| Evaluation of the North Carolina Partnership for Children and Smart Start’s Race to the Top-Early Learning Challenge:  **Assuring Better Child Health and Development (ABCD) Program Final Report** |
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**Submitted by:**

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**About EvalWorks, LLC**

EvalWorks, LLC is an independent evaluation and survey research firm located in Durham, NC founded by Dr. Amy A. Germuth dedicated to helping clients improve the efficiency, effectiveness, and impacts of their programs.

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**Executive Summary**

Under the Race to the Top - Early Learning Challenge (RTT-ELC) grant, the North Carolina Partnership for Children (NCPC) worked with Community Care Network of NC (CCNC) to implement the Assuring Better Child Health and Development (ABCD) program across the state to build statewide capacity and effectiveness for health and developmental screening for young children. The ABCD model is designed to increase health and developmental screening and referral rates within the medical home for all young children by integrating routine developmental screening into well-child visits using either the Ages and Stages Questionnaire (ASQ) or the Parents Evaluation of Developmental Skills (PEDS). Medical professionals are also taught to use the Modified Checklist for Autism in Toddlers (MCHAT).

Evaluation of the ABCD program provides evidence of the success of the ABCD Program in North Carolina, particularly in increasing developmental and autism screening rates using validated tools.

By March 31, 2016, ABCD Coordinators had worked in all of North Carolina’s 14 Community Care Regions, served 246 practices (surpassing their target of 110 by 136 or 123%) and 1,345 providers (270% of their target of 495). Based on best estimates provided by the medical practices, these practices serve roughly 85,000 children birth-5 enrolled in Medicaid (target = 42,900). The analysis of all tracking form data, provided by ABCD Coordinators, indicated that ABCD Coordinators had conducted 5,749 technical assistance sessions via email, phone, or Skype with providers/practices; had provided 587 onsite training sessions; and had made 6476 visits to practices. Additionally they had reviewed 13,656 medical charts of children birth-5 served by participating practices. Chart reviews revealed the following:

* Of 10,104 children due for developmental screening, 9,154 (90.6%) were screened. Target = 90%
* Of 1,151 children found at-risk based on a developmental screening, 689 (59.9%) were referred for further assessment or services or were already receiving services.
* Of 3,677 children due for autism screening, 2,733 (74.3%) were screened. Target = 70%
* Of 497 children found at-risk based on autism screening, 94 (18.9%) were referred for further assessment or services.

Additional data used to supplement chart review data for this evaluation came from interviews with ABCD Coordinators, interviews with ABCD medical practices, and data from the North Carolina Infant-Toddler Program on follow-up services provided to children. To understand these findings, please note that practices are identified as Level 1, 2 or 3 practices. Level 1 practices are new to ABCD and in which ABCD Coordinators are just beginning to work with. Level 2 practices are those that Coordinators have worked with enough to believe that they have made changes in how they manage screenings and referrals such that there is a high probability that all children needing screenings and or referrals will receive them. Level 3 practices are ones that coordinators have worked with in the past but are no longer working with as intensively. Such practices can be considered as being in the "maintenance" phase.

Findings from multiple data sources and multiple types of data (quantitative and qualitative) provide evidence of the following:

**ABCD increases medical providers’ screening rates for developmental delays and autism.**

* Developmental screening rates among ABCD practices went from 85.2% to 96.3%, an 11.1 percentage point increase.
* Autism screening rates increased from 78.7% to 86.7%, an eight percentage point increase.
* 65% of medical practices interviewed reported that they changed the developmental screening tool they use and 50% changed their autism screening tool.
* 40% of medical practices interviewed noted that they began using a validated developmental screening tool and 35% said the same for autism screening tools.
* Statistical analyses revealed that practices that are not funded by RttT (thus indicating that they have worked longer with ABCD) and those with higher ABCD levels are statistically significantly more likely to screen children for developmental delays and autism.
* No difference exists in screening rates when disaggregated by child’s insurance type.

**ABCD increases medical providers’ referral rates for developmental delays and autism, although referral rates for autism are much lower than referral rates for developmental delays.**

* Practices at Level 3 referred 77.5% of children versus 68.4% of children at baseline based on developmental screening results, an increase of 9.1 percentage points.
* Data related to autism screenings were mixed with Level 1 providers referring at a higher rate than baseline (25.5% versus 19.3%), but Level 3 practices only referring 16.7% of children whose screens were positive.
* Eighty-five percent of medical practices that were interviewed indicated that they are more likely to refer now than take a “wait and see” approach because of working with an ABCD Coordinator.
* Statistical analyses revealed that practices that are not funded by RttT (thus indicating that they have worked longer with ABCD) and those with higher ABCD levels are statistically significantly more likely to refer children for autism.
* Coordinator’s suggestions for low referral rates include that some practices don’t refer because they say that they do not hear back from these organizations as to the outcomes of the referrals; that the bar for children to qualify for services with the Part C provider, Children’s Developmental Services Agency (CDSA) for children ages birth to two or the Part B provider, the Exceptional Children’s Preschool Program (EC), for children ages 3 to 5 is too high, so they refer to private practices instead; and that some practices believe that it takes their local CDSA and EC programs too long to follow up on referrals.

**ABCD increases the “appropriateness” of medical providers’ referrals.**

* The percentage of appropriate referrals (i.e., to the local Children’s developmental services Agency (CDSA) or Exceptional Children’s Preschool Program) increased from 75.1% at baseline to 100% for Level 3 practices.
* Children were referred to the CDSA or Exceptional Children’s Preschool Program agencies at similar rates regardless of insurance type.

**Physicians tend to refer Medicaid children more frequently than children with private insurance although insurance type has no bearing on screening rates.**

* By insurance type, most practices screened a similar percentage of non-Medicaid children as Medicaid children (87.0% and 88.2%, respectively, overall) for developmental delays and 26.0% of non-Medicaid children and Medicaid children for autism.
* However, including baseline data, 61.3% of children with Medicaid were referred for services related to developmental screening results versus 47.3% of children without Medicaid. When referrals for autism screenings were reviewed, children with Medicaid were more likely to be referred for further assessment than children with private insurance (rates were 23.4% versus 14.6%). The reasons for this are not clear.
* A review of where children were referred by the type of insurance they hold revealed that, for the most part, children are referred to the same places at the same rates, regardless of their insurance, for both developmental and autism screenings.
* More advanced statistical analyses also revealed that children with Medicaid are more likely to be referred based on developmental screening results than those with private insurance.

**Practices need ongoing systematic support to maintain high screening and referral rates.**

* Discussions with Coordinators indicated that, on average, practices need about two years to get to the point that they have increased and then maintained screening and referral rates in alignment with best practices. Many noted that some of this time is highly dependent upon how much relationship building is needed. Coordinators whom medical practices knew from past work with Smart Start or CCNC, or who were affiliated with CCNC, were able to gain the practices’ trust and buy-in more quickly than if they were new to the practices or were not affiliated with CCNC. However, time is needed to obtain buy-in and build relationships and then to get practices up to standards. Timing also plays a role, as ABCD Coordinators explained that starting to work with a practice during cold and flu season takes longer than if you start working with them in the middle of summer.

**ABCD services are continually needed by practices.**

* Data support what ABCD Coordinators experienced, that as persons within medical practices, CDSA, Exceptional Children’s Preschool Programs, etc. leave positions; new state or federal policies, guidelines, or practices are enacted; development or autism screening instruments change; electronic health records are implemented; etc., medical practices need ongoing technical assistance and support, such as the ABCD program, to effectively address and adjust to these changes.

**Introduction**

**The Assuring Better Child Health and Development (ABCD) Program Model**

Under the Race to the Top - Early Learning Challenge (RTT-ELC) grant, NCPC worked with Community Care Network of NC (CCNC) to implement the Assuring Better Health and Development (ABCD) program across the state to build statewide capacity and effectiveness for health and developmental screening for young children.

The ABCD model is a proven, universal approach to screening young children in primary health care settings for developmental delays and autism. The ABCD model is designed to increase health and developmental screening and referral rates for all young children within the medical home by integrating routine developmental screening into well-child visits using either the Ages and Stages Questionnaire (ASQ) or the Parents Evaluation of Developmental Skills (PEDS). Medical professionals are also taught to use the Modified Checklist for Autism in Toddlers (MCHAT). The Smart Start ABCD model employs ABCD coordinators to provide training, technical assistance, and coaching to medical practices to assist them in integrating developmental screening, referral, and follow-up into their practices.

In 2002, the ABCD model was piloted in ten North Carolina counties, with support of the Commonwealth Fund. Medical practices participating in the pilot increased developmental screening rates during well-child visits and increased referrals for early intervention services. In July 2004, the success of the ABCD pilot program led to a change in state Medicaid policy such that practices performing Health Check/Medicaid well-child visits are now required to screen children for developmental delays at specific times with a standardized screening tool.

Prior to implementation of this grant, six Smart Start Local Partnerships supported ABCD in nine counties via five ABCD Coordinators, who provided training and on-site technical assistance to medical practices. Under the RTT-ELC grant, NCPC expanded the program statewide by increasing the number of ABCD Coordinators and linking to the fourteen CCNC regions. CCNC is an innovative quality assurance network of physicians utilizing Medicaid to provide incentives to improve care based on the American Academy of Pediatrics Bright Futures National Standards. By December 31, 2015 17 ABCD Coordinators (not all full-time) were providing services across all of the 14 Community Care regions in NC. Some Coordinators were funded by local Smart Start funds with the expansion supported by the Race to the Top grant funds. Enough funding under the RTT-ELC grant was available in 2016 to support eight ABCD Coordinators for an additional three months.

The close collaboration and partnership between Smart Start and CCNC, at both the state and local level, utilized CCNC’s statewide system of Quality Assurance to leverage the early childhood system’s resources and strengths to cooperatively build statewide capacity for early screening of young children. ABCD coordinators worked as team members with CCNC Quality Improvement personnel and pediatric specialists to build the infrastructure for sustained developmental and autism screening and referral of young children in medical homes.

When the program began, NCPC anticipated that by December 2015:

* 110 primary health care practices will have received ABCD training and TA since 1/1/14;
* 495 medical providers will have participated beginning 1/1/14; and
* 42,900 Medicaid-enrolled children birth-5 (estimated) will have been served by participating practices beginning 1/1/14.

NCPC projected that the following outcomes will have been achieved by the end of the program:

* 75% of Medicaid-enrolled children at 15 months and at 3-6 years are up-to-date in the schedule of well-child care.;
* By 12 months of age, 95% of Medicaid-enrolled children receive developmental screenings;
* By 24 months of age, 85% of Medicaid-enrolled children receive developmental screenings in the previous year;
* By 36 months of age, 75% of Medicaid-enrolled children receive developmental screenings in the previous year;
* By age 5, 75% of Medicaid-enrolled children receive developmental screenings in the previous two years;
* 70% of children with developmental concerns in participating medical practices will be referred for further evaluation; and
* 55% of children referred for evaluation or services by participating medical practices and found eligible receive the follow-up services.

By March 31, 2016, ABCD Coordinators had worked in all of North Carolina’s 14 Community Care Regions, served 246 practices (surpassing their target of 110 by 136 or 123%) and 1,345 providers (270% of their target of 495). Based on best estimates provided by the medical practices, these practices serve roughly 85,000 children birth-5 enrolled in Medicaid (target = 42,900). Across this time, ABCD Coordinators conducted 5,749 technical assistance sessions via email, phone, or Skype with providers/practices; provided 587 onsite training sessions; and made 6476 visits to practices. As part of visits, they reviewed 13,656 medical charts of children birth-5 served by participating practices.

**Evaluation of the ABCD Program**

The evaluation of the ABCD program began Nov. 1, 2013 with three primary objectives:

1. Assess the extent to which the program achieved its intended outcomes and the factors related to these outcomes;
2. Provide information that can be used for ongoing program improvement; and
3. Identify key components of sustainability such that program directors can use this information to positively affect the program's potential for sustainability.

The evaluation was designed to answer the following overarching questions identified by NCPC:

1. To what degree is the RTT-ELC ABCD program achieving each of the anticipated outputs and outcomes identified?
2. What are the key factors related to outcomes?
   1. How long does the ABCD coordinator need to work with the medical practice in order for the expected outcomes to each change at least 10 percentage points?
   2. What are the characteristics of the practice, community, ABCD coordinator, or other factors that are key for producing the expected outcomes?
3. What are the key components of sustainability?
   1. Once the ABCD coordinator completes work with a practice, what types of supports are necessary to sustain the results?
   2. What are the characteristics of the practice, community, ABCD coordinator, or other factors that are key for maintaining the outcomes over time?

To answer these questions, EvalWorks employed a formative and summative evaluation designed to assess initial implementation efforts, challenges, and successes; identify areas of improvement and ways to realize changes; gather evidence of program success; and collect evidence and drivers of program sustainability. The formative and summative evaluations utilized a mixed-methods approach where data from one type of method (quantitative or qualitative) is not just triangulated, but merged, connected, and/or embedded with data from the other type of method. For this evaluation, this included gathering qualitative and rating data from ABCD coordinators about medical providers and merging these data with data collected from medical providers participating in the program.

The table on the next page provides information about the data sources, methods, and analyses that were planned to answer the overarching evaluation questions identified by NCPC. As is shown, all coordinators participated in a survey and interview in spring 2014 and a focus group in spring 2015 to better understand drivers of and barriers to outcomes and sustainability, related to their training, technical assistance, and coaching of medical staff. The surveys, interviews, and focus groups were also meant to discern what the coordinators viewed as the major needs of medical staff and barriers within infrastructures of the medical homes/practices that they served, with respect to conducting developmental and autism screenings.

Additionally, the evaluator conducted phone surveys with lead ABCD contacts at 20 medical practices across the state to discern:

* Major needs of medical staff;
* Barriers within the capital and infrastructures of these medical homes/practices to increasing screening and referral rates;
* ABCD influence on providers’ knowledge and comfort with assessing a child’s social and emotional development;
* Providers’ experience with implementing standardized screenings;
* Providers’ experience with referring children for follow-up services;
* ABCD influence on knowledge of referral resources; and
* Suggestions for increasing the sustainability of NCPC’s ABCD efforts.

**Limitations**

The main limitations to this report are the limited number of data related to children deemed at-risk based on their MCHAT scores. Lack of current Medicaid billing data also limited the ability to compare findings from chart reviews to actual billing data and compare screening rates of ABCD practices to non-ABCD practices. Because of challenges in collecting data on the use of follow up services from the chart reviews, the evaluation team utilized data from the North Carolina Infant-Toddler Program that oversees CDSAs, so findings should be viewed with caution as not all CDSAs provide the data using the same definitions/notations.

**Table 1.**

**Evaluation Crosswalk: ABCD**

|  |  |  |  |
| --- | --- | --- | --- |
| **Question** | **Data Needed** | **Data Collection Methods** | **Analyses** |
| 1. **To what degree is the RTT-ELC ABCD program achieving the following outputs among participating regions and practices?** 2. 110 primary health care practices will have received ABCD training and TA beginning 1/1/14 3. 495 medical providers will participate beginning 1/1/14 4. 42,900 Medicaid-enrolled children 0-5 (estimated) will be served in participating practices beginning 1/1/14 5. 75% of Medicaid-enrolled children at 15 months and at 3-6 years are up-to-date in the schedule of well-child care. 6. By 12 months of age, 95% of Medicaid-enrolled children will receive developmental screenings. 7. By 24 months of age, 85% of Medicaid-enrolled children will receive developmental screening in the previous year. 8. By 36 months of age, 75% of Medicaid-enrolled children will receive developmental screening in the previous year. 9. By age 5, 75% of Medicaid-enrolled children will receive developmental screening in the previous two years. 10. 70% of children with developmental concerns in participating medical practices will be referred for further evaluation or services. 11. 55% of children referred for evaluation or services by participating medical practices receive identified follow-up services. | * Number of participating practices * Number of medical providers by practice * Number of Medicaid-enrolled children served by participating practices * Number of Medicaid-enrolled children up-to-date in terms of well child visits and developmental screenings * Number of Medicaid-enrolled children with developmental concerns who are referred * Number of Medicaid-enrolled children who are referred who receive follow-up services | * Medicaid data that NCPC will provide * Chart review data | * Descriptive analyses of numeric survey data * Inferential statistics may be used with comparative data and include such calculations as t-test to assess whether screening, referral, and treatment rates, etc. are statistically significantly different over time. * Thematic analyses of interview and qualitative survey data * Regression analyses |
| 1. **What are the key factors related to outcomes?** | * Outcome data (See above) * ABCD Coordinator data * Medical provider/practice data * Community/population data | * ABCD Coordinator Survey and Phone Interviews * Medical Provider /Practice Survey * Review of community /population databases |
| 1. How long does the ABCD coordinator need to work with the medical practice in order for the expected outcomes to each change at least 10 percentage points? |
| 1. What are the characteristics of the practice, community, ABCD coordinator, or other factors that are key for producing the expected outcomes? |
| 1. **What are the key components of sustainability?** |
| 1. Once the ABCD coordinator completes work with a practice, what types of supports are necessary to sustain the results? |
| 1. What are the characteristics of the practice, community, ABCD coordinator, etc. that are key for maintaining the outcomes over time? |

**Methodology**

For this program, the evaluator worked with the ABCD Program Manager and the Quality Assurance and Evaluation Director at NCPC to better understand the program, including its history in NC, and to identify past data that may be available for making comparisons. The evaluator also participated in calls and meetings with ABCD Coordinators to understand how they conduct chart reviews (where screening and referral rates are identified) and to ensure that this process was standardized and streamlined across all coordinators. Using feedback from the coordinators, the lead evaluator and program manager updated the "Chart Review Worksheet" used by the Coordinators when conducting chart reviews at medical practices and developed the "Output Data Tracking Form" to ensure that additional data relevant to the evaluation were also collected. ABCD Coordinators provided these data to the evaluator and program manager on a quarterly basis from October 2014 to March 2016. The evaluator analyzed these data quarterly to assess progress toward stated outcomes.

Additionally, all ABCD Coordinators completed a short web survey in March 2014. This survey was designed to understand better the work in which they were engaged and what support they believed was most needed to ensure that practices increased and maintained their screening and referral rates. Based on their responses, a set of follow-up questions were developed and asked of all but one ABCD Coordinator as part of phone interviews in April 2014. These questions allowed the interviewer to probe more in-depth about the work of the Coordinator. In spring 2015, the evaluator conducted another focus group with all coordinators, again to better understand drivers of and barriers to outcomes and sustainability related to their training, technical assistance, and coaching of medical staff.

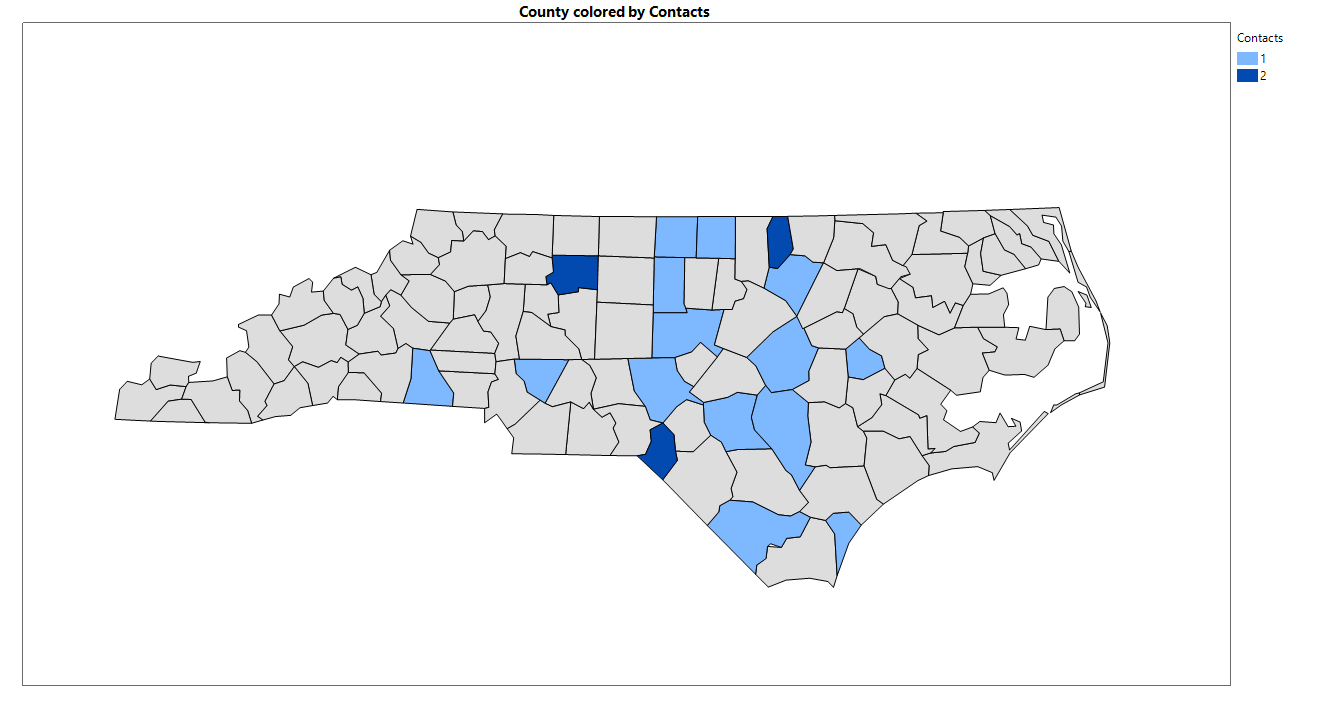
In late summer of 2015, the evaluator contacted multiple medical practices from across the state that were participating in the ABCD program to ask them to participate in a short phone survey. The survey asked about the impact of ABCD on medical personnel’s knowledge and comfort related to screening and referring children with suspected developmental delays and/or autism.

To select the sample of medical practices that might participate in the phone interviews, the evaluator asked all ABCD Coordinators to identify a minimum of three medical practices that they worked with and ask their main contact at each about their willingness to participate. The names of the contacts who agreed to participate were then provided to the evaluator along with the name of the practice at which they work, their phone number, and email address. The evaluator then contacted these persons first by email and then via phone, as necessary, to arrange times to conduct a short phone interview. Contacts were told that the phone survey was meant to understand how ABCD has affected their knowledge, skills, and practices and that their name, and that of the medical practice at which they work, would not be reported or linked to any information that they provided.

Thirty-six persons were contacted and invited to participate in the phone survey. Twenty (55%) completed the interview, representing 20 separate practices. Together these practices employed over 75 medical providers serving over 20,000 children birth-5, of which approximately 76% received Medicaid. Sizes of practices ranged having from 1 to 12 providers and included county health departments (2), pediatric-only practices (9), and family practices (9). Additionally, across the 231 medical practices being served by ABCD at that time, 112 (48%) were considered Level 1 practices, 93 (40%) were considered Level 2, and 26 (11%) were considered Level 3 (those who had worked the ABCD Coordinators the longest). The practices where someone participated in the interview, in comparison, included three times as many Level 3 practices (seven or 35%), the same percentage of Level 2 practices (nine or 45%), and many fewer Level 1 practices (four or 20%) (those who worked with ABCD Coordinators the least amount of time). Those that participated in the interviews represented 17 counties (20% of those counties that were participating at that time) but where 37% (85 of the 231) practices were located.

***Figure 1.***

***Location of Medical Practices Participating in Interviews***



Note: Light blue indicates one medical practice participated in interviews; dark blue indicates two participated.

**Findings**

**Increasing developmental screening rates is easier than increasing autism screening rates.**

One of the roles of ABCD Coordinators is to train physicians and other members of medical practices about the value of developmental and autism screening. Focus groups conducted with ABCD Coordinators at two different time points (March 2014 and April 2015) revealed that one of the first things they do when working with medical practices is ensure that the practices are utilizing valid screening tools. These are the Parents’ Evaluation of Developmental Status (PEDS) or Ages & Stages Questionnaire (ASQ) for developmental screenings and the Modified Checklist for Autism in Toddlers – Revised (MCHAT-R/F) for autism screenings. Along with the need for greater education about using and scoring specific screening instruments, some coordinators noted that they have to work to dispel myths about what counts as a standardized screening tool since some practices assume that asking the screening questions included in many electronic health records (EHRs) constitutes “screening.”

Many Coordinators reported that in terms of screenings, practices tended to have more questions about autism screening. For example, Coordinators noted that often physicians were confused about when to conduct autism screenings versus developmental screenings, the need to screen children regardless of whether they appear to have a developmental delay, and the need to screen children for autism at 18 and 24 months regardless of the outcome of their developmental screen. Many also noted that as turnover among physicians or other staff occurred, additional work was often necessary to get practices back on track regarding conducting screenings (developmental and autism) at the appropriate times.

Practices have more questions about autism screenings than screenings for developmental delays.

Chart reviews conducted by coordinators comprise much of the evaluative data related to screening and referral rates, including the information presented here. By March 2016, Coordinators had reviewed and provided data on 13,656 medical charts of children birth-5 served by participating practices.

The tables below provide an overview of developmental and autism screening rates after grouping medical practices by whether they are considered Level 1, 2, or 3. Baseline data represent data ~~f~~rom chart reviews conducted by coordinators before providing ABCD services to respective practices.

Practices are identified as "Level 1" when ABCD Coordinators begin working with them. One of the first things coordinators do is conduct a baseline chart review and meet with staff to understand procedures that are, or are not, in place to ensure the proper screening and referral of the children who are seen. Coordinators then work with staff to develop *systems* to increase the likelihood that all children are screened at the recommended ages using a valid and reliable instrument, and that children who need additional evaluation are referred to the appropriate agency. As systems are developed, coordinators often conduct a second chart review to determine if children are actually receiving the screenings and referrals that are indicated.

Level 2 practices are ones that Coordinators have worked with enough to believe that they have made changes in their practices around screenings and referrals such that there is a high probability that all children needing screenings and or referrals will receive them. Coordinators usually complete additional chart reviews on a periodic basis (e.g., semi-annually) to ensure that systems are still operating successfully, such that all children receive the recommended screenings when due and that providers use valid and reliable instruments.

Level 3 practices are ones that coordinators have worked with in the past but are no longer working with as intensively. Such practices can be considered as being in the "maintenance" phase. Coordinators may only reach out to them a few times a year and may conduct chart reviews every 12-18 months. If chart reviews reveal that screening and referral rates have declined, coordinators begin working with these practices more intensively and they are again considered a Level 2 practice. Reasons for declines in referral rates often result from changes in staff, such as the loss of the person responsible for ensuring screenings and referrals are completed, to new persons coming on board who are unfamiliar with conducting screenings and referring children.

As shown below, Level 1 practices (those that have worked with ABCD Coordinators the least amount of time) screened 91.6% of children birth-5 due for screening for developmental delays compared to 85.2% at baseline. Level 3 practices (those that have worked with ABCD Coordinators the longest) screened 96.3% of children birth-5 who were due for screening, 10% more than baseline. Qualitative data provided by providers as part of the medical practice phone interviews indicated that in many cases, at baseline, medical practices were making determinations using non-standardized screening tools or procedures.

**Table 2.**

**Screening Rates: Developmental Delays - Child Due for Screening**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Practice Level** | **No. Charts Reviewed** | **Child Due for Screening** | | | **Child Screened**  **When Due** | | |
| Baseline | 4,346 | 3,518 | 80.9% | 2,999 | | 85.2% |
| Level 1 | 5,619 | 4,821 | 85.8% | 4,414 | | 91.6% |
| Level 2 | 2554 | 2111 | 82.7% | 1942 | | 92.0% |
| Level 3 | 1088 | 1065 | 97.9% | 1026 | | 96.3% |

As a second check of the data, findings were further disaggregated by whether the child whose chart was reviewed received Medicaid or not. As is shown in Tables 3, by insurance type, most practices screened a similar percentage of non-Medicaid children as Medicaid children (87.0% and 88.2%, respectively, overall). Chi-square analyses indicated that overall rates were not statistically significantly different. Please note that insurance type for some children was not available.

**Table 3.**

**Screening Rates by Insurance Type: Developmental Delays - All Children**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **No. Charts Reviewed** | **Child**  **Screened** | |
| Medicaid | All | 9963 | 8790 | 88.2% |
| Baseline | 3309 | 2729 | 82.5% |
| Level 1 | 4445 | 3983 | 89.6% |
| Level 2 | 1492 | 1394 | 93.4% |
| Level 3 | 717 | 684 | 95.4% |
| Non-Medicaid | All | 3489 | 3034 | 87.0% |
| Baseline | 1031 | 855 | 82.9% |
| Level 1 | 1708 | 1488 | 87.1% |
| Level 2 | 569 | 527 | 92.6% |
| Level 3 | 181 | 164 | 90.6% |

Table 4 provides data related to autism screenings across practice levels. Among children due to receive screening with the MCHAT, 86.7% received such screening among Level 3 providers, in comparison to 78.7% at baseline. However, data indicate that more Level 1 providers conducted autism screening when a child was due than those at Level 2, a finding that is hard to explain. Of note, by the end of December 2016, coordinators reported that all medical providers with which they work were using or transitioning to the MCHAT-R/F, the latest and most reliable version of the MCHAT.

Screenings for developmental delays increased by 11 percentage points to 96.3% from baseline to Level 3 and, for autism, by 8 percentage points to 86.7% from baseline to Level 3.

**Table 4.**

**Screening Rates: Autism - Child Due for Screening**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Practice**  **Level** | **No. Charts Reviewed** | **Child Due to Receive MCHAT** | | **Child Received**  **MCHAT** | |
| Baseline | 4,346 | 1,235 | 28.4% | 972 | 78.7% |
| Level 1 | 5,619 | 1995 | 35.5% | 1674 | 83.9% |
| Level 2 | 2554 | 615 | 24.1% | 419 | 68.1% |
| Level 3 | 1088 | 278 | 25.6% | 241 | 86.7% |

When data related to autism screenings were disaggregated by insurance type, they revealed that about 26% of children in both groups were screened. Again, insurance type was not available for all children.

**Table 5.**

**Screening Rates by Insurance Type: Autism - All Children**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **No. Charts Reviewed** | **Child**  **Screened** | |
| Medicaid | All | 9963 | 2624 | 26.3% |
| Baseline | 3309 | 841 | 25.4% |
| Level 1 | 4445 | 1268 | 28.5% |
| Level 2 | 1492 | 307 | 20.6% |
| Level 3 | 717 | 208 | 29.0% |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Non-Medicaid | All | 3489 | 910 | 26.1% |
| Baseline | 1031 | 255 | 24.7% |
| Level 1 | 1708 | 451 | 26.4% |
| Level 2 | 569 | 156 | 27.4% |
| Level 3 | 181 | 48 | 26.5% |

As Figure 2 makes clear, the percentage of children screened when due for autism lags behind those screened when due for developmental delays, at all levels. What is not clear is why this is the case. Reasons may include that the MCHAT-R/F takes longer to conduct than the PEDS or ASQ, that physicians don’t screen for autism unless developmental screens or parents indicate concerns, physicians feel more comfortable discussing developmental screening results, etc.

***Figure 2.***

***Comparison of Percent Screened by Level and Screening Type***

**Developmental Screenings**

**Autism Screenings**

**Increasing screening rates is easier than increasing referral rates.**

Coordinators’ experiences and chart review data indicate that increasing screening rates is easier than increasing referral rates. Many coordinators reported the need to educate practices about referring versus taking a “wait and see” approach. Even among physicians who know the value of referring children, some still hesitate to do so. One coordinator noted that the practices she works with seldom refer to their local CDSA or Exceptional Children’s Preschool Program because they do not hear back from these organizations as to the outcomes of the referrals. Another reported that the physicians in the practices she works with believe that the bar for children to qualify for services with the CDSA or Exceptional Children’s Preschool Program is too high, so they refer to private practices instead where there are no requirements for eligibility of services. Another reported that many physicians at the practices that she supports have expressed concern that their local CDSA and EC program take too long to follow up on the referrals the physicians make.

Regardless of the reason, there is evidence from chart reviews of physicians’ hesitancy to refer children when screenings indicate such a need. As shown below, at baseline, only 68.4% of children whose developmental screening scores suggested that they were at-risk were referred, whereas 77.5% were referred among Level 3 practices. While any increase is better than none, overall referral rates are well below screening rates.

**Table 6.**

**Referral Rates: Developmental Delays - All Children**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Practice Level** | **Child**  **Screened** | | **Child Scored**  **At-Risk** | | **Child Referred for Services\*** | |
| Baseline (4,346) | 3,588 | 82.6% | 421 | 11.7% | 288 | 68.4% |
| Level 1 (5,619) | 5618 | 100.0% | 591 | 10.5% | 383 | 64.8% |
| Level 2 (2,554) | 1923 | 75.3% | 206 | 10.7% | 152 | 73.8% |
| Level 3 (1,088) | 839 | 77.1% | 89 | 10.6% | 69 | 77.5% |

\* Or already receiving services

A critical aspect of the ABCD Coordinators’ work includes helping providers identify the most appropriate place to refer children who may have a developmental delay. As shown below, at baseline, 46.3% of referrals were to either the CDSA or Exceptional Children’s Preschool Program. For Level 1 practices, 53.0% of referrals were to either CDSA or EC program. This climbed to 63.5% for Level 2 practices and to an even larger percentage (80.4%) for Level 3 practices. Results indicate that medical practices are indeed responding to the ABCD Coordinators message to refer to CDSAs and Exceptional Children’s Preschool Programs.

Local CDSAs (for birth through 2.5 years of age) and Exceptional Children's Preschool Programs (for ages 2.5 to 5 years) are the most appropriate places to refer children whose screenings suggest they may be at-risk for developmental delays. When referrals were reviewed by children’s age, 90 of the 327 referrals (27.5%) to CDSAs were for children 2.6 years of age or older whereas 5 of the 59 referrals (8.5%) to the Exceptional Children’s Preschool Program were for children under 2.6 years of age. Of the 90 referrals to CDSAs which were age inappropriate, a third (28 or 31%) were made by medical practices just beginning to work with ABCD coordinators; in comparison, only one of the five age inappropriate referrals to the Exceptional Children’s Preschool Program were made by practices new to ABCD.

**Table 7.**

**Where Referred for Developmental Delays - All Children\***

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Practice Level** | **Referrals Where Agency Identified\*** | **CDSA** | | **Preschool Exceptional Children's Program** | | **Care Coordination for Children (CC4C)** | | **Other Therapy** | | **Other** | |
| Baseline | 258 | 101 | 39.1% | 19 | 7.4% | 12 | 4.7% | 83 | 32.2% | 43 | 16.7% |
| Level 1 | 326 | 151 | 46.3% | 22 | 6.7% | 14 | 4.3% | 99 | 30.4% | 40 | 12.3% |
| Level 2 | 115 | 59 | 51.3% | 14 | 12.2% | 5 | 4.3% | 22 | 19.1% | 15 | 13.0% |
| Level 3 | 51 | 36 | 70.6% | 5 | 9.8% | 1 | 2.0% | 4 | 7.8% | 5 | 9.8% |

\* Not all chart reviews indicated where children were referred. Some children are referred to multiple places at once. In such cases, all places were included in the above counts.

As a second check of the data, findings were further disaggregated by whether the child whose chart was reviewed received Medicaid or not. As is shown in Tables 8 and 9, most practices screened a similar percentage of non-Medicaid children versus Medicaid children (87.0% and 88.2%, respectively). However, including baseline data, 61.3% of children with Medicaid were referred for services versus 47.3% of children without Medicaid. Chi-square tests indicated that this difference was statistically significant (p<xx)

**Table 8.**

**Referral Rates by Insurance Type: Developmental Delays - All Children**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **No. of Charts Reviewed** | **Child**  **Screened** | | **Child Scored**  **At-Risk** | | **At-Risk Children Referred for Services** | |
| Medicaid | All | 9963 | 8790 | 88.2% | 1002 | 11.4% | 614 | 61.3% |
| Baseline | 3309 | 2729 | 82.5% | 326 | 11.9% | 207 | 63.5% |
| Level 1 | 4445 | 3983 | 89.6% | 446 | 11.2% | 249 | 55.8% |
| Level 2 | 1492 | 1394 | 93.4% | 160 | 11.5% | 103 | 64.4% |
| Level 3 | 717 | 684 | 95.4% | 70 | 10.2% | 55 | 78.6% |
| Non-Medicaid | All | 3489 | 3034 | 87.0% | 281 | 9.3% | 133 | 47.3% |
| Baseline | 1031 | 855 | 82.9% | 93 | 10.9% | 41 | 44.1% |
| Level 1 | 1708 | 1488 | 87.1% | 122 | 8.2% | 55 | 45.1% |
| Level 2 | 569 | 527 | 92.6% | 46 | 8.7% | 26 | 56.5% |
| Level 3 | 181 | 164 | 90.6% | 20 | 12.2% | 11 | 55.0% |

A review of where children were referred by the type of insurance they hold revealed that, for the most part, children are referred to the same places at the same rates, regardless of their insurance.

**Table 9.**

**Where Referred for Developmental Delays by Insurance Type – All Children**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **Referrals Where Agency Identified\*** | **CDSA** | | **Preschool Exceptional Children's Program** | | **Care Coordination for Children (CC4C)** | | **Other Therapy** | | **Other** | |
| Medicaid | All | 727 | 318 | 43.7% | 60 | 8.3% | 53 | 7.3% | 185 | 25.4% | 111 | 15.3% |
| Baseline | 255 | 100 | 39.2% | 18 | 7.1% | 16 | 6.3% | 73 | 28.6% | 48 | 18.8% |
| Level 1 | 316 | 136 | 43.0% | 20 | 6.3% | 23 | 7.3% | 95 | 30.1% | 42 | 13.3% |
| Level 2 | 115 | 54 | 47.0% | 18 | 15.7% | 13 | 11.3% | 13 | 11.3% | 17 | 14.8% |
| Level 3 | 41 | 28 | 68.3% | 4 | 9.8% | 1 | 2.4% | 4 | 9.8% | 4 | 9.8% |
| Non-Medicaid | All | 152 | 70 | 46.1% | 12 | 7.9% | 5 | 3.3% | 39 | 25.7% | 26 | 17.1% |
| Baseline | 47 | 16 | 34.0% | 4 | 8.5% | 3 | 6.4% | 17 | 36.2% | 7 | 14.9% |
| Level 1 | 65 | 33 | 50.8% | 5 | 7.7% | 1 | 1.5% | 12 | 18.5% | 14 | 21.5% |
| Level 2 | 30 | 13 | 43.3% | 2 | 6.7% | 1 | 3.3% | 10 | 33.3% | 4 | 13.3% |
| Level 3 | 10 | 8 | 80.0% | 1 | 10.0% | 0 | 0.0% | 0 | 0.0% | 1 | 10.0% |

\* Not all chart reviews indicated where children were referred. Some children are referred to multiple places at once. In such cases, all places were included in the above counts.

Of children screened for autism, on average, 16% scored positive, indicating a need for further evaluation. Baseline data and data collected on Level 1 practices indicate higher referral rates than those of Level 2 and 3 practices. Again, this is hard to explain. Referral rates for all practices (12.6% - 25.5%), regardless of level, are well lower than desired.

**Table 10.**

**Referral Rates: Autism - All Children**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Practice**  **Level** | **Child Received**  **MCHAT** | | **Child Scored Positive on MCHAT** | | **Child Referred**  **for Services\*** | |
| Baseline (4,346) | 1,097 | 25.2% | 187 | 17.0% | 36 | 19.3% |
| Level 1 (5,619) | 1,544 | 27.5% | 192 | 12.4% | 49 | 25.5% |
| Level 2 (2,554) | 415 | 16.2% | 87 | 21.0% | 11 | 12.6% |
| Level 3 (1,088) | 246 | 22.6% | 36 | 14.6% | 6 | 16.7% |

\* Or already receiving services

When compared to the percentage of children referred for further assessment for developmental delays, the percent referred for autism is much lower, across all levels, and overall rates for both are quite low.

***Figure 3.***

***Comparison of Percent Referred by Level and Screening Type***

**Developmental Screening**

**Autism Screening**

As is shown in the table below, the majority of children referred for further assessments when suspected to have autism were referred to the local CDSA, the most appropriate referral given the ages of these children.

**Table 11.**

**Where Referred for Autism - All Children**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Practice Level** | **Referrals Where Agency Identified\*** | **CDSA** | | **Preschool Exceptional Children's Program** | | **Care Coordination for Children (CC4C)** | | **Other Therapy** | | **Other** | |
| Baseline | 16 | 11 | 68.8% | 1 | 6.3% | 1 | 6.3% |  | 0.0% | 3 | 18.8% |
| Level 1 | 44 | 29 | 65.9% | 3 | 6.8% | 1 | 2.3% | 4 | 9.1% | 7 | 15.9% |
| Level 2 | 5 | 3 | 60.0% | 1 | 20.0% | --- | 0.0% | 1 | 20.0% | --- | 0.0% |
| Level 3 | 4 | 4 | 100.0% | --- | 0.0% | --- | 0.0% | --- | 0.0% | --- | 0.0% |

\* Not all chart reviews indicated where children were referred. Some children are referred to multiple places at once. In such cases, all places were included in the above counts.

When data related to autism screenings were disaggregated by insurance type, they revealed that about 26% of children in both groups were screened, those with Medicaid were more likely to be referred for further assessment (rates were 23.4% versus 14.6%). Similar to the finding with respect to referrals for developmental delays, the Chi-Square value associated with whether a child was referred for further assessment based on his or her MCHAT score by insurance type resulted in a p-value < .05, indicating that the difference in referral rates by insurance type is due to more than chance.

Statistically significantly more children with Medicaid are referred when developmental delay or autism screens indicate a need versus children with insurance other than Medicaid.

**Table 12.**

**Referral Rates by Insurance Type: Autism - All Children**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **No. of Charts Reviewed** | **Child**  **Screened** | | **Child Scored**  **At-Risk** | | **At-Risk Children Referred for Services** | |
| Medicaid | All | 9963 | 2624 | 26.3% | 354 | 13.5% | 83 | 23.4% |
| Baseline | 3309 | 841 | 25.4% | 115 | 13.7% | 29 | 25.2% |
| Level 1 | 4445 | 1268 | 28.5% | 143 | 11.3% | 39 | 27.3% |
| Level 2 | 1492 | 307 | 20.6% | 65 | 21.2% | 9 | 13.8% |
| Level 3 | 717 | 208 | 29.0% | 31 | 14.9% | 6 | 19.4% |
| Non-Medicaid | All | 3489 | 910 | 26.1% | 151 | 16.6% | 22 | 14.6% |
| Baseline | 1031 | 255 | 24.7% | 71 | 27.8% | 8 | 11.3% |
| Level 1 | 1708 | 451 | 26.4% | 51 | 11.3% | 12 | 23.5% |
| Level 2 | 569 | 156 | 27.4% | 22 | 14.1% | 2 | 9.1% |
| Level 3 | 181 | 48 | 26.5% | 7 | 14.6% | 0 | 0.0% |

A review of where children were referred, when suspected to have autism, by type of insurance they hold, revealed that, for the most part, children are referred to the same places at the same rates, regardless of their insurance, as was true of when they were suspected to have developmental delays.

**Table 13.**

**Where Referred for Autism by Insurance Type – All Children**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Insurance Type** | **Practice**  **Level** | **Referrals Where Agency Identified\*** | **CDSA** | | **Preschool Exceptional Children's Program** | | **Care Coordination for Children (CC4C)** | | **Other Therapy** | | **Other** | |
| Medicaid | All | 66 | 42 | 63.6% | 5 | 7.6% | 1 | 1.5% | 6 | 9.1% | 12 | 18.2% |
| Baseline | 15 | 10 | 66.7% | 1 | 6.7% | 0 | 0.0% | 1 | 6.7% | 3 | 20.0% |
| Level 1 | 39 | 25 | 64.1% | 2 | 5.1% | 1 | 2.6% | 3 | 7.7% | 8 | 20.5% |
| Level 2 | 8 | 3 | 37.5% | 2 | 25.0% | 0 | 0.0% | 2 | 25.0% | 1 | 12.5% |
| Level 3 | 4 | 4 | 100.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Non-Medicaid | All | 10 | 8 | 80.0% | 0 | 0.0% | 1 | 10.0% | 0 | 0.0% | 1 | 10.0% |
| Baseline | 2 | 1 | 50.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 1 | 50.0% |
| Level 1 | 7 | 6 | 85.7% | 0 | 0.0% | 1 | 14.3% | 0 | 0.0% | 0 | 0.0% |
| Level 2 | 1 | 1 | 100.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Level 3 | 0 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |

\* Not all chart reviews indicated where children were referred. Some children are referred to multiple places at once. In such cases, all places were included in the above counts.

**Few physicians are made aware of whether or not a child receives follow-up services.**

Chart reviews indicated that very few organizations to which children were referred for evaluation or services because of suspected developmental delays or autism provided information back to physicians about the status of the referral. Across 676 referrals for suspected developmental delays identified via chart reviews where outcomes could be tracked, the status of 329 (51%) was not known. Slightly over a third (267 children or 41%) received services whereas 32 (5%) did not receive services. Reasons included child was found ineligible (5 children), parents could not be contacted (8 children), parents declined services (11 children), and no reason provided (8 children). For 16 children in the sample, not enough time had passed between the time the referral was made and when referral determinations are made.

Across 676 referrals for suspected developmental delays identified via chart reviews where outcomes could be tracked, the status of half of the referrals was not known.

Similarly, among children referred for suspected autism, a review of comments included by ABCD Coordinators indicate that in some cases, organizations were unable to reach families (n=8), in other cases the parent/family refused evaluation/services (n=51), or in still other cases the chart review was completed before the time period within which the child should have been assessed had passed (n=11). In a few cases, coordinators wrote that a provider’s “referral” indicated that a parent had been given the phone number for the local CDSA and instructed to contact them (n=5).

**Practices need ongoing systematic support to maintain high screening and referral rates.**

Discussions with Coordinators indicated that, on average, practices need about two years to get to the point that they have increased and then maintained screening and referral rates in alignment with best practices. Many noted that some of this time is highly dependent upon how much relationship building is needed. Coordinators whom medical practices knew from past work with Smart Start or CCNC, or who were affiliated with CCNC, were able to gain the practices’ trust and buy-in more quickly than if they were new to the practices or were not affiliated with CCNC. Coordinators viewed obtaining buy-in and building relationships as critical components of their work. Depending upon the amount of buy-in granted and relationship-building necessary, getting into a practice to conduct chart reviews could take anywhere from one month to several months. Others noted that the time required to get practices up to best standards also depend on how many practices a coordinator is working with. Another pointed out that timing also plays a role, explaining that starting to work with a practice during cold and flu season takes longer than if you start working with them in the middle of summer.

Multiple coordinators noted that even when practices are at Level 3, they still require support to increase or maintain high screening and referral rates. As one coordinator stated unequivocally, “If ABCD goes away, everything will fall apart. We have seen that in old ABCD counties – it seems like we are starting from scratch because of health care [policy] changes and people turnover.” Another commented, “Practices that were good to begin with got it – they will continue to move on with slight slippage, but with other practices – everything will fall apart. They will backslide.” These coordinators noted that even if they provide all practices in their CCNC regions with resources, cheat sheets, etc., changes to instruments, turnover among staff at local agencies, etc. means that these resources need updating on a continual basis.

“If ABCD goes away, everything will fall apart. We have seen that in old ABCD counties – it seems like we are starting from scratch because of health care [policy] changes and people turnover.”

With such intensive efforts, results are positive. Medical practices that participated in the interviews revealed that before working with an ABCD Coordinator, 85% had a formal process for determining which children were due for developmental screening and 80% had a formal process for determining which children were due for autism screening. However, just over half (60%) had a formal process for making referrals whereas fewer than half (40%) had a formal process for tracking referral outcomes prior to working with ABCD (Figure 4).

***Figure 4.***

***Key Screening and Referral Processes in Place Prior to ABCD (N=20)***

Since working with an ABCD Coordinator, the greatest changes medical practices noted related to their knowledge of a) how to make a referral for suspected developmental delays, b) where to refer a child with suspected developmental delays, and c) how to access Early Intervention Services and the types of services that their county’s Early Intervention programs offer. The least change related to their comfort making referrals, comfort following up on referrals, and comfort discussing developmental and autism screening results with parents, although interviewees frequently noted that these were processes that personnel were already comfortable doing. For these items, respondents were asked to rate on a scale of 1 = Not improved at all to 5 = Has improved greatly, the level of change that had occurred among providers and other staff at their practice.

**Table 14.**

**Degree of Change Since Working with an ABCD Coordinator**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **n** | **Min.** | **Max.** | **Mean** | **sd** |
| 1. Knowledge about how to make a referral for suspected developmental delays | 20 | 1 | 5 | 4.20 | 1.11 |
| 1. Knowledge of where to refer a child with suspected developmental delays | 20 | 1 | 5 | 4.20 | 1.06 |
| 1. Knowledge regarding how to access Early Intervention Services | 20 | 2 | 5 | 4.15 | 0.93 |
| 1. Knowledge of the types of services that your county’s Early Intervention program offers | 20 | 2 | 5 | 4.10 | 0.85 |
| 1. Comfort administering a valid autism screening tool | 20 | 2 | 5 | 4.05 | 1.10 |
| 1. Knowledge of valid autism screening tools available for use | 20 | 2 | 5 | 4.00 | 0.97 |
| 1. Comfort scoring that autism screening tool | 18 | 2 | 5 | 4.00 | 1.14 |
| 1. Knowledge of valid developmental screening tools available for use | 20 | 2 | 5 | 3.95 | 0.94 |
| 1. Knowledge about how to make a referral for suspected autism | 20 | 1 | 5 | 3.95 | 1.05 |
| 1. Comfort administering a valid developmental screening tool | 20 | 1 | 5 | 3.90 | 1.21 |
| 1. Knowledge of where to refer a child with suspected autism | 20 | 1 | 5 | 3.90 | 1.17 |
| 1. Comfort scoring that developmental screening tool | 18 | 1 | 5 | 3.78 | 1.52 |
| 1. Comfort making referrals | 20 | 1 | 5 | 3.55 | 1.47 |
| 1. Comfort discussing developmental and autism screening results with parents | 20 | 1 | 5 | 3.47 | 1.61 |
| 1. Comfort following up on referrals | 20 | 1 | 5 | 3.15 | 1.46 |

Across the 20 practices, respondents indicated that the greatest changes made within their practices since working with an ABCD Coordinator were that:

1. Providers were more likely to refer a child for further screening than taking a wait and see approach,
2. Providers referred more children suspected of developmental delays than in the past, and
3. Workflow processes had changed to better accommodate the use of developmental and autism screening tools.

In addition, of those interviewed, 13 practices (65%) began using a different developmental screening tool than they had used previously, whereas 10 practices (50%) changed the type of autism screening tool they had used. Many of these changes involved providers moving away from using screening tools that were either not validated, not up-to-date, or both. Figures 5-8 provide more detail of such changes.

***Figure 5.***

***Changes in Use of Screening Tools* *(N=20)***

***Figure 6.***

***Changes in Reach and Frequency of Screenings (N=20)***

***Figure 7.***

***Changes in Referrals (N=20)***

***Figure 8.***

***Changes in Work Flow Processes (n=20)***

When asked the open-ended question “Were there any additional changes that have occurred other than those specifically asked above since your practice began working with ABCD?”, two respondents commented that more staff in their office received education about the importance of screenings and the referral process, two others noted that providers are able to reach out to ABCD Coordinators to get questions answered more quickly, and of each of the two interviewees noted the following: providers have begun providing summaries of screenings to parents, providers have increased their knowledge of resources that they can provide to parents when screening results suggest that there might be concerns, and providers are promoting dental flossing now as part of their well-child visits.

Other reported benefits of ABCD include a) that staff receive education about the importance of screenings and the referral process, b) providers are able to reach out to ABCD Coordinators to get questions answered more quickly, c) providers have begun sharing summaries of screenings to parents, and d) providers have greater knowledge about resources that they can point parents to when screening results suggest that there might be concerns.

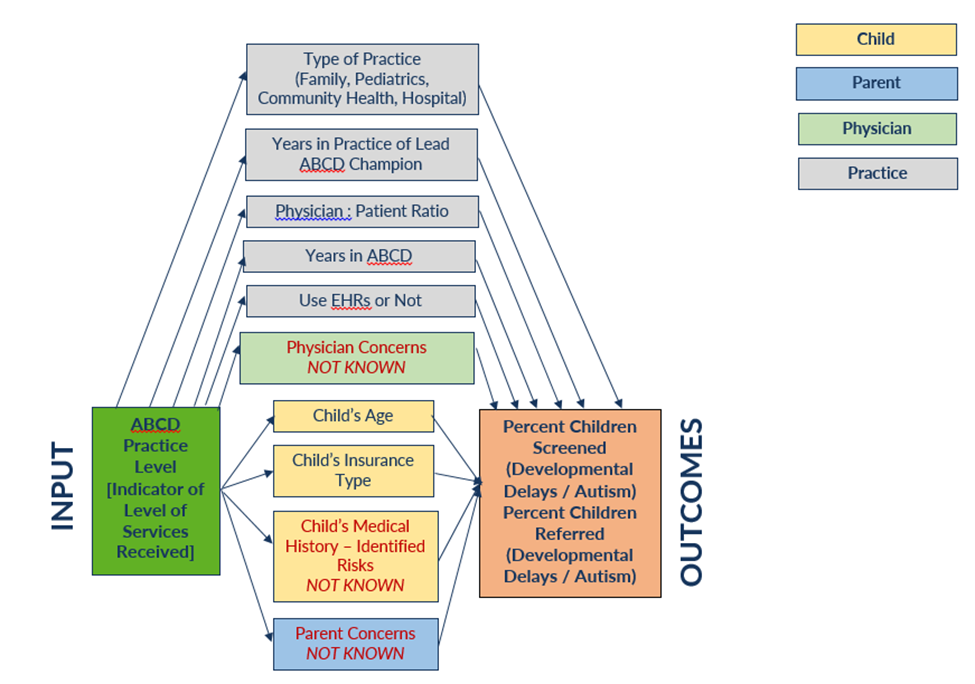
While these responses reflect the respondents’ perceptions, where tracked, these data match closely to the chart review data for these sites, where for many the greatest changes have been in referring and tracking children versus improved screening rates. The reasons for this may include that a) a large proportion (80%) of respondents work in practices at Levels 2 or 3 and recency effects, which are often found during surveying, may mean they are most likely to remember making changes related to these efforts versus earlier efforts related to screening children, b) many practices initially chosen for inclusion in the ABCD program were selected based on serving high numbers of children versus being selected solely on issues related to screening, and c) few practices in North Carolina refer as many children as current guidelines suggest should be referred, making referrals an area that ABCD Coordinators work on with almost all practices.

**Statistical Modeling of Outcomes**

In another attempt to assess the impact of ABCD on physician’s screening and referral rates, we hypothesized factors that may affect whether a child is screened and/or referred. We developed this model, shown in Figure 9, with input from the ABCD Program Coordinator and Evaluation Director to reflect all potential confounders, including ones for which we may have no data (e.g., indication of parent concerns, physician concerns, and whether child has an identified risk such as being born premature, etc.) As is shown on the right of this figure, we used color-coding to indicate the association of the variable; variables in yellow boxes represent child-level variables, those in blue represent parent-level variables, etc. To model the relationship shown in this figure, we used linear regression. Linear regression is a statistical analysis procedure that identifies how well independent variables (in this case, length of time a practice has participated in the ABCD program as measured by the practice’s ABCD level) predict dependent variables (in this case, whether a child is screened and whether (if indicated) a child is referred).

**Figure 9.**

**Hypothetical Model to Predict Screening and Referral Rates**

****

The *actual model* we first tested is identified in the next table. As is shown, all data are practice-level data and include percent screened (developmental delays) as the dependent variable and the following independent variables:

* Practice Type (1 = Pediatrics, 2 = Family Medicine, 3 = Other, such as hospital, urgent care, or health department)
* Number of providers in the practice (including physicians, nurse practitioners, and others involved in screening)
* Total number of patients seen by the practice (as a measure of practice size)
* ABCD Level (1, 2 or 3)
* Length of time the Key ABCD champion has been at the practice
* Chart review number related to the screening rates used in this analysis

This model resulted in an R-square value of .689, indicating that the model explains approximately 69% of the variance associated with this model. Statistically significant predictors of developmental screening rates include the number of providers in the practice (with practices with more providers indicating greater percentages of children were screened) and the number of chart reviews that have been conducted (with practices where more chart reviews have been conducted indicating greater percentages of children were screened). These predictors can be explained given that offices with greater numbers of providers have more providers available to conduct screenings and practices where more chart reviews have been conducted indicate that it has worked longer with an ABCD Coordinator and thus is likely to be following best practices.

**Table 15.**

**Statistical Modeling; Predicting Developmental Screening Rates**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Unstandardized Coefficients (B) | Std. Error | Standardized Coefficients (Beta) | t | Sig. |
| (Constant) | 8.10 | 9.64 |  | 0.84 | 0.41 |
| Practice Type (Dummy Code 1) | -0.36 | 5.61 | -0.01 | -0.06 | 0.95 |
| Practice Type (Dummy Code 2) | 5.44 | 5.85 | 0.12 | 0.93 | 0.36 |
| # Providers in Practice | 4.23 | 1.28 | 0.39 | 3.31 | 0.00 |
| Total Number of Patients | 0.00 | 0.00 | 0.21 | 1.72 | 0.10 |
| ABCD Level (Dummy Code 1) | 0.36 | 10.40 | 0.01 | 0.03 | 0.97 |
| ABCD Level (Dummy Code 2) | 15.68 | 9.57 | 0.39 | 1.64 | 0.11 |
| How long key champion has been with practice | 0.03 | 0.39 | 0.01 | 0.07 | 0.95 |
| Chart Review Number | -6.08 | 1.22 | -0.70 | -4.96 | 0.00 |

Using the same independent variables to explain autism screening rates, the model explained approximately 59% of the variance associated with it, and identified the same independent variables as were predictive in the model above.

**Table 16.**

**Statistical Modeling; Predicting Autism Screening Rates**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Unstandardized Coefficients (B) | Std. Error | Standardized Coefficients (Beta) | t | Sig. |
| (Constant) | 1.55 | 6.23 |  | 0.25 | 0.80 |
| Practice Type (Dummy Code 1) | 1.04 | 3.63 | 0.04 | 0.29 | 0.78 |
| Practice Type (Dummy Code 2) | 6.08 | 3.79 | 0.24 | 1.61 | 0.12 |
| # Providers in Practice | 1.64 | 0.83 | 0.26 | 1.98 | 0.06 |
| Total Number of Patients | 0.00 | 0.00 | 0.33 | 2.38 | 0.02 |
| ABCD Level (Dummy Code 1) | 1.76 | 6.73 | 0.07 | 0.26 | 0.80 |
| ABCD Level (Dummy Code 2) | 10.39 | 6.19 | 0.46 | 1.68 | 0.10 |
| How long key champion has been with practice | -0.36 | 0.25 | -0.23 | -1.43 | 0.17 |
| Chart Review Number | -2.35 | 0.79 | -0.48 | -2.97 | 0.01 |

As the database used in these analyses included data aggregated to the practice level, we did not test models to predict referrals rates since the number of children requiring referrals, by practice, were so small.

Using a different database, one where data were included at the child level (versus aggregated to the practice level, like above), logistic regression analyses were conducted to identify predictors of whether a child is screened or referred. A logistic regression was conducted because the dependent variable (received screening when due / received referral when indicated) are categorical (in fact, binary) in nature versus continuous as screening or referral rates are. For these analyses, only children who were due to receive developmental screenings or autism screenings were included. Four statistically significant predictors of whether a child receives a developmental screening emerged. Based on whether Beta values are positive or negative and how data were coded, a child is more likely to receive a developmental screening when due if he or she is: 1) at a practice where the Coordinator is not funded by RttT (an indicator that it has worked with ABCD longer), 2) at a practice where more chart reviews have been conducted (again, indicating that it has worked longer with an ABCD Coordinator and likely to be following best practices), 3) at a practice with a higher ABCD level (another indicator that it has worked longer with an ABCD Coordinator and likely to be following best practices), and 3) younger. In terms of whether a child whose screening indicates the need to refer him or her, older children and children with Medicaid are more likely to be referred.

**Table 17.**

**Statistical Modeling: Predicting Whether a Child Receives Developmental Screening**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **B** | **S.E.** | **Wald** | **df** | **Sig.** | **Exp(B)** |
| (Constant) | -0.13 | 0.65 | 0.04 | 1.00 | 0.84 | 0.88 |
| RttT Funded | -0.61 | 0.07 | 75.66 | 1.00 | 0.00 | 0.54 |
| Chart Review Period for Practice | 0.43 | 0.07 | 38.18 | 1.00 | 0.00 | 1.54 |
| ABCD Level |  |  | 73.72 | 3.00 | 0.00 |  |
| ABCD Level(1) | 1.96 | 0.58 | 11.64 | 1.00 | 0.00 | 7.11 |
| ABCD Level(2) | 2.20 | 0.49 | 20.51 | 1.00 | 0.00 | 9.07 |
| ABCD Level(3) | 1.59 | 0.36 | 19.71 | 1.00 | 0.00 | 4.88 |
| Child’s Age | -0.01 | 0.00 | 24.87 | 1.00 | 0.00 | 0.99 |
| Child’s Insurance Type | 0.06 | 0.08 | 0.66 | 1.00 | 0.42 | 1.06 |

**Table 18.**

**Statistical Modeling: Predicting Whether a Child Receives a Referral**

**Based on Developmental Screening Results**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **B** | **S.E.** | **Wald** | **df** | **Sig.** | **Exp(B)** |
| (Constant) | 0.63 | 0.87 | 0.53 | 1.00 | 0.47 | 1.88 |
| RttT Funded | -0.22 | 0.13 | 2.90 | 1.00 | 0.09 | 0.80 |
| Chart Review Period for Practice | -0.04 | 0.09 | 0.16 | 1.00 | 0.68 | 0.96 |
| ABCD Level |  |  | 3.76 | 3.00 | 0.29 |  |
| ABCD Level(1) | -0.87 | 0.78 | 1.24 | 1.00 | 0.27 | 0.42 |
| ABCD Level(2) | -0.70 | 0.67 | 1.12 | 1.00 | 0.29 | 0.49 |
| ABCD Level(3) | -0.16 | 0.46 | 0.12 | 1.00 | 0.73 | 0.85 |
| Child’s Age | 0.01 | 0.00 | 14.86 | 1.00 | 0.00 | 1.01 |
| Child’s Insurance Type | 0.29 | 0.14 | 4.42 | 1.00 | 0.04 | 1.34 |

In terms of predicting whether a child receives autism screenings, statistically significant predictors are whether the child is:

1. at a practice where the ABCD Coordinator is not funded by RttT, an indicator that it has worked with ABCD longer,
2. at a practice where a greater number of chart reviews have been conducted, which like whether or not it is RttT funded is strongly correlated with ABCD level,
3. at a practice with a higher ABCD level, and
4. younger, which is consistent with the age range in which children should receive autism screenings (at 18 and 24 months).

In terms of predicting whether a child whose autism screening suggests the need for additional screening receives such a referral, statistically significant predictors were if he or she is seen at a practice where the ABCD Coordinator is not funded by RttT, if he or she was seen at a practice with a higher ABCD level, and if he or she is older.

**Table 19.**

**Statistical Modeling: Predicting Whether a Child Receives Screening for Autism**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **B** | **S.E.** | **Wald** | **df** | **Sig.** | **Exp(B)** |
| (Constant) | 5.54 | 0.55 | 100.13 | 1.00 | 0.00 | 254.34 |
| RttT Funded | -0.37 | 0.09 | 16.91 | 1.00 | 0.00 | 0.69 |
| Chart Review Period for Practice | -0.32 | 0.05 | 35.44 | 1.00 | 0.00 | 0.72 |
| ABCD Level |  |  | 92.04 | 3.00 | 0.00 |  |
| ABCD Level(1) | -3.49 | 0.50 | 48.37 | 1.00 | 0.00 | 0.03 |
| ABCD Level(2) | -2.68 | 0.43 | 39.41 | 1.00 | 0.00 | 0.07 |
| ABCD Level(3) | -2.41 | 0.29 | 68.90 | 1.00 | 0.00 | 0.09 |
| Child’s Age | -0.01 | 0.01 | 5.86 | 1.00 | 0.02 | 0.99 |
| Child’s Insurance Type | 0.04 | 0.09 | 0.25 | 1.00 | 0.62 | 1.05 |

**Table 20.**

**Statistical Modeling: Predicting Whether a Child Receives a Referral**

**Based on Autism Screening Results**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **B** | **S.E.** | **Wald** | **df** | **Sig.** | **Exp(B)** |
| (Constant) | -3.47 | 1.81 | 3.70 | 1.00 | 0.05 | .03 |
| RttT Funded | -1.17 | 0.26 | 19.86 | 1.00 | 0.00 | 0.31 |
| Chart Review Period for Practice | 0.21 | 0.21 | 1.00 | 1.00 | 0.32 | 1.24 |
| ABCD Level |  |  | 8.14 | 3.00 | 0.04 |  |
| ABCD Level(1) | 1.42 | 1.64 | 0.76 | 1.00 | 0.38 | 4.16 |
| ABCD Level(2) | 1.46 | 1.34 | 1.19 | 1.00 | 0.27 | 4.32 |
| ABCD Level(3) | -0.11 | 0.90 | 0.02 | 1.00 | 0.90 | 0.89 |
| Child’s Age | 0.03 | 0.01 | 7.23 | 1.00 | 0.01 | 1.03 |
| Child’s Insurance Type | 0.49 | 0.29 | 2.85 | 1.00 | 0.09 | 1.62 |

**Relationship to Outcomes**

For this evaluation, multiple goals were identified. These are included in the tables below, along with the target percentages and actual percentages achieved (for Medicaid children only and all children). Actual percentages were calculated using data from the most recent chart reviews for providers who were considered Level 2 or 3. This decision was made as Level 2 and 3 providers have worked with ABCD Coordinators long enough to have made changes in their practices around screenings and referrals.

As shown below in Tables 15 and 16, four of six targets were met for children with Medicaid and five of six were met for all children, regardless of insurance type.

**Table 21.**

**Goals Related to Developmental Screenings**

|  |  |  |  |
| --- | --- | --- | --- |
| **Goal** | **Target** | **Results** | |
| **Medicaid Children Only** | **All Children** |
| 75% of Medicaid-enrolled children at 15 months and at 3-6 years are up-to-date in the schedule of well-child care. | 75% | **94.1%** | **93.9%** |
| By 12 months of age, 95% of Medicaid-enrolled children will receive developmental screenings. | 95% | **92.2%** | **92.1%** |
| By 24 months of age, 85% of Medicaid-enrolled children will receive developmental screening in the previous year. | 85% | **92.1%** | **91.9%** |
| By 36 months of age, 75% of Medicaid-enrolled children will receive developmental screening in the previous year. | 75% | **92.0%** | **91.9%** |
| By age 5, 75% of Medicaid-enrolled children will receive developmental screening in the previous two years. | 75% | **91.4%** | **91.2%** |
| 90% of reviewed charts will note that children received developmental screenings with a validated screening tool at their most recent well-child visit. | 90% | **91.3%** | **91.1%** |
| 70% of children with developmental concerns in participating practices will be referred for further evaluation or services. | 70% | **68.7%** | **74.9%** |

In terms of targets related to autism screening, the target for screening was met for both children with Medicaid and all children regardless of insurance type, whereas the increase in the percent of children referred was below 10% for both groups.

**Table 22.**

**Goals Related to Autism Screenings**

|  |  |  |  |
| --- | --- | --- | --- |
| **Goal** | **Target** | **Results** | |
| **Medicaid Children Only** | **Medicaid Children Only** |
| 70% of reviewed charts will note that children received autism-specific screening at designated well-child visits (18 and 24 months). | 70% | **80.6%** | **73.9%** |
| Chart reviews will show a 10% increase of the percent of children ages birth-5 with developmental concerns who have been referred for further evaluation to the CDSA or Exceptional Children’s program. | 10% | **17.3%** (Developmental) | **9.1%**  (Developmental) |
| **1.8%**  (Autism) | **6.2%**  (Autism) |

As Table 17 indicates, 62.0% of children referred for further evaluation by participating medical practices received this service. Slightly over 5% (5.3%) of children birth through two years of age identified as at-risk received early intervention services from the CDSA. The percent of children three to five years of age identified as at-risk and receiving services from the Exceptional Children’s Preschool Program was also 5.3%.

**Table 23.**

**Goals Related to Referrals and Intervention Services**

|  |  |  |
| --- | --- | --- |
| **Goal** | **Target** | **Actual** |
| 55% of children referred for evaluation or services by participating medical practices receive identified follow-up services. | 55% | **62.0%\*** |
| 5% of the total birth through age 2 population will have been identified and will have received early intervention services from the CDSA. | 5% | **5.3%** |
| 5% of the total three to five year old population will have been identified and will have received early intervention services from the Exceptional Children’s Preschool Program. | 5% | **5.3%** |

\*Based on data from the North Carolina Infant-Toddler Program related to children referred to a CDSA for further evaluation by their physician in 2013-14.

**Summary and Discussion**

**ABCD increases medical providers’ screening rates for developmental delays and autism.** The findings in this report provide evidence that the ABCD Model and ABCD Coordinators have had a large impact on improving practices' screening rates. For example, developmental screening rates among ABCD practices went from 85.2% to 96.3%, an 11.1 percentage point increase whereas autism screening rates increased from 78.7% to 86.7%, an eight percentage point increase. Statistical analyses revealed that ABCD level is a statistically significant predictor of whether a child is screened for developmental delays and autism or referred for autism. Moreover, all ABCD practices are using valid and reliable developmental and autism screening instruments, with 65% and 50% of medical practices interviewed reporting that they changed the developmental and autism screening tool that they use, respectively, and 40% and 35% noting that they began using a validated developmental and autism screening tool, respectively. Data further revealed that there is no difference in screening rates by child’s insurance type.

**ABCD increases medical providers’ referral rates for developmental delays and autism, although referral rates for autism are much lower than referral rates for developmental delays.** Findings further demonstrate that the ABCD model improves practices' referral rates, especially in relation to developmental screenings. For example, whereas at baseline 68.4% of children were referred when developmental screening results were positive, practices at Level 3 referred 77.5% of children, an increase of 9.1 percentage points. Data related to autism screenings were mixed with Level 1 providers referring at a higher rate than baseline (25.5% versus 19.3%), but Level 3 practices only referring 16.7% of children whose screens were positive. Eighty-five percent of medical practices that were interviewed indicated that they are more likely to refer now than take a “wait and see” approach because of working with an ABCD Coordinator.

**ABCD increases the “appropriateness” of medical providers’ referrals.** The percentage of appropriate referrals (i.e., to the local CDSA or Exceptional Children’s Preschool Program) increased from 75.1% baseline to 100% for Level 3 practices. Furthermore, children were referred to these agencies at similar rates regardless of insurance type.

**Physicians tend to refer Medicaid children more frequently than children with private insurance although insurance type has no bearing on screening rates.** Findings revealed that although there is no difference in screening rates by child’s insurance type, physicians tend to refer children with Medicaid more frequently than those with private insurance do. Statistical analyses revealed that children with Medicaid are more likely to be referred based on developmental screening results than those with private insurance. Unfortunately, data do not provide evidence of why this is so. Of note, the percentage of appropriate referrals (i.e., to the local CDSA or Exceptional Children’s Preschool Program) increased and children were referred to these agencies at similar rates regardless of insurance type.

**Practices need ongoing systematic support to maintain high screening and referral rates.** Discussions with Coordinators indicated that, on average, practices need about two years to get to the point that they have increased and then maintained screening and referral rates in alignment with best practices. Many noted that some of this time is highly dependent upon how much relationship building is needed. Throughout relationship building, ABCD Coordinators provide a multitude of services such as education, technical assistance, chart reviews, provider network building and expansion, outreach, etc. in order to support providers’ abilities to screen, and refer children and engage parents in meaningful conversations about their child’s development and developmental services available, if needed.

**ABCD services are continually needed by practices.** ABCD Coordinators also experienced that persons within medical practices, (CDSA, Exceptional Children’s Preschool Programs, etc.) leave positions; new state or federal policies, guidelines, or practices are enacted; development or autism screening instruments change, electronic health records are implemented, etc. medical practices need the support ABCD provides to effectively address and adjust to these changes. Data also support these assertions as they revealed many Level 3 practices required the frequency and intensity of Level 2 services to adjust to physicians and others leaving, practices that changed to using electronic health records often began screening with non-validated tools or with less frequency, and that practices that did not know who or where to refer were less likely to refer children.

**In summary, evaluation of the ABCD program provides evidence that the ABCD model works in NC to increase screening and referral rates through education, technical assistance, coaching and oversight.** This in turn has great implications for children with developmental delays and/or autism who may not be identified for services until they enter formal schooling, after much critical time has passed. The consequences for delaying or not screening and referring are serious for that child and family and has potential long-term negative impacts. By supporting increased screening and referral rates, ABCD has great potential for ensuring that North Carolina’s children in need of services are identified in a timely manner and provided services that enable them to be successful in life.