ketothiolase deficiency							
Congenital adrenal hyperplasia	10%						
Methylmalonic acidemia (CblA and CblB forms)							
Cystic fibrosis							
Congenital hypothyroidism					2%	2%	27%
Citrullinemia	90% (a)						
Carnitine uptake defect	40% (a)						
Glutaric acidemia type I							
Classical galactosemia	14%				10%	90%	
Hb S/C disease							
Hb S/ β -thalassemia							
Homocystinuria (due to CBS deficiency)		100%			5%	33%	11%
3-OH 3-CH3 glutaric aciduria	20%						
Isovaleric acidemia							
Long-chain L-3-OH acyl-CoA dehydrogenase deficiency							
Multiple carboxylase deficiency	20%		10%		5%		5%
Medium/short-chain L-3-OH acyl-CoA dehydrogenase deficiency							
Maple syrup disease		25%	50%		50%		
Methylmalonic acidemia (mutase deficiency)							
Phenylketonuria		48%	48%	5%	25%		
Propionic acidemia							
Sickle cell anemia (Hb SS disease) Hb							
Trifunctional protein deficiency							
Tyrosinemia type I							
Very long-chain acyl-CoA dehydrogenase def.							

Sources: Unless otherwise noted, estimates come from Carroll and Downs (2006). (a) HRSA (2005). <http://www.mchb.hrsa.gov/screening/>

Table 7. Effectiveness of Early Screening in Preventing Sequelae

Disease	Death by Age 5	Physical Disabilities			Developmental Delay		
		Severe	Moderate	Mild	Severe	Moderate	Mild
3-Methylcrotonyl-CoA carboxylase deficiency							
Argininosuccinic acidemia							
Biotinidase deficiency					100%		
β-Ketothiolase deficiency							
Congenital adrenal hyperplasia	80%						
Methylmalonic acidemia (CblA and CblB forms)							
Cystic fibrosis					100%		100%
Congenital hypothyroidism							
Citrullinemia							
Carnitine uptake defect							
Glutaric acidemia type I							
Classical galactosemia	66%				0%	0%	0%
Hb S/C disease							
Hb S/β-thalassemia							
Homocystinuria (due to CBS deficiency)		100%	100%	100%	100%	100%	100%
3-OH 3-CH3 glutaric aciduria							
Isovaleric acidemia							
Long-chain L-3-OH acyl-CoA dehydrogenase deficiency							
Multiple carboxylase deficiency	98%						
Medium/short-chain L-3-OH acyl-CoA dehydrogenase deficiency							
Maple syrup disease		93%	93%	93%	53%	53%	53%
Methylmalonic acidemia (mutase deficiency)							
Phenylketonuria		100%	100%	100%	100%	100%	100%
Propionic acidemia							
Sickle cell anemia (Hb SS disease) Hb							
Trifunctional protein deficiency							
Tyrosinemia type I							
Very long-chain acyl-CoA dehydrogenase def.							

Sources: Carroll and Downs (2006).

D. Early Hearing Detection and Intervention

1. Overview

Although there are high screening rates at birth for congenital hearing loss, follow-up rates for abnormal screening results are low in most states. Integrating the EHDI information system with other child health information systems has the potential to greatly improve early detection of hearing loss, specifically through the improvement of follow-up rates (Exhibit 5). During this crucial development period, when timely medical care and early childhood interventions are received, future expenditures for special education are reduced and earnings potential increases (White, 1997).

As summarized by White (2002), research shows that children with hearing loss who receive appropriate intervention (e.g., prior to 6 months of age):

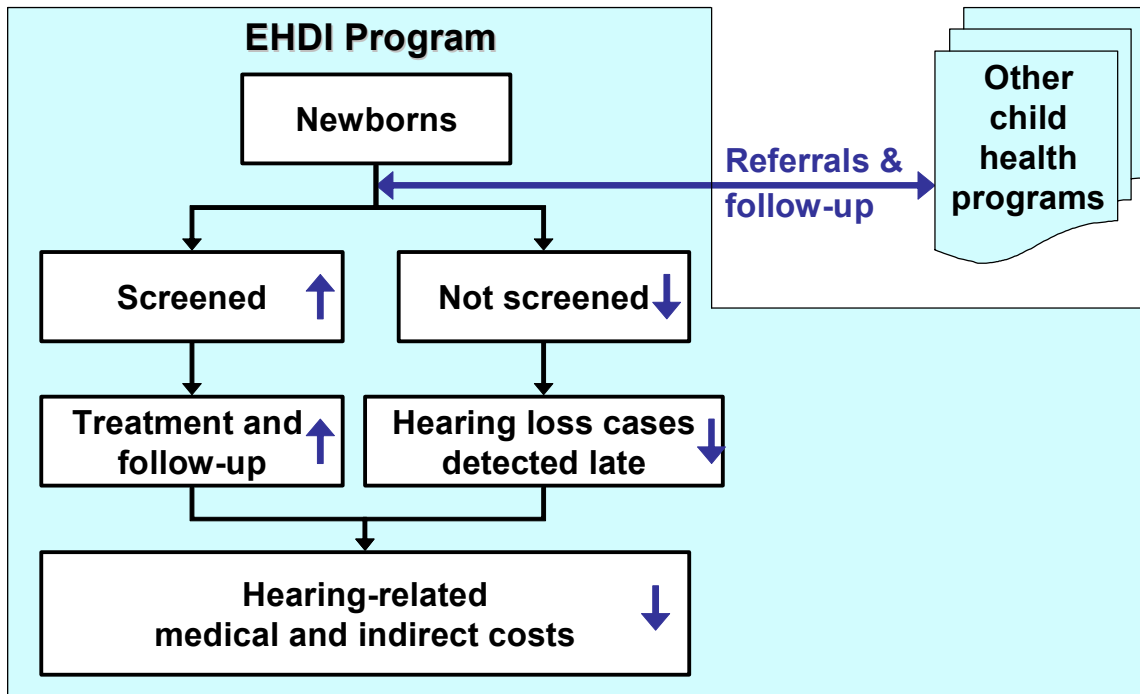
- can be mainstreamed into regular elementary and secondary education classrooms (Joint Committee on Infant Hearing, 2000);
- demonstrate significantly improved speech and reading comprehension than children identified after 6 months of age (Yoshinaga-Itano and Apuzzo, 1998); and
- have less need for extensive habilitation during the school years, therefore reducing the burden on the IDEA Part B program (Ross, 2001).

Furthermore, compared to children with normal hearing, children with hearing loss

- are more likely to be held back at least one grade (Bess, 1985);
- miss more conversation/speech in the classroom and may be inappropriately labeled as having a behavior problem (Flexer, 1994); and
- are more likely to graduate from high school at a lower reading level (Gallaudet Research Institute, 1996).

When primary care physicians, audiologists, WIC case workers, and others in the public health system have information that a child should receive additional testing, follow-up rates are likely to improve. Relatively little is known, however, about the impact of CHIS integration on improved follow-up rates and enrollment in early intervention programs. The BCM allows the User to model the financial implications of improvements in initial screening, follow-up, and enrollment in an intervention program prior to age 6 months under alternative sets of assumptions.

Exhibit 5: The EHDI Component of the BCM



2. Data

The BCM contains the following state-level data for 2004 and uses this data as the default in the business case unless the User overwrites the estimates with new data (Table 8).

- **Newborn screening rates:** The total number of newborns is multiplied by the percentage of those screened for hearing loss, to estimate the number of children screened and the number of newborns not screened.
- **Referral rates:** Estimates of the total number of children referred to audiologists is calculated by multiplying the percentage of screened newborns that are referred for diagnostic audiologic evaluation by the number of children screened. Multiplying referral rates to the number of newborns not screened produces estimates of the number of newborns who should have been referred to an audiologist but were not referred in a timely manner.
- **Follow-up rates for referrals:** These rates are used to estimate the number of children with adverse screening results who are recommended for audiologist visits, but who are lost to follow-up.
- **Hearing loss rates:** The percentage of audiologic evaluations with hearing loss is used to estimate the number of children diagnosed early, as well as the number of cases of hearing loss cases with late diagnoses.
- **Early intervention enrollment:** The percentage of newborns with hearing loss that are enrolled in an early intervention before 6 months of age is used to calculate the costs of early hearing loss detection for comparison against the

benefits of early hearing loss detection.

For each case of congenital hearing loss, an estimated 31.8% of cases are diagnosed as moderate to profound bilateral hearing loss; 68.2% are mild and/or unilateral hearing loss.

The average age of detection of congenital hearing loss (in the absence of detection at birth) is 2½ to 3 years, and many children are not identified until age 5 to 6. The default value for average delay used in the BCM is 33 months. The delay length variable, and the impact of CHIS integration on delay length, are included in the model for reporting purposes only and do not affect the cost and benefit estimates of CHIS integration.

While it is recommended that children with hearing loss receive audiologic evaluations every six months through age 3, research on the impact of these evaluations (or lack thereof) on benefit outcomes of interest is insufficient; therefore follow-up for these evaluations is not modeled in the BCM.

Table 8. Newborn Hearing Screening and Interventions Percentages: 2004

State	Screened	% of Screened Referred to Audiologist	% of Referrals Receive Audiologic Evaluation	% Audiologic Evaluations with Hearing Loss	% with Hearing Loss Enrolled in Early Intervention
Alabama	96.3%	5.2%	58.6%*	30.8%*	58.1%
Alaska	88.8%	1.8%	17.3%	57.1%	75.0%
Arizona	84.3%	1.9%*	58.6%*	30.8%*	77.4%*
Arkansas	94.7%	0.5%	47.8%	34.1%	100.0%
California	78.2%	0.5%	73.7%	41.8%	42.3%
Colorado	97.4%	0.5%	66.7%	90.5%	77.4%*
Connecticut	100.0%	0.8%	84.3%	22.0%	43.3%
Delaware	97.4%	0.3%	100.0%	52.5%	77.4%*
District of Columbia	98.0%	0.5%	100.0%	12.0%	100.0%
Florida	98.0%	1.4%	88.1%	30.8%*	77.4%*
Georgia	97.5%	1.9%*	58.6%*	30.8%*	77.4%*
Hawaii	98.8%	1.0%	90.3%	38.9%	83.1%
Idaho	91.9%	0.6%	95.3%	27.0%	77.4%*
Illinois	97.3%	0.6%	58.6%*	30.8%*	100.0%
Indiana	98.0%	1.8%	49.8%	10.4%	67.1%
Iowa	80.0%	1.9%*	58.6%*	30.8%*	77.4%*
Kansas	97.7%	5.5%	88.3%	3.4%	69.2%
Kentucky	96.2%	3.9%	17.2%	9.0%	100.0%
Louisiana	96.3%	5.8%	50.7%	3.7%	71.4%
Maine	88.9%	2.9%	28.0%	26.0%	23.1%
Maryland	87.9%	1.0%	36.7%	55.8%	77.4%*
Massachusetts	98.9%	1.3%	88.5%	24.9%	64.4%
Michigan	93.8%	3.6%	9.6%	37.9%	28.7%
Minnesota	84.6%	4.5%	48.0%	2.3%	100.0%
Mississippi	99.0%	1.1%	78.0%	19.3%	100.0%
Missouri	97.9%	2.1%	36.6%	22.4%	39.8%
Montana	87.6%	0.1%	58.6%*	30.8%*	57.1%
Nebraska	97.2%	1.9%*	58.6%*	30.8%*	77.4%*
Nevada	96.4%	2.6%	58.6%*	30.8%*	77.4%*
New Hampshire	93.8%	0.9%	25.2%	58.1%	100.0%
New Jersey	98.2%	4.5%	48.8%	4.0%	51.0%
New Mexico	92.0%	4.4%	58.6%*	30.8%*	100.0%
New York	94.5%	0.6%	20.4%	20.9%	86.2%
North Carolina	95.1%	1.9%*	58.6%*	30.8%*	77.4%*
North Dakota	95.7%	0.3%	58.6%*	30.8%*	100.0%
Ohio	76.3%	5.3%	19.7%	11.7%	100.0%
Oklahoma	93.8%	3.3%	12.5%	25.5%	88.2%
Oregon	92.5%	2.0%	61.2%	8.8%	10.6%
Pennsylvania	96.1%	1.1%	38.5%	18.5%	68.6%
Rhode Island	99.8%	0.7%	86.0%	43.8%	97.1%
South Carolina	98.4%	2.8%	74.3%	7.6%	98.8%
South Dakota	94.3%	0.4%	76.9%	43.3%	100.0%
Tennessee	57.2%	4.3%	53.0%	2.9%	100.0%
Texas	97.6%	0.2%	41.2%	93.1%	77.4%*
Utah	97.1%	0.8%	69.4%	23.4%	66.2%
Vermont	94.5%	0.4%	56.0%	50.0%	71.4%
Virginia	97.5%	3.0%	81.5%	3.5%	79.1%
Washington	88.0%	0.3%	75.0%	65.3%	77.4%*
West Virginia	96.8%	0.7%	52.0%	21.8%	100.0%
Wisconsin	95.1%	2.0%	58.6%*	30.8%*	100.0%
Wyoming	98.1%	0.4%	100.0%	77.3%	100.0%

Sources: <http://www.cdc.gov/NCBDDD/ehdi/dips.htm#DSHPSHWA> * State estimate unavailable, national average used as default.

Improved screening and follow-up rates, coupled with early intervention, results in higher short-term costs to the government and private payers. The default estimate of the percent of these costs paid by the government is set at 50%, with the remaining 50% paid for by private insurers and families. The BCM default values for national estimates of these higher costs are set at \$30 for the initial hearing screening, \$14.23 per child recommended for further testing for tracking a two-stage screening, and \$150 per visit with an audiologist.

Estimates of the average cost per child enrolled in an early intervention are unavailable in the literature, therefore the BCM contains placeholder estimates as shown in Table 9.

Table 9. Cost per Child Enrolled in an Early Intervention Program

Moderate to profound bilateral hearing loss	\$10,000*
Mild and/or unilateral hearing loss	\$6,000*

Source: *Placeholder estimate pending more precise data.

For modeling purposes we assume that children with early detection of hearing loss incur the same medical costs as children with a similar level of hearing with late detection. Further, in the BCM we assume that children with moderate to profound bilateral hearing loss receive cochlear implants, at a cost of \$60,000 (per child), while children with mild and/or unilateral hearing loss receive a digital hearing aid at a cost of \$2,100. For the BCM we estimate the present value, at birth, of costs associated with a cochlear implant or hearing aid; consequently, the cost is slightly higher for cases of hearing loss with early detection. We assume that children with early hearing loss detection receive a cochlear implant, or hearing aid, at 12 months of age (PV=\$58,300 for implant and \$2,000 for hearing aid), while children with delayed detection are treated at four years of age (PV=\$53,300 for implant and \$1,900 for hearing aid).

Estimates of the impact of early hearing loss detection and intervention on special education costs and lifetime earnings potential are described later in this document.

E. Lead Screening

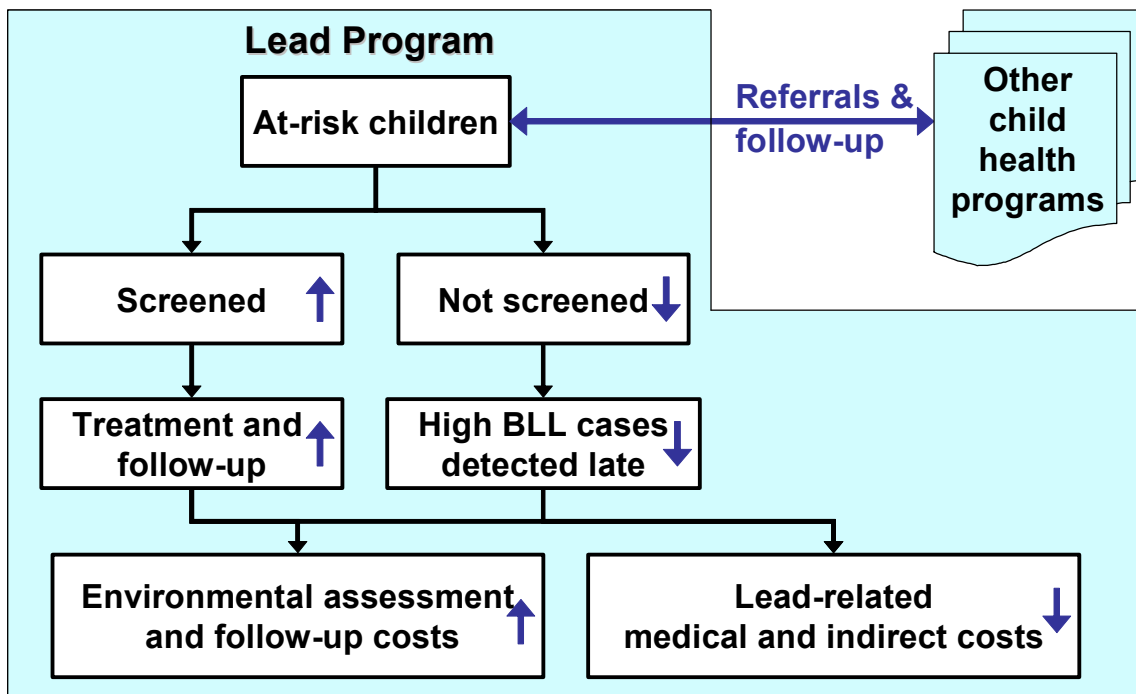
1. Overview

Children with high lead exposures, as measured by high blood lead levels (BLL), are at risk for permanent neurological problems that reduce mental capacity and contribute to other health problems. It is recommended that children who are at risk for lead exposure receive periodic BLL screenings. There are multiple services and interventions provided to children with above normal BLL, including home environmental assessments, follow-up visits (for BLL monitoring), and, in cases of extremely high BLL, chelation therapy and hospitalization.

By integrating information from the Lead Program (e.g., screening, follow-up services) with other health information systems, potential improvements in screening rates and continued monitoring through follow-ups could be realized (Exhibit 6). The resulting improved care has the potential for improved early identification and intervention for

children with high BLL. Although increased screening and interventions will raise the cost of lead screening in the short term, the long-term payoff is reduced medical and indirect costs associated with high BLL.

Exhibit 6: The Lead Component of the BCM



2. Data

The data used to model the impact of integration on reduced BLL levels comes from many sources. The types of data used include the following:

- Recommendations for screening and treatment and follow-up rates (Tables 10 and 11),
- State-level screening rates,
- Treatment rates and costs (Table 12),
- Disability rates and costs (discussed later), and
- Miscellaneous other costs and inputs (Table 12).

Table 10. Screening Recommendations and Compliance with Follow-up Testing for Children with High BLL

Age	Percent of Children Recommended for Lead Screening *	Percent Compliant With Recommended Follow-up Testing if High BLL (a)
age <1	10%	58.0%
age 1	40%	59.0%
age 2	40%	57.0%

age 3	30%	53.0%
age 4	1%	45.0%
age 5	1%	37.0%

Sources: * Estimates vary by state. Placeholder estimate pending more precise data. (a) Kemper et al (2005).

Table 11. Recommended Care for Children with High BLL

	Environmental Assessment Rate (a)	Follow-up clinician visits (b)	Provider Assessment Rate (c)	Chelation Therapy (a)	Hospitalization (a)
10-14 µg/dl	0%	1	0%	0%	0%
15-19 µg/dl	100%	1	0%	0%	0%
20-24 µg/dl	100%	8	20%	0%	0%
25-44 µg/dl	100%	8	50%	0%	0%
45-69 µg/dl	100%	8	100%	100%	0%
>=70 µg/dl	100%	8	100%	100%	100%
% cases that follow through with referral	100%		80%	100%	100%

Sources: *Placeholder estimate pending more precise data.

(a) <http://www.cdc.gov/nceh/lead/publications/books/plpyc/chapter8.htm>

(b) <Http://www.leadsafeby2010.org/articles/longtermcosts.htm>

(c) Based upon expert opinion.

Table 12. Lead Program Inputs

Data Element	Estimate
Percent of lead screening/treatment costs paid by government	90%
Lead blood screening	\$ 16.25 (a)
Environmental assessment	\$ 676.75
Follow-up testing for children with high BLL	\$ 92.20*
Cost per year for case management (including cost for physical, psychosocial development, neurological, speech, or nutritional assessment)	\$ 825.19*
Cost of chelation therapy	\$ 1,290.80*
Cost of hospitalization per child (age 0-5) for lead poisoning	\$ 4,997 (b)
Reduction in IQ points for each 1 µg/dl that goes undetected	0.25 (c)
Percent reduction in lifetime earnings per 0.25 decrease in IQ	2.39% (d)

Sources: * Placeholder estimate pending more precise data.

(a) American Academy of Pediatrics web site, estimate based on 2004 Medical Clinical Diagnostic Lab fee schedule.

(b) Vergara AE et al. Lead poisoning: costs of care in the United States, 1988-1992. JAMA 1996;276:1221

(c) Estimated based on findings from Schwartz et al. (1985) and Landrigan et al. (2002), (d) Salkever (1995).

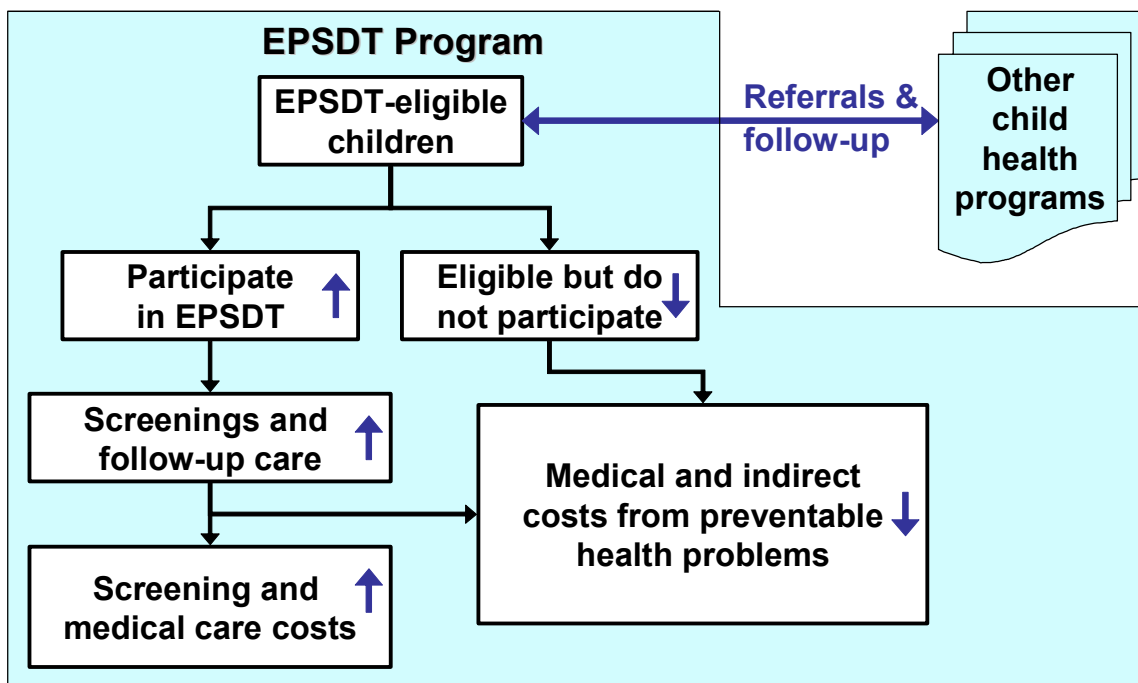
F. Early Periodic Screening and Diagnostic Testing

1. Overview

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, Medicaid's child health component, helps ensure that low-income children receive appropriate pediatric care. As part of this program, children in Medicaid receive periodic screenings used to detect physical and mental conditions, to review health and developmental history, and to review the child's vaccination and other laboratory tests (e.g., lead screening).

The primary benefit of integrating EPSDT information with other information systems is improved rates of screening and follow-up care, which serve to increase the early detection of health problems, avoiding avoid more costly treatment later (Exhibit 7).

Exhibit 7: The EPSDT Component of the BCM



2. Data

Default data contained in the BCM include state level estimates of the proportion of population EPSDT eligible, participation rates for those EPSDT eligible, number of screenings per EPSDT participant, screening compliance ratio, percent of screenings referred for corrective treatment, and compliance with referral for corrective treatment (Table 13); and cost estimates for EPSDT-related visits and value of follow-up care (Table 14).

Table 13. EPSDT Eligibility, Participation, and Compliance Rates

	Estimated proportion of population EPSDT eligible (a)	Estimated participation rate for EPSDT eligible (a)	Expected number of screenings per EPSDT participant (a)	Screening Compliance Ratio (a)	Percent of screenings referred for corrective treatment (a)	Compliance with referral for corrective treatment *
Age <1	75%	66%	5.16	51%	4%	90%
Age 1-2	66%	61%	1.34	60%	25%	90%
Age 3-5	55%	39%	0.77	53%	14%	90%
Age 6-9	41%	17%	0.38	43%	18%	90%
Age 10-14	35%	16%	0.46	36%	16%	90%
Age 15-18	30%	9%	0.36	23%	22%	90%
Age 19-20	17%	3%	0.22	6%	54%	90%

Sources: * Placeholder estimate pending more precise data. (a) National estimates reported here; state level data available at: <http://www.cms.hhs.gov/MedicaidEarlyPeriodicScrn/downloads/epsdt2005.pdf>

Table 14. EPSDT Inputs to the BCM

EPSDT	Estimate
Cost per EPSDT screening	\$77.62
Cost per case for referred treatment	\$81
% EPSDT screening/treatment costs paid by government	80%
Cost per case when needed treatment missed/delayed	\$163

Sources: * Placeholder estimate pending more precise data.

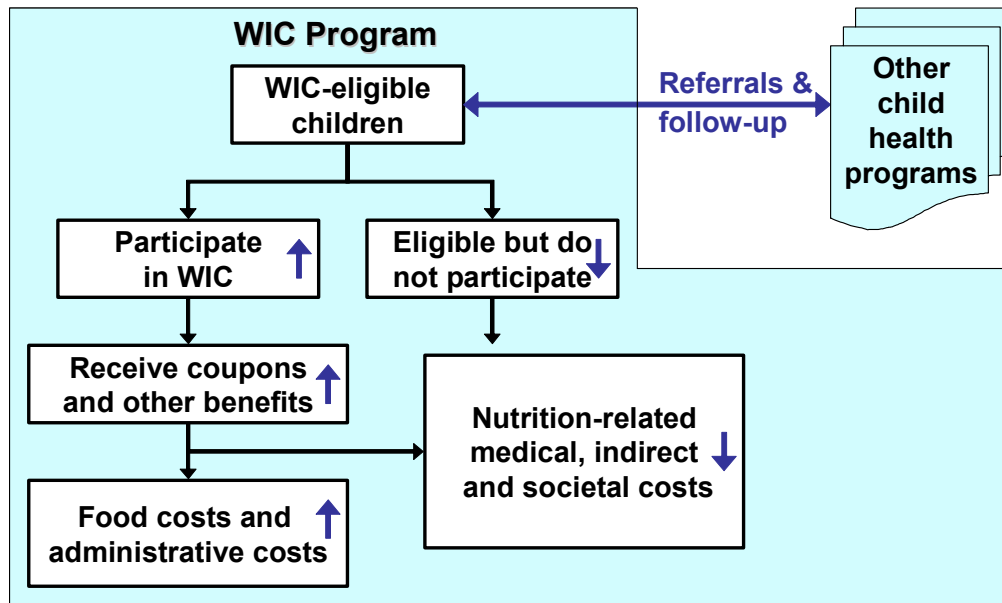
G. Women, Infants, Children Program

1. Overview

The Women, Infants, Children (WIC) Program provides nutritious food to low-income women who are pregnant, nursing or have recently delivered, as well as to low-income children under age 5. WIC also provides nutrition education, as well as referrals to health care and social service agencies. Integration of the WIC information system with other child health information systems creates the potential to improve both WIC participation and coordination of care with other child health programs, as well as the prevention of nutrition-related health and other developmental problems (Exhibit 8).

For example, information sharing between WIC and public health clinics reduces the need for multiple measurements of the same child and improves the referral process to other government agencies. In many communities information is shared by making multiple copies of various documents to send or fax to other agencies. Electronic data sharing, through CHIS integration, can greatly improve both the efficiency and effectiveness of information sharing.

Exhibit 8: The WIC Component of the BCM



2. Data

The primary data inputs for the WIC component of the BCM include the following:

- **WIC eligibility rates.** Eligibility rates will differ by state depending on each states' economic conditions and eligibility guidelines. Bitler, Currie and Scholz (2003) estimate, that, at the national level, approximately 58% of infants and 57% of children age 1-4 are eligible to participate in WIC; the BCM uses these as default estimates.
- **WIC participation rates.** Participation rates vary by state, and the BCM uses data from Oct 2004 to May 2005 to estimate the average number of participants per month by state and by child age (Table 15).
- **Average cost per child per month for participating in the program.** The default data used in the BCM are state-specific estimates of the average food cost per child per month, from Oct 2004 to May 2005 (Table 15). The BCM assumes food costs to be a cost to the government and a benefit to children/families. Non-food per child per month costs are unknown; a placeholder estimate of \$15 is used, which covers program administration as well as the cost of providing educational and counseling services to families.
- **Average benefit per child per month for program participation.** The benefits of WIC participation (in addition to the value of the food coupons) include the prevention of health problems occurring due to poor food intake. Quantitative estimates of this benefit are unavailable; a placeholder estimate of \$20 per child per month is used in the BCM. A portion of this benefit is realized by the children/families, while other components of this benefit are realized by the government in the form of reduced future health and social service expenditures. The exact portion of benefits realized by children/families is

unknown, but the BCM uses default estimates allocating 80% of benefits to children/families, and 20% of benefits to the government. As with other parameters in the model, this assumption can be modified by the User.

Table 15: WIC Participation and Average Monthly Food Costs

State	Participants Age 0-11 Months	Participants Age 1-4 Years	Average Monthly Food Cost
Alabama	33,262	55,866	\$44.43
Alaska	6,438	13,977	\$43.20
Arizona	46,854	86,861	\$36.81
Arkansas	24,405	38,720	\$35.96
California	293,773	687,641	\$38.58
Colorado	22,531	40,346	\$80.48
Connecticut	14,400	26,691	\$41.96
Delaware	5,370	9,549	\$33.59
District of Columbia	4,437	7,381	\$43.21
Florida	100,353	173,885	\$38.31
Georgia	71,287	124,060	\$36.44
Hawaii	8,055	16,853	\$52.04
Idaho	9,314	19,638	\$31.14
Illinois	81,103	127,452	\$41.57
Indiana	39,343	59,835	\$33.00
Iowa	15,577	36,137	\$33.10
Kansas	17,336	34,188	\$33.28
Kentucky	30,502	61,658	\$38.98
Louisiana	41,781	66,262	\$43.04
Maine	5,661	12,073	\$26.99
Maryland	29,721	50,444	\$30.65
Massachusetts	26,927	59,238	\$34.47
Michigan	53,587	117,477	\$34.62
Minnesota	28,824	64,158	\$35.20
Mississippi	31,596	46,906	\$40.66
Missouri	36,342	60,398	\$33.51
Montana	4,595	11,711	\$35.77
Nebraska	10,192	20,885	\$35.50
Nevada	13,671	21,992	\$31.39
New Hampshire	4,242	8,634	\$31.04
New Jersey	37,784	71,442	\$37.66
New Mexico	16,166	33,077	\$36.48
New York	121,273	239,012	\$44.72
North Carolina	58,391	109,283	\$38.82
North Dakota	3,329	7,481	\$42.13
Ohio	83,219	123,983	\$34.00
Oklahoma	30,445	59,145	\$32.22
Oregon	20,926	56,214	\$36.40
Pennsylvania	62,531	123,226	\$33.23
Rhode Island	5,600	11,743	\$36.40
South Carolina	30,489	48,300	\$36.93
South Dakota	5,528	11,103	\$33.26
Tennessee	42,333	71,801	\$41.54
Texas	221,544	450,461	\$31.62
Utah	18,148	32,437	\$28.08
Vermont	3,316	9,644	\$41.10
Virginia	35,535	66,697	\$34.39
Washington	36,965	85,956	\$42.72
West Virginia	11,901	26,240	\$36.19
Wisconsin	27,412	58,437	\$34.18
Wyoming	2,876	6,515	\$29.42
United States	700,487	1,358,665	\$34.62

Source: Estimates for Oct 2004 to May 2005

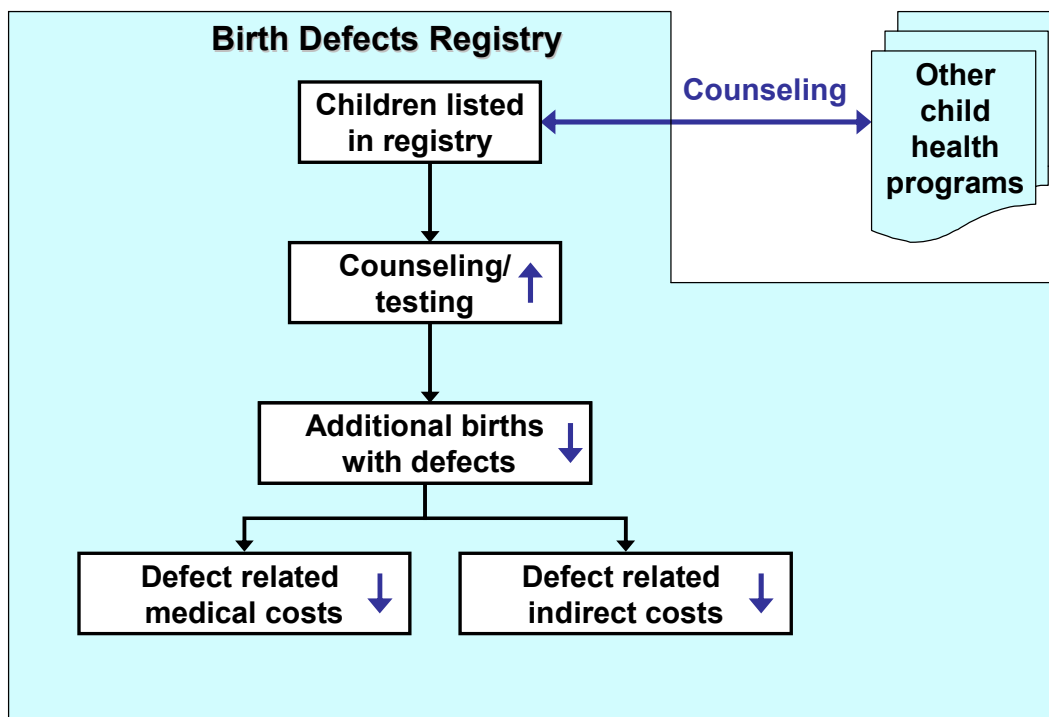
H. Birth Defects

1. Overview

Birth defects registries and surveillance is a recently incorporated component of the BCM. It has been included in order to calculate the net costs and benefits incurred due to the integration of Birth Defects with other Child Health Information Systems, such as LEAD, EPSDT, and NDBS. Any benefits realized from the integration of these systems would result from increases in information sharing, leading to the prevention of mothers who currently have children with birth defects having a second, or additional, child with the same congenital abnormality. For instance, the mother of a child with spina bifida might be counseled to achieve the correct level of folic acid supplementation during a second pregnancy, in the course of a visit in which the attending nurse or physician has access to information shared through systems integration with the Birth Defects Registry.

Unfortunately, only children already born with a birth defect or congenital abnormality are included in the Birth Defects registry, which means the only true cost savings that could be realized through integration are dependent on the probability of a woman with one child with a birth defect having a second child with the same condition. Therefore, benefits can only be realized if, through system integration or additional information sharing, the birth of the second child with the applicable birth defect can be prevented, or the resulting condition ameliorated in either severity or cost.

Exhibit 9: The Birth Defects Component of the BCM



2. Data

The primary data inputs for the Birth Defects component of the BCM include the following:

- **Birth Defects Prevalence Rates:** The prevalence rates come from a variety of sources, including CDC Surveillance reports, as well estimates reported from state surveillance data and a number of other sources. Some data has been extrapolated from the national level in absence of state-specific prevalence rates.
- **Probability of a second child with a birth defect (given a first child with said birth defect):** For birth defects resulting from genetic abnormalities, or predisposition, these estimates are more readily available. However, probabilities of second children with birth defects such as fetal alcohol syndrome are much more subjective, and can be modified to reflect the data the user believes is most accurate.
- **Lifetime cost of included birth defects:** Estimates of the direct (medical) and indirect (productivity and lost earnings) costs of birth defects also come studies in the literature. The discrepancies in the severity of various birth defects, along with the difficulties in calculating value of life and disability cost estimates make precise estimates of lifetime cost for different congenital abnormalities difficult at best.
- **Average reduction in probability of second child with birth defect, given system integration:** These estimates, used in the BCM, come from a combination of expert opinion and resources in the literature, and can be modified to reflect how you think systems integration will affect the delivery of care in your given state.
- **Years of life and productivity lost due to each birth defect:** Again, these estimates come from a combination of sources, and are dependent on a number of assumptions, including the productive capacity of those with birth defects as well as the cost to society incurred as a result of their absence from the workforce or premature mortality. As such, these inputs are quite subjective and can be modified by the User to reflect what he or she believes to be the most accurate data.

The birth defects component of the BCM would particularly benefit from the accumulation of information and user-defined inputs that grow as the model is used by a greater number of people.

1. Other Child Health Program Information Systems

The BCM was developed with the capacity to add additional child health programs. The model currently contains limited information regarding Birth Defects Registries/surveillance (BDR) Systems. Using information on rates of birth defects the model estimates the number of children in a particular state who might be included in a BDR system. This information is used to calculate potential efficiency savings from data

entry using a centralized, ICHIS. Many of the potential benefits of integrating BDR systems with other child health information systems have not yet been documented. One exception is the potential of using the registry to refer children to the Early Intervention Program (Farel et al, 2003).

Other child health programs whose information systems could potentially be incorporated include Chronic Disease Registries, Early Intervention Program, and Children with Special Health Care Needs.

III. Population, Economic and Other BCM Inputs

The BCM uses data collected from a wide variety of sources to model the number of children participating in different child health programs and to compute the medical and other costs and potential savings associated with CHIS integration

A. Demographics

When a BCM User selects a state and year for analysis, the model accesses Census Bureau population projections contained in a data table embedded in the model. This table contains estimates of the number of children, by age, for the selected state and analysis year, and also contains newborn population projections for subsequent years. This information, when combined with the estimates of the participation rates for children in different programs, yields estimates of the number of screenings and vaccinations, cases of hearing loss, children at risk for newborn diseases, and number of children participating in various child health programs.

In addition to population data, the BCM is preloaded with state-specific estimates of infant race/ethnicity (the percent of infants Black and Hispanic). This information is used to calculate more precise estimates of the number of newborn disease cases in which prevalence rates differ by race and ethnicity.

The BCM also contains annual, state-level mobility data from the Census Bureau for the following measures: percent of children under age four that move to a new county within the state, the percent of children under age four that move out of the state, and the percent of children under age four who have moved into the state. Using this information, more precise estimates of the number of children in a particular state in future years can be calculated and can also be used to produce estimates of the amount of data entry resulting from these movements within and between states.

B. Health Care Costs

The BCM contains national data on the average health care costs associated with the use of corresponding services (Table 16). These costs are combined with estimates of the healthcare utilization associated with communicable childhood diseases to estimate the average cost per case of disease. Additionally, the cost of physician office visits is used in different places in the model to quantify the financial impact of CHIS integration on use of physician services.

Table 16. Health Care Utilization Costs (in 2006 dollars)

Medical Costs	National Average	Source
Hospital ICU day	\$2,500	www.advocatehealth.com/system/about/news/fact-eicu.html
Hospital inpatient day (excluding ICU)	\$1,567	Estimate for 2003 from personal communication with the American Hospital Association regarding the average cost per adjusted inpatient day at community hospitals.
Physician office visit	\$71	Albee et al. (2000) http://statecoverage.net/pdf/tx11.pdf
Rehabilitation hospital for physical therapy (per day)	\$1,552	Albee et al. (2000) http://statecoverage.net/pdf/tx11.pdf

C. Costs Attributed to Disability

Quantifying the benefits of preventing cases of newborn diseases and hearing loss requires the use of detailed data on the medical, special education, productivity, and long-term care costs of hearing loss and the sequelae of newborn diseases. However, relatively little detailed information is available in the literature, although some studies (e.g., CDC, 2004) provide aggregate estimates for selected conditions (Table 17).

Table 17. Lifetime Medical Costs Per Case (in 2006 dollars)

Disability	Direct Medical	Direct non-medical	Lost Productivity	Total
Mental retardation	\$159,000	\$114,000	\$862,000	\$1,135,000
Hearing loss	\$30,000	\$140,000	\$292,000	\$462,000
Vision impairment	\$41,000	\$102,000	\$485,000	\$628,000

Source: CDC. 2004. Economic Costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and Vision Impairment—United States, 2003. MMWR. January 30, 2004. 53(03):57-59.
<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm>

Estimates in the literature can vary substantially. For example, while CDC (2004) estimates the present value of lifetime medical costs associated with mental retardation to be \$159,000, Ireys et al. (1996) estimate that the average annual medical expenditures attributed to mental retardation are approximately \$20,000 per year (in 2006 dollars), which yields a lifetime present value (at birth) of approximately \$582,000.

The NDBS and Lead components of the BCM contain data on the probability of sequela associated with different newborn diseases and high lead exposure, as well as the severity of mental retardation and physician disability in terms of severe, moderate, and mild cases. The BCM calculates the present value of lifetime disability costs using estimates of the increased annual medical care, lost productivity, special education, and long-term care costs attributed to disability.

Children with physical and mental disabilities often have special education needs that result

in higher education costs. In the BCM, it is assumed that these higher costs are borne by the government. The National Education Association (NEA) estimates that the average education cost per student cost was \$8,081 for students not receiving special education and \$18,106 per student enrolled in special education (Table 18). The present value at birth for the additional costs of special education for kindergarten through 12th grade, using discount rate of 3%, is close to \$95,000.

Table 18. Average, National Education Cost per Student per Year

Additional Education Costs per Year (age 5-18)	Average Annual Cost (2006 dollars)	Present Value for K-12*
Education costs in absence of special needs	\$8,081	\$76,354
Average annual cost per special education student	\$18,106	\$171,080
Additional cost for special education	\$10,025	\$94,725

Source: <http://www.nea.org/specialed/index.html> * Present value using a 3 percent discount rate.

In the BCM, lost earnings are used as one component of the indirect costs associated with disability. The current national average earnings for people between the ages of 18 and 65 is \$40,261 per year (BLS, 2005) and, using a 3 percent discount rate, the present value of future earnings at time of birth is an estimated \$598,000 (Table 19). The BCM also contains data and assumptions regarding the future earning capacity of persons with mental and physical disabilities. A case of severe mental disability, resulting in zero future earning capacity, yields a productivity loss of \$598,000; while a case that reduces earning capacity to 74 percent of the national average earnings (as in the case of mild developmental problems [Carroll and Downs, 2006]) results in a productivity loss of \$156,000. The BCM assumes that these lost productivity costs are borne by both the individuals themselves and their families.

Research shows that prolonged exposure to lead can result in learning disabilities responsible for productivity losses and higher special education costs. In the business case scenario, we assume that lead poisoning occurs at approximately 2 years of age. Schwartz et al. (1985) report that a child's IQ falls by 0.25 points for each 1 µg/dl increase that goes undetected (see also, Landrigan et al., 2002), and Salkever (1995) finds that for each 0.25 decrease in IQ, lifetime earnings decline by 2.39%. The combination of this information with the present value (at age two) of expected lifetime earnings suggests that prolonged BLL of 10-14 µg/dl is associated with a decrease of 1 percent in earning capacity, with a PV cost of \$7,100. Productivity losses increase steadily with increases in BLL; a child with a BLL of 70+ µg/dl has only 64% of the earning capacity of the typical child not exposed to high lead levels, with a PV cost of \$214,000 per case. Schwartz (1994) finds that 20% of children with BLL over 25 need some form of special education (assistance from reading teacher, psychologist, or other specialist) for an average of 3 years.

The BCM estimates the cost and benefits of CHIS integration from the perspective of families/employers/private insurers, the government, and society. The BCM User can modify the assumptions regarding the allocation of costs and savings, but the default

costs/savings estimates in the BCM allocate 40% to the government and 60% to families/individuals/private insurers. Likewise, the default estimates for care giver costs/savings are allocated 40% to the government and 60% to families/individuals/private insurers. All productivity costs/savings are allocated to families/ individuals/private insurers; all special education costs/savings are allocated to the government.

Table 19. Present Value of Lifetime Costs Attributed to Disability

Disability	Medical Costs		Productivity Loss		Special Education		Residential Care and Caregiver Services		Total
	Annual	PV of Lifetime**	Earnings Capacity	PV of Lifetime**	% Requiring	PV of Lifetime**	Annual	PV of Lifetime**	
Mental retardation									
Severe to profound (IQ ≤ 39)	\$6,504*	\$532,331	0%	\$532,331	100%*	\$95,000	\$40,000	\$1,141,000	\$2,027,000
Moderate (IQ of 40 to 54)	\$6,000*	\$232,895	56% (a)	\$232,895	80%*	\$95,000	\$15,000	\$428,000	\$942,000
Mild (IQ range 55 to 69)	\$4,000*	\$138,619	74% (a)	\$138,619	25%*	\$24,000	\$5,000	\$143,000	\$428,000
Physical disability									
Severe	\$40,000*	\$1,165,000	0%*	\$239,000	100%*	\$95,000	\$40,000	\$1,141,000	\$2,624,000
Moderate	\$10,000*	\$291,000	80%*	\$120,000	50%*	\$47,000	\$10,000	\$285,000	\$735,000
Mild	\$2,000*	\$58,000	95%*	\$30,000	20%*	\$19,000	\$2,000	\$57,000	\$162,000
Hearing loss (detection)									
Moderate-profound bilateral (early)		\$58,300 (d)	80%*	\$120,000	50%*	\$47,000			\$217,300
Moderate-profound bilateral (late)		\$53,300 (d)	70%*	\$179,000	80%*	\$76,000			\$297,300
Mild/unilateral (early)		\$2,000 (e)	100%*	\$0	10%*	\$9,000			\$11,000
Mild/unilateral (late)		\$1,900 (e)	90%*	\$60,000	20%*	\$19,000			\$76,900
High lead level									
10-14 µg/dl			99% (b)	\$7,000					
15-19 µg/dl			96% (b)	\$25,000					
20-24 µg/dl			93% (b)	\$43,000					
25-44 µg/dl			85% (b)	\$87,000		\$5,300 (c)			
45-69 µg/dl			72% (b)	\$167,000		\$5,300 (c)			
>=70 µg/dl			64% (b)	\$214,000		\$5,300 (c)			

* Placeholder estimate pending more precise data. ** Present value at birth using a 3 percent discount rate. Sources: (a) Carroll and Downs (2006). (b) Estimated based on findings from Schwartz et al. (1985), Landrigan et al. (2002), and Salkever (1995). (c) Schwartz (1994). (d)

Estimated cost for cochlear implant and the necessary post-surgery adjustments and training is \$60,000 http://www.nidcd.nih.gov/health/hearing/coch_moreon.asp. [PV estimates assume surgery at 12 months of age when hearing loss detected early, and at 4 years when hearing loss detected late]. (e) Strom (2006) reports that the average cost for a digital hearing aid in 2005 was \$2022 <http://www.hearingreview.com> [PV estimates assume surgery at 12 months of age when hearing loss detected early, and at 4 years when hearing loss detected late].

D. Other Inputs to the BCM

1. Value per Hour of Time

CHIS integration could save labor hours for some individuals through reduced time for data entry and streamlined processes (e.g., parents, clinicians, and public health department staff), while increasing hours for other people (e.g., computer programmers and government staff involved in CHIS integration development/implementation and maintenance). Default values for the estimated value per hour of time for different occupations are state-specific based on mean, hourly wages obtained from the Bureau of Labor Statistics (BLS) Occupational Employment Statistics (OES) survey for 2004 (Table 20). All value per hour estimates assume a 30 percent fringe benefit rate on top of mean hourly wage.

Table 20. Value per Hour of Time

Occupation	Proxy: 2004 mean hourly wage plus benefits (estimates vary by state) for
Public health department staff	Medical and public health social workers
Public health program director	"Managers, all other" occupation
Computer programmers	Computer programmers
Parent	All occupations
Clinician	Registered nurses

Source: http://www.bls.gov/oes/oes_dl.htm. All value per hour estimates assume a 30 percent fringe benefit rate on top of mean hourly wage.

2. Integration Costs

The implementation and maintenance costs of CHIS integration have not been well documented. The BCM does not attempt to estimate the cost of CHIS integration, although the User can enter estimates of government personnel time, as well as other cost factors, to create a CHIS integration cost that is subtracted from the gross benefits of CHIS integration to estimate the net benefits of integration.

For example, if a User inputs estimated hours for public health department staff and program directors due to CHIS integration implementation and development, the BCM will use the aforementioned value per hour estimates discussed to calculate the cost of government personnel time for CHIS integration.

3. Mortality Data

As discussed in previous sections, the BCM contains mortality rates associated with certain newborn and communicable childhood diseases to estimate the productivity loss associated with sequelae. Although the true value of each child is priceless, the literature on "value of life" reports a wide range of estimates of the cost per premature death for the inclusion of mortality in cost-benefit analyses. Estimates that only include the present value of lost future earnings tend to be the most conservative (lowest), while estimates that include both productivity loss and emotional/psychic toll are often at the

higher end of the scale. The BCM reports estimates of the number of lives saved through CHIS integration. For costing purposes we use the more conservative present value of lost future earnings as a savings estimate. The national estimate of lost productivity for a child saved has a present value of \$598,000. For comparison, the Environmental Protection Agency uses a value of \$6.9 million per statistical life saved in cost-benefit analyses to inform policy decisions.

In addition to disease mortality rates, the BCM contains state-specific estimates of the annual mortality rate per 100,000 children ages 1–14 (national average = 0.201%). This data comes from state vital records and is primarily from 2003 and 2004, although a few states report 2001 and 2002 data. The primary purpose of this data is to obtain more precise estimates of the number of children of different ages in the projection years.

E. Impact of CHIS Integration on Screening, Follow-up, and Participation Rates

The literature contains a dearth of information on the impact of the integration of child health information systems on screening, follow-up, and child health program participation rates. Consequently, the estimates of these rates contained in the BCM are based on expert opinion. Such estimates could vary substantially by state, based upon the structure of each state's public health system. For example, co-located public health programs might have referral patterns that differ substantially from programs that are not co-located. The following tables summarize the information used in the BCM to estimate the impact of ICHIS.

Estimates of the impact of integration are cumulative, but are weighted by the percentage of children in the child health program whose information system is integrated with immunization registries. For example, if a state integrates its immunization registry with the WIC information system, the default estimate of the impact will show that for infants 3 months of age the percentage of infants in WIC who are vaccinated late will decline by 50% (Table 21). If 95% of all infants in the state (both WIC and non-WIC participants) are vaccinated by 3 months of age, then the improvement (under the assumptions in the following table) are that the overall vaccination rate will improve from 95% to 97.5% for WIC participants (i.e., the percent vaccinated late drops by 50%). If only half of all infants in a state are in the WIC program, then this improvement in vaccination rates will only apply to this 50% of the children, so the overall impact on the state's vaccination rate for calculating the benefits of integration is a rise in the vaccination rate from 95% to 96.25%.

**Table 21. Impact of Integrating Immunization Registries with
Other Child Health Program Information Systems**

	3 months	5 months	7 months	13 months	19 months	24 months	25-60 months
Percent reduction in children vaccinated late if integrated with:							
Vital Records, NDBS or EHDI	0%	0%	0%	0%	0%	0%	0%
Lead	0%	0%	0%	20%	20%	20%	20%
EPSDT	0%	20%	20%	20%	20%	20%	20%
WIC	50%	50%	50%	50%	0%	0%	0%
Birth defects	0%	0%	0%	0%	0%	0%	0%
Reduction in average delay (days) if integrated with:							
Vital Records, NDBS or EHDI	0	0	0	0	0	0	0
Lead	0	0	0	0	30	30	30
EPSDT	0	10	20	20	30	30	30
WIC	0	10	20	20	30	30	30
Birth defects	0	0	0	0	0	0	0
Percent reduction in invalid doses (doses received too early) if integrated with:							
Vital Records, NDBS or EHDI							0%
Lead							0%
EPSDT							20%
WIC							20%
Birth defects							0%
Percent reduction in extrimmunization if integrated with:							
Vital Records, NDBS or EHDI							0%
Lead							0%
EPSDT							20%
WIC							20%
Birth defects							0%

Note: Estimates are cumulative, but are weighted by the percentage of children in the child health program whose information system is integrated with immunization registries.

Table 22. Impact of Integrating EHDI Information System with Other Child Health Program Information Systems

	Percent reduction in missed initial hearing screenings	Percent reduction in failure to receive recommended audiologic evaluation	% infants with hearing loss enrolled in intervention by age 6 months
Vital Records, Immunizations, or NDBS	80%	0%	0%
Lead	0%	0%	0%
EPSDT	100%	20%	20%
WIC	100%	50%	50%
Birth defects	0%	0%	0%
Chronic diseases	0%	0%	0%
Early intervention	0%	0%	0%
CSHCN	0%	0%	0%

Table 23. Impact of Integrating NDBS Information System with Other Child Health Program Information Systems

	Percent reduction in infants not tested	Percent reduction in infants lost to follow-up	Reduced days to notification
Vital Records, Immunizations, or EHDI	100%	100%	0
Lead	0%	0%	0
EPSDT	0%	0%	0
WIC	0%	0%	0
Birth defects	0%	0%	0
Chronic diseases	0%	0%	0
Early intervention	0%	0%	0
CSHCN	0%	0%	0

Table 24. Impact of Integrating Lead Information System with Other Child Health Program Information Systems

	<1 Yr	1 Yr	2 Yrs	3 Yrs	4 Yrs	>4 Yrs
Percent increase in children tested for lead						
Vital Records, Immunizations, NDBS and EHDl	0%	10%	10%	10%	10%	0%
EPSDT	0%	20%	20%	20%	20%	0%
WIC	0%	20%	20%	20%	20%	0%
Birth defects	0%	0%	0%	0%	0%	0%
Chronic diseases	0%	0%	0%	0%	0%	0%
Early intervention	0%	0%	0%	0%	0%	0%
CSHCN	0%	0%	0%	0%	0%	0%
Percent increase in treatment follow-up						
Vital Records, Immunizations, NDBS and EHDl	0%	0%	0%	0%	0%	0%
EPSDT	50%	50%	50%	50%	0%	0%
WIC	50%	50%	50%	50%	0%	0%
Birth defects	0%	0%	0%	0%	0%	0%
Chronic diseases	0%	0%	0%	0%	0%	0%
Early intervention	0%	0%	0%	0%	0%	0%
CSHCN	0%	0%	0%	0%	0%	0%

Table 25. Impact of Integrating EPSDT Information System with Other Child Health Program Information Systems

	0	1-2	3-5	6-9	10-14	15-18	19-20
Percent increase in EPSDT participation Ratio							
Vital Records, Immunizations, NDBS or EHDl	20%	0%	0%	0%	0%	0%	0%
Lead	0%	20%	20%	0%	0%	0%	0%
WIC	0%	20%	20%	0%	0%	0%	0%
Birth defects	0%	0%	0%	0%	0%	0%	0%
Chronic diseases	0%	0%	0%	0%	0%	0%	0%
Early intervention	0%	0%	0%	0%	0%	0%	0%
CSHCN	0%	0%	0%	0%	0%	0%	0%
Percent increase in EPSDT screening compliance							
Vital Records, Immunizations, NDBS or EHDl	0%	0%	0%	0%	0%	0%	0%
Lead	10%	20%	20%	0%	0%	0%	0%
WIC	10%	20%	0%	0%	0%	0%	0%
Birth defects	0%	0%	0%	0%	0%	0%	0%
Chronic diseases	0%	0%	0%	0%	0%	0%	0%
Early intervention	0%	0%	0%	0%	0%	0%	0%
CSHCN	0%	0%	0%	0%	0%	0%	0%

Table 26. Percent increase in WIC participation from Integrating WIC Information System with Other Child Health Program Information Systems

	<1 Yr	1 Yr	2 Yrs	3 Yrs	>3 Yrs
Vital Records, Immunizations, NDBS or EHDl	10%	0%	0%	0%	0%
Lead	0%	20%	20%	0%	0%
EPSDT	0%	0%	0%	0%	0%
Birth defects	0%	0%	0%	0%	0%
Chronic diseases	0%	0%	0%	0%	0%
Early intervention	0%	0%	0%	0%	0%
CSHCN	0%	0%	0%	0%	0%

IV. Summary

A. Business Case Model Strengths and Limitations

Estimating the business case for CHIS integration is a complex undertaking. There are numerous components to such an analysis, and creating a flexible tool that can be used by states with different situations further increases the complexity of such a tool. This complexity, inherent in the design of this tool, reflects its ability to model a wide range of potential CHIS integration scenarios, but this flexibility is one of the unique strengths of this tool.

Although this study produces the most complete estimates to date of the business case for integrating child health information systems, this version of the BCM should nonetheless be considered a first step towards the production of reliable estimates of potential benefits resulting from CHIS integration in terms of lives saved, lives improved, and cost savings. The quality of data in the BCM varies considerably between different components of the model. Some estimates for model parameters, gleaned from the literature, are based on multiple studies demonstrating high-quality scientific research. Other estimates gleaned from the literature are based on a limited number of studies and/or studies that (often due to data limitations) contain less reliable estimates.

Due to a dearth of information in the literature, many parameter estimates in the BCM are “placeholders”. We believe these placeholder data are, for the most part, conservative but realistic estimates. We anticipate that as people use the BCM, they will aid in the identification of more precise estimates that can be used to improve this modeling tool. The placeholder estimates also provide a map indicating the types of information needed to conduct a business case and data that states might track.

The benefits of CHIS integration are numerous, and the BCM models only a portion of these benefits. The model was developed in such a way that additional costs and benefits of systems integration can be added at a future date.

B. Areas for Additional Research

Development of the BCM identified numerous areas where additional research could make substantial contributions to the business case for CHIS integration (as well to help public health programs identify ways to improve the efficiency and effectiveness of services provided). The following are examples of needed research:

- **Impact of CHIS integration on rates of screening, follow-up, and program participation:** States that are considering CHIS integration (as well as states that have recently integrated their systems) can provide important information on the short-term and long-term impact of CHIS integration on screening, follow-up, and program participation rates. Baseline data collected prior to integration can be compared with data collected in each of the subsequent years following integration to help inform how these rates have changed. Documentation of the characteristics of each state’s child health program is

important for researchers to fully understand how CHIS integration improves screening and follow-up rates. For example, integrating the WIC information system with immunization registries might allow for a clinician to vaccinate children who arrive at the local WIC center, thus improving timeliness of the vaccination. In this example, CHIS integration facilitates a change in the way child health programs operate, and these organizational/process changes should be documented to identify best practices and quantify their impact on quality of services and child health.

- **Integration implementation and maintenance costs:** Little information is publicly available on the costs to develop, implement, and maintain integrated systems. Information that would be useful to states considering integration include:
 - Amount of government staff time (e.g., in hours or FTEs) spent at each stage of the development, implementation, and maintenance process. This information is most useful when estimated for multiple levels of workers (e.g., program director level, program staff level) to help calculate more precise cost estimates.
 - Contractor costs.
 - Equipment and other costs.
- **Sequelae prevalence and costs:** Numerous diseases are modeled in the BCM; for many of these diseases, additional research on the prevalence and cost of sequelae could contribute to more precise estimates of the benefits of improved rates of screening and follow-up care.

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