I want to express my sincere appreciation to the individuals who took the time to share their knowledge and experiences with me:

Josephine Cialone, Sherry Franklin, Cynthia Frazier, Wanda Gurkins, Christine Hinson, Diana Miller, Bonnie Lesko, Lee Lichtenwalter, Bonnie Przelomski, and Janice Sommers
# Table of Contents

ABSTRACT ....................................................................................................................... 4

INTRODUCTION .................................................................................................................. 4

METHODS ............................................................................................................................ 5

BACKGROUND .................................................................................................................... 7

IMPORTANCE OF NUTRITION-RELATED EARLY INTERVENTION .................................................. 7

COMMUNITY-BASED CARE ................................................................................................... 8

EARLY SYSTEMS OF CARE ................................................................................................... 9

NC DEVELOPMENTAL EVALUATION CENTERS ...................................................................... 9

NUTRITION SERVICES IN THE DEC SYSTEM ...................................................................... 10

SYSTEMS IN TRANSITION ................................................................................................... 12

LEGISLATION: POLICIES AFFECTING EARLY INTERVENTION SERVICES .................................. 12

ADVOCACY: THE FAMILY-CENTERED CARE MOVEMENT ......................................................... 14

DEC TO CDSA TRANSITION ................................................................................................ 15

EARLY INTERVENTION INFRASTRUCTURE ........................................................................... 15

RD POSITIONS DECLINE WITH BUDGET CUTS .................................................................... 15

INTERAGENCY CONSORTIUM DISSOLUTION ......................................................................... 16

RD-ROLE REFORMATION .................................................................................................... 16

COMMUNITY-BASED "TRAVEL" CLINICS TO HOME-BASED EVALUATIONS ......................... 17

NC HEALTH DEPARTMENTS AND EARLY INTERVENTION NUTRITION CARE ......................... 17

EARLY INTERVENTION NUTRITION CARE ............................................................................. 18

INTERAGENCY NUTRITION SERVICES .................................................................................. 19

INFORMATION SHARING ..................................................................................................... 20

THIRD-PARTY REIMBURSEMENT FOR NUTRITION SERVICES ............................................... 21

REIMBURSEMENT FOR MEDICAL NUTRITION THERAPY ....................................................... 21

REIMBURSEMENT FOR NUTRITION SUPPLIES ..................................................................... 22

REIMBURSEMENT FOR FORMULAS ........................................................................................ 23

REIMBURSEMENT FOR NUTRITION SUPPLEMENTS ............................................................. 23

EARLY INTERVENTION NUTRITION SERVICES TODAY .......................................................... 23

CONCLUSION ...................................................................................................................... 24
Abstract

North Carolina’s early intervention nutrition services for children with developmental disabilities change over time and are influenced by factors that include research, advocacy, and legislation. Nutrition services provided by Registered Dietitians (RDs) of local Children’s Developmental Services Agencies (CDSAs), as part of the NC Early Intervention Infant-Toddler Program (NC ITP), is one of the original components of the state’s system of community-based nutrition care. The evolution of this system, as described by CDSA Registered Dietitians and other key players and partners is previously undocumented. Informed by interviews with individuals involved in NC CDSAs and a review of published and unpublished literature, this paper presents the history of NC’s community-based nutrition care system from the introduction of nutrition services in NC Developmental Evaluation Centers (DECs) to the transition of these centers into CDSAs; important interactions between CDSAs and other agencies; and how these transitions affect nutrition care for NC’s infants and toddlers with special needs.

Introduction

Birth to age three is an especially critical time period in shaping the foundation of growth and development (Regalado and Halfon 1311-1322). Nutrition-focused care is an essential component of early intervention services for children with developmental disabilities (DDs) as children with special health care needs are often at increased risk of nutrition-related health problems (Latif et al., 2010). Early nutrition intervention plays an important role in improving the health of infants and toddlers with DDs by enhancing their development and minimizing other potential DDs (Goode, Diefendorf, & Colgan, 2011).
This paper discusses the evolution of NC’s community-based systems of nutritional care by focusing on the North Carolina Early Intervention Infant-Toddler Program (NC ITP). The NC ITP strives to help infants and toddlers with developmental delays (DDs) or established developmental conditions reach their growth and developmental potential through interdisciplinary services, including medical nutrition therapy (MNT) (NC Department of Health and Human Services, 2012). The NC Early Intervention Branch (NCEI), part of the NC Division of Public Health, is the lead agency for the ITP.

CDSAs, delivering these community-based interdisciplinary intervention and evaluation services, are the lead local agencies of the ITP. The CDSAs are responsible for contacting those who may be eligible for nutrition services, enrolling those who are eligible, and providing continuing care according to an appropriate, family-led, Individualized Family Service Plan (IFSP) (NC division of medical assistance: Children’s developmental service agencies (CDSAs) Medicaid and health choice clinical coverage policy no: 8J.2012).

Over the past thirty years, many changes and arguably great progress took place in the development of nutrition-related care provided by NC’s CDSAs. The evolution of the CDSA’s nutrition services is not previously documented. Through primary interviews, this paper illustrates NC’s progress in nutrition-services development for infants and toddlers with DDs; describing the system of care during its earliest, formative years and providing evidence for why this system of care exists as it does today. The history of these changes reflects increased understanding of MNT’s importance in enhancing child growth as well as increased understanding in how nutrition services may be best delivered to children with DDs.

Methods

Much of the information needed to write this paper was gathered through key-informant
Interviews conducted with individuals who are (were) central to CDSA program delivery and CDSA program planning, both past and present. Interviews were also conducted with individuals who are not or were not directly employed by the ITP, but are connected to these services through partner programs, such as the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), Medicaid, and the Community Alternatives Program for Children (CAP/C). The names of these key informants including a brief description of the information they provided are presented in Table 1. These interviews focused on how the role of nutrition and RD-provided nutrition services within the DECs/CDSAs and partnering agencies changed from the 1980s through today. Key informants were asked to describe the changes in how these services are delivered and the reasons for why these changes happened. These key informant interviews provided the information needed to develop a more complete story on how North Carolina’s nutrition services for infants and toddlers came to fruition. Information was also gathered through research on key policy changes and research on the impacts of nutrition therapy on child growth and development.

Table 1: Key Informants and Their Role in the Care Delivery System

<table>
<thead>
<tr>
<th>Informant</th>
<th>Role and Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Josephine Cialone</td>
<td>Nutrition Program Supervisor (Within the NC Division of Public Health Nutrition Services Branch) Provided information about early history of nutrition in the DEC system</td>
</tr>
<tr>
<td>Sherry Franklin</td>
<td>Quality Improvement Unit Manager/Part C Coordinator Provided information about Infant-Toddler Program (ITP) structural changes that occurred over the past twenty years</td>
</tr>
<tr>
<td>Cynthia Frazier</td>
<td>Pediatric RD, CDSA at East Carolina University Provided information about RD role reformation and evolution of interagency relationships in Greenville CDSA’s catchment area</td>
</tr>
<tr>
<td>Diana Miller</td>
<td>Pediatric RD, CDSA at Pinehurst Provided information about RD role reformation and evolution of interagency relationships in Pinehurst CDSA’s catchment area</td>
</tr>
<tr>
<td>Bonnie Przelomski</td>
<td>Pediatric RD, CDSA at Rocky Mount Provided information about RD role reformation and evolution of interagency relationships in Rocky Mount CDSA’s catchment area</td>
</tr>
</tbody>
</table>
| **Wanda Gurkins**  
Greenville  
| ---  
| **Social Worker with Pitt County Health Department**  
| **Provided information about the evolving relationship between the Infant-Toddler Program and North Carolina Health Departments, with a focus on the Pitt County Public Health Department and local CDSA**  
| **Christine Hinson**  
Greenville  
| ---  
| **Case Manager with Community Alternatives Program for Children (CAP/C)**  
| **Provided information about the evolving relationship between CDSAs and CAP/C and about how CAP/C provides wraparound services when a child is not eligible to receive Medicaid’s nutrition-related supplies**  
| **Bonnie Lesko**  
Greenville  
| ---  
| **RD with Pitt County Health Department WIC Program**  
| **Provided information about how nutrition information and interagency cooperation between WIC RDs and CDSA RDs—with a focus on Greenville catchment area—have evolved over time**  
| **Lee Lichtenwalter**  
Durham  
| ---  
| **RD with Durham County Health Department Nutrition Services**  
| **Provided information about how nutrition information and interagency cooperation between health department RDs and CDSA RDs—with a focus on Durham catchment area—have evolved over time**  

**Background**

**Importance of Nutrition-related Early Intervention**

Successful nutrition-focused early interventions are defined as those that improve children’s function, feeding capabilities, and everyday care (McWilliam, 2010). Such interventions that impact child growth and development include nutrition services provided within community-based or clinic-based settings. In the 1995 randomized clinical trial of home-based nutrition intervention for children with failure to thrive (FTT), 130 infants younger than twenty-five months, from low-income families, were recruited from pediatric clinics and enrolled in a nutrition clinic (Black, Dubowitz, Hutcheson, Berenson-Howard, & Starr, 1995). Anthropometric measurement data and developmental assessments were collected over the course of a year in which families received in-clinic or in-home growth monitoring, nutrition counseling, recommended menus, and other nutrition-support services.
With high retention rates for all participants, the data collected found that home interventions had beneficial effects on infant cognitive development, receptive language development, growth, and the quality of the home environment (Black et al., 1995). These results provide reinforcement for continuing statewide programs, such as the NC ITP, that offers home-based MNT to children who are FTT. Early nutrition service beneficiaries also include infants and toddlers with other disabling conditions related to feeding and growth impairment. Examples of disabling conditions include gastrointestinal or metabolic disorders (Latif et al., 2010). Positive outcomes of early nutrition intervention services extend beyond measurements of growth and development. Nutrition services help to increase children's school-readiness, which makes a strong argument for why nutrition is an essential component of early intervention programs (Reichman, 2005).

Community-based Care

Community-based nutrition services, specifically home-based services, are an important part of states' efforts to improve developmental and growth outcomes of infants and toddlers with DDs or those at risk of developing DDs. Federal policies, notably Part C of the Individuals with Disabilities Education Act (IDEA)—originally established in 1975 as the Education for All Handicapped Children Act (EHA)—provide a blueprint for states' health care programs for children with DDs, such as the NC Early Intervention ITP (Shortell, Gillies, Anderson, Mitchell, & Morgan, 1993). In NC, nutrition services for children from birth to three years of age are offered in diverse settings such as hospitals, daycare centers, local health departments, and within families' homes. The relationships or networks formed between these different organizations create systems of coordinated care for these infants and toddlers (Shortell et al., 1993).
NC’s community-based nutrition services, notably the services provided by the Children’s Developmental Services Agencies (CDSAs), continue to evolve as they are shaped by policies and by the actions of key individuals and organizations within this network. Eighteen CDSAs currently exist to provide EI services to NC children below the age of three (NC early intervention infant-toddler program: The earlier you know, the better they’ll grow, 2011). As of August 2012, ten RDs deliver nutrition services to children in nine of the eighteen catchment areas, with over forty-five counties served (North Carolina directory of state, regional and local nutritionists, 2012). Although services may be successfully delivered in various settings, federal policies like IDEA promote the expansion of community-based programs such as NC’s CDSAs, which is the focus of this paper (Goode et al., 2011).

**Early Systems of Care**

**NC Developmental Evaluation Centers**

From the early to mid-1900s, institutionalized care was the primary way in which most adults and children with developmental delays (DDs) or disabilities were served in North Carolina (About UW lend: History, 2012). Close to forty years ago, legislative efforts that promoted deinstitutionalization for individuals with developmental disabilities created a shift toward increased community-based health care services. Because of these changing policies, systems of community-based care supporting individuals with disabilities or delays started in NC as early as the 1970s (J. Cialone, personal communication, September 18, 2012).

During this time, Early Intervention was housed in the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, (DMH/DD/SAS) while a network of nineteen Developmental Evaluation Centers (DECs) were housed in the Division of Health
Services (now known as the Children and Youth Branch) (J. Cialone, personal communication, September 18, 2012). These DECs were funded by state and federal money to conduct developmental evaluations on children of all ages and offer specialized therapy to these children within their homes, DECs, child care centers or within the least restrictive environment (D. Miller and J. Cialone, personal communication, October 19 and September 18, 2012). The DECs worked in an interagency consortium with staff from the state health departments whose primary responsibility was to determine child eligibility and ensure children’s enrollment in services. The consortium also arranged for DEC staff to conduct assessments to determine what specific services were needed. In the early 1980s, nutrition services were not available through DEC care (Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000). The interdisciplinary services provided to qualifying infants and toddlers typically included developmental intervention, physical therapy, occupational therapy, and speech language therapy (J. Cialone, personal communication, September 18, 2012).

**Nutrition Services in the DEC System**

An early 1980s nation-wide initiative led by the Department of Health and Human Services Maternal and Child Health Bureau (MCHB) pushed to enhance nutrition-related services for children with special needs (J. Cialone, personal communication, September 18, 2012). In 1984, Josephine Cialone led a statewide needs assessment with the assistance of special funds provided by the MCHB. This assessment documented the nutrition-related services available for NC children with special needs. The unpublished information gathered from this study revealed that while Registered Dietitians (RDs) were serving children with DDs within NC’s local health agencies, the nutrition staff within these settings did not feel competent in providing the level of intervention needed by children with complex medical issues (J. Cialone,
personal communication, September 18, 2012). Thus, the 1984 report developed from this assessment—through a contract from the University of North Carolina at Chapel Hill—gave recommendations to provide training for these RDs working within WIC and at local health departments.

The study also reflected the need for additional nutritionist positions to be created and housed within the existing DECs. The focus of the DECs was to help children progress and advance to the best of their ability to ensure preparedness for school (B. Przelomski, personal communication, October 30, 2012). The function of these DEC RDs was to help children reach educational milestones by improving their nutritional health. The DEC RDs would evaluate children and make recommendations for nutrition care and management. The criteria that established and currently establish which children receive nutrition services vary between DECs (now CDSAs) and may depend on variables such as case load and RD clinical judgment (B. Przelomski and C. Frazier, personal communication, October 30, 2012).

The desired nutrition positions were eventually established with grant funds. After gaps in nutrition care were identified, a state-level RD position was established in 1985, funded by the MCH Block Grant funds, filled by Cialone (personal communication, September 18, 2012). In this new position, Cialone designed demonstrations or pilot projects to prove the efficacy of nutrition care for children with DDs. Grants from North Carolina’s Developmental Disabilities Counsel, the KB Reynolds Foundation, and the Cannon Foundation funded five new RD positions housed within five existing DECs. These five RDs provided direct nutrition services to children, aged birth to twenty-one years, and trained local health agency RDs and nutritionists by serving as consultants to these fellow nutritionists. The newly created positions worked to cultivate better communication between the DECs and the WIC Programs. The increase in
guidance and information exchanged between the organizations’ RDs aimed to enhance the quality of nutrition care these children received by filling information gaps.

Over a three-year period after these RDs were hired, 1986-1989, Cialone and the new RDs collected additional data to look at the impact of these new DEC positions. Collected data included records of children’s anthropometric measurements over time including weight, length or height, head circumference, and triceps skinfold (B. Przelomski, personal communication, October 30, 2012). This study also looked at how many different food groups that DEC-enrolled children consumed and how the number of food groups from which children ate changed with the addition of nutrition services. Ultimately, the data collected compared resulting functional differences that occurred between children receiving the DEC’s nutrition-care and those not receiving nutrition-care. The information from these studies is unpublished, but described as meaningful and demonstrative of MNT’s importance in improving the health status of children with DDs (J. Cialone, personal communication, September 18, 2012).

**Systems in Transition**

*Legislation: Policies Affecting Early Intervention Services*

The results from the 1986-1989 unpublished study became important in the late 1980s as federal legislation began to mandate early intervention (EI) services. In 1986, Amendments PL 99-457 made to the Education for the Handicapped Act (EHA) (PL 94-142) mandated how states should provide programs and services to infants and toddlers and strengthened incentives for states to serve children three to six years of age (*History: Twenty-Five Years of Progress In Educating Children With Disabilities Through IDEIA 2007*; Meisels, 1989).
Part H of PL 99-457 authorized the creation of EI programs that provide services to children from birth to three years with DDs and those at risk of DDs, biologically or environmentally (Meisels, 1989). This amendment gave federal funding to states that were willing to implement and maintain the outlined statewide systems of services for eligible children and their families (Oser & Cohen, 2003). The purpose of including children aged birth to three in Part H was to ensure that more children are prepared to enter preschool with success (The world's leading website on learning disabilities and ADHD: IDEA 2004.2010). This amendment was significant in recognizing the malleability of young children’s development and the ability of environment to alter growth (Meisels, 1989). These policies recognized research that showed that infants and toddlers identified as at-risk, but not receiving intervention services, moved into the lowest function groups amongst their peers as they aged (Oser & Cohen, 2003).

In 1990, Congress renamed the EHA as the Individuals with Disabilities Education Act (IDEA), Public Law 101-476, and Part H became known as Part C (National assessment of IDEA overview.2011). The goal of Part C, like Part H, remained to minimize potential DDs and ready infants and toddlers for success in school and beyond (Oser & Cohen, 2003). Part C is mandatory, but providing services for infants and toddlers who are “at-risk” (biologically/environmentally) without a specified special need is optional for states (B. Przelomski, personal communication, October 30, 2012). Nationally, nutrition services are not a mandatory component of Part C, but NC’s state government chose to include nutrition in its early intervention programs because of the cogent arguments made by nutrition advocates like Cialone.

IDEA reaffirmed the requirements of the Education for All Handicapped Children Act (PL 94-142) to provide free and appropriate public education by establishing individualized
education programs (IEPs) (Howell, 1998). Part B of IDEA authorizes grants to states that cover educational services for children with DDs three through twenty-one years of age (Verstegen, 1994). Some RDs with the NC DECs provided nutrition services to children through twenty-one years of age up until 1994-1995 (B. Przelomski, personal communication, October 30, 2012). Although these policies shifted the focus of DEC services to birth to age three, some DEC RDs still visited older children within preschools and schools—up until 2004—to make sure that those through age of five (and sometimes older) received adequate care (B. Przelomski and C. Frazier, personal communication, October 30, 2012).

Advocacy: The Family-Centered Care Movement

In 1987, at a conference cosponsored by MCHB, the Surgeon General of the US Public Health Service called for the establishment of a nation-wide agenda to improve the lives of children with DDs through more family-centered, community-based care (Brewer, McPherson, Magrab, & Hutchins, 1989). Prominent nutrition organizations such as the Academy of Nutrition and Dietetics (formerly the American Dietetic Association) also took the stance that supported community- and family-centered services for persons with DDs (Position of the American dietetic association: Nutrition in comprehensive program planning for persons with developmental disabilities.1997).

Family-centered care (FCC) is defined as the “philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special needs” (Brewer et al., 1989). Part C, formerly Part H, reflect this philosophy in that it requires Individual Family Service Plans (IFSPs) to be developed with each family when their child receives CDSA EI services (Meisels, 1989). However, this national movement brought changes to how the NC DEC interdisciplinary teams conducted evaluations and delivered care (C.
Frazier, personal communication, October 30, 2012). NC DEC health service delivery transitioned from being about what the health professionals wanted for the children served to what the families wanted and considered appropriate intervention. These changes that made families partners in identifying, delivering, and administering services was led by organizations like the MCHB with the intent to help family members cope and better understanding their children’s conditions (Brewer et al., 1989).

**DEC to CDSA Transition**

*Early Intervention Infrastructure*

As early as 2000, an external evaluation began to try to determine the best infrastructure to set timelines and limit gaps in ways services, including nutrition services, were provided within the DEC system (S. Franklin, personal communication, September 18, 2012). At stake was the question of whether or not the existing system had an appropriate state lead agency design to provide the best care for families. A large stakeholder group was assembled of workers and families to better define what EI should look like within the DEC system.

As a result of the 2000 assessment of the DEC infrastructure, a new system structure was developed. In 2004, CDSAs transitioned to replace the DECs as the new local lead agencies for EI services (S. Franklin, personal communication, September 18, 2012). EI was now under the CDSAs, not Mental Health (W. Gurkins, personal communication, October 26, 2012).

*RD Positions Decline with Budget Cuts*

The presence of RDs within the DEC/CDSA system increased and then declined before these structural changes took place. By the mid-1990s, as a result of compliance with the EHA's
Part H Amendment, federal, state, and MCHB funds became available to create RD positions in most every NC DEC. Durham County was one exception in that no RD position was ever established at its DEC, but a position was housed in the local health department (L. Lichtenwalter, personal communication, September 24, 2012). While the infrastructure analysis was conducted in the early 2000s, budget cuts started to take place, from both state and federal funding (J. Cialone, personal communication, September 18, 2012). RD positions within DECs started to be cut as position vacancies were created.

**Interagency Consortium Dissolution**

The transition to CDSAs dissolved the previously existing interagency consortium and gave the CDSAs responsibility for case management, child evaluations, and eligibility determination (S. Franklin, personal communication, September 18, 2012). Referrals previously went to states’ health departments, consortium representatives, and DECs. When the CDSAs gained oversight for their regions and became the primary referral site, referrals were expected to increase because the system became easier to navigate for those making the referrals. Now, instead of nutrition services being provided to children from birth to five years of age, the new CDSAs were limited to arranging services for children from birth to three years of age.

**RD-role Reformation**

The structural changes, including the consortium dissolution, reformed the RD role. More generalists were hired within the CDSAs to determine child eligibility, a role previously assumed by RDs and other DEC clinicians. The change freed up more time for RDs to focus on actual service delivery (J. Cialone, personal communication, September 18, 2012). Another change in this system was that the CDSAs moved away from trying to be the providers of care to
evaluating and helping children gain access to services through public and private providers. The CDSAs now worked to identify where infants and toddlers could get services and in some cases these services were delivered outside of the CDSA.

Community-based “Travel” Clinics to Home-based Evaluations

The ways in which evaluation services were delivered also changed during this transition. Before the transition to CDSAs, DEC staff held children’s evaluations in community spaces called “travel clinics”. Travel clinics were held primarily in rural areas of NC (B. Przelomski, personal communication, October 30, 2012). The goal of the travel clinics was to make services more accessible to children and families (J. Cialone, personal communication, September 18, 2012). Families brought their children to these clinics for eligibility determination assessments and routine checkups that included a nutrition/feeding assessment (B. Przelomski and C. Frazier, personal communication, October 30, 2012). The transition from DECs to CDSAs eliminated the travel clinics and moved all evaluations into families’ homes. Physician and nurse positions within some catchment areas were abolished with these changes (C. Frazier and D. Miller, personal communication, October, 19, 2012).

NC Health Departments and Early Intervention Nutrition Care

NC Health Departments play an important role in early intervention nutrition services for children with special needs. Pediatric RD roles at both Durham and Pitt County Health Departments provide examples of how NC Health Departments deliver early intervention MNT services to this population. The roles of RDs within these two counties’ health departments changed as EI services and system infrastructure evolved. Policy changes, such as the 1996 Health Insurance Portability and Accountability Act (HIPAA), changed health department
nutrition services by limiting communication between DEC/CDSA RDs and health department RDs. Past and current health department nutrition services are provided independent from the NC ITP, but both agencies work toward similar goals of helping improve children's health outcomes (L. Lichtenwalter, personal communication, September 24, 2012).

**Early Intervention Nutrition Care**

DEC/CDSA nutrition services are part of a system of care that includes cooperation with local health departments. Although each NC Health Department is unique, the evolving relationships between the local DECs/CDSAs and the Durham or Pitt County Health Departments provide a snapshot of this system. The Durham County Health Department, has delivered nutrition care to children with DDs aged birth to twenty-one since at least the late 1980s. The age-range of children served remains the same to this day, but the Durham Health Department reformed the way it provides nutrition care. This reformation was an independent event, but notably took place around the time that the DECs transitioned to CDSAs (L. Lichtenwalter, personal communication, September 24, 2012).

At the Durham department, nutrition care services were provided exclusively within families' homes during the 1980s and 1990s (L. Lichtenwalter, personal communication, September 24, 2012). Currently, the department’s RDs divide their time providing nutrition services between two settings: the department clinic and children’s homes. RDs within the Pitt Public Health Department, in contrast, did not and do not deliver services within children's homes (B. Lesko, personal communication, October 26, 2012). It must also be noted that residents of Durham County are in close proximity of clinics and major hospitals that play large roles in developing research and delivering services to children with special needs (L. Lichtenwalter, personal communication, September 24, 2012). NC Health Departments in rural
areas may need to function differently in regards to how local children are followed as location can affect how quickly or comprehensively a child with DDs is identified and followed by outside providers. For these reasons, quality and comprehensiveness of nutrition care delivery within NC Health Departments as well as structure of services varies from region to region.

Interagency Nutrition Services

Local health departments supported DEC-led nutrition-care delivery during the 1980s and 1990s and still provide support to this system of care today. During the 1990s, the children that were high risk, but on the lower end of the risk spectrum could go back to the health department to be served (J. Cialone, personal communication, September 18, 2012). This lightened the caseload of DEC staff and improved care coordination between local health departments and DECs. Also at this time, feeding clinics that did feeding assessments for young children were set up around the state. These specialty clinics often took place at local health departments and involved health department staff as well as its primary DEC staff. DEC staff was trained on how to complete team evaluations. These clinics filled in care gaps, as there were not many services available in many areas for children with feeding issues.

Because of these relationships, the DEC to CDSA transition created changes within health departments. When the DECs transitioned into CDSAs, the RD at Durham County Health Department, as an example, saw reduced identification of children with growth concerns who may benefit from nutrition services (L. Lichtenwalter, personal communication, September 24, 2012). The reasoning for this reduction is unclear, but changes in onsite medical personal—specifically loss of physician and nurse positions—within some CDSAs may have led to a decline in children being referred to as many different services as they once were (L.
Lichtenwalter and D. Miller, personal communication, September 24 and October 19, 2012). However, some RDs describe their referrals as having increased over the years, so these changes may vary depending on CDSA location and other variables (B. Przelomski and C. Frazier, personal communication, October 30, 2012).

Durham County is unique to the NC infant-toddler nutrition service system because no RD was ever employed by the Durham DEC or CDSA. In Durham, during the 1980s and 1990s, the primary role of the health department’s RD was to provide home-based MNT services. These services provided were completed independent from the delivery of the local DEC’s services (L. Lichtenwalter, personal communication, September 24, 2012). Durham’s RD did not partner directly with the DEC to fill potential gaps in nutrition care services for children served, but the DEC was able to refer to this RD for nutrition information. The DEC also identified children with growth or feeding problems, or those at risk of these problems, and referred these children to the health department RD.

**Information Sharing**

Appropriate information sharing strengthens the efficiency and quality of clients’ care within the nutrition-care delivery system (*Information Technology in Health Care. 2004*). Information sharing between DECs or CDSAs and health departments changed as federal policies changed and these programs consequently adapted. Before the 1996 Health Insurance Portability and Accountability Act (HIPAA), patient information related to nutrition needs was shared freely between some DEC and health department RDs (B. Lesko and C. Frazier, personal communication, October 26, 2012). HIPAA limited the information that could be shared between agencies without full release forms completed by children’s families (*HIPAA privacy rule and*

Some CDSA RDs describe themselves as now having very little communication about their clients with outside agencies (B. Przelomski and C. Frazier, personal communication, October 30, 2012).

As an example of how interagency relationships adapted to HIPAA, when WIC recertification is now completed, families are asked if their children have medical concerns (B. Lesko, personal communication, October 26, 2012). Developmental disabilities are brought up in this way to not violate patient privacy. If DDs are a concern, families are then asked if they receive CDSA services. WIC RDs are only then able to refer children with DDs to other agencies—if needed and if parents are in agreement—to receive extra nutrition support. These agencies may include CDSA referral for eligibility evaluations. When a child’s CDSA participation becomes transparent, it makes it easier for a health department RD to gain permission to consult with the CDSA RD for information on what services the child is already receiving and likewise what issues, concerns, or suggestions that the CDSA RD may have.

Third-party Reimbursement for Nutrition Services

Reimbursement for Medical Nutrition Therapy

Monetary reimbursement is necessary for DEC/CDSA RDs to continue delivering quality nutrition services. The initial statewide assessment in 1984 indicated the need to appeal to Medicaid to bolster expansion of reimbursement to RDs in local health departments and DECs by providing these agencies with reimbursement for MNT services (J. Cialone, personal communication, September 18, 2012). The data collected during the period after which the first RD positions were created was also used to demonstrate MNT importance in DEC services and
supported the availability of reimbursement for RD services. In the earlier years following
nutrition’s introduction to the DEC system, MNT reimbursement generated enough funds in
some DECs to establish additional RD positions. Morganton, Charlotte, and Cullowhee are the
first locations that hired more than one RD.

Reimbursement for Nutrition Supplies

The cooperation needed from Medicaid to create more comprehensive nutrition services
goes beyond funding RD positions. Adequate reimbursement for other nutrition-related entities,
such as formulas and feeding equipment, are crucial in optimizing the health of program
participants. DEC/CDSA RDs request when and what nutrition materials, like enteral or oral
formulas, are appropriate for their infant/toddler clients (C. Hinson, personal communication,
September 28, 2012). For many clients, formulas and feeding equipment are an important part of
their nutrition care plan. For this reason, the role of health insurance within EI services,
especially Medicaid, significantly impacts the care that many participating families receive.

Coordination with programs outside of Medicaid was, and often still is, necessary to
provide wraparound services to augment services not reimbursable by Medicaid (C. Hinson,
personal communication, September 28, 2012). These programs include WIC, CAP/C, and the
previously existing Children’s Special Health Services (CSHS) (C. Frazier, personal
communication, October 30, 2012). RDs within the DECs/CDSAs were and still are required to
gain familiarity with how essential nutritional products can be obtained from manufacturers in
order to meet family-established medical nutrition therapy (MNT) goals. CDSA RDs are directly
involved in identifying what services clients are receiving and how nutrition-related formulas
and feeding supplies can be obtained through these organizations.
Reimbursement for Formulas

From the 1980s into the 1990s, Medicaid limited reimbursement to enteral formulas, excluding reimbursement for oral formulas (J. Cialone, personal communication, September 18, 2012). The CSHS, formerly the Crippled Children’s Services, exclusively covered oral formulas up until the early 2000s (C. Frazier, personal communication, October 30, 2012). The CSHS provided wraparound services to fill gaps where Medicaid did not cover oral formulas. For infants and toddlers with special needs who do not qualify for programs like Medicaid or WIC, CAP/C is a Medicaid waiver program that provides nutrition-related supplies and formula to eligible, medically fragile children. Often, children may qualify to receive nutrition supplies through a combination of these providers, CAP/C, WIC and Medicaid (C. Hinson, personal communication, September 28, 2012).

Reimbursement for Nutritional Supplements

In addition to formulas, oral supplements and other nutrition supplies are needed by children to support reaching nutritional goals. In the 1990s and today, Medicaid covers enteral and oral formulas and modular products (C. Frazier, personal communication, October 30, 2012). Although WIC covered oral formulas during the 1990s, WIC did not cover dysphasia care products such as Thick-IT. CSHS, similar to its wraparound relationship with Medicaid and oral formulas, covered nutritional supplements and formula thickeners like Thick-IT. CAP/C covers additional feeding supplies including enteral feeding supply kits and food thickeners to be used within the home setting. After CSHS was dissolved in the early 2000s, Medicaid expanded coverage to include formulas (C. Frazier, personal communication, October 30, 2012).

Early Intervention Nutrition Services Today
Today, EI services are still provided within the NC ITP system through local CDSAs. MNT services as well as eligibility determination assessments are provided within families’ homes (C. Frazier, personal communication, October 30, 2012). The ten RDs who currently serve clients in fewer than half of NC Counties continue to establish different criteria, depending on their caseload and clinical judgment, that determines which clients they serve (B. Przelomski and C. Frazier, personal communication, October 30, 2012). The budget cuts that took place during the early 2000s remain apparent, as the number of RDs within this system remains low relative to the number of CDSAs within NC (North Carolina directory of state, regional and local nutritionists. 2012). Thus, geography is a major determinant in whether or not a child is eligible for receiving CDSA nutrition services as many otherwise eligible children reside outside the existing boundaries of CDSA-offered care.

Health departments and other agencies, including those that offer third-party reimbursement, continue to play an important role in current CDSA-provided nutrition services. WIC RDs within health departments, such as the Pitt County Health Department, as an example, provide supplementary supplies, such as oral or enteral formulas for infants and toddlers, including children with special needs (J. Cialone, personal communication, September 18, 2012). Medicaid reimburses for both oral and enteral formulas while CAP/C continues to function as a Medicaid waiver program, which provides formulas to medically fragile children who otherwise, based on income, do not qualify for Medicaid (C. Hinson, personal communication, September 28, 2012).

**Conclusion**

Although the NC Infant-Toddler EI Program’s nutrition services are still relatively early in existence, many important developments occurred over this thirty-year period. The conducted
interviews and research presented in this paper capture some of this history and the trends that took place, including the trends toward more family-centered care decisions and home-based services. Many factors are responsible for the changes that resulted in today’s system of nutrition care delivered by the CDSAs and its cooperating agencies, such as local health departments and Medicaid. Developments in early intervention research and policies resulting from new information contribute to these changes. Advocacy, changes in the dietetic profession, and the perception in how and where therapies are best delivered also continue to shape NC’s system of nutrition EI care. Understanding these changes may shed light on where services are heading and how the dietetic profession best fits into this system to help NC meet the special needs of future infant-toddler populations.
References


http://depts.washington.edu/lend/about/history.html


http://www2.ed.gov/policy/speced/leg/idea/history.html


http://www.unc.edu/~ahowell/exceplaw.html#wc


http://www.medpac.gov/publications%5Ccongressional_reports%5CJune04_ch7.pdf


State Department of Health. Retrieved November 5, 2012, from


NC division of medical assistance: Children's developmental service agencies (CDSAs)

Medicaid and health choice clinical coverage policy no: 8J. (2012). NC Department of
Health and Human Services. Retrieved November 5, 2012, from

NC early intervention infant-toddler program: The earlier you know, the better they'll grow.
2011.pdf

5, 2012, from
NCPublicHealthNutritionists.pdf

infants and toddlers with disabilities to reauthorize part C of IDEA. Washington, D.C.:


