

Using the Colorado Birth Defects Monitoring Program to Connect Families with Services for Children with Special Needs

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ABSTRACT

Background and Methods: The Community Notification and Referral Program (CNRP), which operates from within the state's birth defects monitoring and prevention program, links children and their families with local public health and early childhood agencies, which then inform families of services and resources in their home communities. In Colorado, many communities have developed systems for identifying, screening, evaluating, and providing services to children with developmental delays or other special needs. CNRP uses the existing infrastructure of services for children with special needs by notifying local community programs of children reported to the birth defects program with birth defects, developmental disabilities, or risks for developmental delay.

Children to be referred to local agencies are identified from the birth defects registry on the basis of diagnosis and residence. Minor or lethal conditions are excluded from referral. CNRP provides the child's name, date of birth, address, phone, guardian, diagnoses, date and source of diagnosis, and length of stay to the local agency. A parental consent process is used under some circumstances.

Results: CRCNS analyzed data from 1621 children referred to local agencies in 1998. The local agencies contacted 34.1% of the families and referred 46.9% of those contacted to early intervention, developmental, evaluation, or other services. They determined that 29.5% could definitely or moderately benefit from developmental services. In a telephone survey of families, 65.4% said they had learned about services, resources, or developmental screening about which they had not been aware.

Conclusion: CRCNS has developed a notification and referral program to link families with services for children with special needs that could serve as a model for other birth defects registries.

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dren with Special Needs (CRCNS), is located in the Colorado Department of Public Health and Environment. It began operating in 1989. It includes a centralized, statewide registry of children in whom birth defects, developmental disabilities or risks for developmental delay are diagnosed prenatally to age 3 years. Conditions eligible for the registry include established medical diagnoses (major congenital anomalies and chromosomal abnormalities, sensory impairments, genetic and metabolic diseases, medical risk factors for developmental delay (infections, injuries, other diagnoses, prematurity, low birth weight), and two environmental risks for developmental delay (maternal age 15 years or less and maternal education less than 12 years in combination with no prenatal visits) (Table 1). Children meeting these criteria are identified from computer links of information from hospitals; vital records (birth, death, and fetal death certificates); the Newborn Genetic Screening Program; the Newborn Hearing Screening Program; laboratories; physicians; and genetic, developmental, and other specialty clinics. About 7,000 or 13%, of births in Colorado each year meet CRCNS's eligibility criteria. About 4.5% of all infants born each year to Colorado residents (~2,400) have major congenital anomalies.

In Colorado, many communities have developed systems for identifying, screening, evaluating, and providing services to children with developmental delays or other special needs. Each local system has evolved in accordance with its resources, demographics, and geographic characteristics. Larger communities have interagency groups that coordinate identification of and services to high-risk children and families, while smaller rural communities operate more informally. Two state agencies also support services to children with special needs. First, the Colorado Department of Public Health and Environment provides Maternal Child Health funds and guidance to local public health and community nursing services for the Health Care Program for Children with Special Needs (HCP). HCP

BACKGROUND AND METHODS

The public health program for monitoring and preventing birth defects, called Colorado Responds to Chil-

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TABLE 1. Eligibility criteria for Colorado responds to children with special needs

1. Resident of Colorado
2. Diagnosed prenatally to 3 years
3. Diagnosed as having one of the following conditions:

ESTABLISHED MEDICAL DIAGNOSES

- Major congenital anomalies
- Chromosomal abnormalities
- Congenital (Perinatal) Infections
 - Congenital syphilis
 - Congenital rubella
 - Cytomegalovirus
 - Toxoplasmosis/Herpes simplex
 - Neonatal hepatitis
- Sensory Impairments
 - Hearing loss
 - Blindness and low vision
- Other Disabilities
 - Specific delays in development
 - Mental retardation
 - Infantile cerebral palsy
- Genetic and Endocrine/Metabolic Diseases
 - Hypothyroidism
 - Disorders of amino acid transport and metabolism
 - Disorders of carbohydrate transport and metabolism
 - Lipidoses
 - Disorders of copper metabolism
 - Cystic fibrosis
 - Other disorders of purine and pyrimidine metabolism
 - Mucopolysaccharidosis
 - Sickle cell anemia

MEDICAL RISK FACTORS FOR DELAY

- Infections
 - Encephalitis
 - Meningitis
- Injuries
 - Head
 - Spinal cord
- Other Diagnoses
 - Amniotic bands
 - Cerebral cysts
 - Cerebral lipidoses
 - Child maltreatment syndrome
 - Chorioretinitis
 - Convulsions/seizures
 - Drug withdrawal syndrome in the newborn
 - Failure to thrive
 - Familial degenerative CNS disease
 - Infantile spasms
 - Muscular dystrophies
 - Noxious influences affecting fetus (includes fetal alcohol syndrome)
 - Renal tubular acidosis
 - Retinal degeneration
 - Werdnig-Hoffman syndrome
 - Intracranial hemorrhage
- Other Conditions
 - Birth weight less than 1500 grams
 - Prematurity less than 32 weeks gestation
 - APGAR 3 or less at 5 minutes
 - Meconium aspiration syndrome
 - Small for gestational age (3% of weight for age)
 - Birth trauma

ENVIRONMENTAL RISK FACTORS

- Maternal age 15 years or less
- Maternal education less than 12 years and no prenatal visits

provides specialty medical services, care coordination, and information for children who have special medical-care needs and their families. The Colorado Department of Education, the lead agency for the federal Individuals with Disabilities Education Act (IDEA) Part C, has sponsored the growth of community systems to identify and assist infants, toddlers, and families eligible for Part C.

The Community Notification and Referral Program (CNRP) began operating as part of the birth defects monitoring and prevention program in Colorado in 1990. CNRP took advantage of the established infrastructure of services for children with special health-care needs in each community by notifying the existing programs of children reported to the birth defects program.

CNRP began under the direction of a state health department task force including parents of children with special needs and representatives of local agencies who wanted to ensure that children identified by the registry were linked with services to prevent secondary disabilities. CNRP was initiated as a federal grant funded pilot program involving 14 counties. The following procedures were developed during this pilot project and describe the current programmatic activities (Figure 1). First, children are identified in the CRCSN database as eligible for CNRP if 1) they reside in a county that participates in the program, and 2) they have a diagnosis that is appropriate for referral. Cases are matched to death certificates to ensure that children who have died are not included.

Not every diagnosis is referred to local agencies. Some conditions are excluded from the notification process: a single diagnosis of a minor health condition, a condition nonviable past the neonatal period, or a condition unlikely to result in developmental delay or other complications. To focus on conditions most appropriate to refer, CRCSN used two processes. First, a panel of four physicians with both clinical and public health experience reviewed a list of all International Classification of Diseases - 9th Revision - Clinical Modification (ICD-9-CM) codes of conditions eligible for the registry and eliminated those least likely to result in complications or developmental delays. Also, each local site was asked to indicate which diagnoses they thought should be excluded from the referral program. The selection of conditions most appropriate to refer allows the local agencies to focus their efforts and resources on children and families most likely to need their assistance.

After eligible children are identified from the database, a notification form for each child is generated. The forms are sent to local agencies monthly. The form includes the child's name, date of birth, address, and parent or guardian's name and phone number, when available. The reported diagnoses; the date of each diagnosis; the hospital or other source (e.g., birth certificate, clinic) of the eligible diagnoses; and the length of stay, if the infant is hospitalized, are also provided.

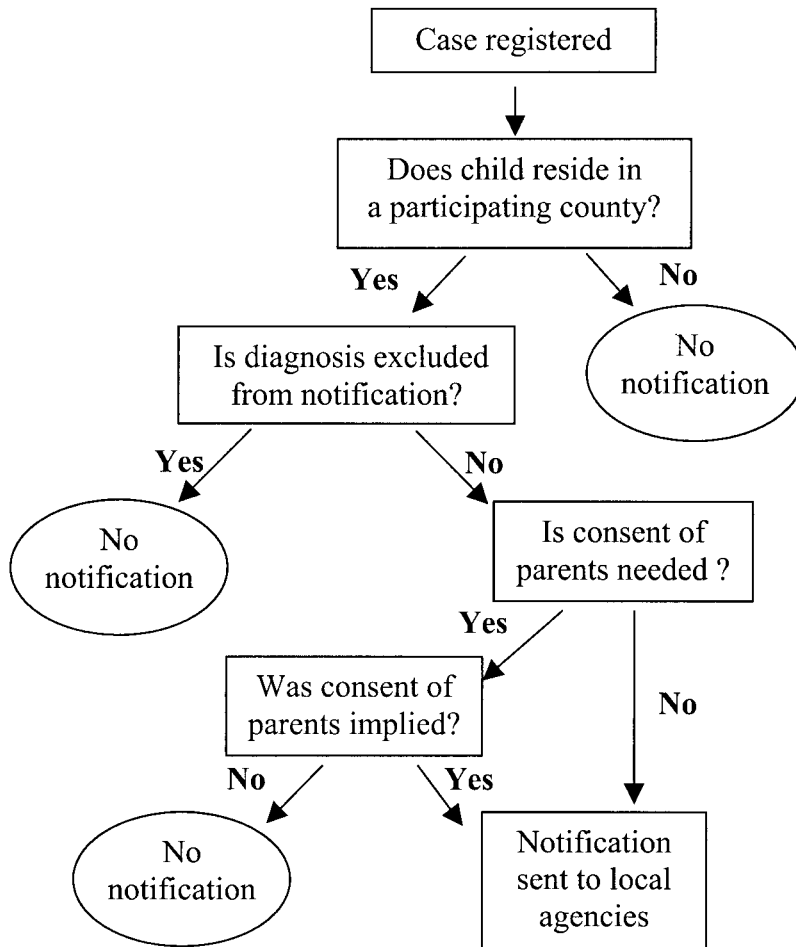


Fig. 1. Colorado Responds to Children with Special Needs, Community Notification and Referral Process

The notification form also includes the following questions:

- Did the agency already know about the child?
- Was the family contacted, and if so, by a home visit, an office visit, or phone?
- Was the child referred to developmental or other services?
- Which services?
- Would the child benefit from referral to developmental services?
- If no contact was made, why not?

The local agency answers these evaluation questions and returns the form to CRCSN.

The local agencies determine which families they wish to contact. A representative from the agencies, usually a public health nurse, a paraprofessional, or a parent with training, contacts the families and links them to services such as Child Find, developmental screening and evaluation clinics, early childhood agencies, specialty medical care providers, therapy, public health nursing or other services and supports as needed by the family.

Confidentiality is important throughout the referral process. CRCSN can share information on cases with

local agencies with certain exceptions; a consent procedure is employed under two circumstances. First, release of information from birth certificates is restricted by statute (C.R.S. 25-2-117). If a child is identified through a birth certificate, the State Registrar of Vital Statistics notifies the parent that the child may be eligible for services. The parent is requested to return the letter if he or she does not wish information on the child to be shared with a local agency. If the parents or the post office return the letter, no information about the infants is released to the local agencies. Second, Board of Health regulation allows CRCSN to share information with local *public health* agencies without parental consent. Consent *is* needed, however, to share information with non-public health agencies. In the six counties served by an early intervention agency instead of a public health agency, CRCSN sends a letter similar to the letter from the State Registrar as described above. Neither CRCSN nor local agencies are permitted to release information to service agencies without written parental consent.

Numerous procedures have changed to make the process more efficient and useful to the sites. Many of these changes – including improvements in the timeliness of the diagnostic data, changes in the formatting of the notification forms, and labels with families’ ad-

TABLE 2. Colorado responds to children with special needs, community notification and referral program children referred to local agencies by year

Year	Notifications	Known		Contacted		Referred		Needing Services	
	<i>N</i>	<i>N</i>	Percentage of notifications	<i>N</i>	Percentage of notifications	<i>N</i>	Percentage of those contacted	<i>N</i>	Percentage of those contacted
1992	911	289	31.7	474	52.0	222	46.8	178	37.6
1993	960	241	25.1	472	49.2	214	45.3	208	44.1
1994	1285	391	30.4	524	40.8	219	41.8	207	39.5
1995	1440	539	37.4	554	38.5	138	24.9	147	26.5
1996	1608	576	35.8	570	35.4	331	58.1	149	26.1
1997	1615	590	36.5	588	36.4	279	47.4	178	30.3
1998	1621	567	35.0	552	34.1	259	46.9	163	29.5
1999	1550	623	40.2	412	26.6	150	36.4	135	32.8
TOTAL	10,990	3816	34.7	4146	37.7	1812	43.7	1365	32.9

Notifications: the number of notification forms completed and returned by the local agencies. Each notification form represents a child identified by CRCSN.

Known: the children who were already known to the local agencies, not all of whom were already informed of or receiving services.

Contacted: the children and their families who were contacted by the local agencies as a result of the notification by CRCSN. They may have been contacted during a home, office visit or by phone. Letters mailed to the family are not included as a contact.

Referred: the number of children and their families who were informed of services or referred to services as a result of the contact by the local agency.

Needing Services: The local agency indicated that the child could either definitely or moderately benefit from referral to developmental services. (The notification form was changed in October 1994 to allow the local agency representative to indicate that s/he had not observed the child directly. This option resulted in a drop in the proportion of children judged to need developmental services for the next 2 years. This option was removed October 1996.)

addresses that would facilitate mailing were made on the basis of feedback from the local agencies.

RESULTS

CNRP has grown and changed since its inception in 1990. Both the number of communities participating and the number of children referred to the local agencies increased. The original 14 counties received information about 712 children in 1990. By 1998, 61 counties received information about 1,621 children (Table 2). In 1998, 1517 letters were mailed notifying parents that their children may be eligible for services. Parents of 1101 (72.6 %) children implied consent by not returning the letter, and these children were referred to the local agencies. Parents returned 222 (14.6%) letters requesting their children's names not be released, the post office returned 194 (12.8%) letters as undeliverable, and these children were not referred to the local agencies.

In 1998, CNRP sent 1634 notification forms to local agencies: 1101 after implied consent was received (as above), and 533 for cases that did not require consent (see Background and Methods). Of the 1634 forms, 1621 (99.2 %) were returned and entered into the database. Results for the referral process are presented below using information from the returned notification forms for 1998. Of the 1621 children, 1054 (65.0 %) were previously unknown to the agency. The fact that a child is already known to the agency, however, does not mean that their families have been informed of services that might be available. They may be registered only with Women, Infants and Children Special Supplemental Nutrition Program (WIC) or through im-

munizations records. Therefore, the number of families contacted, referred to and needing services is important. The local agencies contacted 552 (34.1 %) of the referred families through home visits, office visits, or phone calls. Although approaches varied, many agencies used introductory letters, especially to families with no phone numbers. These letters often include information on the agency, community resources, and child development.

Of the 552 families contacted, the representatives visited 133 (24.1%) of the families in their homes and talked to another 12 (2.2 %) during an office visit. Phone contact was the most common method of contact, 433 (80.3 %). (Families may have been contacted by more than one method, therefore the total number of contacts adds up to more than 100%.)

The agencies referred 259 (46.9%) of the families they contacted to services or resources needed by the family. The resources included developmental screening and evaluation, public health programs, early intervention programs, financial assistance, parenting classes, medical services, recreational programs, family support groups, and other services. Representatives helped families apply for financial benefits, accompanied new parents to their child's developmental evaluation as an advocate, and helped complete the Individual Family Service Plans (IFSP) required by IDEA.

The families of 1069 (65.9 %) children were not contacted by the local agencies. A fourth of those families had already been informed of available services. Another 7% had moved. The agencies were unable to contact over half of the families within 60 days after they received the notification forms. Sometimes re-

peated phone calls went unanswered or the family did not have a telephone and did not respond to a letter. Some agencies had inadequate resources and were able to make only a limited effort to contact the family.

The representative contacting families was asked to determine the extent to which each child could benefit from developmental services. Of the children from families contacted, 163 (29.5%) were determined to be able to definitely or moderately benefit from developmental services. Another 41 (7.4%) were already receiving developmental services by the time the agency contacted them. The representatives indicated that 231 (41.8%) of the children did not need developmental services at the time of contact.

In 1996, CRCSN surveyed 237 families by telephone to determine whether the families found the contact by a local agency to be helpful. All 474 families contacted by a local agency during May 1995 through May 1996 were eligible. Of these, 237 (50.0%) completed the survey. Two thirds (155) (65.4%) responded that they had learned about services, resources or developmental screening of which they had not previously been aware. Ninety-four (39.7%) said that talking to the representative had helped the child or the family, and 58 (24.5%) said that they had received services or developmental screening as a result of the contact.

DISCUSSION

The evaluation of CNRP demonstrates that CRCSN identifies children that local agencies might otherwise miss because 65.0% of children were unknown to the referring agency (35.0% were already known). Though excessive duplication of services is inefficient, some overlap of referrals to the agencies may be welcome. A complete absence of overlap may indicate that children are "falling through the cracks". The agencies also determined that a substantial number of children (29.5

%) whose families they had contacted could benefit from the available services.

Until 1996, CRCSN used federal grant funds to support the agencies' efforts to contact families. Resources for public health agencies that support outreach to children and their families are not always readily available, and since the inception of this program the percentage of families contacted (Table 2) has decreased. The lack of resources to provide outreach to families of children at risk for developmental delay or other problems is a key issue for many agencies.

The local agencies determined that that 41.8% of the children whose families were contacted had no need for developmental services at the time of contact. Because CRCSN identifies children who have *risks* for developmental delay, only a proportion of these children will experience delay or need services at the time of contact. Some children may be developmentally on track in infancy or at the time of the contact but may experience problems later. Also, the condition for which the child was registered may have been corrected (e.g., cleft lip, clubfoot, cardiac abnormalities). The families may still benefit from information concerning the normal development of children, parenting techniques, or health and developmental resources.

CONCLUSION

The birth defects monitoring and prevention program is a valuable means of identifying infants and young children with special needs or risks for developmental delay and linking them with services or other resources in the communities. Lack of funding for outreach to families of children with special needs or at-risk for developmental delay hampers the efforts of local agencies and limits the number of children who can be referred. This program could serve as a model for other birth defects registries.