Current First 5 LA Developmental Screening Investments Final Overview Report

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Review of Current First 5 LA Developmental Screening Investments: Executive Summary

In September 2011, First 5 LA approved a \$900,000 allocation to focus on the early identification of autism and other developmental delays to increase the number of children who are screened, receive referrals to early intervention services, and are integrated into Los Angeles County's various systems of care. In May 2013, First 5 LA approved an additional \$1.6 million, bringing the total allocation to \$2.5 million. This amount includes \$400,000 for a Technical Assistance provider to advise the grantees on protocols, processes, and outcomes.

To provide context for evaluating new developmental screening programs, First 5 LA issued a solicitation to conduct a review of existing developmental screening efforts funded by First 5 LA.² This Executive Summary accompanies a report of the findings from this review.

The review included the following programs funded by First 5 LA that conduct developmental screening of children 0-5 years of age:³

- The 211 Developmental Screening and Care Coordination Project
- Welcome Baby's child development screenings
- Children's Bureau of Southern California Matching Funds Screening Program
- The Child and Family Center Matching Funds Screening Program

These four programs conduct developmental screening in a variety of settings: through a telephone-based information and referral service; in the context of support and information provided to new mothers up to 9 months postpartum; with participants in several types of community based parenting groups; and through mental health consultations in preschools. Some have the potential to screen thousands of children per year, while others reach smaller, more specific target populations.

A few caveats should be noted about the four programs included in this review of current First 5 LA developmental screening investments. First, Welcome Baby's developmental screening activities were in a pilot phase at the time of this study. Program efforts were in the process of ramping up, and the data reported may not reflect full implementation of developmental screening in this program. Second, for two of the four screening programs studied – Children's Bureau and the Child and Family Center – First 5 LA provided matching funds and thus did not fully fund those screening activities.

² Solicitation for the First 5 LA Developmental Screening Environmental Scan, August 2013.

³ At the direction of First 5 LA, the Los Angeles Universal Preschool Child Signature Program (CSP) was not included in the project, as it was just beginning its developmental screening efforts at the time of this study.

Brief summary of data collected

Two major approaches were used for data collection to inform the review of current First 5 LA developmental screening investments. Qualitative data were collected through a semi-structured interview with managers of the four programs studied, while quantitative data were collected from each program to indicate, when available, information about the characteristics of the families served, the results of developmental screening provided, and service system linkages that emerged from the developmental screening.⁴

Major themes about First 5 LA developmental screening efforts

Interviews with program managers from the four programs studied identified a number of themes about their program's developmental screening practices, as well as issues in linking families with needed developmental services.

Developmental screening tools in use

The primary developmental screening tools in use by the programs studied are the **Ages and Stages Questionnaires**, **3**rd **Edition** (ASQ-3) including the **ASQ: Social-Emotional** (ASQ-SE), as well as the **Parents' Evaluation of Developmental Status** (PEDS) and the related **PEDS: Developmental Milestones** (PEDS:DM). The ASQ and PEDS instruments are broad screening tools that examine a range of areas of development and behavioral skills in young children. In addition, autism-specific screening is conducted by one of the four programs studied using the **Modified Checklist of Autism in Toddlers** (M-CHAT).

How developmental screening tools are used

The programs included in this review use developmental screening in several different ways. Some offer developmental screening to all families that their program serves with children age 0-5 years; others conduct developmental screening only if a specific concern is noted or there is reason to believe the child is at risk. In some cases, programs may use both strategies, providing screening using the PEDS for all new families with children age 0-5 years, and then following up for ongoing monitoring using the ASQ measures. In all programs studied, developmental screening is conducted by staff who are not only trained in the use of the screening tools, but also have a background in early childhood development or a related field so that their clinical judgment informs the interpretation of developmental screening results. For all of the programs studied, any concerns raised by the results of developmental screening are followed up with referrals to more detailed assessment, evaluation, and specialized services as appropriate for each child and family.

⁴ In addition, qualitative interviews with selected 211 staff, referral partners, and parents who received developmental screening, as well as a review of selected recorded calls in which screening was offered and/or provided, were collected for a more detailed descriptive study of the 211 Developmental Screening and Care Coordination project. This descriptive study is summarized in a separate report (Melchior & Brink, 2014). These data also informed the broader review of current First 5 LA developmental screening investments.

What kinds of follow-up occurs after developmental screening

The programs included in this review vary in the extent to which follow-up occurs and the type of care coordination that can be provided. Some programs, which provide fairly intensive clinical services with relatively small caseloads, are able to closely work with families on a continuing basis to ensure they connect with services to which they are referred when developmental screening results identify concerns requiring follow-up. Others, by design, are not able to do extensive follow-up. For example, Welcome Baby conducts developmental screening towards the end of the program's involvement with the mother-child dyad, because it can only be done when the baby is old enough. Given this program's large caseloads, it is not designed to provide intensive case management or provide long-term follow-up. In the case of the 211 Developmental Screening and Care Coordination project, the fact that the screening is conducted by telephone introduces some challenges around obtaining written consent to share information between providers to assist in the care coordination process, as well as for tracking and documenting service uptake. Still, 211 provides fairly extensive care coordination follow-up, especially considering the size of their caseloads and that the developmental screening is not provided within the context of more intensive face-to-face clinical services.

Major strengths and weaknesses of screening tools, protocols, and systems

Managers of the programs studied identified a number of strengths and weaknesses of the developmental screening tools and protocols in use by all four programs. Overall, the screening tools and protocols provide a mechanism for gathering information that is both technically rigorous and parent-friendly. Some programs have developed strategies to work around some relative weaknesses of the screening tools. For example, in order to compensate for limitations associated with parent self-report, the Child and Family Center incorporates teacher ratings and clinical observations to provide multiple perspectives on the child being screened. While this approach is more intensive than a typical screening based on the perspective of one rater, it still qualifies as a screening rather than an assessment, as the results of the screening do not result in a definitive diagnosis and the screening tools are not intended to be used for diagnostic purposes. The developmental screening tools in use by First 5 LA-supported programs are well established in the broader literature and among the most widely used developmental screening tools available. The following figure summarizes the major strengths and weaknesses identified by the stakeholders interviewed related to their program's developmental screening tools and protocols.

Screening Tools Screening Protocols (ASQ, PEDS, M-CHAT) Provide inherent staff guidance · Informative and empowering for Evidence-based, standardized parents STRENGTHS Easy to score and administer Open communication with families Parent-friendly Effectively connect families to needed services Provide immediate results Limitations of relying on parent Data and outcome tracking WEAKNESSES report Limited program capacity Need for clinical judgment and Limitations of the referral network sensitivity Measurement limitations Practical considerations

Figure I. Summary of strengths and weaknesses of developmental screening tools and protocols identified by program managers interviewed.

Strengths and Weaknesses of Screening Tools

The program managers interviewed appreciated that the developmental screening tools in use by their program provide inherent guidance to the staff who do the screening. They described the screening tools as evidence-based, reliable and valid, and easy to score and administer. They found the tools to be parent-friendly in their administration and in helping them communicate screening results. The stakeholders interviewed pointed out that although the screening tools are useful for identifying possible developmental delays and behavior issues, they still require clinical judgment and sensitivity to properly administer, interpret, and explain findings to parents. Other issues mentioned as relative weaknesses included some limitations in relying on parent report of their child(ren)'s behavior, technical measurement issues, and some practical considerations in the administration of the screening tools.

Strengths and Weaknesses of Screening Protocols

The qualitative interviews with program managers identified a number of strengths of the developmental screening protocols used by the four programs included in this review. These stakeholders see the screening protocols as informative and empowering for parents, and helpful in promoting open communication with families. The developmental screening protocols help to effectively connect families with young children to needed services. Especially for programs that use online screening protocols, which provide immediate results and other benefits compared to traditional paper-and-pencil measures, this was identified as a particular strength. Some areas for improvement were also identified, including aspects of data collection and outcome tracking, and limitations in program capacity to provide developmental screening.

Barriers to Connecting Families and Children to Needed Services

The program managers interviewed noted a number of issues that affect system capacity to link families with resources when concerns are identified through their developmental screening efforts. Changes to funding, eligibility requirements, and the availability of services were all mentioned as issues that affect their program's ability to connect families who have children who screen at-risk for a developmental delay or autism spectrum disorder (ASD) to additional assessment and evaluation. A lack of service integration was also mentioned as a barrier. Resources that could potentially help address these systems-level issues included capacity building, policy change, and restoring recent funding cuts.

In addition, results from separate qualitative interviews conducted with selected referral partners of the 211 Developmental Screening and Care Coordination project also identified some "big picture" challenges in ensuring that young children who are at-risk for possible developmental delays and/or autism spectrum disorder are connected to additional services.

Those stakeholders discussed challenges in the ability to reach some families for ongoing follow-up, especially when families move or have phone numbers disconnected. As also mentioned in the Program Manager Interviews, getting consent forms signed and returned can sometimes create challenges in being able to share data between providers to assist in care coordination and documenting service uptake. These stakeholders also mentioned shifts in the service network, changing eligibility requirements, and limited resources as affecting the ability to connect families with young children with developmental services – especially if the concerns reflected a relatively mild delay.

Major Quantitative Findings

The review of current First 5 LA developmental screening investments also examined quantitative data from the programs studied in order to describe, to the extent possible, the number and characteristics of the population screened, the developmental screening provided, and the number and types of referrals made based on developmental screening results and their outcomes.

All four programs studied collect some quantitative data, but the types of data, level of detail, and availability of information varied considerably across the four programs.

Cumulatively, within the most recent one-year period, the four programs were estimated to have provided developmental screening to a total of 4,275 children age 0-5 years.

⁵ See Melchior and Brink (2014). *211 Developmental Screening and Care Coordination Project: Descriptive Study*.

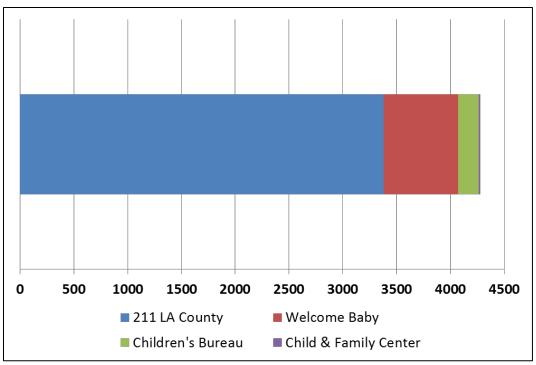


Figure II. Estimated Number of Children Age 0-5 Years Screened in Most Recent Year by Program

Time Frame: January 1, 2013 – December 31, 2013 for 211 LA County and Welcome Baby; July 1, 2012 – June 30, 2013 for Children's Bureau and Child & Family Center

Note: These numbers do not include First 5 LA developmental screening investments that were just starting up at the time of this study (i.e., LAUP CSP) or other upcoming First 5 LA projects (i.e., Early identification of Autism and Other Developmental Delays/First Connections). Welcome Baby was in a start-up/pilot phase so their numbers reflect the program before it is at full capacity.

Because the data varied so widely across these programs, it is not feasible to combine the data in additional detail to provide aggregate numbers. A number of factors affect the ability to combine these data across programs. Some programs provided raw data while others provided summary reports. In addition, the programs provided data at different levels of detail. For example, some programs document whether or not a referral was made at a very broad level, while others track specific types of service referrals. There is also considerable variation in the extent to which the completion of referrals is documented and how completion of the referral is verified. Some programs use a stringent definition in which the completion of the referral must be verified by the agency to which the family was referred. Others rely on parent report to document when service uptake occurs. Follow-up and referral verification can be resource-intensive, and in some cases, programs do not have extensive resources to conduct follow-up with families to find out the status of referrals they made as a result of developmental screening.

Conclusions and Lessons Learned

The four programs included in this review offer and conduct developmental screening of children age 0-5 years using a variety of approaches and settings. Regardless of the program's specific methods of implementation, developmental screening is made available to diverse Los Angeles County families with young children. Some programs target families with children in a specific age range (e.g., newborns, preschoolers), while others offer screening for any child 5 years of age or younger. For the children screened, the families may have had a concern about their child that triggered the screening, or the screening may have brought issues to the forefront that were not necessarily a presenting concern for the family at the time of the screening.

Commonalities and differences among First 5 LA's screening approaches

Among the four programs included in this study, all have in common the use of evidence-based and widely accepted developmental screening tools. Developmental screening is implemented by staff with appropriate training and qualifications. All four programs take care to ensure that the screening provided is parent-friendly and clinically sensitive. Screening results are explained to the parents in their own language. If referrals are made, these programs support families and help empower them to navigate the sometimes complicated service network to connect their child(ren) with developmental services.

Across these programs, developmental screening occurs in different contexts, ranging from face-to-face intensive clinical services to telephone-based information and referral. The programs offer developmental screening at different engagement points in their program – some as part of the intake process, while others screen periodically within the context of dropin services. Some provide "Level 1" screening in which all children in a setting are screened regardless of suspected risk for developmental delay, while others conduct "Level 2" screening which narrows down the population of children offered screening to those with a particular developmental or behavioral concern.

The programs studied utilize different approaches to care coordination. While all four programs support families and help to empower them to navigate the referral network of developmental services, the programs vary in the extent to which they provide hands-on active care coordination in linking families to additional assessment, evaluation, and intervention services. These differences emerge due to a number of factors, including program design, capacity, and the ability to get original signed consent forms for information sharing between agencies.

Within the context of care coordination and service system linkage, programs also vary in the way they document completion of service referrals. For example, some programs require independent verification from the agency to which the family was referred (e.g., a Regional Center or school district). Others rely on parent reports of having received the services to which they were referred as sufficient documentation of service uptake. Because these methods can yield different information, the programs may appear to vary in terms of their "success rates"

of completing service system linkages depending on the method of verification they use. While independent verification from the service providers is the gold standard, it can be resource intensive to conduct that level of follow-up.

Finally, the programs studied vary considerably in their quantitative data capacity – in terms of data to document the number and characteristics of the screening population, the developmental screenings provided and their results, and resulting referrals and their outcomes. Some programs have dedicated data systems and can easily perform queries to answer specific questions; others interface with electronic health record systems that are required by other funders (e.g., Department of Mental Health) and may or may not have easy access to their data for other purposes.

Limitations

By design, this study was descriptive and was intended to illustrate the developmental screening tools, practices, and protocols used by four programs funded by First 5 LA. It was not designed to be population-level research and samples were intentionally small. In addition, the time and scope of the data collection all occurred within a short window of a few months. The information presented in this report is not intended to be exhaustive. Additional information may be available, qualitative and/or quantitative, that provides a more complete picture of developmental screening activities offered and provided by these organizations.

It should also be noted that data collection using the Program Manager Interviews was designed to be exploratory; themes were coded from answers to open-ended questions. Similarities and differences among the programs studied were identified based on these open-ended questions. If the stakeholders interviewed were presented with a list of issues and asked to indicate if those specific issues were true for their program, that method might result in a somewhat different picture of the similarities and differences among the programs.

Best practices to infuse into developmental screening investments

Programs supported by First 5 LA to provide developmental screening have implemented a number of attributes that may be considered best practice: the use of well-established developmental screening tools that are both technically rigorous and parent-friendly, as well as the availability of qualified and empathic staff to provide developmental screening. Some programs find using computer-assisted screening programs to be beneficial, while others are more comfortable using paper-and-pencil screening tools with the families that they serve. Both methods yield accurate and timely screening results.

Best practices in care coordination involve approaches that are child- and family-centered, and help to empower families to access needed developmental services. Although programs vary in their care coordination models, their resources available for ongoing follow-up, and their ability to document outcomes, they share the focus of working with families to help them connect with appropriate resources.

Because programs vary in their capacity to collect data from their developmental screening efforts, it may be desirable to develop specifications to facilitate pooling data across First 5 LA-supported programs that offer developmental screening to families with young children. Enhancing this capacity would permit a greater understanding of the reach and impact of First 5 LA's developmental screening investments.

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Review of Current First 5 LA Developmental Screening Investments

In November 2013, The Measurement Group (TMG) was awarded a contract to conduct a review of current First 5 LA developmental screening investments. This report includes a review of the relevant literature on developmental screening tools for children birth to five years of age. It presents an overview of the developmental screening efforts of four programs receiving funding by First 5 LA, including: what screening tools are in use, how they are administered and what follow-up procedures are in place. In addition, this report summarizes available data that illustrate previously observed outcomes among the programs studied.

This report is presented in two major sections. Part I is a review of the professional literature on developmental screening of young children. Part II describes the methods and results of the review of First 5 LA's current developmental screening investments.

Part I: Literature Review of Developmental Screening Tools for Children from Birth to 5 Years of Age

This literature review examines a number of developmental screening instruments in use by programs funded by First 5 LA as well as selected similar measures. The developmental screening tools included in this review are used to screen for developmental concerns broadly as well as specifically for concerns that may indicate autism spectrum disorder, or ASD. A list of references cited is included as Appendix A.

Purpose of developmental screening in young children

Developmental screening is defined as "a general overview of a child's abilities in order to determine those children that may require additional evaluation and assessment to determine whether there are developmental delays or other issues that need to be addressed." The Centers for Disease Control and Prevention report that less than half of children with developmental disabilities and related issues such as delays in language are identified before starting school (CDC, 2014). The purpose of developmental screening in young children is to broadly identify areas of possible concern as early as possible, suggest when more detailed and specialized assessment is needed, and ultimately facilitate linkage to intervention and supportive services when they are most effective. Screening results are not diagnostic, although ideally they can serve as an initial indication of issues that may be identified through more detailed assessment. Bricker and colleagues (2013) describe appropriate uses of screening measures as including: quick assessment of developmental skills, making referrals, determining the need for more comprehensive assessment and evaluation, permitting developmental

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⁶ http://www.tests.com/glossary. Accessed April 17, 2014.

surveillance when used periodically, and tracking children at risk. The same authors state that using screening measures as the basis for diagnoses, making treatment decisions, or monitoring a child's progress in detail are all *inappropriate* uses of screening tools.

The 2011/2012 National Survey of Children's Health (NSCH), surveyed more than 28,000 households with at least one child age 0-5 years via telephone survey using a complex survey design. Among 28,559 parents asked if they had concerns about their young child's learning, development, or behavior, 40.1% expressed such a concern. In the same survey, 15.2% of children 4 months to 5 years of age were identified as at moderate risk for developmental, behavioral, or social delays and 11.0% were at high risk based on parent responses to a modified Parents' Evaluation of Developmental Status (PEDS; Glascoe, 2010) screener administered as part of the NSCH telephone survey. Developmental screening is an important part of identifying children with, or at risk for, developmental delays. With developmental screening tools that have been shown to have reasonable accuracy, professionals can make suggestions that allow children at risk for developmental delays to receive needed early intervention services (Hamilton, 2006). Access to early intervention services has been shown to be associated with better educational and social outcomes through adulthood (Reynolds, Temple, Robertson & Mann, 2001).

Typically, developmental screening is the initial step in a process designed to 1) identify children at risk for developmental delay and related issues, 2) get those for whom further assessment and/or evaluation is indicated to the appropriate resource(s), and 3) link children with identified developmental delays or with relevant diagnoses to needed intervention and support services. This sequence is represented in the figure below.

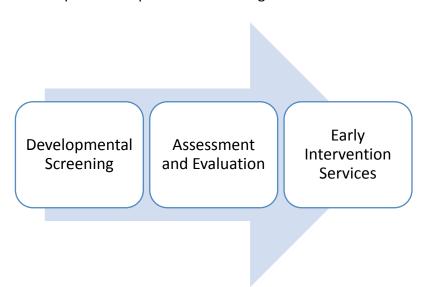


Figure 1. Idealized sequence of developmental screening, assessment/evaluation, and early intervention services.

Settings in which developmental screening typically occurs

Developmental screening can occur in a range of settings, but is most frequently discussed within the context of healthcare, social services, and early childhood education settings (Bricker, Macy, Squires, & Marks, 2013).

The American Academy of Pediatrics (AAP) issued a statement in 2006⁷ that included an algorithm for developmental surveillance and screening, as well as identified a number of best practices in developmental screening. The AAP policy statement recommended that young children receive evidence-based developmental screening at least three times before their third birthday, at the 9, 18, and 24-30 month well child visits, and any time the parent or physician has a developmental concern. The AAP also recommends routine autism screening at 18 and 24 months (Plauché Johnson & Myers, 2007; AAP 2010). Building on these recommendations, the Affordable Care Act specifically names autism screening as a covered preventive service for children at 18 and 24 months, as well as behavioral assessments (which include developmental screening) within the context of well-baby and well-child visits (Department of Health and Human Services, 2014).

As important as these recommendations are, the degree to which they are followed by US healthcare practitioners appears to vary widely. Although some maintain that inexpensive, efficient developmental screening can exist in primary care offices (Carey, 2002) and research suggests that the number of pediatricians using at least one standardized screening tool has increased significantly (Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011), it remains that despite the recommendations for monitoring and screening, many pediatricians fail to use effective means to screen their patients (Sand et al., 2005). Some studies show doctors in the US tend to rely more on clinical judgment to decide when and if to screen and less on using formal developmental screening instruments (Hamilton, 2006; Sices, Feudtner & McLaughlin, 2003; Sices 2007). Pediatricians report a variety of barriers to implementing developmental screening protocols, such as lack of time, trained staff, reimbursement and resources (Dobrez et al., 2001).

Several strategies have been suggested as ways to increase doctor and nurse familiarity and comfort with developmental screening tools. Some approaches involve using physicians (e.g., Earls & Hay, 2006) or nurses (e.g., Wagner, Jenkins, & Smith, 2006) as champions of developmental screening who help implement developmental screening practices in health care settings. Academic detailing is another strategy, which "involves educational outreach through a personal visit by a trained person to health professionals in their own settings," similar to the model used by pharmaceutical sales representatives to educate physicians about their products (Honigfeld, Chandhok & Spiegelman, 2012).

In addition, some families with young children may not fully access well child visits with a pediatrician and thus miss the opportunity for developmental screening at those visits. Many

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⁷ The AAP reaffirmed its support of this position in 2011, when the original policy statement expired.

families with limited resources may not have a medical home, with some estimating more than one out of four children in the US do not have regular access to healthcare (Redlener, Brito, Johnson, & Grant, 2007). Poverty is associated with other health risks ranging from inadequate access to preventive health care services, to poor nutrition.

Children living in poverty are 1.3 times as likely to have a developmental delay and 1.4 times as likely to have a learning disability as children who are not poor (Wood, 2003). Children who are poor are at increased risk for such issues due to myriad and complex family, social, and economic factors. There is a strong association between poverty and poor pregnancy outcomes (e.g., Brooks-Gunn & Duncan, 1997). These children are also likely faced with higher levels of stress due to their environments. Frequent stress responses are linked with anatomic changes and dysregulations in the brain (Shonkoff, Garner, Siegel, et al., 2012; McEwen, 2007). With these changes comes an increase in physical and mental health problems, opening the possibility for later academic barriers (Gunnar & Quevedo, 2007). Increased vulnerability occurs during periods of rapid brain development, such as early childhood. Wood (2003) reports that poverty during early childhood has a greater effect on educational attainment than it does later in childhood.

Given these challenges, it is also important that developmental screening resources be accessible in settings other than pediatric offices. Some authors have suggested that turning toward community-based resources (such as childcare providers) for developmental screening may be a more effective way to reach children who go undiagnosed and untreated (Branson, Vigil, & Bingham, 2008). Bricker and colleagues (2013) argue that by coordinating and centralizing developmental screening activities to specialized community programs (rather than asking all providers to do developmental screening), administrative tasks can be reduced and already limited resources used efficiently. Community programs often serve a high volume of high-risk clients who would benefit from increased access to screening outside of primary care (Roux et al., 2012). On the other hand, community programs may have a role in increasing access to clinic-based developmental screening. For example, in an examination of the effect of implementing a developmental screening pilot program at WIC sites, it was found that the similarities shared with a pediatric setting (scheduled visits, established rapport, connection to other resources) would allow for a natural transition into offering more formal screening (Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005).

Professional qualifications and training to conduct developmental screening

In general, developmental screening can be performed by individuals with a wide range of education and experience. That is, a specific degree or set of credentials is not usually required. Unlike assessments which usually require advanced training and specific user qualifications⁸, professionals and paraprofessionals in a variety of fields can be trained to implement screening

⁸ Some commercially published autism-specific screening tools do have user qualifications, such as the Social Communication Questionnaire (SCQ) and the Pervasive Developmental Disorders Screening Test-II (PDDST-II). User qualification requirements prohibit users who do not meet the qualifications from purchasing the measures from the publisher.

tools within the context of healthcare, social services, early childhood education, or other community settings. Typically, publishers of evidence-based screening tools provide users extensive training materials, including user manuals, online training, and comprehensive resources for using the screening tools, interpreting the results, communicating results to caregivers, and making referrals based on screening results.

Types of developmental screening tools

The screening tools reviewed here can be classified as either broad band (general) or autism-specific. Broad band screeners, including the *Ages and Stages Questionnaire* (ASQ; Squires, Potter, & Bricker, 1999) and the *Parents' Evaluation of Developmental Status* (PEDS; Glascoe, 2010), are designed to address a range of developmental and behavioral domains and make recommendations for further evaluation and follow-up in areas of identified risk. Broad band screening measures are designed to address general developmental skills in young children (Bricker et al., 2013). In contrast, autism-specific screeners, including the *Modified Checklist for Autism in Toddlers* (M-CHATTM; Robins, Fein, & Barton, 1999), are designed and used to screen for autism only. Other "narrow band" screeners exist that are focused on other specific areas of development and/or behavior.

Summary of selected existing broad band screening tools

In the most recent AAP policy statement (2006) that included recommendations for developmental screening, the authors included a summary of nine general developmental screening tools, three screening tools specifically focused on language and cognitive functioning, two motor screening tools, and six autism-specific screening tools. Each of the screening tools is designed for a different age range, with some developed for use at a specific age or stage (e.g., newborn, toddler), while others can be used with a wide range of ages (e.g., 0-6 years). While the AAP article (2006) is careful to state that it does not approve or endorse specific screening tools, and the list of screening tools is not exhaustive, it provides a useful start for considering the most prominent broad band tools for developmental screening in young children.

Information about developmental screening tools, both broad band and condition-specific, is available from a number of sources, including the 2006 AAP policy statement, Bricker and colleagues' (2013) volume describing various community approaches to developmental screening and early detection of children with developmental delays, Macy's (2012) summary of evidence supporting developmental screening instruments, and a number of web sites, including those of the National Early Childhood Technical Assistance Center (NECTAC; http://www.nectac.org/~pdfs/pubs/screening.pdf) and the Children's Health Fund (<a href="http://www.childrenshealthfund.org/sites/default/files/dev-and-mental-health-primary-care-screening-tools.pdf).

The ASQ and PEDS measures that are used by one or more of the First 5 LA-supported programs are included in the AAP's list of broad band screening tools and are some of the most widely used and psychometrically sound developmental screening tools available. In the rest of this literature review, we focus on the ASQ and related measures (ASQ-3 and ASQ-SE) as well as the PEDS and related measures (the PEDS and the PEDS: Developmental Milestones, or PEDS:DM) as broad band developmental screening tools, and the M-CHAT as an autism-specific screening tool. These measures are widely used, have strong evidence of reliability and validity, and are used by programs currently supported by First 5 LA to offer developmental screening.

Overall strengths and weaknesses

Both the ASQ and the PEDS have been shown to be effective developmental screening tools. However, some studies have shown differences between the two exist and should be considered. For example, one study that examined sensitivity (the proportion of children correctly identified as needing further assessment by the screening tool) and specificity (the proportion of children correctly included as developing typically by the screening tool) in the ASQ and the PEDS found that though both tools have reasonable psychometric properties for developmental screening in primary care settings, the ASQ had significantly higher sensitivity and specificity across a variety of age groups (Limbos & Joyce, 2011). Another found significant discordance between PEDS and ASQ developmental screens, with a third of the children who underwent both screens at the same primary care visit failing one but not the other (Sices, Stancin, Kirchner, & Bauchner, 2009).

One challenge for developmental screening tools used with young children is the identification of developmental concerns in children with physical problems that may affect the presentation of developmental delays (for example, hearing loss). In one study, ASQ scores were relatively ineffective at identifying non-communication related developmental concerns in children with hearing loss, even though 32% of the population in the study had a developmental delay outside of communication (Wiley & Meinzen-Derr, 2013). Prematurity can have an effect on developmental screening results as well (Kuban et al., 2009; Johnson & Marlow, 2009).

Among concerns with screening tools in general, some have questioned the utility of relying on parental concern as evidence in completing developmental screening tools. Deakin-Bell and colleagues (2013) found that although an evaluation of the open-ended parental comments on the ASQ did not meet the National Health and Medical Research Council guidelines for adequate psychometric properties, they still found value in observing caretaker comments. Other studies have found that certain types of parental concerns can better predict an actual mental health problem or developmental delay than others (Glascoe, 1997; Glascoe, 2003); noting the presence of these predictive concerns can substantially reduce over-referrals to autism-specialty services (Glascoe, Macias, Wegner, & Robertshaw, 2007). After reviewing a number of relevant studies, the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society concluded that parental concerns about developmental and behavior problems were highly predictive of actual developmental delays (Filipek et al., 2000).

Another issue that has been raised is the idea that if a developmental screening tool tends to produce false positives (that is, when the screening shows a possible developmental delay but further evaluation does not identify an actual delay), that can lead to systematic over-referring, which can, in theory, create a strain on resources required for further assessment and intervention. At the level of individual families, there is also potential for parents to worry about their child's developmental progress if the basis for such concern is unfounded (e.g., Cadman et al., 1987). Sices (2007) reports that developmental screening practices generally yield accurate results, and cites the ASQ in particular as having a low false positive rate. Glascoe⁹ (2001) shared another perspective in that children with false positive developmental screening results may still be at some level of risk, and may benefit from referral to additional services to assist with education, language, or cognitive skills.

There has been a shift toward making developmental screening more widely available in the community, including making screening tools available online. This can save valuable resources for providers and allow for faster, real-time screening results to be delivered to the parents. Mode of administration does not appear to affect the validity of developmental screening tools. For example, in a study that looked at converting the ASQ to an online format, it was found that the paper-pencil and web-based measures can be considered equivalent with no mode effect present (Yovanoff, Squires, & McManus, 2013). However, the use of online tools can also create a divide between economically disadvantaged families and those with reliable access to computers and the Internet (Hambidge, Phibbs, Beck, & Bergman, 2011).

Review of major "broad band" developmental screening tools: ASQ and PEDS

At the four programs studied for this project, the tools primarily used are designed to be low-cost, low barrier, and easy for staff and parents to complete. The primary developmental screening tools currently in use at these programs are the ASQ, ASQ-SE, PEDS, and PEDS:DM tools. The PEDS and ASQ tools, as well as related ASQ-SE and PEDS:DM, respectively, rely on eliciting observations and/or concerns from parents, providing a quick way to use parental observations to monitor child development. In community environments (as compared to primary care settings), using parental observations in conjunction with these tools provides a solution for quick, low cost screening (Bricker & Squires, 1989; Glascoe & Marks, 2011). The National Academy for State Health Policy also recommends these developmental screening tools because they are "simple questionnaire[s]" that "may improve the accuracy of the screening process while empowering them and conserving valuable professional resources." As this literature review is designed to complement the review of four First 5 LA-supported programs that use the ASQ and PEDS tools, Table 1 provides more detailed information about the ASQ-3, the ASQ-SE, the PEDS, and the PEDS:DM instruments in terms of criteria for evaluating potential developmental screening tools. 11

⁹ Glascoe is the author of the PEDS test.

¹⁰ http://www.nashp.org/identifying-children-and-families-at-risk

¹¹ Source for evaluation criteria: Marian Williams & Marie Poulsen, personal communication, February 2014.

Table 1. Criteria for Evaluating Potential Developmental Screening Tools: Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|--|--|--|---|---|
| Age Range | 1 month – 66 months. ¹³ | 3 months – 66 months. ¹⁴ | Can be used from birth to 8 years of age (7 years 11 months). 15 | Can be used from birth to 8 years of age (7 years 11 months). 16 |
| Source of | Parents or caregivers complete | Parents or caregivers complete | Parent concerns are elicited to | Based on parent report. Can be |
| Information | the questionnaires. Professionals, paraprofessionals, or clerical staff scores them. | the questionnaires. Professionals, paraprofessionals, or clerical staff scores them. | complete the screening. It is best completed by interview format. | completed by parent self- report, interview, or administered directly to children. |
| Domains assessed | Five developmental areas: communication, gross motor, fine motor, problem solving, and personal-social. | Self-regulation, compliance, communication, adaptive behaviors, autonomy, affect, and interaction with people. | Children's language, motor skills, self-help, early academic skills, behavior, and socialemotional/mental health. | Each item addresses a specific developmental domain. Fine motor, gross motor, expressive language, receptive language, self-help, social-emotional, and for older children, reading and math. |
| Normed on a large number of children from diverse backgrounds | ASQ-3 revised in 2009 based on data collected since 2004. National sample consisted of 15,138 children and is representative of the U.S. population in geography and ethnicity, and includes representation across socioeconomic groups. | Normative studies included 3,014 preschool-age children and their families, representative of the U.S. population, distributed across eight age intervals from 6 months through 60 months. | Re-standardized in 2012 on 49,150 families in a nationally representative, diverse sample in 38 U.S. States and Canada. 17. | Standardized and validated on more than 1600 children around the US, who participated from health care settings as well as day care centers and preschools. 18 |

Source for evaluation criteria: Marian Williams & Marie Poulsen, personal communication, February 2014.
 http://agesandstages.com/asq-products/asq-3/asq-3-at-a-glance/

http://agesandstages.com/asq-products/asqse/asqse-at-a-glance/

www.pedstext.com/LearnAboutPEDS/IntroductiontoPEDS.aspx

http://www.pedstest.com/AboutOurTools/LearnAboutPEDSDM.aspx

¹⁷ http://www.pedstest.com/ComparisonofPEDSToolsandASQTools.aspx

¹⁸ Because the items for the PEDS:DM were selected from two Brigance tools (Inventory of Early Development-II and Comprehensive Inventory of Basic Skills-Revised), the norms for the PEDS:DM are based on the norms for these two tools.

Table 1. Criteria for Evaluating Potential Developmental Screening Tools: Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|--|---|---|--|---|
| Appropriate reading level for the population | 4 th – 6 th grade level. | 5 th – 6 th grade. | 4 th - 5 th grade level. | 1 st – 2 nd grade level. |
| Available translations | Available in English, Spanish and French. For pediatricians, the electronic patient interview (ASQ-PTI) is also available in English, Spanish, Somali, and Hmong. Translations are in development in a "number of languages." ¹⁹ | Available in English, Spanish and Norwegian. For pediatricians, the electronic patient interview (ASQ-PTI) is also available in English, Spanish, Somali, and Hmong. Translations are in development in a "number of languages." 20 | The PEDS is printed in English, Spanish, and Vietnamese, with licensed translations available in over 21 different languages, with others in progress. When translating the tools, the author typically uses a range of bilingual health care providers to create and test the translation with families and staff. To address dialect issues, translation teams are built (e.g. to translate Spanish, teams include Argentinians, Mexicans, Chileans, Spaniards, etc.) with the goal of creating a single translation that works well for all groups. If this is not possible, unique translations are created for each speaker group. ²¹ | The PEDS:DM is published in English and Spanish, both for online and print versions. Licensed translations can also be obtained in Arabic, Chinese, French Canadian, Portuguese, Serbian (Cyrillic), with other languages in progress. 22 |

http://agesandstages.com/what-is-asq/languages/
thtp://agesandstages.com/what-is-asq/languages/
http://agesandstages.com/what-is-asq/languages/
http://www.pedstest.com/Translations/PEDSinOtherLanguages.aspx
http://www.pedstest.com/Translations/PEDSinOtherLanguages.aspx

Table 1. Criteria for Evaluating Potential Developmental Screening Tools:

Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|---|--|---|---|--|
| Validated/norms collected in the last 10 – 15 years | Norms for the ASQ-3 were developed using questionnaire data collected between January 2004 and June 2008. | Validity, reliability, and utility studies were conducted on ASQ:SE between 1996 and 2001. | Re-standardized in 2012 on a nationally representative sample of 49,150 families in 38 U.S. States and Canada. ²³ | Published in 2007. Standardized on a nationally representative sample of 1,619 children around the US. |
| Reliability ²⁴ and Validity ²⁵ | Validity = .8288. Test-retest reliability ²⁶ , measured by comparing the results of two questionnaires completed by the same parent at a 2-week time interval, is .91. Inter-rater reliability ²⁷ , measured by parent agreement on classifications, is .92. ²⁸ | Test-retest reliability, measured by comparing the level of agreement when a random sample of parents completed two questionnaires at 1 – 3 week intervals, is .94. Concurrent validity ²⁹ = .8195, with an overall agreement of .93. ³⁰ | Test-retest reliability studies were conducted on 193 children and revealed 94% agreement in PEDS Paths and parents' concerns. Inter-rater reliability was established on 355 children for both categorization of concerns (95% agreement) and for correct assignment to PEDS Paths (97% agreement). 31 | Inter-rater reliability is between .82 and .96. Test-retest reliability is .9899. 32 |

²³ http://www.pedstest.com/ComparisonofPEDSToolsandASQTools.aspx

Reliability refers to the degree to which a test produces similar scores each time it is used; stability or consistency of the scores produced by an instrument (www.apa.org/research/action/glossary.aspx).

Validity refers to the extent to which a test measures what it was intended to measure (www.apa.org/research/action/glossary.aspx).

Test-retest reliability is a measure of consistency of the scores of the same people on the same test given on two different occasions (www.apa.org/research/action/glossary.aspx).

In statistics, inter-rater reliability, inter-rater agreement, or concordance is the degree of agreement among raters (http://en.wikipedia.org/wiki/Inter-rater_reliability).

http://agesandstages.com/asq-products/asq-3/asq-3-at-a-glance/

²⁹ Concurrent validity is demonstrated when a test correlates well with a measure that has previously been validated (http://en.wikipedia.org/wiki/Concurrent_validity).

³⁰ http://agesandstages.com/asq-products/asqse/asqse-technical-qualities/

http://www.pedstest.com/Research/PEDSStandardization.aspx

Brothers, Glascoe, & Robertshaw, 2008.

Table 1. Criteria for Evaluating Potential Developmental Screening Tools:

Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|--|--|--|--|---|
| Sensitivity ³³ and Specificity ³⁴ | Sensitivity ranged from 75% for the 6 month questionnaire to 100% for the 4-, 14-, 16-, and 54-month questionnaires; 86% overall agreement. Specificity ranged from 70% for the 14-month questionnaire to 100% for the 2-, 16-, and 54-month questionnaires, with 85% overall agreement. 35 | Sensitivity ranged from 81% - 85%, with 78% overall sensitivity. Specificity ranged from 90% - 98%, with 95% overall specificity. ³⁶ | Sensitivity = 86%; specificity = 74%. 37 | The PEDS:DM has sensitivity and specificity between 70% and 93% across ages and developmental domains. 38 |
| Administration and scoring | Each questionnaire takes 10 – 15 minutes to complete and 1 – 3 minutes to score. | Each questionnaire takes 10 – 15 minutes to complete and 1 – 3 minutes to score. | When administered online, takes 10 – 15 minutes and provides real-time automated scoring. When administered on paper, takes about 5 – 10 minutes for parents to complete and 1 – 2 minutes to score. | Takes about 5 minute to administer, one minute to score. |

³³ Sensitivity refers to the proportion of children correctly identified as needing further assessment by the screening tool and who perform below the expected level on a standardized assessment (Wagner, Jenkins, & Smith, 2006).

³⁴ Specificity refers to the proportion of children correctly included as developing typically by the screening tool and who perform at the expected level on a standardized assessment (Wagner, Jenkins, & Smith, 2006).

³⁵ http://agesandstages.com/asq-products/asq-3/asq-3-technical-qualities/

http://agesandstages.com/asq-products/asqse/asqse-technical-qualities/

http://www.pedstest.com/Research/PEDSStandardization.aspx

http://www.pedstest.com/AboutOurTools/LearnAboutPEDSDM/ResearchReviewandCompliance.aspx

Table 1. Criteria for Evaluating Potential Developmental Screening Tools: Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|------------------|----------------------------------|--|-----------------------------------|---------------------------------|
| Free or low cost | One time investment for each | As of 2010, a complete ASQ-SE | As of 2010, a starter kit for | As of 2010, the PEDS-DM |
| | program with no reordering. | Starter Kit costs \$194.95. This | PEDS cost \$36 and includes 50 | Screen Starter Kit cost \$275; |
| | Starter kit is \$250.00 and | kit contains eight | PEDS response forms, 50 | including the manual, screening |
| | includes ASQ-3 User's guide, | photocopiable print masters of | reusable score/interpretation | materials, and 100 reusable |
| | photocopiable master set of | the questionnaires and scoring | forms, and a 12-page brief | record sheets. No |
| | questionnaires, and scoring | sheets, a CD-ROM with | guide to scoring and | photocopying is allowed; |
| | sheets. | printable PDF questionnaires, | interpreting results. 40 No | additional packs of 100 forms |
| | | and the ASQ-SE User's Guide. ³⁹ | photocopying is allowed, so | are available for \$32 each. 41 |
| | In 2009, the ASQ Pro and ASQ | | forms must be reordered as | |
| | Enterprise, online management | In 2009, the ASQ Pro and ASQ | needed. | For the online version, payment |
| | systems for singe- and multi- | Enterprise, online management | | is made quarterly and varies |
| | site programs, were | systems for singe- and multi- | For the online version, payment | depending on number of |
| | introduced. Programs must | site programs, were | is made quarterly and varies | screens administered. Same |
| | purchase the starter kit for the | introduced. Programs must | depending on number of | pricing as PEDS tool. |
| | ASQ-3, then can utilize the | purchase the starter kit for the | screens administered. | |
| | online system for screening, | ASQ-SE, then can utilize the | However, each screen will cost | |
| | scoring, and stowing the | online system for screening, | at most \$2.75 and at the least | |
| | results. The annual subscription | scoring, and stowing the | \$2.06, with estimates indicating | |
| | fee for ASQ Pro is \$149.95 with | results. Same pricing as ASQ-3. | that screens cost roughly \$2.50 | |
| | 50 free screens; for the ASQ | | for most clients. | |
| | Enterprise, the annual fee is | | | |
| | \$499.95 with 100 free screens. | | | |
| | Sliding scale pricing after that | | | |
| | for both tools. | | | |

https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/teaching/eecd/Assessment/Ongoing%20Assessment/compendium-profiles.pdf https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/teaching/eecd/Assessment/Ongoing%20Assessment/compendium-profiles.pdf https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/teaching/eecd/Assessment/Ongoing%20Assessment/compendium-profiles.pdf

Table 1. Criteria for Evaluating Potential Developmental Screening Tools:

Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|---------------------|---------------------------------|--------------------------------|---|----------------------------------|
| Ease of integration | The ASQ-3 permits results of | The ASQ-PTI allows, for a fee, | The PEDS Online website | PEDS:DM results can be |
| with an Electronic | the screening to be entered | for completion of the ASQ-SE | indicates that it is possible to | integrated with EHR in a similar |
| Health Record (EHR) | into the EMR by entering the | online and for results to be | link a program's EHR with PEDS | fashion as results from a PEDS |
| | child's scores without | interfaced to a program's EHR. | Online with 3-4 hours of | assessment. For more |
| | permission from the publisher. | | collaboration between the | information, please see the link |
| | The program may also create | | program IT and PEDS staff IT. | in the footnote. ⁴⁵ |
| | fields in the EMR that identify | | Another suggestion is to copy | |
| | ASQ-3 questions by number | | and paste PEDS results into the | |
| | only or scan non-modifiable, | | local EHR. | |
| | completed questionnaires into | | | |
| | the system. However, the ASQ- | | For more information, please | |
| | 3 may not be made to be | | see the link in the footnote. ⁴⁴ | |
| | interactive and incorporated | | | |
| | into the EMR. ⁴² | | | |
| | =l .co.p=: !! | | | |
| | The ASQ-PTI allows, for a fee, | | | |
| | for completion of the ASQ-3 | | | |
| | online and for results to be | | | |
| | interfaced to a program's | | | |
| | EHR. ⁴³ | | | |

⁴² "1-If a practice uses the paper questionnaire and then enters only the child's scores into the EMR that would not require any permission from Brookes [the publisher]. 2-If the practice's EMR has fields that identify the ASQ questions by number only (not including the text of each question) along with spaces to indicate what the parent has marked for the answers, that would not require any permission from Brookes. 3-If a practice scans a completed ASQ questionnaire into the EMR (and/or the Information Summary Sheet), as long as that completed questionnaire is not interactive and not modifiable that would not require any permission for Brookes. This is...equivalent of a practice photocopying a completed ASQ questionnaire and placing it into the child's paper file. 4-Any use (EMR or otherwise) that complies with their current ASQ photocopying release is acceptable; A copy of the release is [available from the publisher]. 5-Making the ASQ interactive and using it in any way, including incorporating it into the EMR, is not something that is allowed without Brookes' prior written consent." http://www.nashp.org/sites/default/files/abcd/abcd.nc.partIII.asq.emr.pdf

http://www.brookespublishing.com/resource-center/screening-and-assessment/asq/asq-online/pti/

https://forepath.org/about EMR Integration.php

https://forepath.org/about EMR Integration.php

Table 1. Criteria for Evaluating Potential Developmental Screening Tools: Comparison of Ages and Stages (ASQ) and Parents' Evaluation of Developmental Status (PEDS) Measures¹²

| Criteria | ASQ-3 | ASQ:SE | PEDS | PEDS:DM |
|------------------------------------|---|---|--|--|
| Available | Yes. The ASQ-3 Information | Yes. The User Manual includes | Yes. The screener comes with | Yes. The PEDS:DM comes with |
| anticipatory guidance materials | Summary sheet provides a list of actions that may follow a screening (based on child's scores). | criteria that provide staff with guidelines for how to interpret ASQ-SE scores and recommended follow-up | guidance about follow-up steps based on the path the child is placed on. | guidance and suggested follow- up steps based on results of the screening. |
| | | actions. | | |

Review of selected autism-specific screening tools

The article that presented the AAP recommendations for developmental screening in primary care settings identified six screening tools specifically focused on autism. While the AAP (2006) states that it does not approve or endorse specific screening tools, this list is a useful start for considering the most prominent autism screening measures for young children. The list of autism-specific screening tools presented in the AAP article includes the *Modified Checklist for Autism in Toddlers* (M-CHAT; Robins, Fein, & Barton, 1999) used by 211 LA County, as well as the following other measures: the *Checklist for Autism in Toddlers* (CHAT; Baird et al., 2000); the *Pervasive Developmental Disorders Screening Test-II Stage 1 Primary Care Screener* and *Stage 2-Developmental Clinic Screener* (PDDST-II; Siegel, 2004); the *Screening Tool for Autism in Two-Year-Olds* (STAT; Stone, Coonrod, & Ousley (2000); and the *Social Communication Questionnaire* (SCQ; Rutter, Bailey & Lord, 2003; formerly known as the *Autism Screening Questionnaire-ASQ*).

The literature on autism screening tools differentiates between Level 1 and Level 2 screening instruments. Level 1 screening tools are designed to be brief and used to find children at risk for ASD in the general population. In contrast, Level 2 screening tools are usually more complex and are used to screen for ASD in children referred because of developmental concerns. For this review, we primarily focus on Level 1 screening tools. Examples of Level 2 screening tools include the *STAT*, as well as the *Baby and Infant Screen for Children with aUtism Traits* (BISCUIT; Matson et al., 2009), which has strong psychometric properties as evidenced in a number of peer-reviewed publications, but is more appropriate for assessing diagnostic features of autism in infants and toddlers, rather than for population-level screening (e.g., Horovitz & Matson, 2014).

Among the Level 1 instruments, the M-CHAT appears to be the most frequently used and studied autism-specific screening tool among children age 16 to 48 months. A search of the PsycInfo database produced 70 articles that were about or used the M-CHAT. The M-CHAT was adapted from the CHAT and optimized for the US healthcare system (the CHAT was developed in Great Britain). The M-CHAT was recently revised (M-CHAT-R/F; Robins, Fein, & Barton, 2009); this review examines both the M-CHAT and the M-CHAT-R/F.

The PDDST-II is another Level-1 autism screening tool designed to identify children at risk age 12 to 48 months, although it is most effective between 18-48 months of age (Duncan, Montgomery, & Francis, 2007). However, there is relatively little peer reviewed published research examining its use (Robins, 2008; Bryson, Rogers, & Fombonne, 2003). McQuistin and Connie (2006) found that a number of the items in the PDDST-II are such that they do not uniquely reflect ASD but may also reflect behaviors associated with ADHD.

The SCQ may be a useful tool for screening for autism and ASD in children age 4 years and older, although it is not appropriate for screening at 18 months to meet AAP autism-specific screening guidelines (Robins, 2008). Research examining the SCQ's utility in toddlers found that

it demonstrated a high rate of false positives and had a poor balance between sensitivity and specificity (Oosterling et al., 2010).

What is the value of autism-specific screening as compared to broad band developmental screening? Research that examined whether a broad band developmental screener and an autism-specific screener yielded similar rates of positive flags for autism concerns found results that suggest the PEDS and the M-CHAT measure very different domains of developmental concerns (Pinto-Martinet al., 2008). The M-CHAT has been found to have good sensitivity, and thus is appropriate for initial screening in the general population (Mawle & Griffiths, 2006; Eaves, Wingert, & Ho, 2006). Children who fail the M-CHAT who have gone on to be subsequently diagnosed often receive diagnoses such as ASD, as well as developmental delay or developmental language disorder; specific behavioral markers are important to consider in arriving at specific diagnoses (Ventola et al., 2007). However, it has been noted that although they are useful for initial screening, some autism-specific screening tools are not designed to differentiate ASD from other developmental delays (Nah, Young, Brewer & Berlineri, 2014).

Overall, the literature on instruments designed specifically for screening for autism in young children is fairly critical. Reviews describe existing screening tools as limited in their ability to accurately predict an ASD diagnosis. According to Bryson, Rogers, and Fombonne (2003), "the early detection of autism is limited by the lack of early-screening instruments that are sensitive as well as specific to autism." In discussing the findings of their large-scale pediatrics-based autism screening study, Chlebowski, Robins, Barton, and Fein (2013) said that "it is important to acknowledge that it may not be feasible to develop a screening instrument with a high sensitivity for ASD that does not also identify children with other developmental delays due to symptom overlap between diagnoses and the heterogeneity of symptom presentation in ASD."

One issue to be aware of in examining autism-specific screeners is that some commercially published measures have specific user qualifications in addition to whatever training would be needed to for appropriate use of the screening tool. For example, the publisher of the SCQ requires users to have at least a master's degree in a relevant field, or a bachelor's degree in a relevant field AND evidence of licensing or certification from an organization that requires training and experience in assessment. The publisher of the PDDST-II requires similar education, experience, certification, and/or licensure. Even if a particular screening tool does not have user qualifications identified by the author or publisher, Charman (2014) noted that "it is critical that those using such screens in clinical practice understand how to interpret data from published studies and consider how screening information is communicated to parents."

Table 2 provides a summary of information about selected autism-specific screening tools with respect to the criteria presented earlier in this report for the ASQ and PEDS broad band screening tools.

Table 2. Criteria for Evaluating Potential Level-1 Autism-Specific Screening Tools

| Criteria | M-CHAT TM | M-CHAT-R/F TM | scq | PDDST-II (Stage 1) |
|---|--|--|--|--|
| Age Range | 16-30 months | 16-30 months | Over 4 years, with a mental age over 2 years | 12-48 months |
| Information source | Parent report | Parent report | Parent report | Parent report |
| Domains assessed | Risk for ASD (Pass/Fail) | Risk for ASD (Low/Medium/High Risk) | Risk for ASD (Total score with cutoff points) | Risk for ASD; further assessment warranted |
| Normed on a large number of children from diverse backgrounds | Development sample <i>n</i> = 1,293 children (2001) | n = 16,071 children screened at 18- and 24-month well-child visits in metropolitan Atlanta and Connecticut | Unknown. Normative data may be presented in manual, which is available for purchase. | "Almost 1000 subjects from different index and comparison samples took part in the development of PDDST- II" (PsycInfo test listing) |
| Appropriate reading level for the population | Approximately 6 th grade | Approximately 6 th grade | Not indicated | Not indicated |
| Available translations | English and 65 translations including Spanish, French, Chinese, Korean, Japanese, Vietnamese, Filipino, Farsi | English and following translations: Albanian, Chinese, French, Korean, Spanish (Spain), Spanish (S. America), and 12 others in progress | English and following translations: Danish, Dutch, Finnish, German, Hebrew, Hungarian, Icelandic, Italian, Japanese, Korean, Norwegian, Romanian, Russian, Spanish & Swedish | English and Spanish |
| Validated/norms collected in the last 10 – 15 years | Replication (n = 3,793) and follow up (n = 1,416) studies (2008) Population screening study (n = 18,989) in geographically diverse sample (2013) | n = 16,071 children screened at 18- and 24-month well-child visits in metropolitan Atlanta and Connecticut | Validated <i>n</i> = 200 children (160 with pervasive developmental disorder, 40 without). Copyright on manual 2003 | Validated n = 681 children at risk for ASD and 256 children with mild-to-moderate other developmental disorders (2004) |
| Reliability and Validity | Cronbach's α ⁴⁶ =.8385 | Cronbach's α =.63 for all items Cronbach's α = .79 for 2-stage scoring ⁴⁷ | Not indicated | Not indicated |

⁴⁰

⁴⁶ Cronbach's α (alpha) is a measure of internal consistency reliability, the extent to which a test yields similar scores across its different parts (www.apa.org/research/action/glossary.aspx). Higher scores (closer to 1.0) indicate greater internal consistency.

Table 2. Criteria for Evaluating Potential Level-1 Autism-Specific Screening Tools

| Criteria | M-CHAT TM | M-CHAT-R/F TM | scq | PDDST-II (Stage 1) |
|-----------------------------|---|--------------------------------|-------------------------------|------------------------|
| Sensitivity and Specificity | Designed to maximize | For initial scoring: | Sensitivity 0.85 (moderate); | Sensitivity 0.85-0.92 |
| | sensitivity; high false positive | Sensitivity .911 | specificity 0.75 (moderate) | (moderate to high) |
| | rate | Specificity .955 | | Specificity 0.71-0.91 |
| | | PPV .138 | | (moderate to high) |
| | Sensitivity 77%-92% | | | |
| | Specificity 27%-43% | For 2-stage scoring: | | |
| | | Sensitivity .667854 | | |
| | PPV ⁴⁸ = .3136 for screening | Specificity .992995 | | |
| | alone | PPV .450509 | | |
| | PPV = .6874 with telephone | | | |
| | follow-up | | | |
| Administration and | Admin time 5-10 minutes | Admin time 5-10 minutes | Less than 10 minutes | 10-20 minutes |
| scoring | Can be scored in less than two | Can be scored in less than two | | |
| | minutes | minutes | | |
| Free or low cost | Available for free download | Available for free download | Commercially published | Commercially published |
| | for clinical, research, and | for clinical, research, and | (Western Psychological | (Pearson) |
| | educational purposes | educational purposes | Services) | Complete kit is \$179 |
| | | | Kit with 20 Current AutoScore | |
| | Also available integrated with | | Forms , 20 Lifetime AutoScore | |
| | PEDS Online (see above) | | Forms, and manual is \$129 | |
| | | | | |
| | | | Unlimited-use administration | |
| | | | and scoring CD \$215.50 | |

⁴⁷ For a child determined to be at medium risk using the M-CHAT R/F, a 2-stage scoring procedure includes a follow-up questionnaire used soon after the original screening to obtain additional information needed to more definitively classify the child as either high risk or low risk (www.nih.gov/news/health/dec2013/nichd-23.htm).

PPV = Positive Predictive Value, which indicates the likelihood that a person with a positive test result would actually have the condition for which the test is used. The higher the value of the positive predictive value (for example, 90 percent would be considered a high value), the more useful the test is for predicting that the person has the condition (https://effectivehealthcare.ahrq.gov/index.cfm/glossary-of-terms).

Table 2. Criteria for Evaluating Potential Level-1 Autism-Specific Screening Tools

| Criteria | M-CHAT TM | M-CHAT-R/F TM | scq | PDDST-II (Stage 1) |
|--------------------------|--------------------------------|-------------------------------|---------------|--------------------|
| Ease of integration with | "If you are part of a medical | "If you are part of a medical | Not indicated | Not indicated |
| an EHR | practice, and you want to | practice, and you want to | | |
| | incorporate the M-CHAT into | incorporate the M-CHAT-R | | |
| | your own practice's electronic | questions into your own | | |
| | medical record (EMR), you are | practice's electronic medical | | |
| | welcome to do so. However, if | record (EMR), you are | | |
| | you ever want to distribute | welcome to do so. However, if | | |
| | your EMR page outside of | you ever want to distribute | | |
| | your practice, please contact | your EMR page outside of | | |
| | <u>Diana Robins</u> to request | your practice, please contact | | |
| | permission." 49 | Diana Robins to request | | |
| | | permission." 50 | | |
| Available anticipatory | Not indicated | Not indicated | Not indicated | Not indicated |
| guidance materials | | | | |

http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html
 www.mchatscreen.com

Screening for maternal depression

Screening for maternal depression is a practice that may be useful in programs that also screen for developmental delays in young children. Among the programs studied for this review, Welcome Baby includes the PHQ-9 as a screen for maternal depression with its program participants, and the 211 Developmental Screening and Care Coordination project has been considering adding this to its protocol. The PHQ-9 is available for free (www.phqscreeners.com) and has been widely studied. Other major depression screening tools include the Beck Depression Inventory-II (BDI-II; Beck, Stern, & Brown, 1996) and the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The BDI-II is commercially published (Pearson Assessment) and the CES-D is in the public domain. For post-partum depression, a frequently used measure is the 10-item Edinburgh Postnatal Depression Scale (EPDS; Cox, Holden, & Sagovsky, 1987), which is in the public domain and has evidence of its reliability and validity in a number of publications.

There are a number of reasons that programs may wish to screen for maternal depression along with developmental screening of young children. Parenting a child with developmental delays can increase parental stress (e.g., Secco et al., 2006), which in turn can lead to poor parental well-being (e.g., Eisenhower, Baker, & Blacher, 2009). There are many ways in which maternal depression is a risk factor for developmental delays and problem behaviors in young children (Schultz et al., 2013). Although the link between maternal depression and developmental delay is not fully understood (e.g., Cornish et al., 2005), it has been pointed out that early intervention programs for young children can provide an opportunity to identify and address depressive symptoms in their mothers (Feinberg, Donahue, Bliss, & Silverstein, 2012). Depression screening for adults is a covered preventive service under the Affordable Care Act (www.healthcare.gov).

Summary

Among the many screening tools for developmental delays in young children, the Ages and Stages (ASQ) family of measures as well as the Parents' Evaluation of Developmental Status (PEDS) and related instruments provide useful, low-barrier, psychometrically sound broad band screening of a range of developmental and behavioral domains in children 5 years of age and younger. Depending on the program, any suspicion of risk for developmental delay, and the point at which screening occurs, an autism-specific screening tool such as the Modified Checklist for Autism in Toddlers (M-CHAT) may be appropriate as well. These measures, which are currently in use by several First 5 LA-funded programs that conduct developmental screening and service system linkage, have been found to be useful tools for identifying children with possible delays or concerns and providing information which can serve as a basis for referral to further assessment, evaluation, and clinical services when appropriate.

⁵¹ User qualifications apply.

Part II: Methods and Findings

Two major approaches were used for data collection to inform this review. Qualitative data were collected through a semi-structured interview with managers of the four programs studied, while quantitative data were collected from each program to indicate, when available, information about the characteristics of the families served, the results of developmental screening provided, and any outcomes about linkage to services that emerged from the developmental screening.

Qualitative Data: Program Manager Interviews

Method

The Program Manager Interview is a semi-structured interview guide designed to elicit information about developmental screening practices at each of the programs studied. The interview protocol was intended to clarify the use of screening tools, their administration and follow-up procedures, as well as the program managers' perspectives on the strengths and weaknesses of the screening procedures. The interview protocol was drafted by The Measurement Group and refined in collaboration with First 5 LA staff. A copy of the Program Manager Interview protocol is included as Appendix B.

A total of 5 interviews were conducted by The Measurement Group (TMG)⁵² with 6 managers from the following programs that receive support from First 5 LA to conduct developmental screening: the **211 Developmental Screening and Care Coordination Project** (Patricia Herrera, MS, Project Director and Cheryl Wold, MPH, Evaluator; interviewed separately); **Best Start LA Welcome Baby** (Lili McGuinness, MSW, LCSW, Clinical Supervisor); the **Children's Bureau of Southern California Matching Funds Grant Program** (Vanessa Mendez, MA, School Readiness Program Coordinator); and the **Child & Family Center Matching Funds Grant Program** (Patricia Conwell, MA, Therapeutic Preschool Program Developer and Gabby Ochoa-DelGaudio, PsyD, Early Childhood Mental Health Consultant and Coordinator; interviewed together). Overall, this group of stakeholders has extensive experience, education, and training in fields closely related to child and family services.

All Program Manager Interviews were conducted by phone. Calls were recorded with the permission of those interviewed for assistance in ensuring the accuracy of notes taken during the call. All interviews were conducted by either Dr. Melchior and/or Ms. Brink. Interviews were conducted between January 14 and January 16, 2014. Responses to the Program Manager Interviews were entered in project databases (in NVivo 10 for qualitative data and in SPSS for quantitative data). Qualitative data were coded for major themes related to the perceived strengths and weaknesses of the screening tools, protocols, and processes of linking families to needed services. Themes were also coded with respect to "big picture" challenges to care

⁵² Interviews conducted by Lisa A. Melchior, Ph.D. and Amber Brink, B.A.

coordination for families with young children who screen positive for possible delays. The interview also served as a method to learn about what data programs collect to track their developmental screening activities.

Findings

Screening Tools and Protocols Used by First 5 LA Funded Programs

The four programs studied primarily use the PEDS (Parents' Evaluation of Developmental Status) and the ASQ (Ages & Stages Questionnaires) for developmental screening. Two of the four programs (211 and Children's Bureau) use the PEDS; the 211 Developmental Screening and Care Coordination project also administers the related PEDS: DM (PEDS: Developmental Milestones) and the M-CHAT (Modified Checklist of Autism in Toddlers) if the child is in the appropriate age range. Three of the four programs use the ASQ-3 (Ages & Stages Questionnaires-Third Edition) and the ASQ-SE (Ages & Stages Questionnaires-Social Emotional) screening instruments. The following figure provides an overview at a glance of the major features of developmental screening practices at these four programs.

Table 3. Overview of Developmental Screening Activities in First 5 LA Supported Programs

| | 211 LA County | Welcome Baby | Children's Bureau | Child & Family Center |
|--|---|---|--|---|
| Estimated Children Screened Most Recent Year | • n = 3,380 screened January 1, 2013 through December 31, 2013 | • n = 689 screened January 1, 2013 through December 31, 2013 (start-up period for this project) | • n = 194 screened July 1, 2012 through June 30, 2013 | • n = 12 screened July 1, 2012 through June 30, 2013 |
| Brief program description | Telephone-based information & referral service | Hospital- and home- based information and support for pregnant women and new moms | Semi-weekly center-based parent/child enrichment groups for families with child age 0-3 Weekly informal school readiness program for families with child age 0-5 Peer-led community enrichment program for families with child age 0-3 | Mental health consultation services in preschool setting |
| Goal of developmental screening relative to program | The primary purpose of the 211 Developmental Screening and Care Coordination project is to offer developmental screening to families with children age 0-5 years and if appropriate, provide linkages to additional resources | Developmental screening is conducted along with other screenings for mother-infant risk factors, including maternal depression | Developmental screening is offered to identify children at risk for developmental delay and make referrals as needed | Developmental screening is conducted as part of a comprehensive child-focused consultation |
| Context of developmental screening | Developmental screening offered to callers with at least one child age 0-5 years, with or without a stated concern | Conducted at 3-4 months postpartum and 9 months postpartum visits | Center-based enrichment: PEDS at intake, ASQ-3 every 4 months School readiness: periodic PEDS screenings Community enrichment: periodic PEDS screenings, followed by ASQ-3 if needed (determined case-by-case) | Flexible protocol can take place in multiple environments (e.g., preschool, home) Incorporates 2 hour clinical observation of child in preschool setting Triggered by teacher or clinician concerns |

Table 3. Overview of Developmental Screening Activities in First 5 LA Supported Programs

| | 211 LA County | Welcome Baby | Children's Bureau | Child & Family Center |
|------------------------------|--|---|--|---|
| Screening tools | • PEDS | • ASQ-3 | • PEDS | • ASQ-3 |
| used | • PEDS:DM | • PHQ-9 (for maternal | • ASQ-3 | • ASQ:SE |
| | • M-CHAT | depression) | | |
| Who conducts screening | • 3 dedicated Care Coordinators | Parent coach who has been working with the mother from prenatal visits, delivery, and postpartum | Center-based enrichment groups: child development educators School readiness: MSW intern or child development educators Community enrichment: child development educators | Early Childhood Mental Health Consultant and Coordinator (doctoral level clinician) |
| Training for screening staff | 6 weeks of training on the tools Training conducted by certified outside consultant Care Coordinators must have at least a bachelor's degree and experience in field related to early childhood development Bilingual English/Spanish | 2-day training about the ASQ: how to implement and administer the screening one day, basic child development class the next Trainer is clinical supervisor or director from Children's Institute, Inc. (CII) Additional training on attachment and bonding due to program focus on mother/baby dyad | The publisher of the ASQ, Brookes Publishing, provides materials that allow for interactive training. Also utilizes training that other agencies in the community may provide | Training provided by the Child Care Resource Center (CCRC), led by a professional trained in the screening Teaches staff how to administer the screening tool, help parents understand the tool and their child's development, talk to parents about the results of the screening, and use the screening results and their judgment to make referrals Screening staff also attend booster trainings as needed |
| Screening results based on | Parent/caregiver response | Parent/caregiver response | Parent/caregiver response | Parent/caregiver response, complemented by teacher and clinician observations |

Table 3. Overview of Developmental Screening Activities in First 5 LA Supported Programs

| | 211 LA County | Welcome Baby | Children's Bureau | Child & Family Center |
|--|--|---|---|---|
| Care coordination and follow-up of referrals | 1 part-time Care Coordinator assistant follows up with family and service provider (with consent of parent) Follow up at 15, 30, 60, and 90 days after screening Available to assist family as needed upon request | Family's progress tracked in case files Follow-up typically with family rather than referral agency, although program sometimes facilitates referrals Not intensive case management due to large caseloads Case typically closed at 9-month visit; subsequent outcomes not tracked | Follow-up occurs informally with parents No set follow-up protocol or interval In special circumstances where family is having a hard time getting connected to services, program may contact referral agency for follow-up | Follow-up occurs primarily with parents Screening results shared with teachers Program helps parents troubleshoot accessing services as needed Helps keep track of waitlists (not formally documented) |

The following sections describe how developmental screening is implemented in each of the four programs studied.

211 Developmental Screening and Care Coordination Project

211 LA County is the largest information and referral service in the US, serving as a gateway to the county's vast and complex social service delivery system. ⁵³ The 211 Developmental Screening and Care Coordination project, which is separate from but housed within the larger 211 LA County, offers free developmental screening to callers with a stated concern about a child age 0-5 years, as well as a sample of callers with children age 0-5 who do not have a stated developmental concern as the reason for their call to 211 LA County.

The 211 Developmental Screening and Care Coordination project uses the PEDS Online system for developmental screening, which includes the PEDS, PEDS:DM, and M-CHAT tools. Because of the nature of their protocols, which involve screening and making referrals over the phone, 211 managers and staff⁵⁴ describe the tools in the PEDS Online system as allowing them to do real-time screens in a quick and accurate manner. These tools have been in use by the 211 Developmental Screening and Care Coordination project since the program was first funded in 2009. Project managers and staff indicated that the tools were chosen because they are reliable screening tools that could be administered as interviews over the phone. The 211 Developmental Screening and Care Coordination project uses the PEDS as its primary developmental screening tool. If the child is present with the parent, the PEDS:DM may be offered for further screening; if the child is between 16 and 48 months the M-CHAT is also used.

Currently, there are three Care Coordinators on staff who perform developmental screening over the phone, and one Care Coordinator assistant who is primarily responsible for follow-up. Callers are connected to a Care Coordinator if they call 211 LA County with a developmental concern or have a child 0-5 years of age and accept the offer to take part in free developmental screening. To qualify for the screening, the 211 Developmental Screening and Care Coordination project requires that the caller is the parent or legal guardian of the child(ren); the child has not been screened in the last year by 211 LA County; the child is not already receiving services from a Regional Center or have an IEP at their school district; the child has not been diagnosed with a delay or a disability. The child may be in an early childhood education program as long as he or she has not been screened or does not receive specialized intervention services.

⁵³ http://www.211la.org/about-us/.

Additional data from qualitative interviews with 211 staff are available from a separate descriptive study of the 211 Developmental Screening and Care Coordination project (Melchior & Brink, 2014).

Screening is offered to all callers with a child 0-5 years of age who call because of a developmental concern. In addition, a sample of callers (at least 2 per week) with a child 0-5 years of age who call 211 for another reason are asked if they are interested in answering a "parent questionnaire" to help them understand about how their child(ren) is (are) learning and good on their age.

⁵⁶ Such as speech therapy, behavioral therapies, or early intervention services.

At the start of each call, the Care Coordinator explains the screening and its purpose, determines eligibility for the screening, obtains verbal consent, and notifies the caller that all calls are recorded for quality assurance purposes. Because the screening takes place over the phone, all of the information provided comes from parent observations elicited by the Care Coordinator. For the PEDS:DM, the parent and child may work together to accomplish tasks or the parent may ask the child to do something (e.g., "write the letter 'A'," "get me two toys," etc.) and report back to the Care Coordinator. If a child screens positive for a developmental delay or concern, the Care Coordinator discusses the results with the parent and suggests next steps. The online screening and resulting PEDS path, and 211 referral database all provide direction for the Care Coordinator to proceed with making referrals that suit the needs of the child and family. Referrals are commonly made to the local Regional Center, Head Start or Early Head Start programs, the school district, or other child and family serving organizations. When making referrals, the 211 Care Coordinators will often conduct 3-way calls with the parent and referral agency to directly connect them or offer a warm hand-off. In other cases, Care Coordinators will give the referral agency advance notice that the family will be contacting them and give the parent instructions with how to directly reach the agency.

Follow-up occurs on both the family and referral agency side. The 211 Care Coordinator Assistant maintains referral tracking spreadsheets for each referral partner which documents the status of referrals that originated from the 211 Developmental Screening and Care Coordination project. Follow-up occurs at 15-, 30-, 60-, and 90-day increments. Throughout the process, the Care Coordinator who conducted the screening will follow-up if the family has any additional needs or questions and will often offer their direct line to the family at the conclusion of the initial call in which screening was performed. Of the 3,380 children who received screening in 2013, half (50%; n = 1,688) screened at high to moderate risk for a developmental delay/disability and received care coordination. The other half (50%; n = 1,692) screened at low risk for a developmental delay/disability and were connected to an early childhood program. Of the 1,688 children who received care coordination, 50.1% were documented to have received services to which they were referred (with the remaining 49.1% pending confirmation of service receipt).

Welcome Baby

Welcome Baby is a program focused on maternal and infant health and consists of 6-9 visits to mothers and their newborns, occurring from the prenatal period until the baby is 9 months old. The program is focused on issues such as attachment, breast feeding, and infant care. Most of the mothers who are enrolled are already in the hospital and are enrolled at bedside. Welcome Baby is part of Best Start, "an effort funded by First 5 LA to transform 14 Los Angeles County communities into places where children can grow up safe, healthy and happy." ⁵⁷

⁵⁷ http://beststartla.org/welcomebaby/

Welcome Baby uses the ASQ as its primary developmental screening tool and has done so since the program's inception five years ago. The program also uses the PHQ-9 depression screener (Kroenke, Spitzer & Williams, 2001), to screen for maternal depression. Because a big part of their program is centered on screening and service system linkage, they also do a more intensive screening in the hospital focused on medical and psychosocial needs.

ASQ screens occur twice during the mother's enrollment in the program: once at the 3- to 4-month postpartum visit and once at the final 9-month postpartum visit. Parent coaches ask the questions of the mother and fill out the form using her answers as well as their own observations. If a child scores below the cutoff on the ASQ, a meeting is held to discuss the needs of the child, what choices and referral agencies exist, and then discussing making an appropriate referral or referrals. Common referrals include the local Regional Center or Early Head Start, though it was discussed that the referrals typically "depend on how low they score and what the need is."

Follow-up on referrals made typically occurs with the family rather than the agency, although sometimes Welcome Baby will facilitate a referral by faxing a consent form to the agency or calling the agency directly. The progress of the family is tracked in case files, documenting whether the family accepts or denies the referral and if they received services. Due to large caseloads, they are not an intensive case management program and are not able to do in-depth follow-up with every case. However, there is frequent calling back and forth between the parent and Welcome Baby staff members to make sure things are moving along. The case is typically closed at the 9-month visit, and unless a mother or baby is very high risk, follow-up also ends at that point. Between January 2010 and December 2013, of the infants referred to a Regional Center or other community-based organization for follow-up, 32.9% were documented to have started receiving developmental services at the 9-month visit.

Welcome Baby has been in a pilot/start-up phase and has operated to date on a relatively small scale. At the time of this study, it is in the process of moving into full implementation. The program is expanding to a greater number of hospitals and thus the number of clients who will be provided developmental screening is expected to increase substantially.

Children's Bureau

Children's Bureau receives matching funds from First 5 LA for three distinct services where developmental screening is performed.

• Children's Bureau has a center-based parent/child enrichment group for families with children age 0-3 years. This is a semiweekly program where families work on attachment and bonding between parent and child, learn about development and age appropriate activities, and build social connections with families with similar aged children. Through this program, which families can be part of for one year, the PEDS is

performed at intake and the ASQ-3 is performed every 4 months by child development educators in partnership with the parent (three times during the program year).

- Children's Bureau offers screening through their school readiness community
 association, which is a weekly Saturday program offered to all families in the community
 with at least one child age 0-5 years. This is more of an informal group, where families
 can attend however many sessions as they are able. Periodic PEDS screenings are
 performed for the families who are in attendance. These screenings are performed and
 scored by an MSW intern or a staff member who asks the family to come talk to them
 away from the group for 15 minutes.
- Children's Bureau offers developmental screening at their community enrichment
 program, which is similar to the center-based enrichment group but is run instead by
 parent facilitators. These are parents who have spent a year in the center-based
 enrichment group and have decided to continue participating by giving back to the
 center and facilitating a group. These events take place throughout the community for 2
 hours a week and have one staff member present who does PEDS screenings for all
 program participants.

Children's Bureau uses both the PEDS and the ASQ as their primary developmental screening tools. One facet of their organization, the school readiness program, has been in existence since 2003 and both tools have been in use at least since that time.

Children's Bureau interviewees stated that they really try to explain the ASQ to the parents so they have a good understanding of the tool before and during the screening. The screenings are administered by staff, who ask questions of the parent in an interview style. The information in the PEDS and ASQ screenings comes from parent observation of the child. For the ASQ, Children's Bureau provides the parent with a copy of the assessment ahead of time so that when they come to the meeting, they are already familiar with the questions. If a child screens positive for a developmental delay or concern, Children's Bureau uses the results from the screening tools to follow-up with families in private and discuss concerns and next steps. Staff members are assigned to families who are enrolled in the program; in the case of the centerbased group, a general staff member is assigned to each group. These Children's Bureau staff members will follow-up directly with the family regarding what the family would like the next steps to be. If the parent agrees to proceed with a suggested referral for services or for additional assessment, staff will proceed with making the referral. Depending on what the concern is and what the parent's level of interest is, common referrals include the school district, local Regional Center, or mental health services for more serious concerns; for less serious concerns or for preventative care, common referrals include things like supportive services, home visits, or parenting coaching for help in building skills for the parent themselves and with the child.

Children's Bureau described the follow-up process as "one of the most challenging parts" of the process because they currently lack an automated system that prompts staff to follow-up or

check in with families. While "teachers and staff at the center-based groups are very good about remembering" and they have an "open dialogue" with the families, there are also challenges with having to remember to follow-up with certain families, playing phone tag with families who may have moved or are not returning phone calls, or parents not communicating outcomes after the referral is made. While follow-up typically occurs with the Children's Bureau staff speaking with the parents, if a family is having challenges in reaching a referral agency, Children's Bureau will sometimes pick up the phone and call the agency to find out what is happening with that case.

Child & Family Center

The Child & Family Center, based in Santa Clarita, is a community-based organization with the mission of "build[ing] a healthy Santa Clarita Valley by providing mental health, behavioral and education services to children, adults and families." The Child & Family Center receives matching funds from First 5 LA to screen children in their mental health consultation program. The Center will screen children if the referral is noted to have developmental concerns, or if the child or family presents with risk factors that may impact the child's developmental progress.

The Child & Family Center uses the ASQ-3 and ASQ:SE measures as their developmental screening tools. They began using the ASQ in 2009 in their birth to 5 services when therapists working with MAT (Multidisciplinary Assessment Team) assessments for DCFS cases wanted a good screening tool to look at the children's developmental milestones. If a child is screened, he or she will receive both the ASQ-3 and the ASQ:SE. The screening is performed with the clinician administering the screening tool as a formal consultation with the parents. The clinician will often include input from a teacher to complement parent reporting. After the screening is performed, teacher and parent insights are combined and all parties have a meeting with the family. The information in the ASQ screenings also incorporate clinical observations from an initial 2 hour observation that occurs at the time of the child's enrollment in the program.

Managers from the Child & Family Center commented that they take a "collaborative approach to each particular child" that is child-focused. The Child & Family Center's developmental screening protocol draws strength from the fact that it is flexible and the assessment can take place in multiple environments (e.g. preschool, home, etc.) to get the most accurate feedback. If a child screens positive for developmental delay, staff come back to the parents and begin making referrals to recommended services but do not provide diagnoses. Because they are in preschools, the Child & Family Center indicated that they are generally referring people to the school districts; given their strong relationships with local schools districts, they typically "have prepped the school districts so that the schools are ready to receive [the child]." If a referral is needed for mental health services, they most often refer to their agency or others like it that can provide the services. For a more severe concern, such as a suspected autism diagnosis,

⁵⁸ http://www.cehildfamilycenter.org/about-us/our-beliefs.cfm

referrals are often made to the local Regional Center for further assessment or diagnostic testing.

Follow-up by program staff occurs mainly with the parents rather than with the referral agencies. The Child & Family Center described troubleshooting with families who may encounter roadblocks in accessing services. The program also attempts to keep track of waitlists where children and families may be waiting to be connected to services, though this does not appear to be formally documented. The Child & Family Center maintains communication with parents throughout the process, as one program manager stated that, "I always tell parents if they have any questions they are free to call me throughout this process," and that after the consultation is done, they can still reach out to her. The program conducts parent feedback surveys using SurveyMonkey.

Perceived Strengths and Weaknesses of Developmental Screening Tools

As part of the Program Manager Interviews, the participants were asked to consider the strengths and weaknesses of the developmental screening tools of their program. Table 4 summarizes the strengths and weaknesses of these screening tools as identified by the program managers interviewed. Following this table, we provide a narrative description of the major themes coded to classify the strengths and weaknesses of the developmental screening tools from the perspective of the program managers.

Table 4. Summary of program manager responses to interview question: What are the strengths and weaknesses of the screening tools your program uses?

| Screening | Number of Programs Using | Dalatina Chromatha | Paletina Washingson |
|------------------|-----------------------------|---|--|
| PEDS, PEDS-DM | the Tool 2 of 4 | Relative Strengths Not so long and intense. Fairly simple for staff to administer. Standardized every two years. | Relative Weaknesses PEDS-DM requires use of other items, which are not always present in the home. |
| | | Online use of tool means you get immediate summaries of results. | Not all of the scoring capabilities are available in Spanish. |
| ASQ-3, ASQ-SE | 3 of 4 | Gives a quick guideline to see what the next steps should be. Easy to understand the results. Flexible assessment. Good teaching tool. Parents and staff | Parents are not always seeing the developmental needs of their children in a very accurate way. Because it requires participation of the child, if the child isn't in the mood, it can take much longer and |
| | | work together to complete it. Tools are in English and Spanish. | need to be spread over several sessions. |

Strengths

The themes summarized here that describe the strengths of the developmental screening tools apply to both the ASQ and PEDS unless otherwise noted. Respondents liked that the screening tools used by their program provide inherent staff quidance. As one program manager stated, "it's also a good tool for staff because the more they really understand the ASQ it helps them know what to look for." Another said, "What I love about it is that it's really a good teaching tool, meaning that there's a lot of implicit guidance." Another frequent strength mentioned was having evidence-based, standardized developmental screening tools with established reliability and validity: "The tools themselves are very reliable and do a fairly good job of predicting." The program managers interviewed found the tools *easy to score and administer*: "It's something that's not so long and intense, so we're able to do it in various settings. It's not as intimidating as maybe the other screenings could be, or as long as the others can be, so it's fairly simple for the staff to administer as well." They also found the tools to be *parent-friendly*; as one respondent explained, "You're going through it with the mom, acknowledging the strengths of the child and the mom and what they're doing together, but you're also really helping them what's coming next. In terms of what to look for, what's important in terms of the screening process and ways you can enhance whatever milestone that is. It really helps the parents."59

Weaknesses

One of the relative weaknesses in the screening tools identified by the program managers interviewed had to do with relying on parent self-report. 60 As one manager explained, "Sometimes, because of self-reporting we see scores that look underreported. Where parents are not seeing the developmental needs of their children in a very accurate way." Another respondent elaborated, "You're getting a "yes" to things because they're afraid of stigma or they don't want their baby to score low. You try and give a lot of positive reinforcement that this is just to help them, help their baby, etc. But you just have to be mindful of that sometimes." As pointed out by the managers interviewed, the screening tools are not a substitute for the *need for clinical judgment and sensitivity*. For example: "The more they do this kind of work, the more they know. You really have to be able to read a lot of subtle cues to see if they are slightly delayed." In addition, this sensitivity is critical in terms of the impact of working with the parents: "When we work with babies that are extremely delayed – Down syndrome, etc. Having to work with those moms and administering the ASQ [in a way] that doesn't make them feel bad or is inappropriate, but you still want to give them these tools." There were some mentions of *measurement limitations* of the developmental screening tools used: "M-CHAT probably errs on the sensitive side," referring to the tendency of the M-CHAT to potentially over-refer children so as to avoid missing a child who may need further assessment

⁵⁹ Although this was mentioned by managers of programs that use the ASQ, the PEDS was also described as parent-friendly by 211 staff in interviews conducted for a separate but related descriptive study of the 211 Developmental Screening and Care Coordination project.

⁶⁰ Although this was mentioned by managers of programs that use the ASQ, some issues with relying on parent self-report were discussed with respect to the PEDS by 211 staff in interviews conducted for a separate but related descriptive study of the 211 Developmental Screening and Care Coordination project.

or assistance. In addition, some *practical considerations* were mentioned: "Sometimes [the ASQ] takes multiple sessions to get it done because it is longer. Sometimes a child isn't in the mood, the baby is asleep or the child wants to do something else. We try to make it more like a game – it's a game for the child, so it's not so tedious, not something they don't want to do. But it does have to be broken up at times."

An additional theme addressed the use of the developmental screening tool in a high risk population which could lead to potentially misleading screening results. Although this concern was only mentioned by one stakeholder interviewed, it also appears in the literature on developmental screening (see Part I of this report). For example, factors such as physical disability or premature birth can affect the results of developmental screening (e.g., Wiley & Meinzen-Derr, 2013; Kuban et al., 2009; Johnson & Marlow, 2009).

The following table summarizes the number of references to each of the themes, coded by program, from the responses of the program managers interviewed. The table indicates how many different agencies mentioned a given topic; however, an individual or an agency could have more than one reference to a given theme. Unless otherwise noted, the themes shown were mentioned by more than one stakeholder interviewed.

Table 5. Strengths and weaknesses of developmental screening tools:

Number of programs mentioning themes coded from Program Manager Interviews

| | Number of Programs with Theme Mentioned (n = 4) |
|--|---|
| Strength | |
| Inherent staff guidance | 3 |
| Evidence-based, standardized | 2 |
| Easy to score and administer | 1 ^a |
| Parent-friendly | 2 |
| Weakness | |
| Relying on parent self-report | 2 |
| Need for clinical judgment and sensitivity | 2 |
| Measurement limitations | 2 |
| Practical considerations | 2 |

^a3 references made by one source.

Perceived Strengths and Weaknesses of Developmental Screening Protocols

As part of the Program Manager Interviews, the participants were asked to consider the strengths and weaknesses of their program's developmental screening protocols. The responses were coded into major themes, as described below.

Strengths

There was a strong consensus among the program managers interviewed that the developmental screening protocols are *informative and empowering for parents*. As one stated, "It starts always with the strengths of the child and what the child is doing. It shows the

parents how much they are benefiting the child." Another explained, "Ultimately we leave it in the hands of the parents, of course. We try not to be intrusive and push them. We try to be informative about the benefits, dispel the myths about what is out there." There were also frequent mentions of how the protocols encourage open communication with families. For example, "I always tell parents if they have any questions they are free to call me throughout this process, any barriers after the consultation is done they can still reach out to me." Others pointed out how the protocols help them effectively connect families to needed services. As one respondent explained, "It's a proactive referral. You can ensure from the beginning that this is going to end up in the next step." There were also references to the benefits of an online system; it was mentioned that, "You get immediate summaries of results. These are things that don't happen when you're doing the paper and pencil." Although mentioned by only one of the program managers interviewed, that manager cited the design of that program's screening protocols as a strength in that the procedures allow developmental screening to be available to a population that might not otherwise have access to screening and subsequent care coordination. Another strength mentioned by only one Program Manager was that the developmental screening protocols help providers avoid duplication of services, since the protocols instruct the staff to ask the parent if the child is already linked to services that he or she would be referred to if suggested by the screening results.

Weaknesses

Some areas for improvement in the programs' developmental screening protocols were identified. The weaknesses most frequently mentioned were related to data and outcome tracking. One program manager stated that, "We've determined that that's an area we want to improve – document those barriers in a quantitative way." Another explained, "I think that we don't really have a good data tracking system in place. What would be helpful would be if there was a way to flag low scores." Another relative weakness relates to program capacity. As one respondent mentioned, "We're creating a demand, so now we have to meet the demand." Some have encountered referral network limitations. For example, one stakeholder mentioned, "If the service doesn't exist or the family needs something apart from what [referral sources] can offer." Because the programs want to make referrals that not only address the needs of the family and child, but are also accessible for the family, program availability or location constraints can sometimes limit what referrals can be made. Although it was only mentioned by one stakeholder interviewed in this context, it was mentioned that parent follow-up can sometimes be difficult because the parent may fear that their child will be diagnosed. Another concern raised by one participant was related to challenges in obtaining written consent to share information between agencies to assist with tracking outcomes.

Table 6 summarizes the number of references to each of the themes, coded by program, from the responses of the program managers interviewed. The table indicates how many different sources agencies mentioned a given topic; however, an individual or an agency could have more than one reference to a given theme.

Table 6. Strengths and weaknesses of developmental screening protocols: Number of programs mentioning themes coded from Program Manager Interviews

| | Number of Programs with Theme Mentioned (n = 4) |
|--|---|
| Strength | |
| Informative and empowering for parents | 4 |
| Open communication with families | 4 |
| Effectively connects families to needed services | 2 |
| Benefits of online system | 1 ^a |
| Weakness | |
| Data and outcome tracking | 3 |
| Program capacity | 3 |
| Referral network limitations | 2 |

^a2 references made by one source.

Consent to Information Sharing

Each program was asked to explain how it obtains consent to share information between agencies to facilitate the care coordination process. Table 7 summarizes this information for the four programs studied.

Table 7. Brief description of consent and information sharing among First 5 LA-supported programs providing developmental screening

| Program | Brief description of how program obtains consent for information sharing |
|--------------------------------------|---|
| 211 Developmental Screening and Care | Consent forms must be sent to the family since the screening occurs via telephone and written consent is required to share client information. |
| Coordination project | The 211 Developmental Screening and Care Coordination project sends a consent form to the client via e-mail or US mail, depending on the client's needs. The client must complete and sign the consent form and return it to 211 in order for 211 to be able to share information from other agencies regarding the client. |
| Child & Family Center | Staff of the Child & Family Center indicated that they do speak with agencies with permission from families or actually sit with them at times. They do not specifically track this in their data. |
| | Regarding information sharing, one representative from the agency stated, "We do tell them that we adhere to HIPAA for confidentiality and let them know that shared info doesn't go out without consent." |
| Welcome Baby | According to Welcome Baby, if it is related to child development, there is always a release completed because the program needs to provide specific information about the child and family. The Parent Coaches carry blank copies and complete them with the family when they identify needed resources. Any referral for child development, parenting and infant mental health would have a completed consent attached for coordination of care. |
| Children's Bureau | • Children's Bureau representatives indicated that while two of their groups do not undergo a formal intake process where consent would be obtained, they do "attach [the consent form] to the short demographic form that they fill out if it's their first time at one of our services." For the other group where a more formal intake process occurs, they consistently use the First 5 Release of Information form to obtain and track consent. |

Big Picture Issues, Challenges, and Barriers to Service Uptake among Families with Young Children at Risk for Developmental Delay

As part of the Program Manager Interviews, the participants were asked to consider if there are any issues, barriers, or challenges that their program faces in getting families with young children connected to services. The responses were coded into major themes, as described below.

There were two types of system-level barriers to service uptake mentioned. The most frequently mentioned was *changes within the referral network*. For example, one manager discussed the "constant changing of Head Start boundaries and service areas. [Programs are] open or closed from one day to the next. You're constantly chasing them down week by week." Another explained how "programs that have been cut have affected our referrals," making it particularly difficult to get children with relatively mild delays into early intervention services. In addition, some of the challenges had to do with getting *consent* forms returned by parents to permit sharing of information between agencies. As one of the managers interviewed explained, "If we could have processes that would allow us to digitize that, that would be a major milestone for this project. The day that telephonic, electronic and recorded consent forms are okayed by the whole referral organizations, we're in business for the underserved populations." Finally, although it was only mentioned once, one respondent mentioned a lack of service integration as a barrier to linking families with needed services.

The following table summarizes the number of references to each of the themes, coded by program, from the responses of the program managers interviewed. The table indicates how many different agencies mentioned a given topic; however, an individual or an agency could have more than one reference to a given theme.

Table 8. Barriers or challenges to connecting families with young children to service system:

Number of programs mentioning themes coded from Program Manager Interviews

| | Number of Programs with Theme Mentioned (n = 4) |
|------------------------------------|---|
| Challenges within referral network | 2 |
| Consent | 1 ^a |

^a2 references made by one source.

Resources or Systems Change Needed to Improve Service Uptake among Families with Young Children at Risk for Developmental Delay

Program managers were also asked for ideas about possible systems-level changes to improve developmental screening and service system linkage for families with young children. The ideas for systems change discussed ways to potentially improve interagency relationships and find ways to increase capacity, as well as ways to increase program sustainability and stability.

The two most frequently mentioned themes had to do with funding and policy change. With respect to *funding*, one program manager interviewed said that, "Our model has been effective at addressing this, but we see a need for the type of program we're offering to get funding that allows us to report outside of the medical eligibility and those requirements." In addition, the impact of budget cuts was illustrated by statements such as, "a few years ago I used to make a lot more referrals to Regional Centers because they had a larger budget for 0-3." With respect to *policy change*, one respondent talked about "...working really hard to...see if they can't really look at this as prevention/intervention rather than treatment." Others mentioned *capacity building* as needed: "We could do more...we don't have capacity [to screen more children]." This theme took a broad view of capacity building, including comments such as increase in staff, program expansion, increase in funding, and linking with new partners. Finally, *data driven changes* were discussed. One respondent explained, "What we're hoping to do is collect enough data to talk about barriers that are encountered day to day." Another resource, although mentioned only once, was more training opportunities in general for staff.

Table 9 summarizes the number of references to each of the themes, coded by program, from the responses of the program managers interviewed. The table indicates how many different agencies mentioned a given topic; however, an individual or an agency could have more than one reference to a given theme.

Table 9. Systems change to better connect families: Themes coded from Program Manager Interviews

| | Number of Programs with Theme Mentioned (n = 4) | | |
|---------------------|---|--|--|
| | with theme wentioned (# - 4) | | |
| Funding | 3 | | |
| Policy changes | 3 | | |
| Capacity building | 2 | | |
| Data-driven changes | 1 ^a | | |

^a3 references made by one source.

Additional Qualitative Data for 211 LA County

As part of this review of current First 5 LA developmental screening investments, additional qualitative data were collected to describe the developmental screening and care coordination provided by 211 LA County through the 211 Developmental Screening and Care Coordination project. In addition to the data presented in this report, semi-structured stakeholder interviews were conducted with selected 211 staff, referral partners, and parents who received screening from the program. The Descriptive Study of the 211 Developmental Screening and Care Coordination project also included a review of calls in which screening was offered and provided, as well as calls in which screening was offered but not provided. These findings are detailed in a separate report (Melchior & Brink, 2014). Many strengths of the 211 LA County developmental screening and care coordination model were identified, such as the following:

- The 211 Developmental Screening and Care Coordination project provides access to effective, evidence-based developmental screening tools and care coordination to families with concerns about their child's development or behavior, as well as families with young children who did not identify such concerns as the reason for their call to 211 LA County. As supported by a number of data sources, the majority of parents who were offered developmental screening called 211 LA County for a reason other than a developmental or behavioral concern. Findings from qualitative interviews with a sample of parents whose children were screened indicated that those parents had not previously had the opportunity to take advantage of such services, and in some cases, were not aware that such services existed before their experience with the 211 Developmental Screening and Care Coordination project.
- The staff (Care Coordinators) who conduct developmental screening at 211 LA County provides professional, empathic, and parent-friendly services to families. The 211 Care Coordinators make proactive, appropriate referrals for families and remain involved in helping them connect with services as long as needed.
- The 211 Developmental Screening and Care Coordination project has developed effective partnerships with a range of relevant referral agencies to link at-risk children to appropriate resources. These partnerships are supported by official MOUs and reflect meaningful collaborations, not just "on-paper" relationships.
- Parents who received screening and care coordination from the 211 Developmental Screening and Care Coordination project expressed satisfaction with the support they received from the Care Coordinators.

Some areas for improvement were identified as well. These issues included the following:

Challenges in obtaining written consent from families to share information sometimes
make it difficult to fully provide care coordination, track referral outcomes, and
document program effectiveness for the hardest-to-reach populations, including
families who are homeless, in an unstable living situation, or who move from one
service area to another, since written consent must be obtained to share information
between agencies.

To address these challenges, the 211 Developmental Screening and Care Coordination project is trying some different approaches to distributing and collecting consent forms through community organizations. Another approach is illustrated by a blanket confidentiality and consent agreement that was under development by the Department of Child and Family Services (DCFS) and the 211 Developmental Screening and Care Coordination project to facilitate sharing of information between DCFS staff and 211 Care Coordinators at the time of this study.

- Staffing and resource constraints limit the number of families to whom screening and
 care coordination can be offered by 211 LA County. Sometimes all Care Coordinators are
 helping other callers when the 211 general information and referral (I&R) staff has a
 parent on the line who is interested in screening; this can necessitate a call-back to the
 parent interested in doing the screening for their child. With thousands of callers to 211
 LA County annually with children age 0-5, only a fraction of those children can be
 screened given current program capacity.
- A number of challenges were identified to service uptake among families with a child at risk. Systems level challenges, including restrictions in eligibility requirements for developmental services, have resulted in children with relatively mild risk not being able to qualify for early intervention services. Many providers interviewed expressed frustration with the lack of opportunity for prevention while the child was relatively young with comparatively milder symptoms. Because of the changes to eligibility requirements for certain kinds of interventions, children cannot access services until they are more severely delayed. Program and budget cuts have also affected the availability of services for children at risk.

Quantitative Data Review

The review of current First 5 LA developmental screening investments included the collection and analysis of quantitative data from the developmental screening programs studied.

Methods

Four programs were included in the request for quantitative data, all of whom currently receive support from First 5 LA for developmental screening: the 211 Developmental Screening and Care Coordination Project, the Child & Family Center, Children's Bureau, and Welcome Baby. Initial information about quantitative data collection capacity was obtained through semistructured interviews with each of the program managers conducted in January 2014. A specific request for quantitative data was sent to each of the respective program managers in February 2014. Programs were asked to provide data for calendar year 2013. Since the initial information suggested that these four programs might not be collecting comparable data, we gave the programs several options for submitting quantitative data in response to this request, including sending raw data following provided specifications, or sending a summary report of those data. The request was customized depending on the information we had for a given program. The following table summarizes the data received in response to this request.

⁶¹ The quantitative data collection protocols were submitted for IRB review to the New England Institutional Review Board (<u>www.neirb.com</u>). The IRB determined that these data collection protocols were exempt from review.

Table 10. Summary of quantitative data received from programs reviewed

| Program | Type of quantitative data received |
|---|--|
| 211 Developmental Screening and Care Coordination Project | Summary presentation (PowerPoint file) reporting quantitative data about number and characteristics of children/families screened, developmental screening results (PEDS, PEDS:DM & M-CHAT) for screenings conducted January 1 – December 31, 2013. Also includes summary of referral outcome data. 211 noted that data concerning outcomes of referrals made late in the year are incomplete due to some confirmations still pending. These data were subsequently updated in June 2014 as part of a separate Descriptive Study of the 211 Developmental Screening and Care Coordination project. Also provided excel spreadsheets with what appears to be raw data, de-identified, with one sheet per indicator. |
| Welcome Baby | Individual-level excel data files (de-identified), one for mother and one for child. The mother file contains all of the visits as well as intake data (including demographic data) and discharge data. The child file contains the ASQ information under the 3-4 month visit (EP 8) and 9 month visit (EP 9) Cumulative data files sent; possible to filter on visit date to select data from 2013. Includes variables to document whether newborn was referred to regional center and whether newborn started to receive developmental services. |
| Children's Bureau | Summary report of characteristics and ASQ-3 screening findings for children screened and assessed FY2012-2013. Screening results presented as % of children screened with ASQ scores in the range on each subscale for "Typically Developing," "Require Monitoring," and "Below Developmental Expectations." Report also includes summary of PEDS screenings, with number of children screened, basic demographic indicators, and summary statistics for the % of children referred for more in-depth screening (including the % with areas of concern in each of the areas targeted by the PEDS). Also provided copy of First 5 LA progress report from July 2013. Included breakdown of demographic characteristics of children screened with PEDS and ASQ from January 1 – June 30, 2013 (first half of year). In response to our request for referral data, we were told it was "not readily available" and that the program was not able to be provided within the timeframe specified. |
| Child & Family Center | Excel file including a compilation of raw client-level data (de-identified) from each participant in the consultation program last year. Includes variables related to characteristics of children screened, referral source, presenting problems, whether or not screened using ASQ (Yes/No), and referrals made. No information about referral outcomes. The program noted that if the child was referred for Mental Health Services funded through the Los Angeles County Department of Mental Health (DMH), they collect and maintain a different data set separately in Welligent (an electronic health record system used by LA County DMH providers); this includes ASQ and ASQ-SE scores (but was not provided to us since it involves children age 0-5 served under a different funding source). |

Findings

Comparability of Data Collected Across Programs

These four programs vary considerably in the amount, type, and format of quantitative data available to describe the characteristics of the children and families served, the screening activities that were provided, referrals made based on the developmental screenings, and the outcomes of those referrals. At a very basic level, we estimate that these four programs provided an initial developmental screening to a total of *4,275 children age 5 years or younger* in the past year. ⁶² Because the data varied so widely across these programs, it is not feasible to combine the data in any more detail to provide aggregate numbers to describe the characteristics of the children screened, the results of the screenings provided, or the referrals made and their outcomes.

The following table summarizes the data from programs that use the ASQ measures for developmental screening. As can be seen, not all programs had data available to address all the measures, as indicated by dashed lines in the table below. Although some programs report ASQ screening data in greater detail, the information from these three programs are comparable at the level of whether individual ASQ scores were below the cutoff, indicating that children with scores in this range are below developmental expectations for their chronological age.

Table 11. Selected pooled screening outcomes for programs reporting ASQ data

| | | | Children's | Child & Family |
|---|--------------|------------|------------|-----------------|
| Measures | Welcome Baby | | Bureau | Center |
| | (3-4 | | (6 to 36 | |
| | months) | (9 months) | months) | (preschool age) |
| Received ASQ Screening | n = 689 | n = 498 | n = 64 | n = 12 |
| ASQ Communications Score below cutoff | 2 (0.3%) | 5 (1.0%) | 14% | |
| ASQ Gross Motor Score below cutoff | 15 (2.1%) | 9 (1.8%) | 9% | |
| ASQ Fine Motor Score below cutoff | 15 (2.1%) | 9 (1.8%) | 8% | |
| ASQ Problem Solving Score below cutoff | 8 (1.1%) | 4 (0.8%) | 8% | |
| ASQ Personal-Social Score below cutoff | 8 (1.1%) | 4 (0.8%) | 8% | |
| Any of the above ASQ scores below cutoff | 42 (5.9%) | 24 (4.8%) | | |
| Referred to regional center or other community- | 25 (3.5%) | 27 (5.3%) | | 50% |
| based organization | | | | |
| Referred to occupational therapy or speech | | | | 58% |
| therapy | | | | |
| Started receiving developmental services | 4 (0.6%) | 6 (1.2%) | | |

⁶² The estimate of the total number of children screened includes 3,380 children screened in calendar year 2013 by the 211 Developmental Screening and Care Coordination project; 689 infants screened at the 3-4 month visit by Welcome Baby in 2013 (the first possible screening); 64 children screened using the ASQ-3 by Children's Bureau at intake to the Center-Based Enrichment program plus 130 children screened in other community parenting programs using the PEDS in FY12-13; and 12 children screened within the context of the Child & Family Center's mental health consultation program in FY12-13. For the purpose of this estimate, calendar year 2013 (January 1 – December 31) and FY12-13 (July 1, 2012 – June 30, 2013) were considered to be "the past year."

It is not possible to present combined outcomes from screenings based on the data received from the two programs using the PEDS. We relied on summary reports from both programs and the two differed in the way that screening outcomes were reported. The 211 Developmental Screening and Care Coordination project reported their screening outcomes according to the level of risk for developmental delay: Path A (High Risk), Path B (Moderate Risk), Path C (Elevated Risk for Behavioral/Emotional Problems and Low Risk for Delay/Disability), and Path E (Low Risk). 63 On the other hand, Children's Bureau reported PEDS results in terms of areas of concern: Global/Cognitive, Expressive Language, Receptive Language, Fine Motor Skills, Gross Motor Skills, Behavior, Social/Emotional, Self-Help, and School Performance. While these data cannot be equated from the summary level reports that were received for this particular study, it should be possible to generate data using either of these metrics from the specific responses given by the parent during the screening. Both metrics have their uses: the risk paths show the general severity of the issues identified in the PEDS screening, while the areas of concern illustrate specific areas of development that may warrant attention. It can be estimated that across these two programs a total of 3,510 children received screening using the PEDS in the past year.

A number of factors affect the ability to pool these data across programs. Because programs were given the option to provide data for this review either from existing reports or from raw data, the ability to pool data elements was limited by the lowest level of detail available in the reports provided (that is, it was not possible to conduct additional analyses of those data). Second, programs collect data at different levels of detail and in different ways. With respect to the developmental screening data, for example, although 211 and Children's Bureau both collect and report data from the PEDS screenings, 211 reports results based on the PEDS Path which shows the relative risk for developmental delay (e.g., "High Risk-Path A" or "Low Risk-Path E"), whereas Children's Bureau reported its screening results in terms of the percentage of children with specific areas of concern (e.g., "Expressive Language" or "Fine Motor"). Some programs document referrals at a very broad level, while others track the specific type of service referral.

There is also considerable variation in the extent to which the completion of referrals is documented and the source of that information. The 211 Developmental Screening and Care Coordination project uses a stringent definition in which the completion of the referral must be verified by the agency to which the family was referred. Other programs rely on parent report to document when service uptake occurs. And in some cases, programs do not have resources to follow up on families to find out the status of referrals they made as a result of the screening.

63 Note, there is no Path D generated by the PEDS Online.

Program-Specific Quantitative Data

211 Developmental Screening and Care Coordination Project

The 211 Developmental Screening and Care Coordination Project has a relatively sophisticated data system to document and track the characteristics of children screened, the results of screenings performed, and the outcomes of referrals to which the families were linked. The program works with an outside evaluator, Cheryl Wold, an experienced community health researcher. The program uses data to share program findings, review data for quality assurance, and disseminate its model of developmental screening and care coordination to others in the field.

The 211 Developmental Screening and Care Coordination project provided a printout of a PowerPoint presentation which summarized major indicators for their activities in calendar year 2013. The 211 Developmental Screening and Care Coordination project has capacity to query its database to address specific information requests.

Overall, there were data from 3,380 callers who participated in developmental screening in calendar year 2013. The program screened children from infants to 5 years of age. The families were diverse in terms of demographic characteristics. Of the 3,380 children screened in 2013, the results of the PEDS & PEDS:DM screening identified 516 (15%) as High Risk (Path A), 864 (26%) as Moderate Risk, and 862 (26%) as Elevated Risk for Behavioral/Emotional Problems and Low Risk for Delay/Disability (Path C). Approximately one child out of three screened (1,138 or 34%) had screening results that placed them in the Low Risk (Path E) category. The screenings performed by the 211 Developmental Screening and Care Coordination project yielded a slightly greater percentage of children scoring on Path A-High Risk than the national comparison sample (15% vs. 11%), a slightly greater percentage of children scoring on Path C-Elevated Risk for Behavioral Emotional Problems/Low Risk for Delay/Disability (Path C) compared to the normative sample (26% vs. 20%). The children screened by 211 had a lower rate of scoring as Low Risk (Path E), 34% vs. 43% for the national comparison sample. In addition, M-CHAT screenings for autism were conducted with 2,261 children age 16-48 months; 237 children had scores that failed the M-CHAT screening (10.5% of those screened), which compares to 9.7% in the normative data. It should be noted that failing the M-CHAT indicates a risk of a possible autism diagnosis but not necessarily a diagnosis of autism spectrum disorder (ASD). According to the PEDS Online Guide⁶⁴, "a failed M-CHAT will result in a recommendation for further assessment by an autism specialist...A passed M-CHAT indicates limited risk for ASD but does not rule out any of the more common disabilities: speech-language impairment, mental retardation, or learning disabilities."

Various rates of failure on the M-CHAT have been reported in other studies, ranging from 5.7% in an unselected sample of children screened during well-child care visits between 16 and 30 months of age⁶⁵ to 21.2% among children screened as reported in an earlier study of the 211

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⁶⁴ Glascoe (2010)

⁶⁵ Ventola, Kleinman, Pandey, Wilson, Esser, Boorstein, et al. (2007)

Developmental Screening and Care Coordination project⁶⁶. These differences may be due to variations in factors such as (but not limited to) pre-existing risk in the screening population, screening method or setting (e.g., telephone interview vs. in doctor's office).

As context, the Centers for Disease Control and Prevention (CDC) report ASD surveillance data from 11 sites across the US. For 2010, these data show the overall prevalence of ASD was 14.7 per 1,000 (one in 68) in children 8 years of age. Although comparable prevalence data are not available for children age 0-5 years, the CDC study reports the median age for any type of ASD diagnosis as 53 months. Again, these numbers reflect diagnosed cases of ASD, in contrast to the numbers reflecting children identified as at risk for ASD pending a more detailed and comprehensive diagnostic assessment and evaluation.

The 211 Developmental Screening and Care Coordination project reported the most common reasons for calling 211 LA County among the families who participated in developmental screening. A developmental concern was the initial reason for the call only 8% of the time; other reasons for calling 211 included seeking resources for early childhood education, child care, government/city services, emergency shelter, food, utility assistance, legal assistance, medical services, and help with basic needs. This does not necessarily mean that these callers did not have a concern about their child's development or behavior; it only means that it was not the stated reason for their call to 211 LA County at that time.

The 211 Developmental Screening and Care Coordination project reported data about programs and service referrals made as a result of developmental screening findings. Of 3,016 referrals made, 31% were to Head Start, 25% were to an Early Head Start Preschool Program, 15% were made to a Regional Center (for children over 3 years of age), in addition to a range of other services as indicated by the family's needs.

The 211 Developmental Screening and Care Coordination project has a strong emphasis on tracking and following up families after the screening, to ensure that the family is effectively linked to services. Of the 3,380 children screened in 2013, 1,561 (46%) received some level of care coordination. Of those, 766 (49%) were confirmed to have received the referral services; another 48% were connected to the recommended referrals, with confirmation pending that the child was receiving services. Only 45 children (3%) had an unknown outcome after follow-up was conducted.

 The 211 Developmental Screening and Care Coordination Project appears to have considerable capacity for quantitative data collection, analysis, and reporting. The project extensively documents information about the population it serves, the developmental screening issues that it identifies, the referrals it makes to link families to developmental services for children age 0-5 years, and the outcomes of those referrals.

⁶⁶ Roux, Herrera, Wold, Dunkle, Glascoe, & Shattuck (2012)

⁶⁷ Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, (2014)

Welcome Baby

Welcome Baby provided individual-level data for mothers and children who were enrolled in their program, in an Excel workbook with two spreadsheets (for women and newborns, respectively). Data available for the mothers included a fairly extensive set of demographic characteristics, information about the pregnancy, information about services provided through Welcome Baby, information about whether certain issues were present for the baby (at the 3-4 month and 9-month postpartum visits; including whether an "infant delay" had been discussed), depression screening for the mother (using the PHQ-2 and/or PHQ-9) and information about the closing status of the mother's case (e.g., last engagement point, reason for closing). Data available for the children included date of birth, gestational age, information about the delivery, and information about the visits provided to the newborn, including data describing ASQ screening performed at the 3-4 months postpartum and 9 months postpartum visits. Welcome Baby reports that it uses individual results from the data collected to help the families the program serves.

It should be noted that at the time of this review, Welcome Baby was in a pilot phase and not yet in full implementation. Even so, the database that was provided included a fairly robust set of indicators in a clear and usable format. It is expected that as it is fully implemented, the program will have a more extensive database available. These data represent children who received developmental screening during calendar year 2013.

Overall, data were provided for 1,479 mothers who entered the program in calendar year 2013. Of those, 451 (30.5%) had a visit at 3-4 months postpartum and 142 (9.6%) had a visit at 9 months postpartum documented to date at which developmental screening was provided⁶⁸. Of the mothers seen at 3-4 months postpartum during 2013 (n = 706), 6 (0.8%) discussed a concern related to a developmental delay at that visit; of those seen at 9 months postpartum during 2013 (n = 508), 10 (2%) discussed a concern related to a developmental delay at that visit.

During calendar year 2013, a total of 1,467 children were born to mothers participating in Welcome Baby. A total of 710 3-4 months postpartum visits occurred during the same time period (again, some of these visits were with babies born in the prior year). Of the infants receiving a 3-4 month postpartum visit, 689 (97%) were screened using the ASQ. A total of 505 9 months postpartum visits occurred during the same time period (again, some of these were for babies born in the prior year). Of the infants receiving a 9 months postpartum visit, 498 (99%) were screened using the ASQ. The table below summarizes the number and percentage of infants screened who obtained ASQ scores below the cutoff at the 3-4 month visit and 9 month visit during 2013. According to the ASQ web site, "scores beneath the cutoff points indicate a need for further assessment."69

⁶⁸ Mothers enrolled in Welcome Baby late in 2013 may not have delivered their baby by the end of the year, or may not have reached the 3-4 months postpartum or 9 months postpartum visits in which developmental concerns would be screened for or discussed.

⁶⁹ http://agesandstages.com/what-is-asq/how-asq-works/

It should be noted that the indicator of whether children referred to community programs have started receiving developmental services may under-count the true "service uptake" of the children receiving such referrals. Welcome Baby works with the mother and child through the pregnancy up to 9 months postpartum, and then by design they close the case. There may be cases in which service uptake occurs after that last program contact. Thus the numbers reflecting the children who started receiving developmental services may under-represent the true level of service uptake among these families.

 Even in this preliminary phase, Welcome Baby appears to have considerable capacity for quantitative data collection, analysis, and reporting. The project extensively documents information about the population it serves, the developmental screening issues that it identifies, the referrals it makes to link families to developmental services for infants, and (to a limited extent) the outcomes of those referrals. The larger roll-out of the project will include a database.

Children's Bureau Matching Funds Grant Program

Children's Bureau uses the PEDS and ASQ-3 for screening in its Center-Based Enrichment, Community Enrichment, and (to some degree) in its Community Association services. Two different reports were submitted in response to our request for data: a brief evaluation report including summaries describing the children screened in FY12-13 and the screening results, and a demographic summary for individuals served from January – June 2013. Referral data were not readily available to respond to the request for this review. The evaluation report provided the following summary of ASQ-3 and PEDS screenings conducted in FY12-13. To Children's Bureau works with their internal evaluator to prepare materials for evaluation reports, report information to First 5 LA, and also to share findings with the program staff. Annually, the program reviews the information as a whole for their program to discuss what the findings mean and use the opportunity for quality improvement.

ASQ Screening Data: The ASQ-3 was administered to Center-Based Enrichment participants only. ASQ findings were presented as "screening" at intake to the program for 64 children, 6 to 36 months of age. These data are summarized in Table 10 above, which presents the combined ASQ screening data from Children's Bureau, Welcome Baby, and the Child & Family Center.

PEDS Screening Data: Children's Bureau also uses the PEDS for developmental screening among Center-Based Enrichment Participants, Community Enrichment Participants, and some Community Association Participants. In FY12-13, program staff screened 130 children 0-5 years of age in the community for developmental concerns with the PEDS. A summary of the sample by age and gender was provided. Table 12 shows the percentage of the children screened with the PEDS who showed developmental concerns and the areas of concern.

⁷⁰ Findings from *Oakwood School Readiness Program (SRP): FY2012-2013 Evaluation Findings*. Received from Vanessa Mendez, 2/26/14.

Table 12. Children's Bureau: Summary of PEDS results at intake for FY12-13 (n = 130)

| PEDS Screening Result | | |
|--------------------------------------|-----|---|
| Referral for professional evaluation | 3% | 33 children (24%) required follow-up: |
| More in-depth screening | 21% | 6% were younger than 1 year of age |
| Areas of Concern | | 24% were 1 year to 23 months of age |
| Global/Cognitive | 1% | 46% were 2 years old |
| Expressive Language | 20% | 24% were 3 years old |
| Receptive Language | 4% | 0% were 4 years of age and older |
| Fine Motor Skills | 2% | |
| Gross Motor Skills | 7% | ■ 64% were boys |
| Behavior | 27% | 36% were girls |
| Social/Emotional | 12% | |
| Self-Help | 3% | • 52% had one area of concern |
| School Performance | 4% | 15% had two areas of concern33% had more than two areas of concern |

Monitoring Development: Of the four programs participating in this review, Children's Bureau is the only one that we are aware of that uses the ASQ-3 for monitoring change in developmental status over time. Children's Bureau provided the following table showing how the rates of developmental concern among the children participating in their programs were demonstrating improvement over the follow-up interval studied (anywhere from 3-4 months to 6-7 months from the initial assessment). It shows the ASQ results in three categories: Typically Developing, Require Monitoring, and Below Developmental Expectations.

Table 13. Children's Bureau: Summary of ASQ-3 results at intake and follow-up (n = 52)

| | Typically | | Below Developmental |
|----------------------|------------|--------------------|----------------------------|
| COMMUNICATION | Developing | Require Monitoring | Expectations |
| Intake Assessment | 71% | 19% | 10% |
| Follow-up Assessment | 67% | 29% | 4% |
| | Typically | | Below Developmental |
| GROSS MOTOR | Developing | Require Monitoring | Expectations |
| Intake Assessment | 79% | 11% | 10% |
| Follow-up Assessment | 83% | 11% | 6% |
| | Typically | | Below Developmental |
| FINE MOTOR | Developing | Require Monitoring | Expectations |
| Intake Assessment | 71% | 21% | 8% |
| Follow-up Assessment | 79% | 17% | 4% |
| | Typically | | Below Developmental |
| PROBLEM-SOLVING | Developing | Require Monitoring | Expectations |
| Intake Assessment | 78% | 14% | 8% |
| Follow-up Assessment | 85% | 9% | 6% |
| | Typically | | Below Developmental |
| PERSONAL-SOCIAL | Developing | Require Monitoring | Expectations |
| Intake Assessment | 83% | 9% | 8% |
| Follow-up Assessment | 79% | 15% | 6% |

Table 13 illustrates the value in being able to monitor developmental status over time. While the percentage of children screening as "typically developing" increased in some areas (i.e.,

Gross Motor, Fine Motor, and Problem Solving), in others they decreased. For the Communication and Personal-Social scores, the percentage of children in this sample in the "require monitoring" range increased from intake to follow-up. While this might indicate that children are performing worse in these areas, the findings could also be a result of other factors, such as differences in the way the screening items were administered from one time to another.

• The Children's Bureau Matching Funds Grant Program appears to have capacity for quantitative data collection, analysis, and reporting. The project documents some information about the population it serves and the developmental issues that it identifies through screening. Additional information is needed to see if data can be provided regarding the referrals the program makes to link families to developmental services for children age 0-5 years, and the outcomes of those referrals.

Child & Family Center

The Child & Family Center collects data for its First 5 LA-funded mental health consultation services. Data were provided in an excel spreadsheet for children who received mental health consultation services in FY12-13. The variables in this spreadsheet included child age and gender, referral source, whether the child was screened with the ASQ, and various types of referrals that were made for the family. The Child & Family Center uses its data to generate information for First 5 year-end reports as well as to inform internal reviews of program effectiveness.

In FY12-13, data are available for 33 children age 5 years or younger. All but one child was between 2 and 5 years of age. Of the 33 children, 12 (36%) were screened using the ASQ. Half (50%) of the children screened with the ASQ received a Regional Center referral and 58% were referred for occupational therapy or speech therapy. Other data provided in the spreadsheet submitted relates to the services provided by the Child & Family Center's mental health consultation team.

• The quantitative data received from the Child & Family Center is somewhat limited in terms of documenting the characteristics of the children receiving developmental screening and the results of the ASQ screenings. In addition, although data were provided that show the number of children referred to developmental services, no information was provided about the status of those referrals. It is possible that such data are collected but are not maintained electronically in an easily accessible format. At present, we are working with staff at the Child & Family Center to clarify how these data relate to other data that are collected by their agency for services provided through the Department of Mental Health (DMH) and maintained in a separate Electronic Health Record system (Welligent).

Discussion

The four programs included in this study offer and conduct developmental screening of children age 0-5 years using a variety of approaches and settings. Regardless of the program's specific methods of implementation, developmental screening is available to diverse Los Angeles County families with young children. Some programs target families with children in a specific age range (e.g., newborns, preschoolers), while others offer screening for any child 5 years of age or younger. For the children screened, the families may have had a concern about their child that triggered the screening, or the screening may have brought issues to the forefront that were not necessarily a presenting concern for the family at the time of the screening.

Managers of the programs studied identified a number of strengths of the developmental screening tools and protocols in use. Overall, the screening tools and protocols provide a mechanism for gathering information that is both technically rigorous and parent-friendly. Some programs have developed strategies to work around some relative weaknesses of the screening tools. For example, in order to compensate for limitations associated with parent reporting, the Child and Family Center incorporates teacher ratings and clinical observations to provide multiple perspectives on the child being screened. While this approach is more intensive than a typical screening based on the perspective of one respondent, it still qualifies as a screening rather than an assessment, as the results of the screening do not result in a definitive diagnosis and the screening tools are not intended to be used for diagnostic purposes. The developmental screening tools in use are well established in the broader literature and among the most widely used developmental screening tools available.

Programs supported by First 5 LA to provide developmental screening have implemented a number of strengths that may be considered best practice: the use of well-established developmental screening tools that are both technically rigorous and parent-friendly, as well as the availability of qualified and empathic staff to provide developmental screening services. Some programs may find using computer-assisted screening programs to be beneficial, while others may be more comfortable using paper-and-pencil screening tools with the families that they serve.

Best practices in care coordination involve approaches that are child- and family-centered, and help to empower families to access needed developmental services. Although programs vary in their care coordination models, their resources available for ongoing follow-up, and their ability to document outcomes, they share the focus of working with families to help them connect with appropriate resources.

The quantitative data available from these four programs permitted a very general examination of the data. The four programs vary in the types and amount of quantitative data they collect, the systems used to maintain data, and the extent to which they track referral outcomes in those data. Capacity for quantitative data collection, warehousing, analysis, and reporting should be evaluated for each program within the context of program size and resources available for supporting the infrastructure needed for such data systems. Because the programs

differ so widely in their capacity to document developmental screening quantitatively, should First 5 LA wish to collect data in common across its grantees that conduct developmental screening, it may wish to consider the development of standards, definitions, and specifications for such data so that it can be pooled across programs to permit collective analysis.

Limitations

By design, this study was designed to be descriptive and was intended to illustrate the developmental screening tools, practices, and protocols used by four programs funded by First 5 LA. It was not designed to be population-level research and samples were intentionally small. In addition, the time and scope of the data collection all occurred within a short window of a few months. The information presented in this report is not intended to be exhaustive. Additional information may be available, qualitative and/or quantitative, that provides a more complete picture of developmental screening activities offered and provided by the organizations included in this review of current First 5 LA developmental screening investments.

It should also be noted that data collection using the Program Manager Interviews was designed to be exploratory; themes were coded from answers to open-ended questions. Similarities and differences among the programs studied were identified based on these open-ended questions. If the stakeholders interviewed were presented with a list of issues and asked to indicate if those specific issues were true for their program, that method might result in a somewhat different picture of the similarities and differences among the programs.

Appendices

A. References Cited

B. Program Manager Interview Data Collection Protocol

Appendix A. References Cited

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Appendix B: Program Manager Interview Protocol

| nterviewer: | Date: |
|-------------|-------|
| | |

First 5 LA Developmental Screening Environmental Scan Program Manager Interview

| Agency: |
|---|
| Respondent: |
| Job Title: |
| Thank you for talking with us today. The Measurement Group is working with First 5 LA to conduct an environmental scan of developmental screening activities in First 5 LA-funded programs. The environmental scan is a systemic overview of the developmental work that First 5 LA is doing, and is being conducted to help plan for future evaluations of developmental screening services. The |

The purpose of this interview is to help us understand how your program uses developmental screening tools, to learn about any follow-up procedures that you may have, and to describe what, if any, data you maintain related to developmental screening. We also want to hear your perspectives on the strengths and weaknesses of the screening procedures. This interview will take approximately 30-60 minutes. Your participation is voluntary. We will summarize the findings in a report for First 5 LA in aggregate. None of your responses will be identifiable or attributed to you or your organization.

environmental scan is primarily descriptive, to give First 5 LA a general qualitative understanding of the

We would like to make an audio recording of the interview to assist us with note-taking. The recording will only be accessed by staff of The Measurement Group who work on this project. We will destroy the recording as soon as we have verified our notes.

Do you consent to participate in this interview as described above?

developmental screening services that it supports.

| _TMG witness initial here – participant consents to participate in the interview and to be recorded. |
|--|
| _TMG witness initial here – participant consents to participate in the interview, but <u>not</u> to be recorded. |
| _ TMG witness initial here – participant does not consent to participate in the interview. |
| If no consent, thank participant and stop here. |

| Interviewer: | Date: |
|--------------|-------|
| | |

Screening Tools

- 1. What developmental screening tools does your program use?
 - a. Do you know how long those tools have been in use by your program? If so, about how long?
 - b. Why do you use these tools? What makes them the best choice for the parents/caregivers you serve? If you use more than one screening tool, when do you use one tool vs. another?
 - c. What are the strengths and weaknesses of the developmental screening tools that your program uses? Please explain.
 - d. The information in the developmental screening is based on: staff observations, parent report, and/or other source(s)?

Screening Protocols

- 1. Please walk me through when developmental screening happens in your program from the perspective of the staff, parent(s), and child(ren)
 - a. In general, how does your program use developmental screening tools and the results from the screenings?
 - b. In what context does developmental screening happen with respect to the child's involvement in your program? For example, is it done as part of your intake process? Where does the screening occur in home? Program office? Are children screened more than once, and if so what triggers subsequent developmental screenings?
 - c. Who does the screenings? What is the professional/paraprofessional background of the screener(s)? What kind of training do staff receive in the use of the screening tools?
 - d. How are the screening tools administered?
 - i. Staff observation?
 - ii. Hand form to parent?
 - iii. Parent self-administers with help from staff?
 - iv. Other method(s)?
- 2. Let's talk about what happens if a child screens positive for a developmental delay or concern.
 - a. What is the process?
 - b. Does the child get any referrals? To what kind of services? Are they internal or external to your program? Please specify for example, are they referred to a regional center? Specific direct services?
 - c. Is there any kind of follow-up to see if the child is connected with the service referrals? What does your program do to follow up on any referrals to services beyond the developmental screening that you provide?
- 3. What would you say are the strengths and weaknesses of your screening protocols?

| Interviewer: | Date: |
|--------------|-------|
| | |

Screening Data

- 1. What kind of data do you track about developmental screening?
 - a. Do you track individual client-level data from developmental screening that occurs in your program?
 - i. What variables do you track at the client level?
 - b. Do you track aggregate or summary level data from the developmental screening that occurs in your program?
 - i. What variables do you track at an aggregate or summary level?
 - c. Do you track the outcomes of any referrals that your program makes? If so, what kinds of information do you collect? Are there any issues or challenges in getting outcome data from your linked providers about the children or families that you referred to their program?
 - d. If you maintain data from developmental screening electronically, what software do you use? How are the data entered in the database?
 - i. Would it be possible to get a data dictionary or list of variables that you collect?
 - e. Does your program use the data in any way, and if so how?
 - i. Would it be possible to get copies of any reports that summarize your developmental screening data?
 - f. Is anything about your program's use of data from developmental screenings described in your program consent forms, or other similar documents?

The Big Picture

- 1. Are there any issues, barriers, or challenges that your program faces getting families with young children to services in the context of the "big picture" of developmental screening among First 5 LA funded programs?
 - a. Issues/barriers/challenges related to linking referrals
 - b. Issues/barriers/challenges related to sharing information
 - c. Other Issues/barriers/challenges
 - d. Etc.
- 2. What resources would help your program better link families with needed developmental services?
- 3. What changes has your program made over time regarding developmental screening? Have you learned any lessons about providing developmental screening?
- 4. What kinds of systems change would you like to see to improve the timeliness and/or cost effectiveness of assessing children who screen positive for possible developmental delays and/or autism and linking them to needed services?
- 5. Is there anything else you would like to share about your program's developmental screening services?

| Interviewer: | Date: |
|--------------|-------|
|--------------|-------|

Your Professional Background

We would like to ask you a few questions so that we can summarize the professional characteristics of the program managers and staff that we interview.

- 1. How long have you been in your current role in this organization?
- 2. How long have you worked in the field of child and family services?
- 3. What field is your professional training in? (e.g., social work, psychology, child welfare, etc.)
- 4. What is the highest degree you have earned?

Thank you! We greatly appreciate your time. Your answers will help First 5 LA to better understand developmental screening services provided by its funded programs and their network of linked service providers. May I contact you if we have any follow up questions as we synthesize the information from our interviews?