

**Infants and Toddlers with Special Health Care Needs in Colorado:
Identification, Description, Needs, and Recommendations
White Paper
Joy V. Browne, Ph.D., C.N.S. and Barbara Deloian, Ph.D, R.N., C.P.N.P.
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Introduction:

Infants and toddlers, as children with special health care needs are a heterogeneous population. Current systems, such as Colorado Responds to Children with Special Needs (CRCNS), the Newborn Hearing Program, and metabolic screening program identify some infants and toddlers with birth defects and medical concerns. However, systems for early identification and referral to community services primarily rely on the child's health care provider and family members. Primary care providers are not currently using standardized developmental screening. The ABCD Project is working across the state to implement this developmental screening program. All too often in Colorado, as well as other states, infants and toddlers are unfortunately not identified as having developmental concerns until they are 2 to 2 ½ years of age. Children with special health care needs, especially infants and toddlers, are often not identified during critical times when families could benefit from available community services.

Purpose of this Paper:

The purpose of this paper is to provide a description for and estimate of the number of Infants and toddlers with special health care needs (I/T SHCN) in Colorado. Evidence supporting their needs, and recommendations for improving the early identification, referral, and intervention services available to infants and toddlers with special health care needs and their families is also included in this document.

Significance:

Infants born with special health care needs are often not identified as such until they meet the established clinical and/or behavioral indicators, or the family is in distress. Early identification of infants with special health care needs provides the opportunity to provide appropriate medical, psychosocial, financial/economic, and preventive services. Otherwise the infant and family may be vulnerable to a variety of short and long term medical and development complications associated with their child's health status.

Health and developmental outcomes for this population of children and their families are impacted in a variety of ways including but not limited to additional medical complications and costs, missed developmental interventions, cognitive delays, and age appropriate socio-emotional maturation. (Behrman and Butler, 2007; Armstrong, 2006; Simpson, Colpe and Greenspan, 2003).

Therefore, early identification of infants and toddlers is essential in the prevention of many health and developmental consequences. The current indicators for "children with special needs" do not identify neonates, infants and toddlers with special health care needs due to the consideration for "chronicity" of their health condition. For infants and toddlers, it may well be too soon to predict the chronic nature of the medical condition. Refining the definition for infants and toddlers could allow improved screening for infants and toddlers with special health care needs. Therefore, the following definitions are proposed.

Neonates with special health care needs: An infant diagnosed at birth with a medical condition that requires supplemental technology or medication for survival past one month of age, hospitalization for more than three weeks after birth, and/or has early regulation, feeding, state or motor concerns that require supportive and/or therapeutic intervention. In addition, it can be anticipated that they will need more than the typical clinic visits for health concerns during the first six months after birth, and/or their family will need supplemental professional assistance to manage daily care.

Infants and toddlers with special health care needs: An infant or toddler with SHCN needs is one who, during the first three years after birth requires technologic, pharmacologic or therapeutic intervention above that of a typically growing child to obtain and/or maintain physiologic or neurobehavioral stability, who require more than the

typical clinic visits during any given year, and/or whose family needs supplemental professional assistance to manage daily care.

Background:

The Maternal and Child Health Bureau (MCHB) defines children and youth with special health care needs (CYSHCN) as “those who have, or are at increased risk for having, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (McPherson, et al., 1998). In 1989, The Omnibus Budget Reconciliation Act (OBRA), Public Law 101-239 amended Title V of the Social Security Act to include the authority and responsibility of MCHB to fully address the needs of all children. In addition the focus under MCHB for CSHCN was to provide leadership in promoting a community-based system of services that is family-centered, comprehensive, coordinated, and culturally competent, thus building services around a medical home approach. The goals for the Title V CSHCN Program include:

1. Families will partner in decision making at all levels and will be satisfied with services.
2. All children and youth with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. All children and youth with special health care needs’ families will have adequate insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life.

Colorado Data on Infants and Toddlers:

The following table is based on available data and describes infants and toddler with special health care needs in Colorado. This table includes data from Colorado Birth Statistics, Colorado Responds to Children with Special Needs, and Part C for 2005.

Colorado: Estimate of Infants and Toddlers with Special Health Care Needs

Data Information and Source	Colorado Statistics 2005	Infants and Toddlers Birth to 3 years of age 2005 data x 3 years Estimate
Colorado Infant Births (Colorado Birth Statistics)	68,922	206,766
Colorado CRCSN Notifications (CRCSN Notifications)	3304	9,912
Colorado Infants born < 2500 grams or 5 ½ pounds (Colorado Birth Statistics)	5446	16,338
Colorado Infants born < 1500 grams or 3 1/3 pounds (Colorado Birth Statistics)	819	2,457
Colorado Infants 1200– 2500 grams or 2 2/3 pounds to 5 ½ pounds (Extrapolated from Colorado Birth Statistics)	5535 *	16,604 *
Colorado Infants born < 1200 grams or 2 2/3 pounds (Extrapolated from Colorado Birth Statistics)	641 **	1,923 **
Colorado Infants and Toddlers (Estimate based on 9 – 15 % of the population of and may be CSHCN)	Range: 68,922 x .09 = 6,203 68,922 x .15 = 10,338 Est. 68,922 x .12 = 8,271 (1)	Range: X 3 years = 18,609 X 3 years = 31,014 Est. X 3 years = 24, 813 (2)

Part C Infants and Toddlers
(Estimate based on 2.5% of the
population)

68,922 x .025 = 1,723

Est. X 3 years 6,892 (4)
Currently Enrolled = 4080

*** Not eligible for Part C**

****Eligible for Part C**

The 2005 preterm birth data and CRCSN data is inclusive of all identifiable diagnoses in the newborn and toddler period that have a high likelihood of medical or related special health care needs, based on the criteria of prematurity and CRCSN designation of birth defects. These data may not include an infant or toddler that is born at 37 weeks gestation but develops a chronic lung disease or the “late preterm” newborn who is increasingly noted to also have special health care and developmental needs (Adams-Chapman, 2006; Wang, 2004). Thus, an accurate estimate of infants and toddlers with special health care needs is not available. The CRCSN data may be the closest estimate of the infants and toddlers with special health care needs. CRCSN provides a “safety net” in an attempt to make sure that infants and toddlers are connected to community resources, however, all too often by the time the CRCSN Notification reaches the public health staff for follow up the family has moved or lived through the most difficult time of having an infant with special health care needs. This delay may often represent a critical missed opportunity when health care issues are particularly acute or when the benefits of early intervention are most palpable. It is also period in which the family most urgently needs care coordination and support from the public system.

In 2006 4,310 children 0-3 received Part C services. 36.8 per cent of these children were identified based on an established condition (physical or mental condition). 57% were based on significant developmental delay. 919 infants 0-12 months were referred to Part C but only 515 infants received services (56%). These infants were generally considered under “presumptive eligibility,” which is based on the medical condition at birth. At this time approximately 4,000 children birth to three years (4) are served by Part C and significant efforts are being made to increase the number of children referred by primary care providers as a result of developmental screening through the Colorado ABCD Project.

At this time there is no data based on the definitions provided. However, the data do demonstrate that there are a significant number of infants who may have special health care needs that are not connected with Part C or HCP and thus may benefit from HCP Care Coordination. Therefore, it is important to establish a more systematic system of early identification and referral to community services to ensure that infants and toddlers with special health care needs are connected to the care they need.

Evidence of Best Practices:

Currently, there is established evidence that early intervention for infants and toddlers with SHCN is considered “best practice.” Early identification and provision of intervention in the neonatal and infant periods has demonstrated decreased adverse outcomes in areas of medical complications and care utilization, neurological organization, cognition special education needs socio-emotional development maternal stress and perinatal mental health ,family impact and long-term adaptive functioning (e.g. Melnyk, et al.; Als, et al, 2004; Als and Piper, 2006; Shonkoff and Meisels, 2000; Behrman and Butler, 2007) . Currently two local programs are providing some developmental surveillance for infants and toddlers who are not eligible for Part C (Boulder County and Tri-County’s Special Infant Project). Both of these programs have been operating for over two years and consistently report that approximately 25% of the infants followed in their programs are referred to Part C at some time during the first year of the infant’s life.

Conclusions:

- Although the Colorado Newborn Hearing Program and Metabolic Screening program are recognized nationally and have excellent early identification and follow up of infants with hearing and metabolic concerns, early identification and follow up of other I/T SHCN is very limited in at this time.
- There is a gap in data regarding the prevalence of I/T SHCN in Colorado, particularly those who are not identified and eligible for Part C. Additionally, based on current evidence, a significant percent of infants, initially identified by Part C, are lost to follow up after their first year. This further contributes to the number of infants and toddlers and their families eligible for supports and services.
- The overall health care system capacity varies across the State from available early standardized developmental screening, identification, and for medically fragile infants to reliance on busy

primary care providers and their follow up of referrals and implementation of intervention strategies.

- If the estimates of I/T SHCN are even one third of the estimated number infants and toddlers birth to 3 years of age, HCP Care Coordination is only able to provide Level 1 Care Coordination (Information, Resource, and Referral) to this population and the rest of the 225,000 children with special health care needs.
- Currently HCP does not have the capacity to provide extensive monitoring, surveillance, and/or follow up to meet the needs of all infants and toddlers, birth to 3 years old, with special health care needs.
- Currently there is no data system or documentation of the supports and services needed by Colorado families in caring for an I/T SHCN.
- Although evidence for both prevention and improved outcomes for infants and toddlers with special health care needs is available, Colorado has not had the resources or health care systems in place to identify and provide best practices for providing health care services for high risk or medically fragile infants and toddlers.
- It is imperative to demonstrate positive child health care outcomes for I/T SHCN, through quality and cost effective health care systems of early identification, referral, follow up, and intervention systems. These outcomes and systems will provide insight into the health care systems that will benefit all children.
- Recent legislation through SB 07-130 emphasizes the need for a medical home approach for easy access, continuous, comprehensive, coordinated, culturally responsive, family centered, and compassionate care for **all** children. Infants and toddlers with special health care needs will demonstrate the benefits of these medical home components and are most in need of such services.
- Professional education rarely addresses the needs of the medically fragile infants and toddlers/ I/T SHCN or their work in interdisciplinary teams, development of systems of care, or in the evaluation of these systems. Thus resources are needed to provide professionals with clinical expertise in caring for I/T SHCN, interdisciplinary team collaboration, program and services evaluation as well as systems development.

Recommendations: Based on these data and on the aforementioned conclusions, the following are recommended for development, implementation, and evaluation.

- Develop, establish, and maintain a systematic and comprehensive identification and data collection strategy based on the proposed definitions of Infants and Toddlers with Special Health Care Needs beginning in the neonatal period.
- Develop evidence-based practices to meet the presumptive needs for Colorado infants and toddlers with SHCN.
- Develop educational programs to meet the specific competency needs of the workforce serving this population.
- Establish minimum workforce standards for all state funded contractors in order to provide exemplary care coordination and support to these infants and their families. Standards should include practice that is community based, family centered, comprehensive, coordinated, and culturally sensitive.
- Develop a system of identification, care coordination, individualized prevention and support services that begin in the Neonatal Intensive Care Unit and continue through the neonatal/infant period.

PROPOSAL:

- Through collaboration with WONDERBabies, develop a pilot program to identify I/TSHCN based on the proposed definitions and report on specified outcomes.
 - White Paper will be presented to WONDERBabies members, August 1, 2007.
- Explore and report on HCP office health care systems models within the state that may be utilized as pilots for funding proposals and possible legislative proposals.

- Utilize data collection and evaluation to seek funding for the development of a model screening, surveillance, care coordination, and premature infant services program for I/TSHCN that is evaluated for cost effectiveness (e.g. reduction in ER or long term hospital visits), referrals to Part C, family satisfaction, primary care provider satisfaction, and developmental outcomes.

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