

## State Systems Summary

State/ Participant	Program/ service	Program housed	functions	Child find	Follow kids	Goal(s)
<b>ILLINOIS</b>						
Trish Wilson	BDR	Illinois Department of Public Health	<u>Surveillance</u> and <u>referral</u> for services	We don't	Referrals to local health departments for <u>up to two years of services.</u>	Assure optimal growth & development; prevent complications; minimize any potential disability, and avoid future preventable high-risk perinatal situations.
Gerri Clark	CSHCN	University of Illinois at Chicago Division of Specialized Care for Children	all: <u>care coordination</u> for medically eligible children, <u>payment</u> for specialty care and diagnostic evaluations, <u>reimbursement</u> for family travel expenses related to specialty care, extensive website, <u>medical home QIT facilitation</u> , <u>transition planning, training, etc.</u>	<u>Outreach</u> to potential referral sources, e.g. hospitals, physicians, state agencies, local health depts., word of mouth	From <u>birth to age 21 years</u> if medical eligibility continues	Access to needed services for CYSHCN, maximizing the individual's potential, improving the systems of care for CSHCN
Not Reported	EI					
Claudia Nash	NBS FU	Dept. of Public Health	<u>Follow up</u> : All abnormal test results are reported to PCP; staff follow presumptive positive cases until resolution; make several attempts at follow up for low level and unsatisfactory; staff follow all diagnosed cases annually until age 16 yrs; staff <u>provide metabolic treatment formulas</u> ; staff also respond to numerous phone/fax requests for duplicate copies of final NBS lab reports; <u>collaborate</u> with other MCH programs and PCPs, hospitals, specialists, local public health agencies and community based family organizations; <u>refer</u> families to local public health agencies; refer families to community based sickle cell disease organization	<u>Research</u> info about child/family such as address and current name in various other databases including WIC/family case management, newborn hearing screening, Medicaid; outreach to referral sources	<u>Presumptive positives until resolution</u> ; diagnosed through <u>15 yrs of age</u>	Assure newborns identified through screening are followed/diagnosed in a timely manner; assure children with a diagnosis continue to be linked with specialty providers; facilitate communication with PCPs and other medical providers; enhance methods of providing education/information about NBS program

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<b>INDIANA</b>						
Courtney Eddy Bob Bowman	BDR	Indiana State Department of Health, Health and Human Services Commision, Division of Maternal and Child Health; Genomics/ NBS within Maternal & Child Health	BDR - <u>medical record audit &amp; review</u> of children;	BDR - children are reported to the system; system does not seek out children.	BDR - N/A;	BDR - hope to begin sending out family-friendly letters, fact sheets, and resource information;
Bob Bowman			BDR & NBS: Ensure that all infants born in Indiana are screened for designated disorders. Monitor and maintain a centralized program to provide diagnosis, follow-up, management, family counseling and support including equipment, supplies, formula and other materials.	The Genomics and NBS program receives information from a number of sources including Vital Records, the NBS lab, audiologists, physicians, and birthing facilities across the state. This information is used to locate children who require follow-up services.	Varies according to program area. Birth Defects and Problems Registry follows children for up <u>to 5 years</u> .	Ensure that all infants born in Indiana are screened for designated disorders. Monitor and maintain a centralized program to provide diagnosis, follow-up, management, family counseling and support including equipment, supplies, formula and other materials.
Courtney Eddy	NBSFU	Genomics/ NBS within Maternal & Child Health	NBS FU - ensure that children with positive NBS receive appropriate & timely follow-up care (including confirmatory dx and enrollment in specialty follow-up clinics as appropriate) ( <u>Follow-up</u> )	NBS FU - state NBS lab notifies ISDH of all children with positive NBS	The NBS program does not have a definitive date to terminate follow-up -until child is enrolled in specialty care ( <u>usually less than 1 year</u> )	NBS FU - to ensure that 100% of children born in IN with a positive NBS receive appropriate and timely follow-up care
Bob Bowman	State NBS Follow-up (NBS FU)					Ensure that all infants born in Indiana are screened for designated disorders. Monitor and maintain a centralized program to provide diagnosis, follow-up, management, family counseling and support including equipment, supplies, formula and other materials.

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Tom Rux	CSHCN	Indiana State Department of Health	<u>Diagnostic evaluations</u> ; comprehensive well child and sick child <u>care</u> ; speciality care and other services related to the eligible medical conditions; immunizations; prescriptions; routine dental care; and <u>community referrals</u> and <u>information</u> . Assist families with <u>medical expenses</u> for eligible medical conditions	Applications are taken at First Steps, the Division of Family Resources, and Riley Children's Hospital. Get referrals from the same, & also Peyton Maning Children's Hospital. Go to transition fairs and health fairs.	Birth to <u>age 21</u> <u>years</u> . Lifetime medical eligibility in the case of Cystic fibrosis.	None / Unknown
Linda West				Referrals from doctors, Riley Children's Hospital , Peyton Manning Children's Hospital, DFS referrals.		
Not Reported	EI					
Gayla Hutsell Guignard	NBS FU	EHDI is housed in the NBS program of the Division of Maternal & Child Health	<u>Monitoring and surveillance</u> of birthing facility for Universal Newborn Hearing Screening (UNHS) programs and <u>follow-up</u> on children who did not pass UNHS, are at risk for hearing loss or who have acquired permanent hearing loss during childhood.	Universal Newborn Hearing Screening is conducted primarily to find children with hearing loss or those children who might acquire hearing loss	Children who do not pass will receive follow- up <u>until hearing</u> <u>status is</u> <u>quantified</u> .	Confirmation of hearing status and enrollment in services (i.e. audiology, early intervention) and receipt of appropriate medical follow-up for those children who are found to have a hearing loss
Molly Pope		Indiana State Department of Health	Heel stick, EHDI, and others	in conjunction with hospitals and early intervention	EHDI follows <u>children through</u> <u>the first year</u>	Increasing the number of pediatric audiologists to improve timeliness of follow-up
<b>KENTUCKY</b>						
Troi Cunninham	BDR NBSFU	Department for Public Health - Division of Maternal & Child Health - Early Childhood Development Branch	<u>Short term follow-up</u> ; <u>coordination</u> w/clinicians & specialists to initiate <u>diagnostic</u> <u>follow-up</u> & we follow until diagnosis completed/treatment started; also ensure that all KY births receive NBS <u>NBS referral</u> for definitive diagnosis, birth defect <u>referral</u> to EI	Medicaid database, clinicians, Local health Departments ; (WIC & clinics); Local Law Enforcement, Hospital NBS Coordinator, Medical records	Through <u>diagnosis</u> <u>confirmed or</u> <u>ruled out &amp;</u> <u>treatment</u> <u>started</u> , if necessary	to ensure that every child born in KY receives NBS & timely follow- up w/specialist
Troi Cunningham						
Sandy Fawbush KY						

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				clinicians; internet searches; Vital stats; NBS lab reports, Hospital Discharge state; Facebook searches		
Not Reported	CSHCN					
Not Reported	EI					
<b>MICHIGAN</b>						
Joan Ehrhardt - MI	BDR	Dept Comm Health, Public Health Administration, Bureau of Epidemiology, Division of Genomics, Perinatal Health and Chronic Disease Epidemiology, Genomics and Genetic Disorders Section	Coordination of cooperative agreement activities for BD <u>surveillance, prevention and linking to services</u> ; presentation of BD surveillance data; development and implementation of prevention strategies; and <u>follow-up</u> of families who have had a child with spina bifida.	Dissemination of information, education of providers and families and systems evaluation. We are developing new activities to use MBDR data for direct referral.	n/a	Increased knowledge, awareness and utilization of resources by individuals with birth defects, their families and providers to optimize longterm outcomes.
Not Reported	CSHCN					
Tiffany Kostelec -	EI	In the Department of Education, it's called Early On. However, my position is Early On Coordinator for Public Health in the Michigan Department of Community Health.	<u>Identification and services</u> for children 0-3 who meet state eligibility definitions.	Child Find is a mandate under IDEA. The Early On Training and Technical Assistance Center is funded to conduct child find activities for children aged 0-3. They also conduct Child Find activities for older children. Local communities	Early On serves children from <u>birth to three</u> . A child may also be eligible for special education which serves <u>children from birth to age 26</u> in the state of Michigan.	There is not necessarily a goal of follow up for Early On. However, as children age out of the program, they are connected to appropriate services, which would include genetics if appropriate. .

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				will also conduct child find activities.		
Vicki Jenks	NBS FU	Bureau of Epi, Department of Community Health	<u>Follow up</u> of all positive, borderlines and unsatisfactory screens. <u>Contact</u> and <u>training</u> of hospital staff, follow up clinics and <u>outreach</u> . Epi statistical analysis of overall program, individual hospitals and disorders. Program QI.	\$86.68 per mandatory screening fee	<u>Historically only until confirmation but we have done 3 year follow up with CH</u> and our clinics do follow CF, Met, SC for longer. The goal is to do them for life.	Confirmation, Dx and into specialist with into 7 days. Follow up through the clinic format. Putting screening in to M CIR for all PCP to access
<b>MINNESOTA</b>						
Daniel Symonik	BDR	Environmental health division	<u>Surveillance, notification/ Referrals</u>	Validated birth defects cases forwarded to appropriate public health agencies	BD program does referral/ Notification; follow-up performed by service agency (local public health, MCSHN)	Meet public health needs of at-risk children
Barb Dalbec - MN	CSHCN	Title V program	<u>Follow-up after</u> diagnosis	Have a developmental screening surveillance program for children from <u>b-3</u> , provide education materials to PCP, work with local public health to locate kids who need services.	depends on which program but our target population is <u>Birth - 21</u> years of age	To assure kids with conditions diagnosed through newborn screening are linked to needed resources and services such as insurance, parent to parent support, specialists, medical home, etc
<b>OHIO</b>						
Anna Starr	BDR	State health dept., Title V CSHCN program	<u>surveillance, referrals</u> to services, <u>education</u> activities	hospitals report children with certain disorders	Hospitals report <u>to age 5 years</u> ; referrals made and outcome of referral studied	children with birth defects are referred to services to improve their health outcomes
James Bryant	BDR	Ohio	<u>Identification</u> of CYSHCN and	Through physician	<u>EI for till age of 3</u>	Families and children receive the

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	CSHCN NBSFU	Department of Health Division of Family	<u>connecting them to services</u> as well as <u>paying for some services</u>	and public health offices	<u>and CYSHCN program till 21 Y/O</u>	services they need and become active parts of our society
Deb Scott- Askura	EI	Ohio Depart- ment of Health	Ohio IDEA Part C and at risk program for children	Child Find activities required by Fed. law	Until <u>age 36 months</u>	Ensure eligible children receive services identified on the IFSP
<b>WISCONSIN</b>						
Elizabeth Oftdahl	BDR	MCH program	Birth defects <u>reporting, prevention</u> activities, <u>referral</u> to services	Regional CYSHCN Centers access birth defects reports and contact families to assure referral to services	<u>Up to age 2</u>	referral to services
Michelle Kempf- Weibel	CSHCN	Family health secion	CYSHCN regional office	Unsure – new	Unsure – new	Appropriate services for this populations
Sharon Fleischfresser	CSHCN	Department of Health Services - Public Health same Bureau as MCH, Genetics, NBS, EHDI, Birth defects surveillance and prevention	Fund 5 Regional Centers that support information, referral and assistance; education/training for families and providers; fund Family Voices and Parent to Parent matching	Education and outreach on developmental screening	CYSHCN program does not "track" kids but services available <u>birth- 21</u>	Goals are c/w the 6 National Performance Outcomes for CYSHCN