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Issue Brief

North Carolina's ABCD Program: Using Community Care Networks to Improve the Delivery of Childhood Developmental Screening and Referral to Early Intervention Services

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ABSTRACT: Between 2004 and 2008, North Carolina's Assuring Better Child Health and Development (ABCD) program quintupled the number of screening tests administered during Medicaid well-child visits to identify young children at risk for developmental disabilities and delays. Referrals to Early Intervention programs quadrupled, helping to increase the percentage of infants and toddlers receiving Early Intervention services statewide—from an estimated 3.0 percent in 2003 to 4.3 percent in 2008. As a result, fewer North Carolina children are entering school with unrecognized or untreated developmental problems. Key elements of the ABCD program include identifying standardized screening tools and training physicians on how to implement them without disrupting the workflow of their practices; building providers' knowledge of referral agencies; helping their practices develop processes for tracking cases; and establishing working relationships with community agencies to enhance communication and bridge gaps in understanding.

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OVERVIEW

Between 2004 and 2008, North Carolina's Assuring Better Child Health and Development (ABCD) program quintupled the number of screening tests administered during Medicaid well-child visits to identify young children at risk for developmental disabilities and delays that can compromise their growth and readiness for school. Referrals to Early Intervention programs quadrupled, helping to increase the percentage of infants and toddlers receiving Early Intervention services statewide—from an estimated 3.0 percent in 2003 to 4.3 percent in 2008. As a result, fewer North Carolina children are entering school with unrecognized or untreated developmental problems.

To implement the program, North Carolina relied on 14 local community care networks—collectively known as Community Care of North Carolina—that serve low-income children and adults enrolled in Medicaid or the Children’s Health Insurance Program. The networks, which strive to forge partnerships between physicians and other local stakeholders, helped introduce easy-to-use screening tools, educated medical providers about community resources, and enhanced communication between those providers and the agencies and organizations to which they refer children for services.

This report profiles the activities of three diverse community care networks that used varied approaches to accomplish the aims of the ABCD program.¹ One hired an Early Intervention specialist to work directly with medical practices; a second partnered with another nonprofit organization that provided funding to hire a local program coordinator; and the third relied on existing community resources to accomplish its goals.

Key elements of the ABCD program include identifying standardized screening tools and training physicians on how to implement them without disrupting the workflow of their practices; building providers’ knowledge of referral agencies; helping their practices develop processes for tracking cases; and establishing working relationships with community agencies to enhance communication and bridge gaps in understanding. In addition, the creation of uniform statewide referral forms may promote more reliable information flow. The experiences of these networks suggest that the Community Care of North Carolina public–private partnership structure has proven valuable in disseminating a statewide initiative in a way that is flexible and responsive to local needs. Critical ingredients of success include supportive state policy, visionary leadership, and collaboration among stakeholders at both the state and local levels.

THE ISSUE

The first five years of life play a pivotal role in a child’s future. During these years, children advance through stages of physical, cognitive, and linguistic

development that are crucial not only for their health and happiness, but also for their academic and life success.² The early identification of developmental disabilities and delays allows some children the opportunity to overcome or adapt to them before entering school; it also may prevent the need for more costly interventions later. For example, recognizing children with speech and language delays or disorders and providing therapy can help them overcome expressive difficulties.³

Identifying and treating such problems requires a well-coordinated system of care at the community level—one that ensures health care providers in private systems and the community agencies that provide Early Intervention services through public systems collaborate with one another. Often, such collaboration is lacking. Many health care providers who have frequent contact with children under age 5 during well-child visits are unaware of the government agencies and nonprofit social service groups that help children with developmental disabilities and delays.

The agencies, in turn, report difficulty communicating with physicians about referrals. They may not get a timely response when they seek to follow-up on a referral or obtain authorization for additional services. Physicians—especially those who are accustomed to receiving written reports after referring patients to a specialist for treatment or consultation—find the haphazard communication frustrating as well. Without receiving some form of feedback after a patient has been referred to a community agency, they may become discouraged from making referrals, or even from conducting developmental screening, because they cannot judge whether their efforts in helping children are effective.

The lack of a well-functioning system to coordinate services for children with developmental deficits puts children who are at risk in further peril. If a parent misunderstands the nature of a referral or has trouble navigating the system, it may take months for the referring physician to discover the problem, during which time a valuable opportunity for treatment is lost. Unfortunately, such events are common.

“In times past, a primary doctor might make a referral and never find out if a family has gotten to that referral because the child may not be due back for an exam for six months. And then the child would come back and you’d find out the parent had trouble making it there, or they didn’t understand when they got the packet of information in the mail from a new agency who it was from,” said Marian Earls M.D., a Greensboro, N.C.–based developmental pediatrician.

In North Carolina, the low rates at which medical practices referred children for Early Intervention services suggested there were many missed opportunities to address children’s problems before they became more limiting and costly to treat. A 1999 study by the state legislature found that only 2.6 percent of North Carolina children ages 0 to 3 were receiving Early Intervention services, even though a statewide task force estimated that as many 8 percent to 13 percent would benefit and qualify for such services.⁴

One of the reasons so few North Carolina children were referred was that medical practices were infrequently screening children for developmental deficits and delays. Within the Medicaid population, only 15.3 percent of the infants and toddlers were tested for deficits in 2000.

ABOUT THE PROGRAM

North Carolina’s ABCD program aims to increase the rate at which providers in the state perform developmental screenings and the rate at which they refer children to other agencies for help. It also seeks to improve service coordination across agencies involved in Early Intervention. A key part of accomplishing these goals is improving communication between medical offices, social services agencies, and families. Toward that end, the program focuses on:

- identifying standardized screening tools and training physicians on how to implement them without disrupting the workflow of their practices; and
- helping providers forge relationships with community agencies and other partners to better coordinate care for children with disabilities.

TARGET POPULATION

ABCD seeks to identify Medicaid enrollees under age 6 who would benefit from Early Intervention services.⁵ This population includes children eligible for services under the federal–state Children’s Health Insurance Program (CHIP); in North Carolina, such children are enrolled in Medicaid until age 6.

To reach that group and ensure their care is well coordinated, the state also needed to encourage collaboration between the pediatric and family medicine practices that care for such children and the agencies that serve children with developmental disabilities. In North Carolina, children with developmental disabilities are served by two public agencies, which fulfill the requirements of the federal Individuals with Disabilities Education Act (known as IDEA). From birth until age 3, children are eligible for evaluation and service coordination services from the state’s Children’s Developmental Services Agencies (CDSA). From age 3 until they enter kindergarten, children with developmental disabilities and delays are served by similar, federally funded programs run by local school systems (Exhibit 1).

In North Carolina, local public health departments and private–public partnerships serve children whose needs are not severe enough to qualify them for CDSA or school services (Exhibit 2 describes a partial list of these groups).

HOW IT WORKS

To help increase rates of developmental screening and referral to Early Intervention services, North Carolina turned to a statewide system of 14 local community care networks—collectively known as Community Care of North Carolina (CCNC)⁶—that serves almost 1 million low-income individuals enrolled in the state’s Medicaid and CHIP programs.⁷ This population included almost 312,000 children under age 6 as of February 2009.

Community care networks are local nonprofit organizations that bring physicians together in a partnership with other local stakeholders such as hospitals, community health departments, and social service

Exhibit 1. Infant-Toddler Early Intervention and Preschool Exceptional Children Programs in North Carolina

Infant-Toddler Early Intervention Program: Eighteen Children’s Developmental Services Agencies (CDSAs) serve the state’s 100 counties under the supervision of the North Carolina Division of Public Health’s Early Intervention Branch. The CDSAs coordinate Early Intervention services for infants and toddlers from birth to age 3 in assigned counties. When a child is referred to a CDSA, the agency determines the child’s eligibility for services, develops an individualized family service plan if necessary, and makes and monitors referrals to community-based providers who specialize in areas of development for which the child needs services. Those may involve cognitive, physical, and adaptive developmental domains as well as social-emotional skills and language acquisition. If such providers aren’t available locally, the CDSA may provide the service directly.

Preschool Exceptional Children Program: North Carolina has 115 local school systems, known as Local Education Agencies (LEA), that coordinate special education and related services for 3-, 4-, and 5-year-old children who have developmental disabilities and delays and have not yet entered kindergarten. They provide these services with technical assistance from the State’s Department of Public Instruction, which is responsible for ensuring that the schools comply with federal and state regulations. For most of these children, school employees (such as licensed psychologists) provide the Early Intervention services; occasionally, the schools hire community providers to do so.

According to North Carolina policy, only the parent of a child or the school system can initiate an official referral for an evaluation for special education services. When a physician notifies the school system that a child may need services, the school contacts the family to determine the need for a referral. When a referral is made, the school system conducts an evaluation, determines eligibility for services, and develops an individualized education program for qualified children. The school system provides the results of the eligibility determination to the physician. The system also will follow up with the doctor if the family refuses services ([Appendix 3](#)).

agencies to help improve the accessibility, quality, and efficiency of care delivery. Together they cover the state’s 100 counties and include 1,324 medical practices with approximately 3,500 to 4,000 primary care physicians.

Each network has a clinical director to lead quality improvement initiatives throughout his or her network. The clinical directors meet as a statewide group to analyze data and set goals for new initiatives. The clinical directors, in turn, present information from these meetings to the medical management committees in their local networks. Those committees, which include representatives of local medical groups, implement the state-level initiatives and develop local improvement initiatives as needed.

Once a network has committed to a quality improvement initiative, such as reducing hospitalizations and emergency department visits among patients with asthma, it typically relies on case managers to communicate the details of the program to local physicians. The case managers are employed by the networks and assigned to work with medical practices to

monitor care and implement a variety of disease management programs. The majority of the case managers are nurses; some are social workers or health educators.

The ABCD program was introduced to the networks in a similar fashion. The networks’ medical management committees determined how to implement the program locally. Some chose to use case managers to convey the details of the ABCD program to medical practices. Other networks partnered with a nonprofit organization, Smart Start, which provided funding to hire ABCD coordinators. Many of these coordinators had a background in early childhood development or social work and special knowledge of developmental screening and Early Intervention services.

Like the case managers, the ABCD coordinators typically worked in network offices and traveled to medical practices to provide education and training to clinicians. The coordinators also served as liaisons between the medical practices and the CDSAs and schools that provided Early Intervention services.

Exhibit 2. Community Programs and Organizations Partnering with CCNC Networks

Many of the CCNC networks that seek to improve screening and referral rates have benefited by partnering with other organizations and programs that focus on improving child development and health care services. These include:

Smart Start, a nonprofit organization that funds programs in every North Carolina county geared to improving the health and educational readiness of children. Programming is determined by the local affiliates (known as Local Partnerships), which assess needs and administer state and private funding. There are 79 such groups in the state, some of which have existed for 10 years or longer. The nonprofit North Carolina Partnership for Children, Inc., provides oversight and technical assistance to the Local Partnerships.²³

Smart Start began seeking greater linkages with the medical community in 2001, when one local Smart Start partnership began working with rural medical practices to support developmental screening. The statewide organization now funds ABCD programs in eight counties, each of which receives \$40,000 per year as part of a two-year grant. In some counties, the Smart Start program works with the local CCNC network. In others, the group works directly with physicians or hospitals. Smart Start receives funding from the state and private donors.

North Carolina has an **Interagency Coordinating Council**, as required by the federal government, which meets quarterly to advise North Carolina's departments of Health and Human Services and Public Instruction and other agencies on the needs of children with disabilities.

The state also has 89 **Local Interagency Coordinating Councils**, which include representatives of CDSAs, schools, health care providers, Smart Start programs, nonprofits, and parents of children with special needs. The Councils promote local Early Intervention services and identify gaps in services or barriers to them at the county level. "There's variation among those councils in part because they are primarily volunteer," said Deborah Carroll, Ph.D., head of the state's Early Intervention Branch, which oversees the local CDSAs. "Some rural counties don't have as many options for whom to call on to even be on the council, and may end up with the same people—the same three people—having to do all the work that 30 people would do in an urban county."

Head Start is a federally funded preschool program designed to meet the health, emotional, and nutritional needs of children. Nationally, 12.8 percent of children enrolled in Head Start have some form of disability.

Medicaid Health Check Coordinators are community outreach workers who are deployed throughout the state to ensure that children enrolled in the Medicaid program receive comprehensive and preventive health, dental, and vision care, known as Early and Periodic Screening, Diagnostic, and Treatment services, as mandated by federal law. The coordinators, whose services are paid for by the Medicaid program, track Medicaid patients using a state database and use this information to help providers identify and reach patients in need of care.

The North Carolina Office of Rural Health and Community Care acts as the CCNC's central office to provide resources, information, and technical support to local networks.

Physician practices are paid on a fee-for-service basis for their participation in their local community care network. They receive an additional \$2.50 per member per month from the state to cover the cost of providing preventive care and around-the-clock access, coordinating specialty care, and participating in the network's care management and quality improvement activities.⁸ The state pays local networks \$3.00 per member per month to support local staffing, provide

case management services, and fund the local quality and efficiency initiatives.

To expand the model of the program to primary care physician practices that were not affiliated with the state's community care network, ABCD project leaders teamed up with representatives of state medical groups, Medicaid, and the Office of Rural Health and Community Care to develop a curriculum for providers that explained how to integrate screening tools into practices and develop a community system for screening and referral.

Community Care of North Carolina encourages collaboration among network leaders on a statewide

basis. An ABCD Quality Improvement Committee draws local community care network executive directors and clinical coordinators together from across the state to share issues and learn from their experiences in implementing developmental screening at the local level.

Another important feature of North Carolina's ABCD program is its state-level advisory group, which was created within the first year of the program to improve communication among providers, community agencies, and government. Members of the advisory group meet on a quarterly basis to address policy and reimbursement issues necessary to sustain the model, among other issues. It includes senior-level representatives of:

- American Academy of Family Medicine (North Carolina chapter);
- North Carolina Pediatric Society;
- Office of Rural Health and Community Care;
- North Carolina Division of Medical Assistance;
- Division of Public Health;
- Department of Public Instruction;
- Child Development Services Agencies;
- North Carolina Interagency Coordinating Council;
- North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services;
- Family Support Network of North Carolina; and
- North Carolina Partnership for Children (also known as Smart Start),

The ABCD advisory group works on tasks that would be difficult to accomplish at the local level, such as expanding the scope of screening to include measures of socio-emotional problems and creating generic referral forms for use by physicians across the state, as well as generic forms for agencies to use to communicate with physicians. The forms that the advisory group produces carry the logos of the participating organizations and government entities to convey widespread

endorsement. The group has created a universal referral form for CDSAs and has collaborated with the North Carolina Department of Public Instruction to create a similar form for the schools ([Appendices 1 and 2](#)).

PROGRAM DEVELOPMENT AND IMPLEMENTATION

A critical step in developing the ABCD program was piloting a method of screening that would appeal to physicians, who reported that tests for developmental disabilities and delays were too costly or time-consuming.⁹ For that, the state turned to Earls, a developmental and behavioral pediatrician whose practice in Greensboro, N.C., cares for children in families with low incomes (at, or below, 200 percent of the federal poverty level). The practice, Guilford Child Health Inc., operates in partnership with two local health systems and county agencies and serves 60 percent to 70 percent of the children covered by Medicaid and CHIP in Guilford County.

Staff from Guilford Child Health clinics worked with employees from the State's Office of Rural Health and Community Care to pilot new screening, referral, and parent education protocols. To screen children for developmental problems, the group decided it would be most efficient to use a parental assessment such as the Ages and Stages Questionnaire, a validated parental survey of child development, and to have parents fill out the survey during scheduled well-child visits.¹⁰

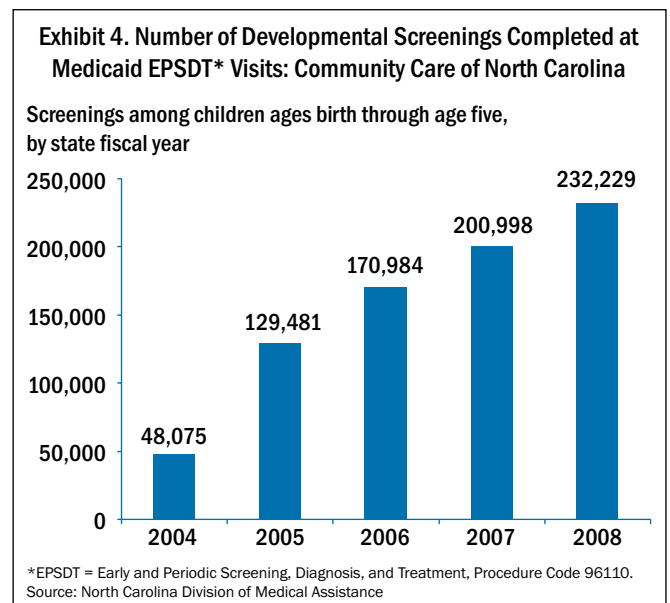
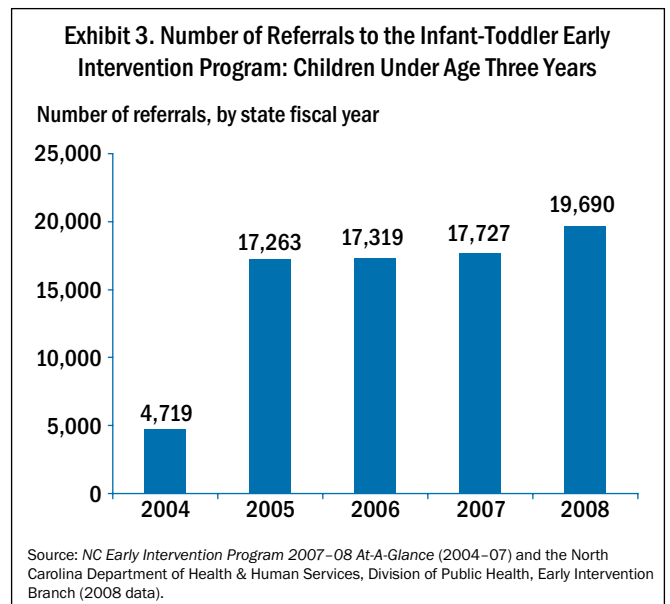
Using a screening tool based on parental assessments, rather than providers' observations, proved to be more reliable because the parents have a more comprehensive view of their children's strengths and weakness. Using parental assessments, which are easy to score, also freed up busy office staff. But using a new tool required provider education and monitoring. To do that, Partnership for Health Management, the CCNC network with which Guilford Child Health is affiliated, hired an Early Intervention specialist to visit practices and review charts. The Early Intervention specialist assisted practices that needed help using the screening tools or making referrals (the profile of Partnership for Health Management, below, offers additional detail about the specialist's role).

- As a result of the new methods of screening and monitoring, the Guilford Child Health clinics in the pilot program increased the percentage of children who were screened for developmental disabilities from 7 percent in 2000 to 62 percent in 2002. By 2009, the rate had increased to 90 percent.
- The rate of referral for Early Intervention services averaged 7 percent of the participating clinics' pediatric patients in the first two years of the pilot (2000 to 2002), compared with a statewide average during this time frame of 2.9 percent.¹¹ By tracking children who received a referral for Early Intervention services, the pilot leaders found that more than 95 percent of families completed their initial evaluation and almost 70 percent received some type of developmental intervention service.

In 2004, based on the success of the pilot project, state Medicaid policymakers mandated that all providers perform developmental screening during well-child visits for children who are six, 12, 24, 36, 48, and 60 months of age. (The visits are paid for under Medicaid's Early and Periodic Screening, Diagnostic, and Treatment, or EPSDT, program.) Since July 2005, North Carolina's Medicaid program has had the right to refuse to pay for a well-child visit unless it includes a developmental screen.¹²

The policy change had a dramatic impact on referrals across the state, said Chris Collins, M.S.W., acting assistant director for managed care for the North Carolina Division of Medical Assistance and acting deputy director of the Office of Rural Health and Community Care. Referrals of children under age 3 to the CDSA increased nearly fourfold, to 17,263 in fiscal year 2005, from 4,719 the year before (Exhibit 3).¹³

The rate of screening for developmental disabilities also has increased dramatically statewide. Eighty percent of well-child visits now include a developmental screen, compared with only 15 percent in 2000. Among children from birth through age 5 enrolled in Community Care of North Carolina, the number of



screenings performed as part of Medicaid EPSDT visits increased nearly fivefold, to 232,229 in 2008 from 48,075 in 2004 (Exhibit 4).

Network Profiles

CCNC gave local networks latitude to develop programs consistent with their particular resources and needs. As a result, the networks used varying staffing models and community partnerships to achieve their shared aims of increased screening, referral, and coordination of care. The following profiles of three CCNC networks illustrate three different approaches in diverse settings: a metropolitan area, a market dominated by a transient military population, and a rural area.

PARTNERSHIP FOR HEALTH MANAGEMENT

Counties: Guilford, Randolph, and Rockingham

Medicaid and CHIP enrollees: 45,529¹⁴

Number of enrollees under age 6: 15,012 (33% of total enrollees)

Practices: 30, ranging in size from a single provider to practices of 20 providers

Medical offices: 37

Providers: 179, including 16 nurse practitioners and 5 physician assistants

Key staff: Claudette Johnson, president; Marian Earls, M.D., medical director

Region: With two large cities (Greensboro and High Point), Guilford County has a variety of services for children with developmental disabilities. Residents of neighboring Randolph and Rockingham counties, which are more rural, tend to cross county lines to use Guilford County's speech and hearing, physical therapy, and mental health specialists.

The Partnership for Health Management (P4HM) includes Guilford Child Health Inc., the Greensboro-based practice that served as a pilot site for the state's ABCD model and serves about two-thirds of the children enrolled in Medicaid and CHIP in Guilford county (the network also includes 29 other physician practices). Guilford Child Health is one of the most advanced practices in the state in terms of the breadth and depth of screening. Its providers not only screen for developmental disabilities, but also for indicators of socio-emotional difficulties such as maternal depression. The network also benefits from having Earls, one of the state's leading authorities on early childhood development, as its medical director.

Activities to Increase Screening

P4HM gave medical practices the option of using one of two tools: the Ages and Stages Questionnaire (ASQ) or the Parents' Evaluation of Developmental Status (PEDS).¹⁵ Both surveys are completed by parents and can be scored in less than five minutes by office staff.

The ASQ, which detects potential problems in the areas of communication, gross motor skills, fine motor skills, problem solving, and personal/social skills, costs \$199.95. Spanish-language editions are similarly priced. After purchasing the kit, practices may make unlimited copies of the questionnaire. The PEDS form, which assesses similar developmental skills, costs \$30 for 50 response forms and 50 scoring forms. Although the tool costs less, its authors do not allow copying, so practices must reorder forms at the same price as supplies are exhausted.

To help practices implement the new screening tools, the network hired an Early Intervention specialist, Amy Jobe, B.S., who has knowledge of developmental disabilities and experience working with families and children. Jobe visited practices to assess their existing protocols and help organize workflow to incorporate screening into the office routine. Her salary was paid with the case management fees the network receives from the state.

Because Jobe kept regular hours in some of the larger providers' offices, she came to play an integral role in the screening. She spent two days a week at the network's largest practice and visited smaller practices as needed. Having dedicated time in the medical practices enabled the providers to schedule more difficult screenings while she was present. For example, Jobe would administer a follow-up social-emotional screening (using a special version of the Ages and Stages Questionnaire) if social or emotional issues were identified in the initial screening. She also performed screenings when language barriers existed.

The network tracks its performance on screening through state-generated quarterly reports, which focus on primary care practices that perform at least 50 EPSDT exams per month. These reports, which are available to every network, indicate whether those practices use the CPT code to bill for a development screen. The state's Medicaid office identifies practices that use the code on less than 70 percent of well-child visits. To help them, P4HM conducts outreach and offers technical assistance in implementing developmental screening into office practice. "For some it was just a billing thing. They didn't know how to use the

CPT code correctly. For others, it was that they were trying to do screening, but because they hadn't gotten it into their office flow very well, they don't always get it done," Earls said.

Among children from birth through age 5 enrolled in P4HM, developmental screenings at Medicaid well-child visits increased more than three-fold, from 3,257 in 2004 to 10,592 in 2008.

Activities to Increase Appropriate Referrals

In addition to training providers about developmental screening, Jobe educated the practices about the community agencies to which they might refer children, as well as other resources. For each of the 15 primary care practices she worked with, she created a notebook that informed providers of the range of services available to children, based on the children's ages and needs. This reference prevented mix-ups that had occurred when practices sent referrals to the wrong agencies (e.g., to the CDSA instead of the school system). In such cases, the resulting rejection letters might go unnoticed for weeks or months by busy office staff. She also helped to streamline referrals that became complicated when parents crossed county lines to see doctors. "Each county can dictate how their programs work, so our Early Interventionist has to know what happens in each county and what those resources are," Johnson said.

Jobe also helped coordinate referrals to Early Intervention and other programs such as Head Start, and found resources for children who didn't qualify for federally or state-funded services.

The percentage of children from birth to age 3 who received Early Intervention services in 2008 was 4.5 percent in the three P4HM counties (ranging from 3.0 percent to 5.5 percent by county). This represented a 70 percent increase from a rate of 2.6 percent in 2003 (ranging from 1.5 percent to 4.5 percent by county).¹⁶

Activities to Encourage Follow-Up

The Early Intervention specialist acted as a liaison between the providers and the community agencies. This proved useful for physicians, who were frustrated by the lack of feedback from agencies and schools. Feedback is especially important to primary care

doctors, who are often asked to sign off on referrals for physical therapy and other services, Earls said.

To keep local providers informed, the specialist created a referral tracking form for the office, which documented the agency to which a child was sent, the services they qualified for, and whether the family had declined services. If a family declined services, she put the form into their doctor's inbox so he or she could follow up with the family immediately.

When necessary, the specialist, who had previously worked for the predecessor agency to the CDSA in Guilford County, could pick up the phone and find out what happened to a child and thus help close the information loop. She typically communicated that information verbally to physicians.

One of Jobe's first assignments was to establish positive working relationships with all of the community groups to which practices might make referrals. "I made appointments and sat down with them and said, 'here is my job. I'm working directly with physicians and can talk to them. What do you want me to take back to them? How would you like for this relationship to work?'"

The specialist also tracked down families who missed appointments. She would talk to these families by telephone or meet with them in their homes to address their concerns and help them overcome barriers to getting services, such as a lack of day care. Earls said the follow-up was crucial: "It is abundantly clear that if left to our own, there would be a lot of families that wouldn't make that first contact. Having this close relationship really makes a huge difference."

The CDSAs found the Early Intervention specialist useful for making contact with physicians, too. Given their busy schedules, physicians might take several days to return a call from a CDSA case manager seeking information about a child. The specialist could expedite this communication in the practices where she kept regular hours.

Families also benefited from having an Early Intervention specialist embedded in the physician practice. "You have a person who is right there in the physician's office who is very knowledgeable about community resources and can take immediate action if the

family so desires and is available, furthermore, for the family's questions, answers, follow-up," said Deborah Carroll, Ph.D., head of the state's Early Intervention branch. "One of the challenges for families is that if they have a child who has special needs, they're managing a huge amount of information and a huge amount of coordination just getting all the appointments done every month. Having someone who can help them and check back with them to make sure something doesn't fall off the list is incredibly beneficial to families."

The specialist found it harder to track children in school systems, especially in districts that did not identify a single point of contact for coordinating services. The Department of Public Instruction does not have the same tradition of communicating with medical practices as do Early Intervention programs, which historically have been embedded in public health departments, Earls said. "That doesn't mean it doesn't happen, especially in individual counties," she said.

Key Insights

P4HM will continue to focus on meeting the needs of children in a holistic fashion. "We can't forget all the kids who don't require Early Intervention but whose families benefit from the anticipatory guidance and the promotion of good developmental stimulation," Earls said. As an example, Jobe cited the case of a teenage mom who lacked social supports and needed guidance to address concerns about her child's eating and growth. Jobe might refer such families to a home visitation program run by the county health department or to other family-based programs and offer educational resources and advice until formal services were in place. "You have to get creative at how you get services started for families," she said.

Promoting a systems approach is key to helping physicians incorporate a new activity such as developmental screening into their practice flow. Physicians have to see "that this is doable without completely blowing the time they have to see kids," Earls warned. To help overcome resistance, the network encourages practices to make changes as part of a broader redesign that will improve staff productivity and access for their patients. "We work with them to see the positive

aspects [of changing their processes], to look at it as part of their daily work, as opposed to some additional tasks that they have to do," said Claudette Johnson, P4HM's executive director.

CAROLINA COLLABORATIVE COMMUNITY CARE

County: Cumberland

Medicaid and CHIP enrollees: 50,558¹⁷

Number of enrollees under age 6: 12,968 (26% of total enrollees)

Practices: 74, ranging in size from one to six providers

Medical offices: 76

Providers: About 180, including mid-level practitioners

Key Staff: Brenda Sparks, R.N., executive director; Carolyn Smith, R.N., clinical coordinator

Region: The population of Cumberland County clusters around Fayetteville, which is home to Fort Bragg and Pope Air Force Base, as well as the county's one health system. The local network finds it challenging to maintain contact with Medicaid patients, who are both transient and unaccustomed to having case managers intervene in their care.

Cumberland County has a high concentration of Medicaid enrollees but, until recently, it did not have the benefit of a community care network to implement and oversee quality initiatives for the Medicaid population. The state, which needed the participation of hospitals, physicians, and public health and social service departments, had difficulty gaining local support for such a network until it persuaded a large physician group to spearhead the effort. Sandhills Physicians, Inc., a Fayetteville-based independent practice association with more than 600 associated physicians, used its sway to rally health system and social service agency partners to join together, forming the Carolina Collaborative Community Care (4C) network in 2005.

As the most recent network to join the CCNC network, 4C has concentrated its efforts on core objectives such as improving outcomes for Medicaid patients suffering from asthma, diabetes, heart failure, and other chronic conditions. It began to focus on the ABCD project when asked to do so by the CCNC central office.

Activities to Increase Screening

4C sent representatives to the state-level ABCD advisory committee meetings, where they learned how to assess existing screening protocols in medical offices and how to educate providers about validated tools and community services. “We were able to get ideas and strategies,” said Carolyn Smith, R.N., the clinical coordinator for the network, “and disseminate this information to our medical providers.”

To relay the information to physicians, the network relied on its case managers, who had established working relationships with providers to manage chronic diseases. The case managers, who are employed by the network and located in its offices, typically visited physician offices once per month. They stressed the importance of developmental screening and referral. If a practice appeared skeptical, a local pediatrician who serves on the network’s medical management committee would visit and speak with the physician or physicians. If a practice remained resistant to change, “we had to get the support of CCNC and Medicaid to say, ‘this is an expectation if you want to take care of Medicaid children.’ That was very helpful,” said Brenda Sparks, R.N., 4C’s executive director.

The network also made use of Medicaid health check coordinators, who are assigned to physician practices but located at the network offices. Health check coordinators, who often have experience working in schools or social work, act as liaisons between Medicaid patients or their parents and the physician or other providers to ensure that children have regular Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) examinations, as required by federal law, and to follow up when they do not. 4C’s three health check coordinators rely on a state database that

indicates which Medicaid enrollees have missed well-child screenings. As part of their job, the coordinators also perform outreach, informing area residents about the Medicaid and HealthChoice programs. The state reimburses the network a set portion of their salaries.

The network also has information from the state on the rate at which affiliated medical practices use the CPT code for developmental screenings when they provide well-child exams. If the network identifies low screening rates at the practice level, the case manager will share data with the office manager showing the need for improvement. If the problem isn’t remedied, the network’s medical director—a local practicing primary care physician—calls the practice and speaks with the appropriate physician about the importance of regular screening. The medical director “has the credibility in the community so that when he asks [physicians] to do something, it appears reasonable,” Sparks said. Medicaid’s regional consultant also will visit practices that appear to have difficulty screening children on a regular basis.

Physicians have to be convinced screening is worthwhile. “If they believe it has value, they will do it. If they think it’s just another thing that Medicaid is asking them to do, and they are not being paid to do so—which they remind you often—then it’s less likely to happen,” said Sparks. The network’s initial assessment found the majority of practices were receptive to using validated screening tools, but lacked information about where to send children who needed additional help.

Among children from birth through age 5 enrolled in 4C, developmental screenings at Medicaid well-child visits increased almost twofold, from 6,450 in 2005 to 11,117 in 2008.

Activities to Increase Appropriate Referrals

The network turned to the Cumberland County Partnership for Children, the local Smart Start program, for help educating medical practices about local Early Intervention services. The nonprofit created literature informing providers where they could send children who were identified as being at risk for developmental delays.

One organization the nonprofit promoted was COLORS (Children’s Organizations Linking Opportunities, Resources, and Support), the Local Interagency Coordinating Council of Cumberland County. The community agencies and organizations that make up the group—including the local CDSA and Smart Start—have reached out to medical practices, child care providers, and families to inform them of local services for children with developmental disabilities and delays. It sponsored an annual conference for child care providers to help them identify potential deficits in children and talk to parents about seeking help from local providers. The group also created a brochure for parents outlining the services that are available for children according to age and developmental challenge.

Cumberland County’s CDSA also actively encourages referrals. Its pediatrician has provided every pediatric practice in the county with information about the agency, said Ann Crane, M.S., its director. The percentage of children from birth to age 3 who received Early Intervention services in 2008 was 3.8 percent (5 percent of children who received Early Intervention services through a program at Fort Bragg are included). This represents a 56 percent increase from a rate of 2.5 percent in 2003.¹⁸

Activities to Encourage Follow-Up

Once a referral is made by a physician’s office to the CDSA, the 4C network does not generally get involved in communications between medical groups and community agencies, Smith said.

The CDSA, however, plays an active role in follow-up. The agency has one intake coordinator, who faxes information to physician practices about patients who have been referred to the agency. If a patient does not show up for the initial evaluation, she informs the referring practice immediately. She also seeks permission from the family to inform the referring physician of the results of the evaluation. “We send them a one-page summary of the intake eligibility assessment. That way they have immediate feedback,” Crane said. The CDSA hopes that providing that information promptly will encourage physicians to sign authorizations for

services quickly. That’s been an ongoing challenge, Crane said.

The network’s collaboration with Smart Start helped to prevent the duplication of effort among the groups working in the area. “We had our Smart Start program trying to develop things related to developmental assessment and it had already been worked on. Because they were a nonclinical group, they were very shy to communicate with the doctors and the doctors rarely communicated back to them, even if they asked them for anything,” Sparks said. Because of the partnership between the network and Smart Start, Sparks was able to inform them of the physicians’ activities.

Key Insights

4C has been less active than other networks in fostering collaboration between medical practices and the agencies that serve children with developmental disabilities for several reasons, the most important of which may be that it lacks a dedicated Early Intervention specialist. “We do incorporate a lot of what [Early Intervention specialists] do,” Smith said. But the network does not do so in as comprehensive a manner. “They will monitor the number of referrals. We have not been involved to that level,” she said. Many of the functions of an Early Intervention specialist—providing education and outreach services and acting as a liaison with local agencies—are now provided by the local CDSA and the Local Interagency Coordinating Council. In the meantime, the network is working on other priorities, including work related to a grant to reduce health disparities and the implementation of chronic care initiatives.

The network believes communication between medical practices and the agencies that provide Early Intervention services is difficult because of the lack of an established relationship and trust between the parties involved. “The agency is saying they can’t get the doctors to do anything, and the doctors are thinking, ‘Well, who are they anyway?’ because they really don’t know who they are.... We were able to bridge that [disconnect], because we understand the importance of Smart Start and CDSAs and [other programs],” Sparks said.

The CCNC's relationship is built in part on paying medical practices a case management fee for each of their patients, which helps open doors to communication from the network. "When we come in and we talk to them about things that are important for Medicaid, things that are important for their children, we have a receptive ear," Sparks said. Her advice to others who are working with physicians to promote developmental screening: "Just be persistent, sharing that it's very important for the well-being of this child... because that is their vision. That is their mission."

SANDHILLS COMMUNITY CARE NETWORK¹⁹

Counties: Harnett, Hoke, Lee, Montgomery, Moore, Richmond, and Scotland

Medicaid and CHIP enrollees: 45,792²⁰

Number of enrollees under age 6: 11,267 (25% of total enrollees)

Practices: 85, ranging in size from 1 to 10 providers

Medical offices: 85

Providers: 202, including mid-level practitioners

Key staff: Tammie McLean, R.N., B.S.N., network coordinator; Jennifer Ormsby, B.S.W., project coordinator

Region: The network serves seven counties, none of which have large cities. Because the area is largely rural, public transportation is limited. Medical practices also tend to be small and face financial challenges.

To provide case management and administer quality improve programs, Sandhills Community Care Network must reach 85 mostly small medical practices spread across seven counties in the south-central portion of the state. Because of their small size and limited resources, many practices have struggled to incorporate developmental screening into their routines. Some report they do not have the money for the tools. Others insist they do not need a formal process for screening.

Activities to Increase Screening

"Some providers don't understand that they need that screening. They think that they can spot the delays without having to have a formalized screening and it's hard to break through that barrier sometimes," Tammie McLean, R.N., B.S.N., Sandhills' network coordinator, said. Other practices were screening all of their pediatric patients but using non-validated tools, such as checklists in their electronic medical record.

To stress the importance of screening using validated tools and to help practices do so, the network partnered with four local Smart Start groups that had received a two-year grant for this purpose from the North Carolina Partnership for Children. The leader of one of the four local Smart Start organizations had approached the Sandhills network to propose a collaboration, knowing it would be difficult to gain access to local physicians without the network's help.

"You can't just call up a practice and say 'I'm so-and-so and I know about developmental screenings and I want to come talk to you about it,'" McLean said. "You can't get in the door. They're busy. They're overwhelmed. They don't see the value in what you're doing."

Like other community care networks, the Sandhills network not only has access to the physician practices through its case management relationships, it also has business partnership agreements in place that allow it to review patients' medical charts as part of the CCNC quality monitoring process. Such partnership agreements take time to establish, as the network discovered when Smart Start asked it to add non-network practices to its outreach program.

The Smart Start grant allowed the network to hire an ABCD project coordinator, Jennifer Ormsby, who previously worked at the local CDSA and has a bachelor's degree in social work. At Smart Start's request, the network targeted the largest practices first—those that served as many as 2,000 Medicaid enrollees under age 5. After doing baseline chart reviews, Ormsby introduced the practices to new screening tools, as necessary.

One of the challenges of the partnership between the Sandhills network and Smart Start is that the Smart Start grant only covered four of the network's seven counties (Those four are Lee, Montgomery, Moore and Richmond counties.) Nonetheless, practices that have received help have valued it. Dellena Nicholson, C.M.A., clinical manager of Community Family Medicine, which has offices in Sanford and Pittsboro, N.C., said the practice has stopped using a software tool that came with its electronic medical record for screening and began using the ASQ. The software often suggested a child's developmental delay stemmed from a problem with hearing or vision and seemed to lack appropriate attention to other types of problems, Nicholson said.

The Sandhills network encourages providers to conduct developmental screening for all of their pediatric patients, not just Medicaid-insured children. McLean described this as a learning process that requires gaining trust, such as by commending a practice for successes achieved with Medicaid patients and sharing stories of children who have been helped by Early Intervention services. "Then we point out that all children are at risk for having developmental delays and wouldn't it be great to give other children the same benefit as children with Medicaid."

The key to effectively working with a physician practice is, first, to identify the "go-to" person who can get things done—whether that is an office manager, a physician, or even a receptionist, McLean said. Then, "you have to meet a practice where they are, and you have to be very nonthreatening and very nonjudgmental. Help them move from the place they are to the place they need to be." Because of staff turnover and other distractions, it can be helpful to educate a practice multiple times. "It doesn't hurt to keep saying the same things over and over until you know it's stuck," Ormsby said.

Among children from birth through age 5 enrolled in the Sandhills Community Care Network, developmental screenings at Medicaid well-child visits increased more than sixfold, from 1,065 in 2004 to 6,819 in 2008.

Activities to Increase Referrals

Once screening procedures were in place, Ormsby performed regular chart reviews to see if children were being screened and referred as needed.

"When I first started this project, a lot of the practices were only referring to private agencies like private speech therapy agencies or physical therapy agencies. And if there was a child that possibly had more going on than just a speech delay, they wouldn't have the multidisciplinary evaluations. ... Something like autism might be overlooked," Ormsby said.

To prevent such problems, she created a referral and resource guide, organized by age, outlining local resources and providing educational brochures for parents as well as forms and instructions for providers to use in making referrals to community agencies. "A lot of the practices ... didn't realize that [early childhood intervention] services and evaluations are available and that there is no cost to the families for the evaluation," Ormsby said.

The network also organized a luncheon for the largest practice and invited staff from the CDSA, school system, and local health department to share information about their role in the Early Intervention process. Although the luncheon was successful in establishing stronger relationships between the groups, it might be hard to replicate for smaller practices, because agency staff often have travel and time constraints that would make small presentations prohibitive, McLean said. To help other practices improve, CDSA staff have given Ormsby feedback about which practices are increasing their referrals and which might need additional assistance.

In 2008, the proportion of children from birth to age 3 who received Early Intervention services was 4.7 percent (ranging from 3.9 percent to 6.6 percent) in the seven counties that make up the Sandhills network. This represented an 8 percent increase from a rate of 4.4 percent in 2003 (ranging from 1.6 percent to 8.5 percent by county).²¹ The relatively small overall increase in children receiving services in this network may reflect the fact that, before the ABCD program, Sandhills network providers delivered more

Early Intervention services than other profiled networks and the state as a whole. Restructuring of Early Intervention programs to modify the agencies that had oversight over the programs earlier in the decade also may have affected local capacity to deliver services. To address disparities in referral rates among counties, the local CDSA opened offices in each county and shifted staff to counties with lower referral rates to increase referrals.

Activities to Encourage Follow-Up

To further strengthen the referral process, Ormsby has been encouraging the local CDSA to send medical practices notices when they determine a child's eligibility for services. She also asks the agency to send providers copies of the agency's evaluation, with parents' consent.

Nicholson says her practice appreciates having someone from the network track referrals. Ormsby spends a half hour in that practice, every other week, reviewing recent screenings. She also ensures that appropriate referrals were made and follows up if the practice has not received a response from the agency to which the child was referred. Before Ormsby did that, "whoever was making the referrals kept up with it, if they had the time," Nicholson said. The follow-up activity is "wonderful when we don't have the manpower here in the office [to do it]. They are helping us from losing that child," Nicholson said.

Ormsby is working with nine local practices, including one small practice that asked the network for help, tailoring her approach to meet their particular needs. For example, Ormsby visits one practice on a biweekly basis to offer assistance with referrals, sits down with some providers for lunchtime discussions, and checks in with others on a periodic basis. She also serves as a resource to the network's case managers and to practices to answer questions as needed.²²

Key Insights

To improve communication between the network and the agencies that serve children, Ormsby serves on the Local Interagency Coordinating Council in every county where she works. "This offers an opportunity to

network and facilitate communication with other local programs in the communities who work with young children," McLean said.

Networks that cover a large number of counties, especially those with multiple school districts that have unique policies for referral, may find it difficult to keep providers informed of referral protocols without inundating them. "I don't want to overwhelm the practices with forms for every single county. So I say, if you have someone [from a different county than yours], call me and I will get you the information," Ormsby said.

The network continues to get inconsistent information about referrals from the schools. While doing chart reviews, "it's still not clear to me which kids are getting services and which are not," Ormsby said. There's no universal form to indicate clearly that a child is receiving services through the schools, she said.

To help make referrals to Early Intervention services more predictable, the statewide ABCD advisory group has created a uniform referral form and process that can be followed by CDSAs statewide. An effort is under way to do the same for the schools. The Department of Public Instruction has produced a flowchart for preschool children and a one-page notification form with a parent signature area for exchange of information between the schools and medical practices. ([Appendices 2 and 3](#)). "We are thrilled with this result from our collaborative efforts," Earls said.

Vivian James, Ph.D., the exceptional children preschool coordinator for the North Carolina Department of Public Instruction, said she hopes the form will help physicians understand what information the schools need from the medical practices. "It was designed to improve our relationship with the medical community... so that they knew what they were supposed to be sending us," she said. Whether the form will encourage a freer exchange of information remains to be seen, however. "I know that my people are so overworked that they perhaps have not been as mindful as they should be [about feedback]." But, she added, "There is a point in time in which the families have responsibility also to provide feedback to that doctor and I don't think we should ever not expect that."

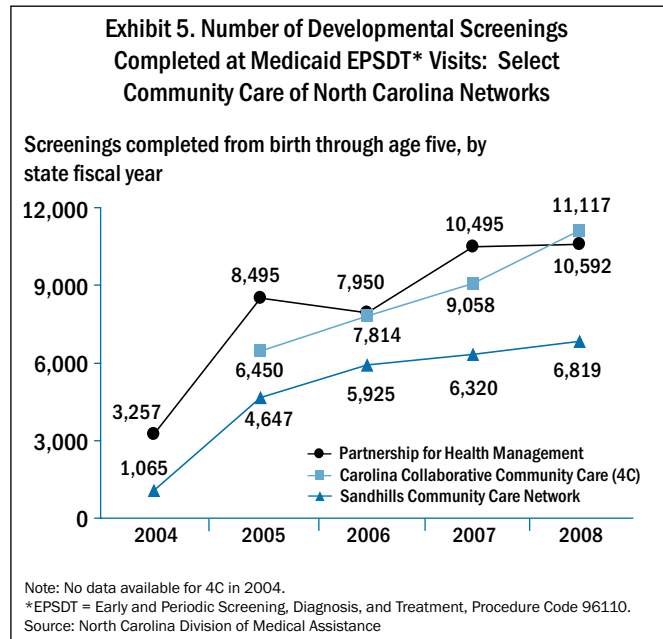
FINANCING AND SUSTAINABILITY

To develop this program, North Carolina sought and received funding from The Commonwealth Fund, which in 1999 launched the Assuring Better Child Health and Development initiative to strengthen the capacity of the health care system to support the development of children from low-income families. As part of the initiative, Medicaid agencies in North Carolina, Utah, Vermont, and Washington received three-year grants to develop and implement innovative strategies to deliver early child health and development services. Smart Start also provided funding to select CCNC network to hire an Early Intervention specialist (Smart Start receives funding from the state and private sources).

Because of the structure of the CCNC, networks have broad discretion in how they spend money on quality improvement initiatives. The approaches the networks use to fund ABCD efforts reflect a wide degree of variation. The Partnership for Health Management uses case management fees to cover the salary of its Early Intervention specialist, while Sandhills Community Care Network has relied on funding from Smart Start to support a similar position. Because the Smart Start grant was limited to two years, the network must find a new source of funding to continue that work. In contrast, Cumberland County has relied on the efforts of community agencies and organizations to provide much of the outreach and follow-up that other networks provide and thus its outlay for the ABCD program is minimal.

RESULTS

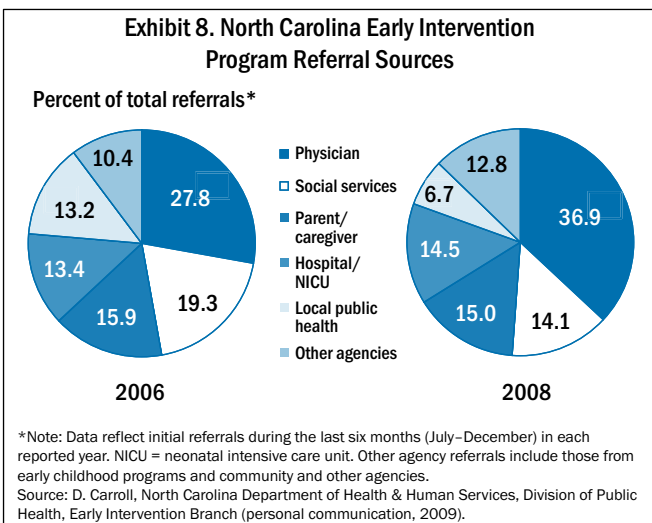
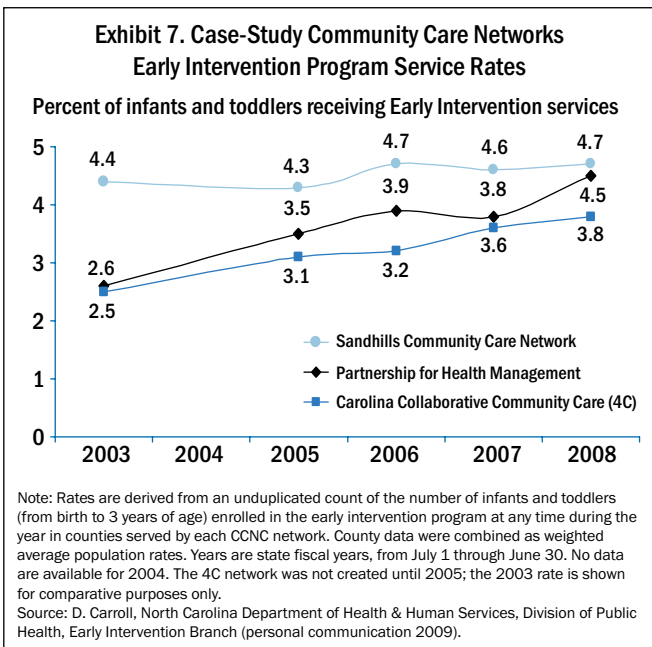
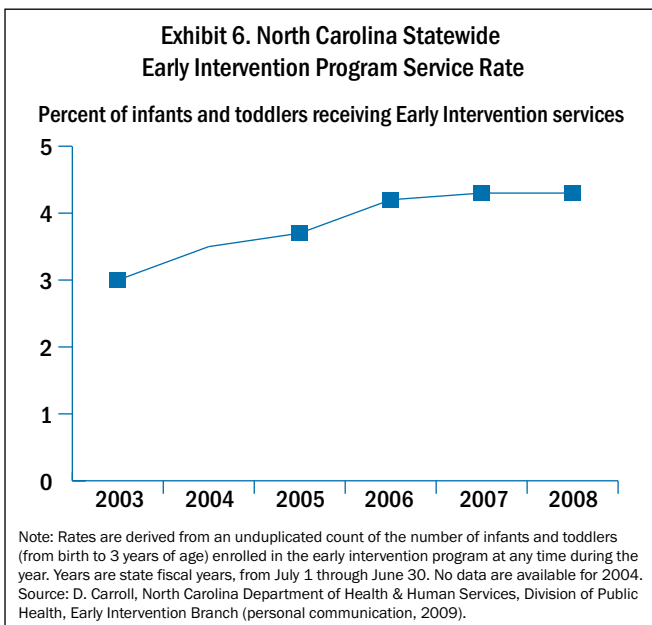
The number of developmental screenings increased nearly twofold to more than sixfold among the three profiled community care networks from 2004 to 2008 (Exhibit 5). Changes may not be directly comparable across these networks because they began their efforts at different points in time. The P4HM network benefited from a pilot project that began in the late 1990s. Although the C4 network was not in operation until 2005, it has now achieved about the same level of screenings as the P4HM network, despite having fewer age-eligible children. Although the Sandhills network



has shown steady improvement in screenings, their screening rate is lower than in the other networks, likely reflecting the challenges of its rural service area and the fact that its intervention is active in only a subset of its counties.

Statewide, the proportion of infants and toddlers who received Early Intervention services reached 4.3 percent in 2008, representing a 43 percent increase from a rate of 3.0 percent in 2003 (Exhibit 6).²⁴ Among the three profiled community care networks, the service rate increased the most in the P4HM network during this time (Exhibit 7). The higher overall rate of services in the Sandhills network may reflect greater socioeconomic challenges in its rural and underserved counties. Early Intervention service rates ranged from 3.0 percent to 6.6 percent in 2008 in the counties served by the three profiled CCNC networks.

In 2006, physicians were responsible for 28 percent of all referrals to the infant-toddler Early Intervention program; by 2008, this proportion had increased to 37 percent (Exhibit 8). This increase in physician referrals may mean that the improvements brought about by the ABCD program are leading to children being reached who would otherwise have been missed by opportunistic referrals based on observation alone without systematic screening. Other sources of referrals—and potential contributors to the overall increase in service



use—including parents and caregivers, hospitals, and local public health and social services agencies.²⁵ The state does not track referrals to Early Intervention programs at the CCNC network level.

LESSONS LEARNED ACROSS THE THREE NETWORKS

Local community care networks have played an important role in propagating childhood developmental screening in primary care. “It was [the CCNC] infrastructure that allowed us to do the spread with ABCD and with other initiatives,” said Earls, the pediatrician who led the pilot program in Guilford County. “ABCD was just one more of the quality improvement initiatives that networks agreed to take on and that practices agreed to do” as part of their participation in community networks. “It’s hugely helpful to have care coordinators in the network that can help you negotiate your initial connections to the community agencies,” she noted.

The experiences of the three community care networks demonstrate that geography plays a critical role in the successful implementation of such programs. Networks in urban areas have the advantage of working with large medical groups, which tend to have enough time and staff resources to devote to such a project.

Networks that operate in rural areas with more dispersed populations and small medical practices face greater challenges in attempting to reach individual practices. Still, these examples show that networks operating in such communities can partner with groups that have similar goals to achieve their aims.

Given the differences among communities, each must choose the model that works best in its local circumstances. For example, in some rural communities in the eastern part of North Carolina, where there are few large pediatric practices, the Smart Start program has chosen to work directly with medical providers to promote developmental screening.

Two key elements of a successful program are supportive state policy and visionary leadership to bring that policy into practice. The state’s Medicaid policy directive requiring developmental screening to be performed as part of Medicaid EPSDT visits acted

as a catalyst to change. That directive was given added impetus by having champions who cared passionately about the topic and worked with other stakeholders to bring about necessary change in systems. “We have many people who are very committed to the kinds of services that kids need, and so there’s a lot of both political will and individual willpower to make systems better,” Carroll said.

Adequate staffing also is critical. Shortages of Early Intervention professionals can pose a significant impediment to such programs, as Smart Start found when its groups tried to extend their program into rural counties of eastern North Carolina. “They cannot hire in that area staff that have the qualifications to be able to successfully pull off the project. There is not a nurse who does public health work who understands the CCNC network and developmental screenings. So they just have to say we can’t do it and give us back the money,” said Stephanie Fanjul, executive director of the North Carolina Partnership for Children.

Given the importance of staff to successful implementation, states wishing to replicate this program should consider investing in training programs for care coordinators. Hiring staff who have had previous experience working for Early Intervention agencies also may help build trust between physician practices and the community agencies, especially in communities where apprehension and frustration exist between them.

States also should recognize that better screening will likely create a need for more specialists and therapists in the referral network, which may challenge government agencies, especially those operating in areas that have difficulty recruiting providers. “A few years ago we found that, in eight of our 100 counties, we did not have speech therapy providers at all in our provider networks. In 23 counties in North Carolina, we did not have physical therapy providers. In a similar number—27 counties—we had no occupational therapy providers,” Carroll said. “It’s a constant struggle trying to get enough providers or provide the services ourselves if we have to.” North Carolina’s Improving Pediatric Access through Collaborative Care, which links pediatric specialists in academic medical centers

to primary care doctors in underserved areas, may provide an example of how to increase access to specialty care.²⁶

The use of universal referral forms is likely to facilitate communication between primary care providers and Early Intervention agencies. Still, states may need to create additional incentives or standardized mechanisms to ensure that community agencies and schools relay information back to physicians. To date, the process appears to be working better for infants and toddlers than for preschool-age children in North Carolina. Local school systems may have little incentive to provide feedback once they have been notified that a preschool-age child may need Early Intervention services. Schools receive funding from the state to provide services and do not need physicians to sign off on orders for special education services. In contrast, CDSAs need to interact with physicians, who must authorize referrals of infants and toddlers to specialty health care services.

A lack of electronic linkages between medical providers and Early Intervention agencies is one obstacle to improvement. The state is considering whether the case management information system used by CCNC case managers could be extended for use by other cooperating agencies, but its initial focus is on behavioral health care. For now, such communication occurs over the phone or via mail in the areas where the network care coordinator has built a good working relationship with the agency.

The ultimate goal is to facilitate communication among primary care providers, Early Intervention agencies, and families. “We want to make sure that families are aware of what’s going on with their child and that they have enough information that they can share with us what the doctor said, and share with the doctor what we said, and give us permission to talk to each other when appropriate,” said Carroll. The agency has established a standardized process for communicating information back to referring medical providers, but service coordinators also need to remind families so that they remember to share information directly with their providers, she said.

Executing a developmental screening and referral program without a CCNC-style network or a similar infrastructure may be challenging. When Earls conducts technical assistance in other states, she requires that the state assemble a team of stakeholders—high-level administrators from the Medicaid and Early Intervention agencies working with the pediatrics and family medicine physician communities—to shepherd changes through the system and overcome bureaucratic obstacles.

Collaboration at both the local and state levels is important. At the local level, community care networks have established relationships with local primary care providers and community agencies that have opened lines of communication between the two. These local partnerships promote effective use of time and resources and avoid the tendency for groups to “reinvent the wheel” when they work independently. Likewise, statewide committees have provided opportunities for stakeholders to break down barriers between disciplines and for local networks to learn from one another’s experiences. Statewide collaboration among stakeholder groups also helps to ensure that policymakers hear a unified message supporting adequate funding for Medicaid and Early Intervention services and “that keeps the doctors in the game,” Fanjul says.

Monitoring is important, too. “Accountability is the biggest thing.... We feel like it’s important to do routine monitoring. We do sampling and we check to see if things are happening well for all the kids that way. That’s how we’ve been able to improve over the last four years from some pretty dismal compliance numbers—around 50 percent or so, to the high 90s,” Carroll said, referring to the percentage of eligible infants and toddlers who are evaluated and enrolled within 45 calendar days of being referred to the CDSA. The local CCNC networks also create a system of community accountability and foster a spirit of healthy competition between communities to do what is best for children.

FUTURE DIRECTIONS

The statewide ABCD advisory group is exploring ways to expand developmental screening, such as to include social-emotional screenings and maternal depression screening. An important step in the process has been securing payment for providers that perform secondary screenings when the primary screening suggests a child is at risk for depression, autism, or other health problems. Those billing codes were created at the beginning of 2009, according to Collins.

In the meantime, the Early Intervention Branch has been working with the North Carolina Pediatric Society to develop a referral flowchart using the M-CHAT (Modified Checklist for Autism in Toddlers) tool, so that all parties understand the process. They are currently working with the pediatric society and the ABCD advisory group to educate providers across the state about screening for autism.

It is not clear what will happen when the current Smart Start grants to local CCNC networks come to an end. Local networks will continue to support the ABCD program, but may not have the resources to provide the same level of education and technical assistance to physician practices. “The results have been certainly worth the effort and the partnerships that have been engaged are very excited about getting such good feedback on the project,” Fanjul said. “As far as the dollars go, that’s our dilemma.”

NOTES

- 1 To gather information, we interviewed a variety of participants, listed in the [Acknowledgments](#), including local community care network executive and medical directors, project coordinators, a case manager, a physician office manager, the head of the state's early intervention branch, the exceptional children preschool coordinator for the North Carolina Department of Public Instruction, and the leader of a statewide public-private initiative promoting early childhood development.
- 2 Institute of Medicine, *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Washington, D.C.: National Academies Press, 2000).
- 3 J. Law, Z. Garrett, and C. Nye, "Speech and Language Therapy Interventions for Children with Primary Speech and Language Delay or Disorder," *Cochrane Database Systematic Review*, 2003 (3):CD004110.
- 4 *Comprehensive Child Health Plan: 2000–2005. Report to the North Carolina Department of Health and Human Services* (Chapel Hill, N.C.: North Carolina Institute of Medicine, 2000).
- 5 Children who are age 5, but have not yet entered kindergarten, are eligible for Early Intervention services.
- 6 As of February 2009, CCNC served a total of 980,763 individuals: 884,097 Medicaid beneficiaries (including 133,574 aged, blind, and disabled individuals) and 96,666 children ages 6 to 19 enrolled in CHIP, which is known as North Carolina Health Choice. Medicaid enrollment included 311,981 children under age 6, including CHIP-eligible children under age 6 who are enrolled in Medicaid. This enrollment represented about 75 percent of all Medicaid and CHIP beneficiaries who were eligible to enroll in managed care programs sponsored by the state (personal communication with Shelley Kier in the CCNC central office, February 2009).
- 7 Physicians receive \$1.50 per member per month for participating in Carolina Access, the state's Medicaid enhanced primary care case management program. They receive an additional \$1.00 per member per month when they join a local community care network.
- 8 For more on CCNC, see a companion case study, D. McCarthy and K. Mueller, *Community Care of North Carolina: Building Community Systems of Care Through State and Local Partnerships* (New York: The Commonwealth Fund, June 2009).
- 9 For more detail on the early stages of the project, see H. Pelletier and M. Abrams, *The North Carolina ABCD Project: A New Approach for Providing Developmental Services in Primary Care Practice* (Portland, Maine.: National Academy for State Health Policy, July 2002).
- 10 Ages and Stages Questionnaire (Baltimore: Paul Brooks Publishing Co.), www.pbrookes.com.
- 11 S. Hay, ABCD Project in North Carolina. www.dbpeds.org/articles/detail.cfm?TextID=109.
- 12 The state has not denied any provider payments under this policy because its audits suggest that providers are generally performing the screening tests but sometimes have difficulty reporting doing so when their billing software does not permit them to record a code for which there is no reimbursement.
- 13 Data provided by the North Carolina Department of Health and Human Services, Early Intervention Branch.
- 14 Data supplied by Community Care of North Carolina, based on February 2009 enrollment. Includes 4,021 aged, blind, and disabled individuals, of whom 164 were children under age 6.
- 15 Parents' Evaluation of Developmental Status. Ellsworth & Wanderer Press LLC, 1013 Austin Court, Nolensville, TN 37135, 1-615-776-4121, www.pedstest.com.
- 16 Personal communication with Deborah Carroll, North Carolina Department of Health and Human Services, Division of Public Health, Early Intervention Branch, 2009.
- 17 Data supplied by Community Care of North Carolina, based on February 2009 enrollment. Includes 7,088 aged, blind, and disabled individuals, of whom 386 are under age 6.
- 18 Personal communication with Deborah Carroll. Data supplied by the North Carolina Department of Health and Human Services, Division of Public Health, Early Intervention Branch, 2009.

- ¹⁹ No affiliation exists between this network and Sandhills Physicians Inc., which appeared in the preceding profile of Carolina Collaborative Community Care.
- ²⁰ Data supplied by Community Care of North Carolina, based on February 2009 enrollment. Includes 5,482 aged, blind, and disabled individuals, of whom 136 are under age 6.
- ²¹ Personal communication with Deborah Carroll. Data supplied by the North Carolina Department of Health and Human Services, Division of Public Health, Early Intervention Branch, 2009.
- ²² Although the Smart Start grant that supports Ormsby's position lasts only two years, the network will seek funding to keep her there.
- ²³ For more on the role of Smart Start, see: J. Rosenthal, C. Hanlon, and C. Hess, *The Role of State Health Policy in Multi-Sector System and Service Linkages for Young Children* (Portland, Maine.: National Academy for State Health Policy, Sept. 2008), pp. 48–49.
- ²⁴ The 1999 estimate was reported in: *Comprehensive Child Health Plan: 2000–2005. Report to the North Carolina Department of Health and Human Services* (Chapel Hill, N.C.: North Carolina Institute of Medicine, 2000). The 2008 data were provided by the North Carolina Early Intervention Branch, Division of Public Health.
- ²⁵ *NC Early Intervention Program 2007–08 At-A-Glance*, North Carolina Department of Health and Human Services, Division of Public Health, Early Intervention Branch.
- ²⁶ L. Suarez, "The Nationwide Shortage of Subspecialty Pediatricians," *Diabetic and Microvascular Complications Today*, Sept./Oct. 2006:15–16.

Appendix 1. Generic Referral Form to the Children’s Developmental Services Agency to Determine Children’s Eligibility for Early Intervention Services

(Insert Letterhead Identification Here)

Referral Form Developmental Screening & Surveillance

Name of Child: _____

Date of Birth: ___ / ___ / ___ Age _____ Sex _____

Address: _____

Medicaid#: _____ Insurance _____ Social Security _____

Parent/ Guardian Name: _____

Home Phone: _____ Work Phone: _____

Race: _____ Primary Language: _____

Developmental/Interdisciplinary Referral:

Concerns:

Screening Tool: ASQ PEDs MCHAT ASQ-SE Other _____
(Please Name)

The ASQ or PEDS and/or MCHAT scoresheet is attached, if completed.

I have discussed this referral with parent(s)

Referred By: _____

Phone: _____


PCP Office: _____

Fax: _____



Final: October 18, 2008

Appendix 2. Generic Notification Form and Confidentiality Release Form for the Exceptional Children Preschool Program

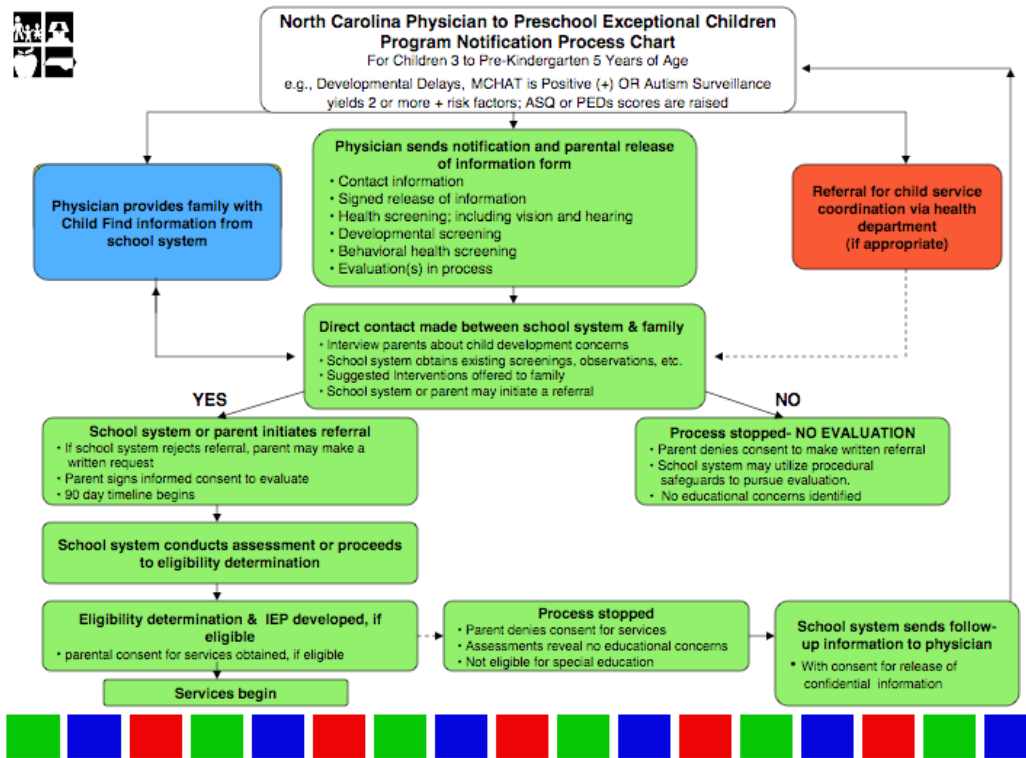


**Physician Notification and Parental Release of Confidential Information Form
to the Exceptional Children Preschool Program**

Directions: To be completed by the appropriate Primary Care Practice and/or Pediatrician (PCP) and sent to the appropriate Exceptional Children Preschool Program contact. Upon receipt, the school system will contact the family to set up a screen and/or referral meeting. The PCP is encouraged to provide the family with the contact name and number for the receiving school system.

Child Contact Information		
Child Name:	Date of Birth:	Gender: M F
Home Address Street:	City:	State: Zip:
Parent/Guardian Contact Information		
Parent/Guardian: _____ Street: _____ City: _____ State: NC Zip: _____ Email: _____	Primary Language: _____ <input type="radio"/> Interpreter is needed due to English as a second language Ethnicity: _____	<input type="radio"/> Interpreter needed due to deafness or a hearing impairment or other accommodation(s) due to disability (please specify): _____
Home Phone: () _____	Work Phone: () _____	Cell Phone: () _____
Physician Contact Information		
Physician Name:	Address:	Office Phone: Office Fax:
Reasons for Notification to Preschool Program (Check all that apply)		
Suspected delay in: <input type="radio"/> Motor skills <input type="radio"/> Cognitive skills <input type="radio"/> Social-Emotional skills <input type="radio"/> Communication skills <input type="radio"/> Behavioral skills <input type="radio"/> Speech-Language skills	<input type="radio"/> Autism <input type="radio"/> **Screen tool (please attach) <input type="radio"/> ASQ <input type="radio"/> PED <input type="radio"/> MCHAT <input type="radio"/> ASQ-SE	<input type="radio"/> Identified condition or diagnosis <input type="radio"/> Specific concerns _____ _____
If parent(s) has agreed to pursue services from the Exceptional Children Preschool Program and is prepared to provide parental consent for release of confidential information at this time, please complete the information below.		
Specific records to be released to and/or received from this office (please check): <input type="checkbox"/> School system evaluation results <input type="checkbox"/> Vision screening/evaluation results <input type="checkbox"/> Hearing screening/evaluation results <input type="checkbox"/> Developmental screening results <input type="checkbox"/> Health screening results <input type="checkbox"/> Social Emotional/ Behavioral Health Screening results <input type="checkbox"/> Other _____	Purpose of the disclosure: <ul style="list-style-type: none"> ▪ Notification for preschool exceptional children program services ▪ Educational/instructional planning 	Party to whom the disclosure will be made: School system name: _____ School system in which the private school is located: _____
I give informed parental consent to disclose the confidential records listed above for the purpose(s) listed above, and to the part listed above:		
Parent/Guardian Signature: _____ Date: _____ Unless otherwise revoked, this authorization expires one year from the date of signature		
<input type="checkbox"/> I request a copy of the confidential records disclosed.		
**Notation: ASQ: Ages and Stages Questionnaire ASQ-SE: Ages and Stages Questionnaire for Social and Emotional Development MCHAT: Modified Checklist for Autism in Toddlers PED: Parent's Evaluation of Developmental Status		
To be completed by school system staff Date received by school system: Follow-up communication with family:		

Appendix 3. Flow Chart: What Happens When a Child Is Referred to the Exceptional Children Preschool Program for Early Intervention Testing and/or Services





**North Carolina Preschool Exceptional Children Program (children 3 to Pre-Kindergarten 5 years of age)
Notification Flow Chart Legend and Notes**

BACKGROUND INFORMATION:

- As of October 2007, the American Academy of Pediatrics (AAP) recommended that all children should be screened for autism at age 18 months and again at age 2, even if there are no signs of developmental delay. When a positive response is obtained, follow-up action should include:
 - Request for simultaneous evaluation for hearing, autism and consideration for special education services.
 - Potential referral to a developmental and behavioral pediatrician, geneticist or neurologist for assistance with an etiologic workup and/or a search for coexisting conditions if indicated.
- According to North Carolina *Policies Governing Services for Children with Disabilities (Policies)*, the following is in effect for the initial evaluation process for children ages **3 through 21**:
 - Each school system (LEA) must conduct a full and individual initial evaluation in accordance with NC 1503-2.4 through NC 1503-2.7 before the initial provision of special education and related services can be provided (NC 1503-2.2(a)).
 - Either the parent of a child or an LEA may initiate a request for an initial evaluation to determine if the child is a child with a disability. Upon an oral request for an initial evaluation from a parent, the LEA shall provide assistance, as needed, in completing a written referral (NC 1503-2.2(b)); and
 - The initial evaluation process must be conducted; eligibility determined; and for an eligible child, the IEP developed; and placement completed within **90 days** of receipt of a written referral (NC 1503-2.2(c)(1)).
- According to the above noted *Policies*, only the parent or an LEA may initiate an official referral. Therefore, information received by the school system from the physician shall be referred to as "Notification" under CHILD FIND.

ACTION STEPS FOR CHILDREN 3 THROUGH 5 YEARS:

- When Primary Care Practices identify developmental concerns, the Exceptional Children Preschool Program requests that the following information be sent to the school system:
 - Notification form with family contact information to appropriate preschool program staff,
 - Signed release of confidential information for communication from and to pediatrician/school system,
 - All screening information available, such as:
 - Health
 - Developmental/Autism
 - Vision and/or Hearing
 - Behavioral Health Services; and
 - Pending physician initiated evaluations which are in process.
 - The Primary Care Physician should:
 - Facilitate communication among the primary care practice, other entities conducting diagnostic assessments and the school.
 - Share available resources with the parent, school system, and other community partners.
- Follow enclosed Flow Chart, as appropriate.

Appendix 4. Setting the Stage for Success: An Office Resource Guide



"Setting the Stage for Success" Developmental Screening and Surveillance

Getting Started

1) Assess current protocols: Developmental Screening and Surveillance

What are we currently using for developmental screening? A formal, standardized tool? _____ Informal Checklist? _____ Nothing? _____

Are we screening routinely at 6 months, 12 months, 18 or 24 months, 36 months, 48 months, and 60 months? Yes _____ No _____. If no, what ages are we missing? _____. Why are they missing?

2) Identify Physician Champion:

A Physician is the "voice" of the quality improvement initiative. They can help facilitate communication with MDs, office staff and other community groups, both formally and informally, about the screening and referral system.

3) Select a Developmental Screening Tool:

A variety of screening tools are available to providers. Please refer to www.dbpeds.org for a complete list. The ASQ and PEDS "have been put to the test in practices throughout NC" and practice staff has overwhelmingly said the ASQ and PEDS work in a busy primary care practice. You may order these screening tools by mail or on-line:

(ASQ) www.brookespublishing.com
Paul H. Brookes Publishing
P.O. Box 10624
Baltimore, MD 21285-0624
(May be photocopied)

(PEDS) <http://www.pedstest.com>
Ellsworth & Vandermeer Press, LLC
P.O. Box 68164
Nashville, TN 37206
(Cannot be copied. Refills must be ordered.)

ABOUT THE AUTHORS

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