Center for Congenital and Inherited Disorders

IDPH
IOWA Department of PUBLIC HEALTH

Why is CCID important to Iowans?

Of the approximately 38,000 babies born in Iowa every year, 1,500 (4%) of them will have some kind of congenital or inherited disorder. In addition, there are many other conditions such as cancer, stillbirth, chronic disease and cognitive disorders, which are known to have a genetic component.

CCID programs focus on congenital and heritable conditions, knowing some conditions are life-threatening if not treated early. Early identification and early intervention is key to the prevention and mitigation of morbidity and mortality related to these conditions.

In addition, research shows early identification and intervention of congenital and inherited disorders reduces lifetime costs of providing special services to children with an undetected condition.

Did you know?

All Iowa newborns are screened for over 50 congenital or inherited conditions (unless the parents refuse). That's over 37,000 babies a year. If 37,000 bassinets were placed end-to-end, they would form a line 21 miles long!

A focus on health equity

The Iowa EHDI program has analyzed five years of newborn hearing screening and diagnosis data and created prediction models to identify high-risk populations for late diagnosis and children that never receive appropriate follow-up. Based on these findings, EHDI program personnel are working with providers and other stakeholders to tailor and provide equitable audiological care.

What does the department do?

- The Early Hearing Detection and Intervention Program ensures universal newborn hearing screening and ensures infants who do not pass their screen are diagnosed and referred to early intervention and family support services in a timely manner.
- Iowa Newborn Screening Program ensures mandated blood spot screening for all Iowa newborns for over 50 conditions on the Iowa newborn screening panel and provides follow-up for abnormal results through diagnosis of a condition or resolution of a normal result.
- Newborn Screening for Critical Congenital Heart Disease — Every newborn receives screening for critical congenital heart disease by pulse oximetry prior to discharge from the birth center. Newborns that fail the screen are referred to specialists.
- Metabolic Food and Formula program — Individuals with a diagnosed inborn error of metabolism, such as Phenylketonuria, that requires low-protein nutrition receive funding support to purchase medically necessary formula and foods.
- Iowa Maternal Prenatal Screening Program — Pregnant women may elect to have prenatal screening for potential fetal birth defects. The program provides testing and follow-up with the woman's provider for any abnormal results.
- Regional Genetic Consultation Service (RGCS) and Neuromuscular and Related Disorders Program (NM) provides regional clinics across Iowa for individuals with congenital and inherited disorders. Services are provided by specialists, genetic counselors, nurse practitioners and nursing staff.

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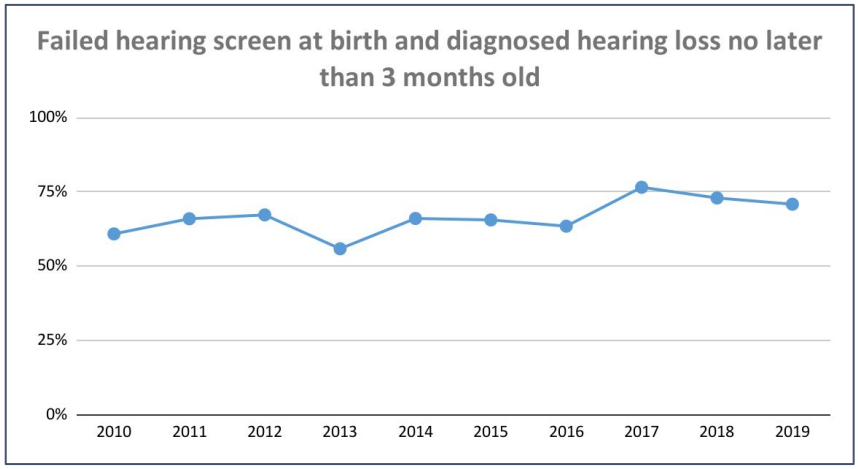
What does the department do? (cont.)

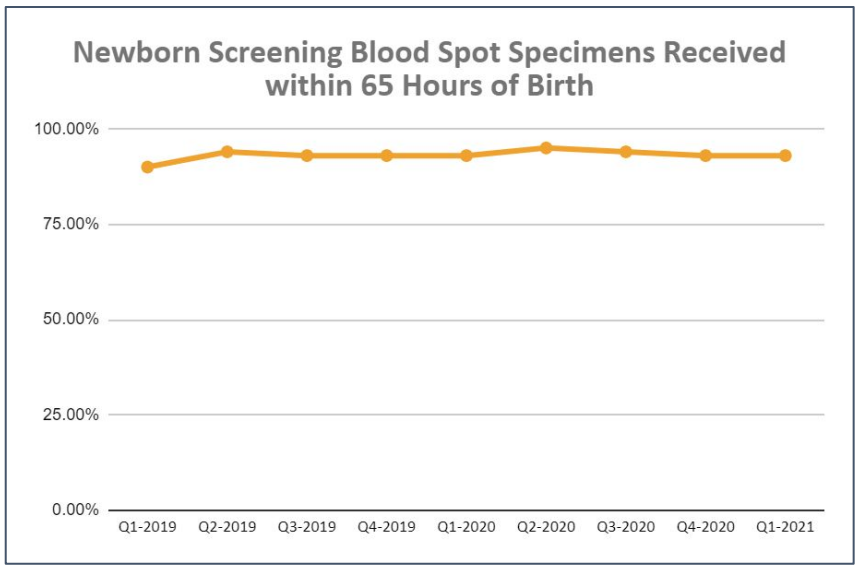
- Iowa Registry for Congenital and Inherited Disorders (IRCID) — Iowa's active surveillance program of reportable birth defects and heritable conditions.
- Stillbirth surveillance and prevention — Cases of stillbirth (fetal death) as reported by birthing hospitals are reviewed by CCID staff for trends and contributing factors.

What can Iowans do to help?

- Support and promote newborn screenings by having your children screened and encouraging others to do the same. If your infant, or the infant of someone you know, did not pass his or her screenings at birth, make sure the infant is re-screened in a timely manner and visit with your primary care provider about next steps through the point of diagnosis and referral to early intervention, family support and genetics, as needed.
- Conduct your family health history and discuss with your healthcare provider.

How do we measure our progress?





Resources

	SFY 2019 Actual	SFY 2020 Actual	SFY 2021 Estimate
State Funds	$1,080,888	$1,058,733	$1,112,725
Federal Funds	$333,702	$335,192	$321,361
Other Funds	$256,709	$310,966	$409,940
Total Funds	**$1,671,299**	**$1,704,891**	**$1,844,026**
FTEs	2.99	2.92	3.15