Colorado **R**esponds to **C**hildren with **S**pecial **N**eeds

CRCSN Notification Follow-Up

POLICY AND GUIDELINES

FY 13
October 1, 2012-September 30, 2013

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What is Colorado Responds to Children with Special Needs?
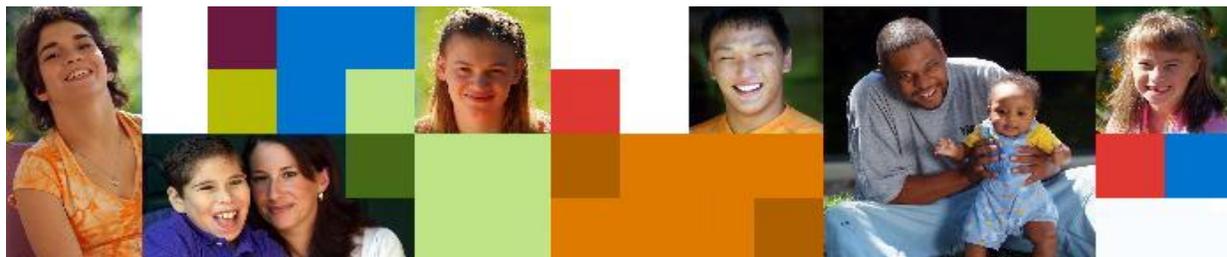Colorado Responds to Children with Special Needs (CRCSN) is the birth defects monitoring and prevention program at the Colorado Department of Public Health and Environment. The program began in 1989 under the guidance of an advisory board of parents, physicians, advocates, and representatives from state agencies.

What is the purpose of Colorado Responds to Children with Special Needs?
- to maintain a statewide, database of pregnancies and young children with birth defects, developmental disabilities, and/or risk factors for developmental delay
- to monitor and investigate the occurrence of birth defects and developmental disabilities
- to prevent birth defects and secondary disabilities due to birth defects and to help connect children and families with early intervention services in their communities
- to provide accurate, aggregate statistics and an unduplicated count of children with special needs to other programs and agencies for program planning and/or to provide statistics to researchers studying causes and risks, the ultimate goal being to prevent future birth defects and developmental disabilities

What information is collected?
Colorado Responds to Children with Special Needs collects information about birth defects among Colorado residents diagnosed before birth and up to age three with one of the eligible conditions. Eligible conditions are listed on a following page. Children meeting these criteria are identified from many sources including hospitals, vital records (birth, death, and fetal death certificates), the Newborn Genetic Screening Program, the Newborn Hearing Screening Program, laboratories, prenatal diagnostic centers, physicians, and genetics, developmental, and other specialty clinics.

About four percent of all births have major congenital anomalies. About 8,000 children or 13 percent of all the births in Colorado each year are identified because they meet CRCSN eligibility criteria, which include risks for developmental delay.

What is CRCSN's authority?
The legal authority to collect birth defects information is based on a statute authorizing the Colorado Department of Public Health and Environment to develop and maintain a system for detecting and monitoring conditions that contribute to preventable or premature sickness, disability, or death (C. R. S. 25-1.5-101 to 25-1.5-105). Under Colorado Board of Health regulations (6 CCR-1009-7) hospitals, health care facilities, and laboratories are required to report birth defects, developmental disabilities, and chromosomal abnormalities diagnosed prenatally and up to age three. Physicians are required to report suspected or confirmed fetal alcohol syndrome under age ten, autism under age ten, and muscular dystrophy.

- Within these statutes, it states that such information held by state and local health departments "shall be strictly confidential. Such reports and records shall not be released, shared with any agency, or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except [under certain limited circumstances]."
- Releasing confidential public health reports or records is identified as a Class I Misdemeanor.
- Because CRCSN is a secondary holder of data, there are stricter confidentiality protocols and

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protections than may have been with the original source.

- Local public health/HCP cannot contact the originating hospital, a referral source, or any other agency to obtain updated address or contract information. This is a breach of confidentiality.
- Under the State Board of Health Regulations, Colorado Department of Public Health and Environment (CDPHE) programs such as CRCSN and local public health agencies can share confidential information about individuals with eligible conditions with one another. Each agency and their employees are subject to the statutes and the local agency HIPAA regulations.
- Every employee having access to CRCSN information should be given a written explanation of the confidentiality requirements before having access or sharing confidential data.

How are children identified by CRCSN?
The majority of the children referred to the local agencies are identified through hospital discharge data collected by the Colorado Hospital Association. Birth certificate data is also used when available.

Selecting Children for Notification
Prior to notifying local public health agencies, children's names are matched to death certificates to ensure that the families of children who have died are not contacted. Single minor conditions that are not risks for developmental delays or special needs are not sent to local public health agencies as notifications.

Referring CRCSN Notifications to local public health agencies is a way to help connect children and families to services in their local communities. It is a way to provide information that may be useful now or in the future. It is a way for families to know what is available in their communities; it goes beyond the medical condition and includes other family support concerns. A public health nurse or staff from the public health agency in the family's community attempts to contact the family with a letter and follow-up calls.

Does CRCSN focus on any special conditions?
The program has several surveillance and prevention projects that focus on specific conditions, including fetal alcohol syndrome, autism, neural tube defects such as spinal bifida, cleft lip/cleft palate and muscular dystrophy (see p. 3 for a complete list). CRCSN collaborates with other agencies, programs, and family support groups concerned with these conditions. Additional information on these projects can be obtained by calling CRCSN.

How do local public health agencies use CRCSN notifications to help families?
CRCSN collaborates with the Health Care Program for Children with Special Needs (HCP) and local public health agencies to connect families with services in their own communities. After a local public health agency receives a CRCSN notification, the designated staff person follows up with the family to share community-based information and resources as needed. Some of services and supports that are frequently provided when a local public health nurse or other public health staff contacts the family include: developmental screening and evaluation, early intervention services, physical and speech therapy, specialty medical care, nutrition services, parenting classes, parent support groups, and/or financial assistance.

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II. Eligibility Criteria for CRCSN

- Resident of Colorado
- Diagnosed prenatally or up to the third birthday as having one of the following conditions:

CONGENITAL ANOMALIES

- Central nervous system
- Cardiovascular
- Circulatory
- Respiratory
- Eye, ear and face
- Orofacial
- Gastrointestinal
- Genitourinary
- Musculoskeletal chromosomal abnormalities
- Congenital anomaly syndromes

GENETIC, ENDOCRINE & METOBOLIC DISORDERS

- Phenylketonuria (PKU)
- Congenital hypothyroidism
- Hemoglobinopathies
- Galactosemia
- Cystic fibrosis
- Biotidinase deficiency
- Congenital adrenal hyperplasia
- Disorders of amino acid transport and metabolism
- Disorders of carbohydrate transport and metabolism
- Lipidoses
- Disorder of copper metabolism
- Other disorders of purine and pyrimidine metabolism
- Mucopolysaccharidoses

OTHER RISK FACTORS FOR DEVELOPMENTAL DELAY

- Encephalitis
- Meningitis
- Injury: head and spinal cord
- Cerebral cysts
- Child maltreatment syndrome
- Chorioretinitis
- Infantile spasms
- Renal tubular acidosis

SENSORY, DEVELOPMENT GROWTH CONDITIONS

- Hearing loss
- Blindness and low vision
- Retinal degeneration
- Speech and motor delays
- Growth and weight delay
- Mental retardation
- Infantile cerebral palsy
- Dystrophy/muscular & spinal
- Degenerative CNS/Cerebral lipidoses

MEDICAL DIAGNOSES & RISK FACTORS for DEVELOPMENTAL DELAY

- Birth outcomes and perinatal conditions
- Birth weight less than 1500 grams
- Prematurity less than 32 weeks gestation
- Small for gestational age
- APGAR 3 or less at five minutes
- Meconium aspiration syndrome
- Birth trauma
- Intracranial hemorrhage
- Convulsions/seizures
- Drug withdrawal syndrome in the newborn
- Noxious influences affecting fetus
- Fetal alcohol syndrome
- Congenital perinatal infections

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III. CRCSN Follow-up Guidelines

A. Responsibilities for CRCSN Notification Follow-Up

1. CDPHE Responsibilities:
   a. Refers local public agencies contracted to do CRCSN notification follow-up to their own local public health agency confidentiality and HIPAA policies.
   b. Ensures CYSHCN Data System functionality for providing electronic CRCSN notifications to local public health agencies and for receiving CRCSN notification reply data from local public health agencies.
   c. Maintains current policy and guidelines for CRCSN notifications and provides technical assistance on implementation of the policy and guidelines.
   d. Monitors local public health agency contract requirements for CRCSN notification follow-up.
   e. Provides and monitors CRCSN data in CYSHCN Data System.
   f. Provides user procedures for CYSHCN Data System data entry in CYSHCN User Manual.
   g. Communicates the availability of monthly CRCSN notification data reports to local public health agencies.
   h. Provide technical assistance to the CYSCHN Data System through the help desk (303-692-2384) Monday thru Friday from 7:30 AM to 4:30 PM.

2. Local public health agency responsibilities that have "opted in" to CRCSN notification follow-up:
   a. Designate agency staff responsible for the CRCSN notification follow-up.
   b. Notifies the CYSCHN Data System help desk (303-692-2384) with any change in name and/or contact information of designated staff.
   c. Provides training to local public health agency staff on agency HIPAA policies and health information confidentiality.
   d. Ensures fidelity to the CRCSN Policy and Guidelines.
   e. Utilizes the CYSHCN Data System to access "Pending System Messages" and CRCSN notifications on or about the 15th of the month.
   f. Completes required data entry in the CYSHCN Data System **within 90 days** of receiving CRCSN notification.
   g. Maintain confidentiality of CRCSN notification information using local public health agency confidentiality and HIPAA policies.
   h. Follows the CRCSN notification follow-up procedures, which includes making a minimum of two attempts to contact a family.

B. CRCSN Notification Follow-Up Procedures
   1. CRCSN notification follow-up procedures include making a minimum of two attempts to contact a family which includes a letter and/or a phone call, based on availability of contact information.
   2. The CRCSN notification follow-up letter will include the web link to the Parent 2 Parent of Colorado resource called "*WHERE DO I START? GENERAL RESOURCES for Parents of Children with Disabilities or Special Needs*", which is available in either English or Spanish
   http://www.p2p-co.org/resources-pdf/P2P/2010%20WDIS%20General%20English.pdf
   http://www.p2p-co.org/resources-pdf/P2P/2010%20WDIS%20General%20Spanish.pdf

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3. After sending the letter, the designated staff should wait approximately 1-2 weeks for the family to respond.
4. If the family responds to the letter with a phone call, the designated staff will provide community-based information and resources for the family as needed.
5. If the family does not respond to the letter, the designated staff attempts the second contact by phone. When a phone number is not available, a second letter is sent.
6. If the designated staff is unable to contact the family, a "Reply Type" and "Reply Result" is entered in the CYSHCN Data System in response to the CRCSN notification. Staff are not required to wait the full 90 days for a family to respond before replying to the CRCSN notification in the data system.
7. Once the "Reply Type" and "Reply Result" is saved in the CYSHCN Data System the information cannot be revised. If the family responds after the reply is completed, the designated staff assists the family as needed. It is acknowledged that documentation of this assistance is not entered in CYSHCN Data System.
8. Use the highest level of contact with the family in documenting the type of communication for the "Reply Type." For example, if a family received a letter and a phone call, the type of communication is entered as a phone call.
9. Refer to the CYSHCN Data System User Manual, in the section called "Notifications" for information about CRCSN notifications in the CYSHCN Data System. Designated staff should check for the "Broadcast Messages" in the CYSHCN Data System on a regular basis.
10. Contact the CYSHCN Data System help desk for technical assistance with the CYSHCN Data System at 303-692-2384 or dale.knochenmus@state.co.us.
11. Use the following CRCSN letters and CYSHCN reports located in the CYSHCN Data System:
    - CRCSN Letters - Attachment 1 and 2, English and Spanish
    - Report 004 – HCP CRCSN Notifications Current
    - Report 009- HCP CRCSN Notifications Outstanding

C. Confidentiality
 1. **Local Public Health Agencies:**
    a. May share CRCSN information about a family and child/youth with other local public health agencies for the purpose of providing community resources and supports.
    b. May communicate with other public health agencies and programs such as Women's Infants and Children's (WIC) programs, Immunization Programs, Nurse-Family Partnership and other prenatal programs, and/or public health nursing for the purpose of determining current or needed services for a child.
    c. When leaving a phone message for a family about a CRCSN notification, verify to the best of your ability, that the person you are speaking with is the contact person identified on the CRCSN Notification Report. Use caution when providing information on a phone message or with another person to avoid breach of confidentiality.
    d. Speak positively to the family during CRCSN notification follow-up. Use words like support, opportunity, and promotion of optimal development for children.
    e. If appropriate, clarify that CRCSN is NOT connected to the department of human services.
    f. In order for local public health agencies to communicate with anyone other than public health agencies about the CRCSN information, the agencies must have a written consent from the family to allow sharing information.

D. Assessment of Family Interest for HCP Care Coordination

Please reference the HCP Care Coordination Policies and Guidelines for the HCP Care Coordination Introduction Talking Points to assess family interest in HCP Care Coordination.

E. Documentation in the CYSHCN Data System

1. CYSHCN Data System Category
   Review the information received from the CYSHCN Data System indicating the child's relationship with HCP:

CYSHCN Data System Category	Definition
Known	Child's record exists in CYSHCN Data System prior to the current CRCSN notification
Unknown	Child's record does not exist in the CYSHCN data system prior to the current CRCSN notification

2. "Reply Type"
   "Reply Type" refers to the type of communication the designated staff had with the family, using one of the following data entry selections in the CYSHCN Data System. The selection should reflect the highest level of contact made or attempted when following up with CRCSN notifications. The list is in the order of the highest level of contact to the lowest level, with one-on-one being the highest.

Type of Communication	Definition
One-on-One	Includes any "face-to-face" communication, with home visit or office visit being the most common examples. This is likely after family has had previous contact by letter, phone or previously received HCP Care Coordination.
Phone Call	Phone call was the highest level of communication completed or attempted with the family.
Correspondence	Letter sent to the family was the highest level of communication completed or attempted with family.
Consultation with Others	No conversation with family: A contact was made with someone other than family, for example: primary care provider, Early Intervention Colorado, or public health program/staff. This is likely to happen when the family is known to HCP and they are currently receiving services from other programs.

	No letter or phone contact attempted with the family. Circumstances that may warrant "No Attempt" include:
No Attempt	• Family is known to HCP and has not responded to multiple previous attempted contacts • Child is terminally ill or known to have died • Child is known to already be receiving other public health services • Child is already receiving HCP Care Coordination services • Child previously contacted and requested no further contact

Note: For FY13, if "No Attempt" is selected, the "Reply Result" is not required in the CYSHCN Data System.

3. CYSHCN data system reply results

Use one of the following data entry selections for documenting "Reply Results" after contact is completed or attempted with a family. This must be completed **within 90 days** from the date of the CRCSN notification.

Reply Results	Description
Information and Resources	Child/Family is provided with information and resources which includes community resources, services and supports.
Family Already Connected to Services	Child/Family is already receiving supports and services from community resources, services and supports, including HCP Care Coordination.
HCP Care Coordination Referral	Child/Family is referred to HCP Care Coordination.
Family has no concerns	Family expressed no concerns at the present time.
Lost to Follow-Up	Unable to contact family due to reasons such as the CRCSN letter was returned as undeliverable, the phone was disconnected or the phone number provided is incorrect, or the family is confirmed to have moved out of state.
No Response from Family	Sent CRCSN letter(s) and/or left phone message(s) with no response from family.

Note: For FY 2013, "Child out of home" and "No Capacity" have been deleted from the "Reply Results" drop down categories in the CYSHCN Data System.

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IV. CDPHE Contacts for CRCSN Notification Questions

For questions and support for CRCSN notifications, contact:
Jennie Munthali
HCP Unit Manger
303-692-2435
jennie.munthai@state.co.us

For questions and support regarding data entry in the CYSHCN Data System contact:
CYSHCN Data System Help Desk
303-692-2384
Dale Knochenmus
Data Coordinator for CYSHCN Data System
dale.knochenmus@state.co.us

Ann Whitehouse
Data Owner for CYSHCN Data System and HCP Care Coordination Nurse Consultant
303-692-2327
ann.whitehouse@state.co.us

If a family has questions or concerns related to CRCSN confidentiality, consents or HIPAA, refer them to:
Margaret Ruttenber, CRCSN Director
Colorado Responds to Children with Special Needs (CRCSN)
303-692-2636
margaret.ruttenbur@state.co.us

[Insert LPHA Logo]

Colorado Department
of Public Health
and Environment

Health Care Program
for children
with Special Needs
Together we'll find the way

[Pick the date]

[Type the recipient name]
[Type the recipient address]

Dear Family of [child's name]:

I work with a community-based program called the Health Care Program for Children with Special Needs (HCP) at the [**insert site name of LPHA**] office. Our program helps parents find resources in the areas of health and child development. We serve children and youth from birth to 21 years old and *there is no charge for our services*.

The Health Care Program for Children with Special Needs may help you with:

- Finding a doctor or other health care provider
- A developmental screening if you are worried about your child's development
- Helpful programs and resources in your community
- Health-related resources and information
- Family support groups
- Answers to your questions
- …And more!

A quick guide to statewide resources from Parent to Parent called "WHERE DO I START?" can be found at http://www.p2p-co.org/resources-pdf/P2P/2010%20WDIS%20General%20English.pdf

The Health Care Program for Children with Special Needs received your child's name from a program called Colorado Responds to Children with Special Needs (CRCSN). CRCSN receives information from hospitals about infants and children who may have medical conditions that require additional health and developmental services.

You may contact our office Monday through Friday, at any time. We are always happy to talk with you or help you in any way we can.

Sincerely,

[Type the sender title]
CDPHE
[Type the sender phone number]

[Insert LPHA Logo]

Colorado Department
of Public Health
and Environment

Health Care Program
for children
with Special Needs
Together we'll find the way

[Pick the date]

[Type the recipient name]
[Type the recipient address]

Estimada familia de <Insert Child's First and Last Name>:

Saludos para usted y su familia de parte de El Programa Para Niños con Necesidades de Salud (HCP por sus siglas en ingles).

Esta carta es un recordatorio de la cita que se programó para su hijo/a. Si no puede asistir a su cita, llame al Coordinador de la clínica del HCP (al número que se encuentra abajo) para cancelar o volver a programar su cita tan pronto como sea posible. **Traiga su tarjeta del seguro medico a su cita.**

 A continuación puede encontrar la información de su cita:

Nombre del médico:

Nombre de la Clínica de especialidades del HCP:

Ubicación:

Fecha:

Hora:

Hay una escala móvil de honorarios en la clínica de especialidades que se basa en los ingresos familiares (proveniente de su última hoja de información/renovación). Los honorarios son $_____ y se deben pagar el día que llegue a la clínica.   Si no puede pagar el monto completo, comuníquese con el Coordinador de la clínica del HCP (al número que se encuentra abajo).

Esperamos que nuestros servicios le sean útiles.

Atentamente,

<Insert Name and Title>

Coordinador de la clínica del HCP

El Programa Para Niños con Necesidades de Salud

<Insert telephone number>

[Insert LPHA Logo]

Colorado Department
of Public Health
and Environment

Health Care Program
for children
with Special Needs
Together we'll find the way

[Pick the date]

[Type the recipient name]
[Type the recipient address]

Dear Family of [child's name]:

I work with a community-based program called the Health Care Program for Children with Special Needs (HCP) at the [Site]. Our program helps parents find resources in the areas of health and child development. We serve children and youth from birth to 21 years old and *there is no charge for our services*.

The Health Care Program for Children with Special Needs may help you with:

- Finding a doctor or other health care provider
- A developmental screening if you are worried about your child's development
- Helpful programs and resources in your community
- Health-related resources and information
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The Health Care Program for Children with Special Needs received your child's name from a program called Colorado Responds to Children with Special Needs (CRCSN). CRCSN receives information from hospitals about infants and children who may have medical conditions that require additional health and developmental services.

 You may contact our office Monday through Friday, at any time. We are always happy to talk with you or help you in any way we can.

Sincerely,

[Type the sender name]
[Type the sender title]
[Type the sender phone number]

[Pick the date]

[Type the recipient name]
[Type the recipient address]

Estimada Familia de (child's name):

Yo trabajo con un programa basado en la comunidad llamado El Programa Para Niños con Necesidades Especiales de Salud (HCP, por sus siglas en ingles) en [insert name of LPHA]. Nuestro programa ayuda a los padres a encontrar recursos en las áreas de salud y desarrollo infantil. Servimos a niños y jóvenes desde el nacimiento hasta los 21 años de edad y *no hay ningún cargo por nuestros servicios.*

El Programa Para Niños con Necesidades Especiales de Salud lo puede ayudar a:

- Encontrar un doctor u otro proveedor de atención medica
- Una evaluación del desarrollo, si usted está preocupado por el desarrollo de su hijo
- Programas de ayuda y recursos en su comunidad
- Recursos relacionados a la salud e información
- Grupos de apoyo a la familia
- Respuestas a sus preguntas
- … Y más!

Una guía rápida a recursos de todo el estado de Padre a Padre llamado "¿Donde Empezar?" Se puede encontrar en http://www.p2p-co.org/resources-pdf/P2P/2010%20WDIS%20General%20Spanish.pdf

El Programa Para Niños con Necesidades Especiales de Salud recibió el nombre de su niño de un programa llamado Colorado Responde a los Niños con Necesidades Especiales (CRCSN). CRCSN recibe información de los hospitales acerca de infantes y niños quienes pueden tener condiciones médicas que requieren servicios adicionales de salud y desarrollo.

Usted puede comunicarse a nuestra oficina de lunes a viernes, en cualquier momento. Siempre estamos dispuestos a hablar con usted o ayudarle en todo lo que podamos.

Sinceramente,

[Type the sender name]
[Type the sender title]
[Type the sender phone number]