PRENATAL TO FIVE DEVELOPMENTAL SCREENING, REFERRAL, AND CONNECTION TO SERVICES IN KING COUNTY

A REPORT FROM A PARTICIPATORY LANDSCAPE ANALYSIS

King County

Best Starts for KIDS

CARDEA

Training, Organizational Development and Research

ACKNOWLEDGMENTS

This work is made possible by the Best Starts for Kids levy. Best Starts for Kids builds on the strengths of communities and families so that babies are born healthy, children thrive and establish a strong foundation for life, and young people grow into happy, healthy adults. Best Starts for Kids is the most comprehensive investment in child development in the nation. King County's investments span from prenatal development all the way through young adulthood, building strength and resilience in our communities along the way.

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EXECUTIVE SUMMARY

BACKGROUND & APPROACH

Best Starts for Kids **builds on the strengths of communities and families so that more babies are born healthy, more children thrive and establish a strong foundation for life, and more young people grow into thriving members of their community. Best Starts for Kids is the most comprehensive approach to child development in the nation. While strategies vary based on community need, all build upon the strength and resilience of children, young people, families, and communities.**

Funded through the King County *Best Starts for Kids* levy, Cardea, WithinReach, and the King County Developmental Disabilities and Early Childhood Supports Division (KCDDECSD) partnered to gain a better understanding of successes, gaps, and disparities related to developmental screening, referral, and connection to services in King County in 2018-2019. Information gathered through this landscape analysis will lay the groundwork for future endeavors and serve as the baseline against which King County will evaluate its efforts to implement universal screening, referral, and connection to services.

To ensure ideas for systems improvement are rooted in and supported by the community, Cardea formed a 12-member Community Expert Council (CEC) to guide the landscape analysis and strategic planning process, in consultation with KCDDECSD and WithinReach. The CEC advisors represent diverse geographic regions of the County and include parents, parenting support providers, professionals from multiple fields (i.e. medical, home-based services, early learning, and childcare), systems thinkers, and health promotion experts. Throughout each phase of data collection, the CEC provided critical input on instrument development and implementation, and facilitating connections to key stakeholders serving pregnant people and families with young children in King County. A national expert who had conducted a similar assessment also provided guidance on approaches and instruments.

From August 2018 through March 2019, Cardea led efforts to gain a comprehensive understanding of current screening and referral practices and experiences, community engagement strategies, training needs, and barriers and facilitators to screening, referral, and service connection in King County. The team implemented three primary information gathering strategies: 1) key informant interviews; 2) a community survey; and 3) discussions through focus groups and community forums. In April and May 2019, four community discussions were held to review the data, identify key findings, and develop community principles (page 115).

KEY INFORMANT INTERVIEWS

Between August and September of 2018, Cardea conducted 15 interviews with 19 key informants identified by the CEC, WithinReach, and KCDDECSD staff. Interviews included kinship or foster family support providers, health care providers, home-visiting providers, statewide policy experts on Child Find and Early Support for Infants and Toddlers (ESIT), parents, and researchers.

COMMUNITY SURVEY

From November 2018 through January 2019, providers and parents/caregivers were invited to respond to an online survey that was shared through 74 organizations across King County. The voluntary and confidential survey was offered in English, Chinese, Russian, Somali, Spanish, Ukrainian, and Vietnamese. There were 761 responses eligible for analysis from 956 responses.

FOCUS GROUPS AND COMMUNITY FORUMS

Between January and March 2019, Cardea partnered with community-based organizations to hear directly from families about their experiences with developmental screening, referral, and connection to services. Cardea engaged 55 parents/caregivers through nine focus groups. Six groups were conducted in English and three groups were primarily conducted in a non-English language.

In March 2019, two interactive community forums were held in North Bend (in partnership with a local community-based agency) and Kent, reaching 42 parents/caregivers. At these forums, participants could choose to participate in discussions similar to the focus groups discussions.

OVERARCHING QUESTIONS

At a high-level, parents/caregivers were asked:

- *What are your experiences with developmental screening? Supportive services?*
- *What did you like and what could be improved about those experiences?*
- *How can King County improve developmental screening and referral?*
- *Where do families naturally go with their children?*

Providers were asked (providers were broadly defined as professionals in early care and education settings who work with pregnant people or families with young children):

- *What does developmental screening look like at your practice?*
- *How often and how do you refer families to supportive services?*
- *How and how often do you coordinate care with other providers? How do you know families connected?*
- *How could the coordination of developmental screening and referral be improved?*

COMMUNITY AND PUBLIC SECTOR DISCUSSIONS

In April and May 2019, Cardea, WithinReach, KCDDECSD, and CEC members led three community discussions and one public sector discussion to review the data, identify key findings, and develop community principles. About 50 King County residents and 30 public sector partners participated in these events.

KEY FINDINGS

MANY PROVIDERS ARE SCREENING USING EVIDENCE-BASED TOOLS DESPITE VARIED SCREENING PRACTICES

Key informants noted that developmental screening was common, although screening practices differed based on type of service (primary care, early learning, home visiting, childcare) and setting (office or home-based), which survey findings corroborated. A majority of all provider type survey respondents reported using validated or evidence-based screening tools, with home-based providers most commonly reporting the use of validated or evidence-based tools (87%) and specialists least often using validated or evidence-based tools (61%). The most common tools interviewees and survey respondents noted using were the Ages and Stages Questionnaire, Third Edition (ASQ-3) and ASQ: Social Emotional, Second Edition (ASQ: SE-2).

While providers reported using validated tools, caregivers participating in the focus group discussions commonly reported never having conversations with any type of professional about their child's development and behavior, especially kinship families. Caregivers who did recall conversations with their providers noted that the process of diagnosis and service connection was smoother for children who were diagnosed prenatally or at birth; caregivers of children with autism recalled needing to continually advocate for their child to receive a diagnosis.

Key informants and survey respondents noted that maternal depression screening was also common among healthcare providers and home visiting providers. Most interviewees and primary care providers who responded to the survey did not formally screen for Adverse Childhood Experiences (ACEs), although the value of ACEs screening was commonly noted by interviewees.

FAMILY-CENTERED, CULTURALLY, AND LINGUISTICALLY RELEVANT TOOLS & SERVICES ARE NEEDED

Providers and caregivers emphasized a need for the developmental screening, referral, and connection to services system to be family-centered, highlighting the desire for culturally and linguistically relevant tools and services. All key informant interviewees discussed concerns about the appropriateness and validity of current screening tools for families of different cultures, races, and linguistic backgrounds, noting that translation and interpretation alone were not sufficient modifications.

> **"The magic and gift of primary care and also the responsibility is that providers have a bucket of trust they can spend in different ways. Their ability to support and encourage families has much to do with trust and also makes them careful about how they spend that trust."**
>
> **—Healthcare provider**

Parents/caregivers participating in focus group discussions articulated multiple ways in which healthcare providers could be more family-centered, including improving provider 'bedside' manner to create screening and service environments that are non-judgmental, strengths-based, and non-confrontational, and ensuring consistent providers to prevent duplicative conservations that detract from time spent providing services. Caregivers relayed positive experiences when the screening was completed by someone who was aware of how culture relates to the unique ways children display growth and development.

Survey results revealed that approximately one-quarter (26%, n=79) of caregivers were not offered the opportunity to complete a questionnaire about their child's development and behavior in another language, if needed. In addition, fewer than half of primary care providers (46%) reported offering screening in Spanish and only 19% reported offering screening in a language other than English or Spanish. Survey participants recommended that **an ideal developmental screening and referral system should be community-centered, accessible to all, include patient navigators and care coordinators, and be flexible to meet parent needs.**

REFERRAL AND FOLLOW-UP PRACTICES ARE NOT AS STRONG AS SCREENING PRACTICES

Although screening for developmental and behavioral concerns appears to be common, there are gaps in referral and follow-up practices. Primary care providers who participated in the survey reported referring a median of 50% of families when concerns were identified during screening, although there was tremendous variation in the consistency of referral. While most interviewed providers referred and linked families as indicated by screening results, they noted common barriers to successful referral and connection to services including not knowing who to refer to, long waiting times between referrals and receipt of services, lack of understanding about next steps, and discomfort around uncertainty about eligibility requirements. Focus group participants also noted that referral and follow-up after maternal depression screening is inconsistent.

Parents/caregivers expressed a desire for shorter waiting periods and a streamlined process for being connected to services. Several parents/caregivers also talked about systemic factors that make accessing referrals challenging—racism, immigration status, lack of insurance, and income inequality. Parents/caregivers also saw providers' gatekeeping practices as barriers to getting referred and connected to services. Families reported having positive experiences when they worked with advocates, coordinators, and home visitors dedicated to supporting the family through screening, referral and service connection.

STRONGER CROSS-SECTOR COORDINATION IS DESIRED—PARTICULARLY BETWEEN HEALTH AND EDUCATION

Enhancing cross-sector coordination was a primary interest across key stakeholder groups. Key informants noted sufficient coordination within sectors, but a lack of coordination across sectors (e.g. service providers are well connected to those who do similar types of work, but not to other types of providers). Although key informants reported that providers in different sectors share common values, they speculated that insufficient resources, staff turnover, lack of communication between providers, and lack of widespread awareness of early intervention and developmental screening are key barriers to successful coordination. They suggested that systems coordination improvements are especially needed to ensure continuous care and provide smoother transitions for children who are transitioning out of Birth-to-Three services. Most parents/caregivers who participated in focus groups and community forums also supported enhanced systems coordination and cross-sector communication, and noted a particular need to improve the transition between Birth-to-Three and Special Education Services.

Survey results also illustrated a need to improve cross-sector communication, with the percentage of early learning/childcare, specialist, and primary care provider (PCP) respondents who reported sharing information about a child's development "often or always" varying based on provider type. Early learning/childcare respondents reported sharing information most frequently with supportive services providers, while specialists reported sharing information most frequently with PCPs. PCPs least frequently reported sharing information with other provider types. Many survey participants indicated that improved communication across stakeholder groups would improve the coordination of the developmental screening and referral system.

MORE COORDINATED ACCESS TO CLEAR RESOURCES & SUPPORTS WOULD BE WELCOMED BY FAMILIES AND PROVIDERS

Parents/caregivers wanted more coordinated or centralized access to information and resources to make it easier for families to navigate the system of care—and also wanted providers to be more aware of the full scope of resources and services available to families so they could connect families to those supports or to source for finding those supports. Parents/caregivers also discussed a need for increased outreach to families about what developmental screening is and where to receive information on how, why, and when to have developmental screening done.

Survey responses aligned with what we heard from families through focus groups, with less than half of parent/caregiver respondents reporting “very good or excellent” knowledge regarding where to go to have their child screened for developmental screening (42%), how to follow-up on a referral after their child received a developmental screening (45%), or where to go to receive supportive services (40%). Many survey participants described a “one stop shop” for accessible screening and referrals as their ideal system to improve coordination of the developmental screening and referral system.

INCREASED ACCESS TO INCLUSIVE SPACES BENEFITS EVERYONE AND REDUCES STIGMA

Stakeholders underscored a widespread need for expansion of spaces that are inclusive of and welcoming to all types of children and families to reduce stigma in the community. In focus group discussions, participants overwhelmingly spoke about the need to reduce stigma around screening, assessment, early intervention, and disability, while creating more inclusive spaces and services, to ensure that families and children with special care needs are embraced by the larger community. Suggested strategies included routinizing developmental screening, public education campaigns, elevating the successes of neurodiverse adolescents and adults, and creating mentorship opportunities for neurodivergent adults to support neurodivergent children.

Additional suggestions from survey respondents were to improve provider training, specifically surrounding provider stigma and biases, to increase the availability of qualified providers.

> **“When you start talking about a culture change, you’re talking about something really long-term. I would love to see all the major stakeholders around the county or around the state, come together in some sort of organized conversation to say, in 50 years, if King County was going to be a truly inclusive environment, what would it look like? How do we get there?”**
>
> **—Focus group participant**

CONSIDERATIONS

Findings from each information gathering strategy should be interpreted in concert because there are limitations to each of the strategies.

Cardea interviewed key informants as recommended by key stakeholders based on their prominence or excellence in the field or their systems-level knowledge; therefore, their practices are likely to be exceptional and atypical. Interview findings also primarily reflect provider perspectives on developmental screening and referral.

Developmental Screening and Referral Community Survey respondents tended to be white, non-Hispanic, female, straight, English-speaking, Seattle-area residents with a combined family income above the area median income, despite wide survey distribution in partnership with community-based agencies. For this reason, it was difficult to assess differences in experiences with developmental screening and connection to services across families with different demographic characteristics or geographic regions.

In contrast, focus group and community forum participants were almost exclusively parents, caregivers, and family members from underserved, marginalized, or underrepresented communities. These discussion group participants provide insight that might not be present in survey responses, but do not reflect provider perspectives.

For all these reasons, findings from one strategy might seem to contradict findings from another strategy. This summary attempts to interpret the findings from each strategy together to provide a description of the current developmental screening, referral, and connection to services landscape in King County.

BACKGROUND ON DEVELOPMENTAL SCREENING, REFERRAL, AND CONNECTION TO SERVICES

THE IMPORTANCE OF DEVELOPMENTAL SCREENING

Key Points

- **Developmental screening is critical to the well-being of children**
- **Many sectors share the responsibility of identifying developmental delays & facilitating access to supportive services**
- **Screening needs to be family-centered and culturally appropriate**
- **Through Best Starts for Kids, King County is committed to building a universal developmental screening and referral system that meets the diverse needs of children and families in the county**

Ensuring healthy development in the early years of a child's life plays a crucial role in establishing a healthy trajectory throughout the life course. This includes positive impacts in self-sufficiency, quality of life, high school completion, and mental and emotional health.[1,2,3,4,5,6] Many factors, including reading, singing, talking, and playing with children optimize development, while other factors, including adverse childhood experiences and toxic stress, disrupt development.[7,8] Although many resources exist to enhance protective factors and mitigate the impact of risk factors, the needs of children with developmental, behavioral, or emotional delays often go undetected or unaddressed until a child struggles in school or in their relationships.

Developmental screenings are a foundational element of health care and well-being for young children, especially those birth through age five, because they offer an opportunity to identify areas of typical development as well as areas of concern or delay. Early identification of needs and provision of appropriate supports and services ensures that interventions occur when children's developing brains are most capable of change. When indicated, appropriate, high-quality, Early Intervention programs can reduce the likelihood that children will experience prolonged or permanent health, learning or developmental delays, and reduce the incidence of future learning, behavior, and health issues.

From a global perspective, the World Health Organization and the United Nations Children's Fund (UNICEF) recommend a twin-track approach that recognizes children with disabilities and their families need targeted services (e.g. Early Intervention) and also need to be included in mainstream programs and services (e.g. health care, child care, and education).[9] Furthermore, they recommend engaging many sectors and stakeholders to share the responsibility of identifying children with delays and guaranteeing access to supportive services. In line with this twin-track approach, the World Health Organization recognizes how shifts toward models of engagement that empower families, encourage comprehensive and centralized access to services, endorse cultural diversity, and apply a life-cycle view are more successful in identifying delays early and connecting children to appropriate supportive services.[10] This method of screening and intervening early across a variety of settings and in a culturally appropriate manner is also the approach recommended by the US Centers for Disease Control and Prevention and Public Health – Seattle & King County.[11]

Through Best Starts for Kids (Best Starts), King County aims to establish a universal developmental screening and referral system, in which screening tools are used in a variety of settings, by a variety of professionals, and with the proper infrastructure in place to ensure timely connection to meaningful family supports. This literature review examines available common screening tools, professional development efforts, and referral infrastructure initiatives that may inform King County's strategic plan for this developmental screening and referral system.

To ensure all children receive routine, proactive developmental screening, validated tools must be used in a variety of settings. Many sectors have taken steps to increase the use of screening tools. Some examples include:

- The American Academy of Pediatrics recommending that developmental screenings are incorporated at each well-child preventive care visit[12]
- Head Start requiring developmental screening within 45 days of starting the program[13]
- Early Achievers, Washington State's quality rating and improvement system, offering improved child care quality ratings to providers that do developmental screenings[14]
- The Washington Kindergarten Inventory of Developing Skills (WaKIDS) measuring kindergarten readiness and providing a valuable look into how well prepared children are for school[15]
- Nurse-Family Partnership, Parents as Teachers, and other evidence-based home visiting models now include regular developmental screening in their curricula
- Cross-sector screening promotion at a federal level, including:
  - The Centers for Disease Control and Prevention's *Learn the Signs Act Early* Campaign, with wide-ranging materials, including professional development modules, a free milestone tracking phone application, a digital library of milestone clips, and other materials to improve surveillance and empower parents across diverse settings[16]
  - *Birth to Five: Watch Me Thrive!*, a cross-federal agency initiative to advance screening efforts nationwide[11]

UNIVERSAL DEVELOPMENTAL SCREENING (UDS) INITIATIVES

OVERVIEW

Key Points

- **Developmental delays are common**
- **Universal screening supports early identification of delays**
- **The American Academy of Pediatrics' recommendations for screening at well-child visits support screening in medical settings, but screening occurs in a variety of community settings too**
- **Screeners should consider what is culturally relevant and appropriate for each family as part of a larger developmental surveillance effort**

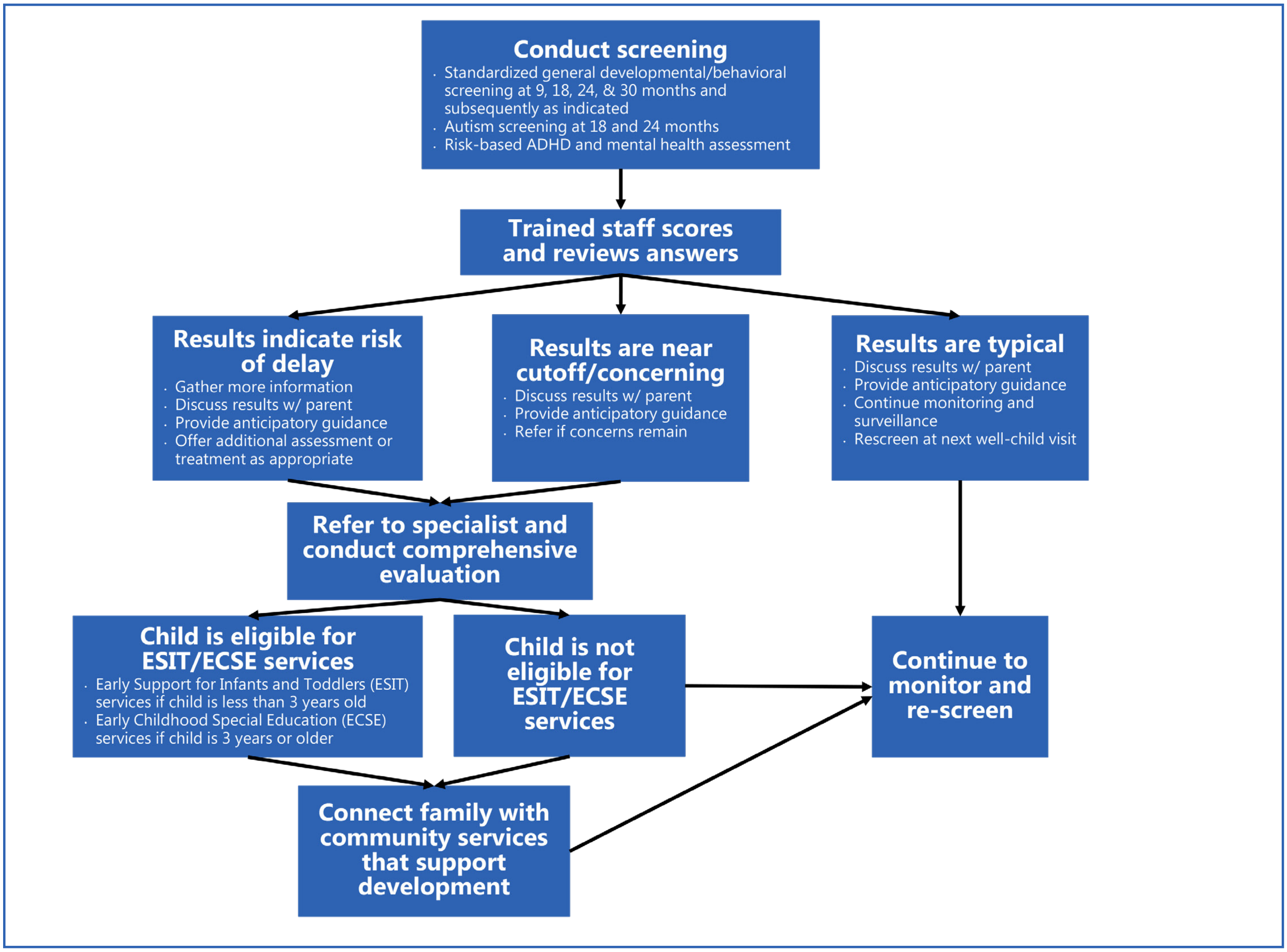
Estimates indicate that about 7% of children in the United States have been diagnosed with a developmental disability and about 5% have been diagnosed with a developmental delay besides autism, with data showing an increase in prevalence of developmental disabilities including autism in recent years.[17] Universal screening is key to the early identification of developmental concerns, which should then lead to further evaluation, diagnosis, and treatment or supports to address any delay or disability. When children who have or are at risk for having worse health outcomes, including developmental delays, receive developmental screening and recommended interventions, they demonstrate improved cognitive, emotional, and language outcomes.[1,2,3,4] Through developmental screenings using standardized tools, children who might have developmental delays or concerns are more likely to be referred to Early Intervention services and access those services in a more timely fashion compared to children who do not receive screening.[18]

In 2006, the American Academy of Pediatrics published its recommendation that developmental screening be routinely administered for every child at 9, 18, and 24 or 30 months of age, in addition to incorporating developmental surveillance at each well-child preventive care visit.[12] According to their recommendations, screening should utilize brief (30 minutes or less) standardized tools that have relatively high sensitivity and specificity, are reliable, and focus on all developmental domains at specific age intervals to identify any potential developmental delays.[12] While screening indicates the possible presence of a developmental delay, it must be followed by more comprehensive evaluation to confirm any issues identified by the screener.[19] Surveillance refers to the process of documenting a child's developmental history, asking parents about their child's development, and observing the child's development in addition to the physical exam without the use of a standardized screening tool, to identify children at risk for delays. For reference, a **glossary of terms** is included on page 102.

Although the American Academy of Pediatrics' recommendations are the current standard for administering developmental screenings, it is important to note that each family has unique needs, and screeners must consider what is culturally relevant and appropriate for each family as part of a larger developmental surveillance effort. While a variety of standardized tools for developmental screening are available in multiple languages, only a few have been validated for cultural relevance in languages other than English (for example, the Ages and Stages Questionnaire, Third Edition (ASQ-3) and the Parents' Evaluation of Developmental Status (PEDS) have been validated in Spanish).

Figure 1 maps the recommended processes for developmental screening and referral for children. This graphic has been adapted from existing developmental screening process maps, including the US Centers for Disease Control and Prevention developmental screening flowchart, the American Academy of Pediatrics developmental surveillance and screening algorithm, the American Academy of Pediatrics autism screening algorithm, and Zuckerman et al.'s (2013) developmental evaluation and referral process.[12,20,21,22,23]

Figure 1. Developmental screening and referral process map



Despite established recommendations for universal screening that have been maintained and reaffirmed for more than a decade,[24] full implementation is far from universal.[25] A 2012 study that surveyed 408 pediatricians across six states found that under 18% of pediatricians followed all three screening recommendations, with screening at 9, 18 and 24 or 30 months ranging from 42% to 52%.[26] Further, in a survey of 302 US pediatricians, only 2% of reported using a screening tool for adverse childhood experiences and only 4% asked about seven core adverse childhood experiences.[27] Research also reveals that disparities persist in screening, timely diagnosis, and intervention for behavioral and developmental conditions across racial, ethnic, and linguistic lines.[2] An analysis of the 2007 National Survey of Children's Health, for example, showed that African American and Latino parents where English was not the primary language were significantly less likely to be asked by providers about developmental or behavioral concerns than white parents.[28]

A number of challenges and barriers to implementing universal developmental screening have been identified in the literature, including those listed in **Table 1** below.

Table 1. **Barriers to implementing universal developmental screening**

Barriers	Evidence		
	Mixed methods study in urban pediatric primary care centers[29]	Program implemented in a Women Infants and Children (WIC) program and pediatric care setting[30]	Interviews with nine[1] Help Me Grow affiliate staff involved in community and clinical screening efforts
Health System Level			
Limited appointment time	■		
Insufficient reimbursement		■	
Poor coordination across early childhood system			■
Provider Level			
Discomfort discussing results		■	
Resistence to using validated screening tools	■		■
Lack of training	■		■
Distrust of parent input	■		
Caregiver/Patient Level			
Cultural/linguistic barriers			■
Transportation barriers			■
Misconceptions about the purpose of screening			■
Fear of stigma/being labeled			■

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[1] Affiliates included Alabama, Alameda County (CA), Contra Costa County (CA), Orange County (CA), Florida, Kentucky, Wayne County (MI), South Carolina, and Utah.

Despite these barriers, there have been some promising interventions across the US to increase rates of screening in both clinical and community-based settings.[31] In a nationwide sample of pediatric practices, sites were able to implement the American Academy of Pediatrics recommendations for developmental screening and referrals, screening over 85% of patients in the recommended age range through division of staff responsibilities and effective monitoring of program implementation activities.[16] In community-based settings, The Early Developmental Screening and Intervention Initiative worked with two communities in California, involving physicians, early care and education programs, and other community organizations supporting care for families, to create streamlined systems for developmental care to support access to services for young children that could be replicated to other communities.[17]

DEVELOPMENTAL AND SOCIAL/EMOTIONAL SCREENING TOOLS

Key Points

- **A variety of standardized tools for developmental screening are available in multiple languages; however, only a few have been validated for cultural relevance in languages other than English**
- **Screening for adverse childhood experiences (ACEs) and post-partum depression are connected to a larger developmental surveillance effort**

In the 2014 compendium of screening measures for young children, the US Department of Health and Human Services' Office of Planning, Research, and Evaluation within the Administration for Children and Families identified 11 quality tools for developmental screening. These are tools that meet standards of accuracy, inclusion of family input, and inclusion of the social and emotional domain.[19] The 11 tools are listed below in **Table 2**. The Modified Checklist for Autism in Toddlers (M-CHAT) is an additional, publicly accessible and commonly used screening tool to identify children 16 to 30 months old who are at risk for autism spectrum disorder. The M-CHAT is available in over 40 languages.

Table 2. General overview of developmental and social/emotional screening tools

Screener name	Domains covered	Age range	Languages available
Ages and Stages Questionnaire, Third Edition (ASQ-3)	Communication; Gross; Motor; Fine Motor; Problem Solving; Personal-Social	1 month – 5 ½ years	Arabic; English; French; Spanish; Vietnamese
Ages and Stages Questionnaires: Social-Emotional, Second Edition (ASQ:SE-2)	Self-regulation; Compliance; Communication; Adaptive functioning; Autonomy; Affect; Interaction with people	6 months – 6 years	English; Somali; Spanish;
Brigance Screens	Expressive language; Receptive language; Gross motor; Fine motor; Academics/pre-academics; Self-help; Social-emotional skills	Birth through end of 1st grade	English
Developmental Assessment of Young Children, 2nd Edition (DAYC-2)	Cognition; Communication; Social-emotional; Physical; Development; Adaptive; Behavior	Birth through 5 years	English
Early Screening Profiles	Cognitive; Language; Motor; Self-Help/Social; Articulation; Home; Health; History; Behavior	2 years through 6 years and 11 months	English
FirstSTEP	Cognitive Language Motor Social- emotional skills Adaptive functioning	2 years 9 months through 6 years 2 months	English
Infant Development Inventory (IDI)	Cognitive; Language; Motor; Social- emotional skills; Adaptive functioning	Birth to 18 months	English
Learning Accomplishment Profile-Diagnostic Screens (LAP-D)	Social Development; Self-Help; Gross Motor; Fine Motor; Language	3 – 6 years	English; Spanish

Screener name	Domains covered	Age range	Languages available
Parents' Evaluation of Developmental Status (PEDS)	Global/Cognitive; Expressive Language and Articulation; Receptive Language; Fine Motor; Gross Motor; Behavior; Social-Emotional; Self-Help; School	Birth – 7 years and 11 months	English, with translation in 14 other languages
Parents' Evaluation of Developmental Status – Developmental Milestones (PEDS:DM)	Expressive, Receptive, & Written Language; Fine Motor; Gross Motor; Social-Emotional; Self-Help; Academic: Pre-Reading, and Pre-Math,	Birth – 7 years and 11 months	English; Spanish
Survey of Well-being of Young Children (SWYC)	Cognitive; Motor; Language; Social-Emotional-Behavioral Functioning; Autism; Family Factors	2 months – 5 years	Arabic; Burmese; English; Haitian-Creole; Khmer; Nepali; Portuguese; Spanish; Vietnamese

*This table was adapted from Birth to 5: Watch Me Thrive! A Compendium of Screening Measures for Young Children

The strength of parent-child relationships and exposure to adverse childhood experiences, or ACEs, are additional considerations for both access to developmental screening and risk of developmental delays. Strong parent-child relationships, marked by parental warmth, are associated with children having higher self-esteem, prosocial behavior, and fewer psychological and behavioral concerns.[32,33,34,35] Research also suggests that children who have faced adverse childhood experiences, including child maltreatment and housing instability, are less likely to score highly on kindergarten readiness scales, when compared with children without these experiences.[36,37,38] Witnessing intimate partner violence as a child can also decrease the likelihood that a child receives the recommended five well-child visits within the first year of life and the likelihood that the child has a regular site for well-child care or a primary pediatric provider, where most children receive developmental screenings.[39] Tools that are used to screen for concerns related to adverse childhood experiences and maternal depression are listed in **Table 3**.

Table 3. Additional social/emotional screening tools

Screener name	Domains covered	Age range	Languages available
Adverse Childhood Experiences (ACE) Questionnaire	Adverse childhood experiences including child abuse and neglect, household challenges, other socio-behavioral factors	19 and up	English; Spanish
Center for Youth Wellness ACE Questionnaire (CYW ACE-Q)	Adverse childhood experiences including child abuse and neglect, household challenges, other socio-behavioral factors	Birth – 12 years	English
Edinburgh Postnatal Depression Scale	Depression symptoms	Any individual in the prenatal or postnatal period	English, with validated translations in over 18 other languages

TRAINING AND PROFESSIONAL DEVELOPMENT FOR UDS

BEST PRACTICES/LESSONS LEARNED

Key Points

- **While many tools are designed for parents to complete, health care and early child care providers also play a key role**
- **Insufficient training impedes routine implementation of developmental screening**
- **Some promising training strategies include learning collaboratives, clinical decision support systems, quality improvement initiatives, e-learning courses, & awareness campaigns**

Some of the most commonly used and evaluated tools, such as the Ages and Stages Questionnaire and the Parents' Evaluation of Developmental Status are designed for parents to complete; however, health care, early learning, and early child care providers play a key role in screening, interpreting results, discussing results with families, and referring to Early Intervention and/or further assessment if needed. Insufficient training for primary health care, early learning, and early childhood providers on appropriately integrating standardized tools into their practices or programs is commonly cited as a major barrier to routine implementation of developmental screening. Training for implementation of developmental screening in other community-based settings is even less likely to be available. In a review of published and unpublished literature, several promising training methods and models have supported improvements in screening rates. These include:

- **Collaborative learning approach:** In Los Angeles, California, the First 5 Early Developmental Screening and Intervention initiative uses a collaborative learning approach based on the Institute for Healthcare Improvement model with providers to increase screening by: eliciting and addressing parents information needs and promoting positive parent-child interaction; introducing parent-completed validated screeners (the Parents' Evaluation of Developmental Status, Ages and Stages Questionnaire) to incorporate into the primary care setting; and linking families to resources.[31] The First 5 Early Developmental Screening and Intervention initiative, has led to an increase in screening rates from under 20% to over 85% in participating physician practices.
- **Academic detailing:** A 2011 pilot study evaluated the impact of an academic detailing module to improve autism and developmental screening practices in 43 pediatric primary care practices in Connecticut.[40] Academic detailing refers to face-to-face structured educational outreach visits that are used to support healthcare professionals in their practices.[41] Providers and office staff from the practices received information from another trained pediatric primary care provider on developmental delays, use of the Modified Checklist for Autism in Toddlers, Ages and Stages Questionnaire and the Parents' Evaluation of Developmental Status screening tools, billing codes for reimbursement, and community resources to connect families with evaluation and intervention services. An audit of medical charts in five practices that received the trainings showed significant increases in screening compared to a matched control group, suggesting the potential of academic detailing as an effective training strategy.
- **Computerized clinical decision support systems:** A 2014 study in four primary care pediatric clinics in Indiana serving 88,000 patients, examined whether using computerized clinical decision support systems to automate the screening of children based on the American Academy of Pediatrics guidelines for developmental delay increased the numbers of children screened at 9, 18, and 30 months of age.[42] Clinics using the system showed a significant increase in the percentage of patients screened compared with control clinics. In addition, the number of

children who ultimately were diagnosed with a developmental delay and who were referred to services increased significantly in the intervention sites, compared to control sites.

- **Engaging the whole team in ongoing quality improvement:** The Enhancing Developmentally Oriented Primary Care project has had much success in increasing developmental screening at primary care sites in Illinois since its launch in 2005.[43] Facilitators of success for the project have been identified as: adopting a Plan-Do-Study-Act quality improvement model; using a team approach, where all members of the clinical and administrative staff feel empowered and understand their role in developmental screening; ensuring there is a single team lead for the initiative; and on-going training based on national screening standards that include understanding of child development, use of common screening tools, and how to provide screening results.
- **Supporting statewide coordination through the Act Early Initiative:** The Centers for Disease Control and Prevention's *Learn the Signs. Act Early* campaign aims to improve early identification of children with developmental delays, including autism, so children and their families can get connected to supportive services. The campaign focuses primarily on educating parents, early care and education providers, healthcare providers, and Women Infants and Children staff about key birth-to-five milestones children should reach in terms of how they act, learn, play, and speak through milestone moment booklets. Each state has an Act Early Ambassador who is tasked with supporting collaboration across sectors and communities to improve screening and referral to Early Intervention services, while normalizing milestone tracking.[44] Evaluations of programs focused on integrating the booklets into Women, Infants, and Children (WIC) Nutrition Clinics and early care and education centers have demonstrated promise in terms of increasing rates of referral for suspected delays and improving parents' abilities to monitor their child's developmental milestones.[45,46]
- **Providing accessible, online courses:** The Centers for Disease Control and Prevention, offers a free, one-hour, four-module online course for early care and education providers titled *Watch Me! Celebrating Milestones and Sharing Concerns* to help providers work with families to monitor development and ensure children get the support they need.
- **Additional practical tools to support providers:** A statewide project in North Carolina that began in the early 2000s and successfully increased screening rates to over 70% of designated well-child visits identified practices that effectively supported providers with improving screening practices.[47] These included: talking guides and resources guides for staff and clinicians, curricula and workbooks that are eligible for continuing medical education credits, posters and materials in the waiting rooms to promote awareness among families, and identification of provider champions.

There are a number of training resources available to support early childhood providers in implementing developmental screening. Help Me Grow National Center provides technical assistance to affiliates in over 28 states, including WithinReach, the Washington State affiliate. WithinReach provides free developmental screenings, connections to early learning and family support and referral to Early Intervention, as well as professional development and support for Early Intervention providers. Also in Washington State, the Washington chapter of American Academy of Pediatrics in collaboration with the State Department of Health, offers regional trainings through the Great MINDS project on the importance of validated screening tools; how to use and bill for screenings; and how to provide patients and families with results, resources, and referrals.

REFERRALS AND CONNECTIONS TO SERVICES

BEST PRACTICES/LESSONS LEARNED

Key Points

- **Providers and families face a complex network of challenges in connecting children to supportive services**
- **Greater systems coordination is needed**
- **Improved training, practice discussing results, and follow-up phone calls are promising practices for supporting referral completion**

Effective referrals are a critical part of the screening process; however, evidence indicates that many settings where children receive screening struggle to attain high referral completion (i.e. family receives further assessments or supports). A nine-month pilot study of 17 practices across the 15 states that were working to implement the American Academy of Pediatrics’ 2006 screening recommendations found that on average, just 61% of children whose screens indicated need for further evaluation were referred for further evaluation, with variation across practices from 27% to 100%.[48] In this study, while screening rates increased over time across practices, referral rates did not. Further analyses showed that children with concerning screenings from the Parents’ Evaluation of Developmental Status tool were significantly less likely to be referred to any source, compared to children with concerning Ages and Stages Questionnaire screens.[48]

Understanding which children may be at greater risk for ineffective or lacking referrals is one step to improving processes that support referral completion. Some barriers to referral completion have been identified in the literature and include those outlined in **Table 4** below.

Table 4. Barriers to referral completion after developmental screening

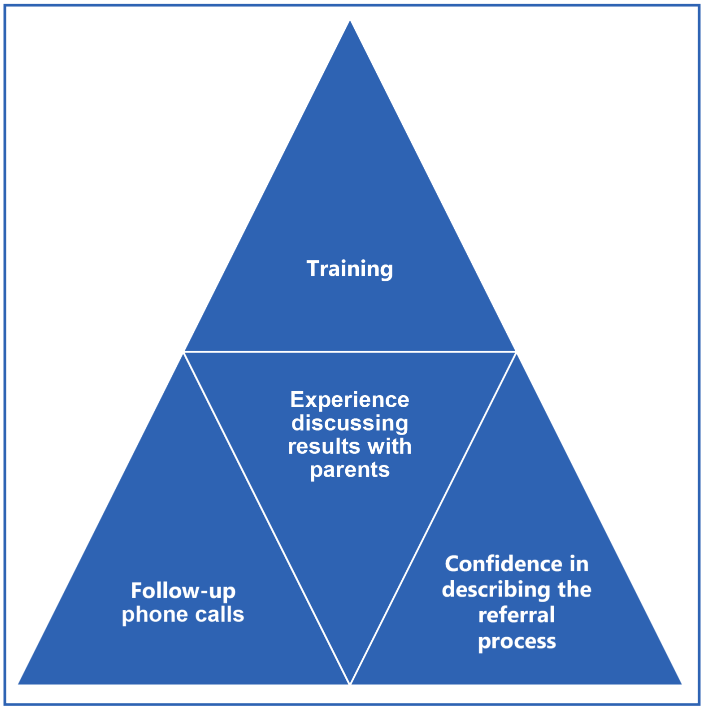
Barriers	Evidence			
	Mixed methods study of clinic practices nationwide[48]	Survey of providers in urban health centers serving Medicaid populations[51]	Audit of child developmental screening records from a community program[52]	Telephone surveys among families participating in Early Intervention[53]
Health System Level				
Lack of referral implementation or tracking systems	■	■		
Insufficient staff			■	
Lack of reimbursement to coordinate referrals between programs/agencies			■	
Provider Level				
Lack of knowledge about Early Intervention system		■		
Distrust in screening accuracy		■		
Distrust of parent input		■		
Lack of confidence in referral systems		■		
Caregiver/Patient Level				
Not understanding reason for referral	■			
Perception that systems won’t meet child’s specific needs				■

Another major challenge described by programs and providers across the country is a lack of a coordinated system for screening, early detection, and intervention. While screening may occur in health care, social services or education settings, activities are often not coordinated and results are rarely shared across agencies or settings.[23] This leads to missed opportunities for referring and linking children to assessment and support services, redundancy, and inefficient use of limited resources.

Very few studies have been published that explore the effectiveness of different strategies or interventions to improve referral completion, and indeed this is a large gap in the literature.[49] In one study, a large urban children's teaching hospital clinic implemented a screening program with the Ages and Stages Questionnaire, reaching a screening rate of over 80%; however, referrals and documentation of referral completion remained low.[50] Initiation of a developmental screening template within the electronic medical records system, in combination with a follow-up phone call to families in the event of a screening close to or beneath the cut-off, led to increased referrals for Early Intervention and evaluation, in comparison to families who did not receive a follow-up phone call.

Another survey of a sample of pediatric providers in Colorado explored factors that impact provider screening and referral patterns. Results showed that providers who expressed confidence in being able to describe the referral system to families were more likely to feel comfortable with discussing an abnormal screen.[51] In addition, providers with recent training and experience discussing results with parents were significantly more likely to express confidence in their skills, underscoring the importance of provider training and education (**Figure 2**).

Figure 2. Factors facilitating referral to supportive services



SUPPORTIVE SERVICES

Key Points

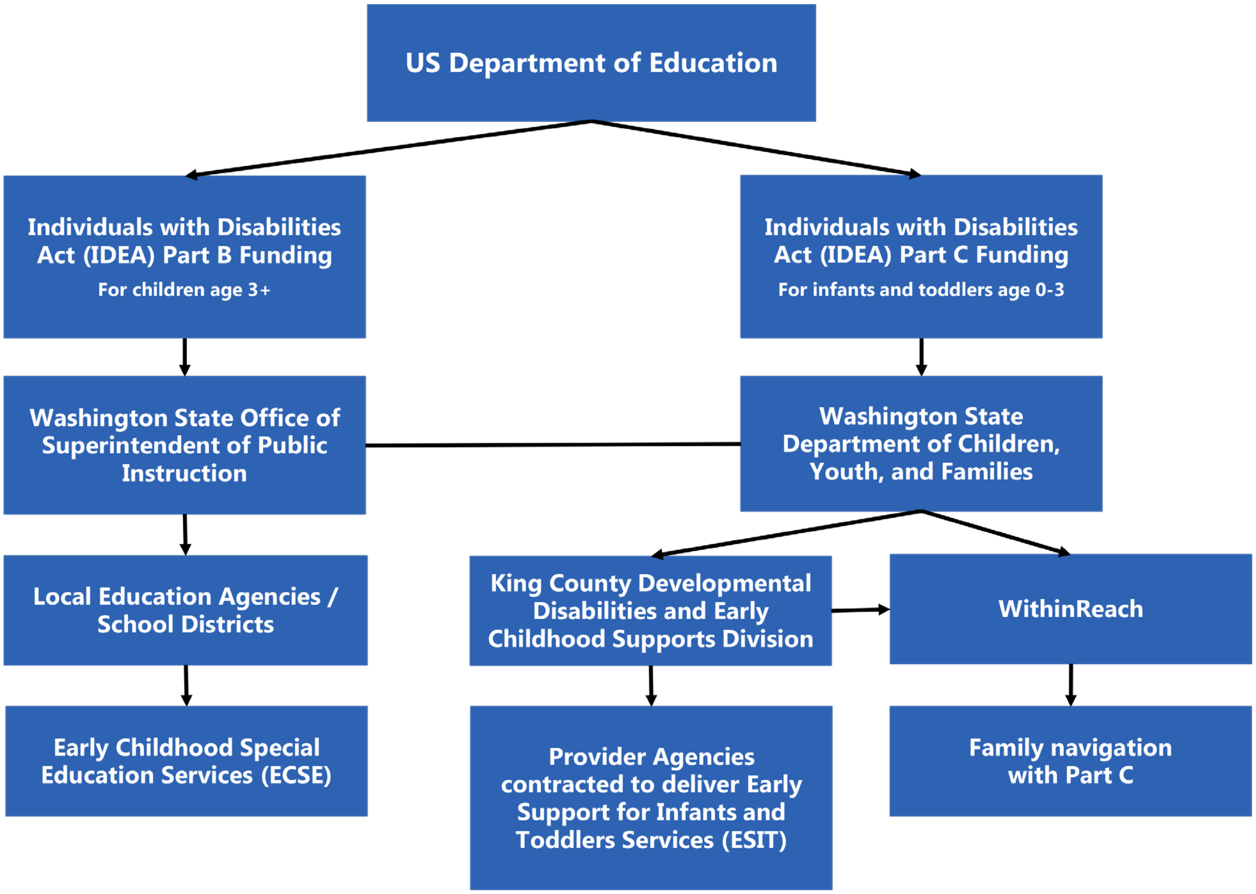
- **Children with a developmental delay need a range of supportive services**
- **Early Support for Infants and Toddlers provides services to children 0-3**
- **Early Childhood Special Education supports children 3+**

When there is a lack of services in the community to meet the needs of children with developmental concerns, pediatricians and other service professionals may be hesitant to implement screening in their practices.[52] Critical to the success of a developmental screening system is the availability and accessibility of services in the community that meet the needs of children identified with a developmental or behavioral concern.

For children with a developmental delay or disability, a range of supports are needed, including obtaining the appropriate diagnosis; therapy and services (e.g., speech therapy, occupational therapy, social work, behavioral supports, or other clinical or health services); classroom placement; and transportation to school or community settings.[53] Barriers to accessing needed services can include a lack of referrals from providers, long waiting lists, ineligibility for certain services, difficulty finding an appropriate provider, and/or inadequate health coverage.[54] During periods of transition, such as from diagnosis to Early Intervention and then during transitions between grade levels and schools, there is often a greater need for services and supports. A systematic review of the literature found that parents and caregivers also provide significant levels of support, ranging from assisting with life skill development to advocating for services outside of the home, which can impact family members in terms of stress, quality of life, marital satisfaction, and psychological and physical health.[53]

In the State of Washington, the Department of Children, Youth, and Families' Early Support for Infants and Toddlers (ESIT) program provides services to children birth to age three who have developmental delays or disabilities.[55] To be eligible for these Early Intervention services funded through the Individuals with Disabilities Education Act (IDEA), Part C, a child must have a 25% delay or score 1.5 standard deviations below their age in one or more of the developmental areas (cognitive, physical, communication, social or emotional, or adaptive). Children with a diagnosed physical or mental health condition with a high probability of developmental delay (e.g. cerebral palsy, microcephaly, Down Syndrome, etc.) are also eligible.[56] Individualized Early Intervention services are available to eligible infants and toddlers in their homes, in child care, in preschool programs or in their communities, and typically include family resource coordination, developmental services, occupational or physical therapy, and speech/language therapy. At age three, the local school district is responsible for providing services and supports, under the Individuals with Disabilities Education Act, Part B. In King County, the Department of Community and Human Services, Developmental Disabilities and Early Childhood Supports Division is the local lead agency for Early Support for Infants and Toddlers Services (ESIT), with WithinReach serving as the primary referral contact for the county (**Figure 3**).

Figure 3. **Flow of funding for supportive services**



COMMUNITY ENGAGEMENT STRATEGIES

Key Points

- **Published literature on effective community engagement strategies for developmental screening is limited**
- **Family navigators, parent advocate groups parent cafes, Books, Balls, & Blocks events, and online tools have shown to be promising strategies for engaging families**

Published research on effective community engagement strategies to support developmental and behavioral screening, referrals and linkage is very limited. However, a number of different promising practices have been identified by agencies and *Help Me Grow* affiliates that support family and community engagement. These strategies include:

- **Use of family navigators**, as in Alameda County, California, to provide family-friendly information and training to help families access specialized education services, and health care for their children.
- Creation of **"parent advocate" neighborhood groups**, as in Louisville, Kentucky, that engage families through a variety of activities designed to provide consistent interaction, learning opportunities, family-centered events and more.
- The **parent café model**, which began in Illinois and now exists nationwide, engages parents in a series of meaningful conversations with other parents about their family and how to strengthen ties through positive social connections.
- **Creating opportunities to bring families together through developmentally appropriate play**, such as through the widely used Books, Balls, and Blocks from Utah, provides an opportunity to increase parental knowledge on child development, strengthen social connections, and implement screening. Books, Balls, and Blocks is a free, 2-3 hour family event for children birth to five in which children can engage in developmentally appropriate play with their parents, while their parents also complete an Ages and Stages Questionnaire -3 screener.
- Creation of **online screening tools,** such as Bright Steps technology currently being piloted in Washington, may allow for greater access and engagement of parents in developmental screening.

In Washington State, the Department of Children, Youth, and Families encourages involvement from families who participate in Early Intervention through participation in the State Interagency Coordinating Council for Infants and Toddlers with Disabilities and the Families. The Council assists the Department of Children, Youth, and Families and other participating agencies in implementing a collaborative and comprehensive statewide system of Early Intervention services for infants and toddlers who have disabilities and their families, offering advice and assistance on policy and coordination issues.[57] Similarly, the King County Interagency Coordinating Council provides oversight of Birth-to-Three services at the local level.

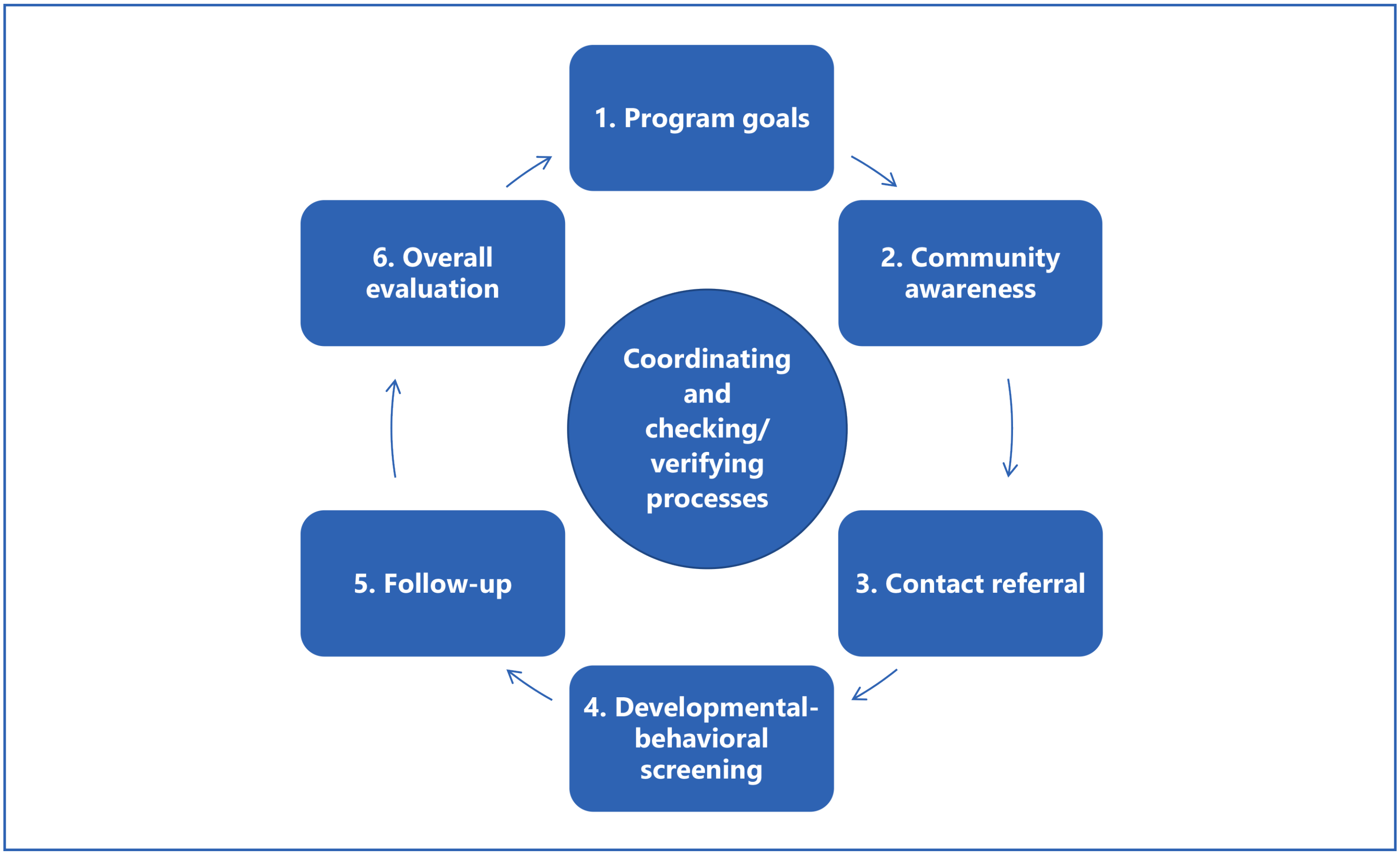
BEST PRACTICES FOR DEVELOPMENTAL SCREENING SYSTEMS COORDINATION

Key Points

- **Two models offer structure for organizing and building systems coordination**
  - **Early Detection Systems Framework**
  - **Help Me Grow Systems Model**

In light of variability across communities in terms of how young children are screened, referred, and linked to services, some experts in child development, Early Intervention, and special education propose an organizing framework to advance systems coordination throughout all stages of the process. Bricker, Macy, Squires, and Marks (2013) advocate for an early detection system that combines ongoing coordinating and checking/verifying processes across six core components: program goals, community awareness, contact and referral, developmental and behavioral screening, follow-up, and overall evaluation (**Figure 4**).[23] The two processes appear in the center of Figure 4 to demonstrate their continuous operation across all six components. The coordinating process facilitates information sharing across the six components and the checking/verifying process supports action and follow-up.

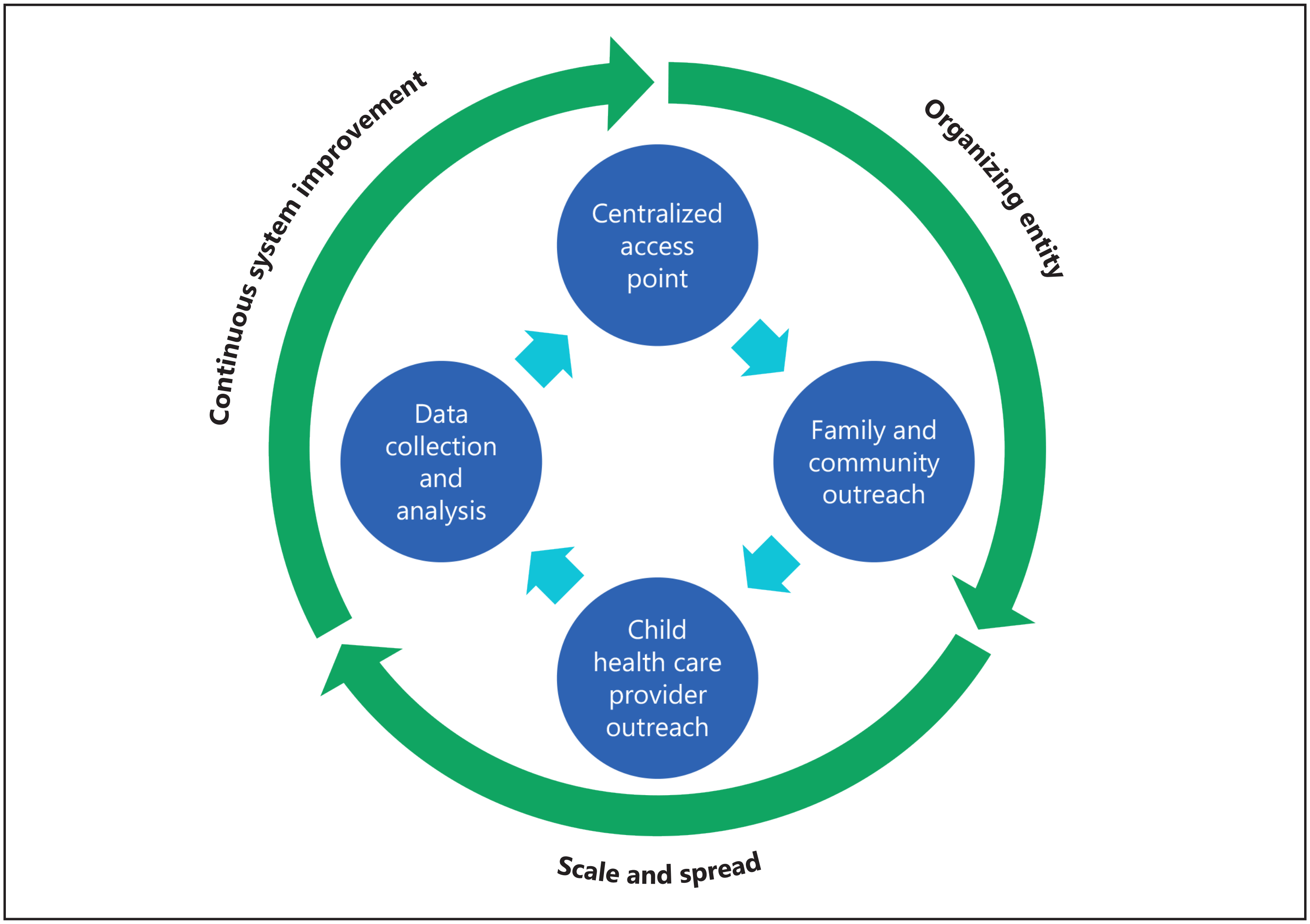
Figure 4. **Early detection systems framework**



A complementary and widely used framework for consideration is the Help Me Grow systems model which is "designed to help states and communities leverage existing resources to ensure communities identify vulnerable children, link families to community-based services, and empower families to support their children's healthy development through the implementation of four core components."[58] **Figure 5** depicts the four core components of the Help Me Grow model that include a centralized access point, family and community outreach, child health care provider outreach, and data collection and analysis, which are supported by a strong foundation of an organizing entity, strategies for scale and spread, and continuous systems improvement.

Application of a framework for a coordinated system of screening, referral and intervention, in combination with a detailed understanding of the current system and existing gaps in King County, and meaningful community participation can support the development and implementation of an effective strategic plan for universal developmental screening locally.

Figure 5. **Help Me Grow System Model**



ADDITIONAL WASHINGTON STATE AND KING COUNTY CONTEXT

WASHINGTON STATE CONTEXT

Key Points

- **22% of children have a developmental, behavioral, or emotional condition**
- **Strategic plans, legislation, federally-funded initiatives, and a statewide Help Me Grow affiliate support progress toward Universal Developmental Screening**

In the State of Washington, an estimated 22% of all children have one or more identified developmental, behavioral or emotional conditions, according to the most recent National Survey of Children's Health, while just 32% of children between the ages of 9 months and 35 months received a screening from a parent-completed developmental tool.[59] While these figures indicate opportunities to improve screening coverage among children, key existing infrastructure and initiatives are currently in place to support universal screening. This structure includes:

- *A Strategic Framework for Universal Developmental Screening (UDS) for the State of Washington*, released in 2010 by the Washington State Department of Health, Office of Maternal and Child Health outlines components for a UDS systems that includes: a public awareness and provider campaign to normalize screening; enrollment of families in a screening program to allow sharing of screening results among programs and providers; parent reminders when children are due for screenings; referral and follow up information for assessments, supports, and services depending on screening results as needed.[60] The infrastructure for this system, however, has yet to be developed
- A comprehensive 20 year Early Learning Plan (2010-2030) that includes implementation of universal developmental and social-emotional/mental health screening and referrals for children from birth to third grade as a key strategy[61], as well as *The Washington State Birth to 3 Plan* that prioritizes developmental screening[62]
- Passage of Senate Bill 5317, which came into effect January 2016, and requires the state Health Care Authority to reimburse physicians for developmental and autism screenings under the American Academy of Pediatrics recommended timeframe[63]
- Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) funding from Substance Abuse and Mental Health Services Administration since 2008 to support capacity building for integration of behavioral health training and services into early childhood care and education systems[64], as well as a *Race to the Top* grant to improve early learning and developmental programs
- Essentials for Childhood grant from the US Centers for Disease Control and Prevention in 2013-2018 to promote safe, stable, nurturing relationships and environments for children and families
- Statewide adoption of the *Help Me Grow* model in 2010, through the affiliate WithinReach, to identify children at risk for developmental and behavioral concerns, and help families access programs and services within the community

These cross-sector initiatives provide frameworks and key infrastructure to enable improved screening and linkage efforts statewide.

KING COUNTY CONTEXT

Key Points

- **Best Starts for Kids seeks to improve health and well-being of all King County residents by investing in promotion, prevention, and early intervention**
- **Nearly half of the $400 million will be allocated to strategies focused on the prenatal to 5 population**
- **Per Best Starts survey data, 21% of children 9 months to 5 years were screened by a doctor within the past year**

In 2015, King County voters approved a nearly $400 million tax levy over five years for the Best Starts for Kids initiative, to improve the health and well-being of all King County residents by investing in promotion, prevention and early intervention for children, youth, families and communities.[65] Best Starts for Kids was developed within the context of and aligns with a number of existing initiatives and policies, including the King County Strategic Plan, the 2015 Youth Action Plan, the Health and Human Services Transformation Plan, and the County's first Equity and Social Justice Strategic Plan.[66] Nearly half of the expenditures will be allocated to initiatives targeted at prenatal to 5 years, with strategy areas, including support for parents, families, and caregivers; screening, intervention and linkage to treatment; cultivation of caregiver knowledge; and, support for high quality child care. According to 2017 Best Starts for Kids Health Survey data, just 21% of children 9 months to 5 years of age in King County received a developmental screening by a doctor or healthcare provider in the last 12 months.[65] This low screening coverage and the implication for children's health and development, affirms King County's decision to invest in the youngest members of the community and their families.

In 2018, Best Starts for Kids collaborated with national, state, and local partners to initiate a strategy for enhancing Help Me Grow in King County. Now, as an official Help Me Grow member, King County is poised to assist families with accessing the support they need, when, how, and where they need it.

CONCLUSION

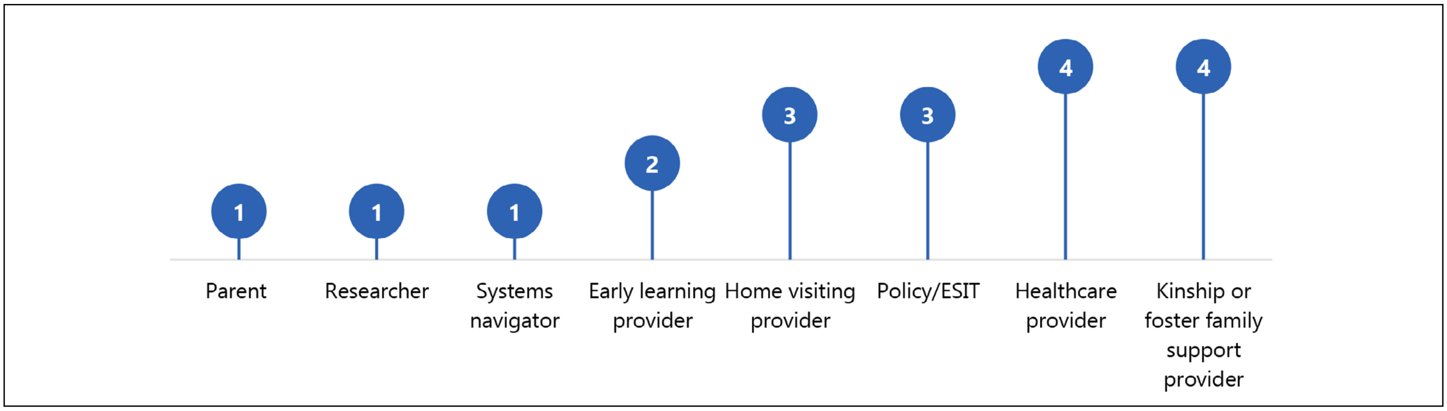
Through the Best Starts for Kids landscape analysis and strategic plan, the Cardea-WithinReach-King County team plans to partner with the Community Expert Council, medical champions, and a broad range of community stakeholders to learn more about the context of developmental screening within King County. Through this process, the team hopes to identify screening and referral gaps and what might cause them to help the community develop supportive systems and structures to ensure all children and their families receive timely, culturally and linguistically appropriate screening and linkage to supportive services, so more young people grow up to be happy, healthy, and successful adults.

KEY FINDINGS FROM KEY INFORMANT INTERVIEWS

BACKGROUND & APPROACH

Between August and September 2018, Cardea interviewed a range of stakeholders to learn about current screening and referral practices or experiences, community engagement strategies, training needs, and barriers and facilitators to screening and referral in King County. Cardea also asked for interviewees' thoughts about how the current system of coordination supports or hinders screening, referral, and connection to services. In total, Cardea conducted **15 interviews** with **19 key informants**. These interviewees included experts in the following areas: four kinship or foster family support providers, four health care providers (three primary care and one specialty care), three home-visiting providers, three statewide policy experts on Child Find and Early Support for Infants and Toddlers (ESIT), one parent, one researcher, and one systems navigator (**Figure 1**). Key informants were identified through recommendations from the Best Starts for Kids Developmental Screening & Referral Community Expert Council, WithinReach, and King County Developmental Disabilities Division. For reference, a **glossary of terms** is on page 102.

Figure 1. **Most interviewees were providers**



KEY FINDINGS

FAMILIARITY WITH DEVELOPMENTAL SCREENING VARIED, YET INTERVIEWEES UNANIMOUSLY AGREED THAT SCREENING IS IMPORTANT

Interviewees expressed a range in the level of familiarity with developmental screening and referral across King County. This was mostly due to the different roles that interviewees played within the system or screening process—some were researchers, others were primary care providers, specialty care providers, parents, etc. Some interviewees regularly conducted screenings, while others used screening results to make decisions about intervention services.

> **"Developmental screening is very important. On a scale from 1 – 10, it's an 11! We know that early intervention is better than remediation later. Identifying children in the community earlier and connecting them to services earlier has a whole host of [positive] outcomes."**
>
> **—Policy/ESIT expert**

Despite the range in familiarity with developmental screening, interviewees agreed that developmental screening is a foundational element of healthcare and well-being for young children, especially those birth through age five.

SCREENING PRACTICES VARIED BY SETTING AND ALL INFORMANTS EXPRESSED CONCERNS ABOUT THE CULTURAL APPROPRIATENESS OF THE TOOLS

Screening practices in offices differed from those in home-based or other practices. For example, primary care providers tended to complete developmental screenings at the American Academy of Pediatrics (AAP) recommended age intervals, while other types of providers tended to describe one-time or bookended screenings meant to support connections to needed services and monitor the child's developmental or behavioral progress. Most interviewees had experience using or taking the Ages and Stages Questionnaire, Third Edition (ASQ-3) and ASQ: Social Emotional, Second Edition (ASQ: SE-2). Other common tools included the Preschool Language Scale (PSL), Modified Checklist for Autism in Toddlers (MCHAT), Teach Strategies GOLD Assessment (TSGA), and the Child Health and Education Tracing (CHET).

Developmental and maternal depression screening were common among healthcare providers and home visiting providers, but most interviewees did not formally screen for Adverse Childhood Experiences (ACEs) as part of their work. However, many inter-

> **"Any written tool, even if it might be in their home language, might not be culturally responsive, especially for a culture that may prefer to do things orally. It's a very middle class, white, American thing to do to give someone a piece of paper to fill out."**
>
> **—Early learning provider**

viewees noted the value of ACEs screening and expressed the desire to incorporate it into their suite of tools and care processes. One informant who routinely screened families for ACEs, noted that they struggled with the appropriate follow-up for families who fell below the referral cut-off score.

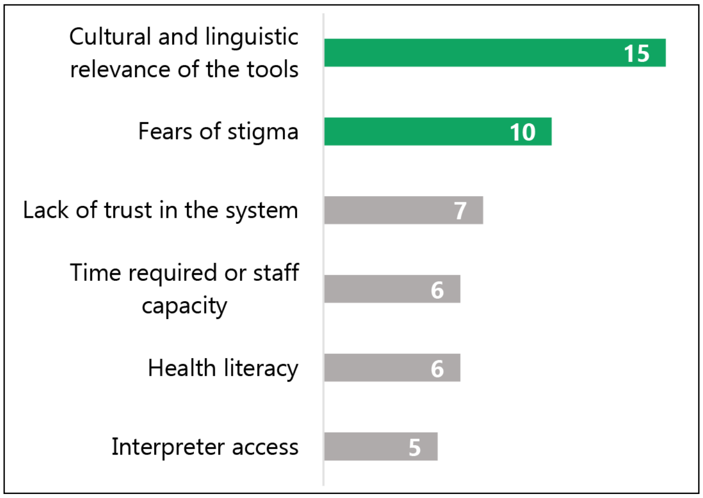
All interviewees had concerns about the appropriateness and validity of the screening tools for families of different cultures, races, and linguistic backgrounds, noting that translating the tools into various languages does not make the screening questions culturally relevant.

> **"Some general systematic ways that inequities get promoted by us and other systems [are] the kids who don't see their same provider as regularly for primary care visits, are less likely to have a screening happen thoroughly, and less likely for that screening to turn into connections to something... Even with good intentions, we create systems that are actually most available to the ones with the least amount of struggle. That is an across the system problem, and we are a part of that system, and a part of that problem."**
>
> **—Healthcare provider**

INTERVIEWEES IDENTIFIED MULTIPLE BARRIERS TO SCREENING

Interviewees mentioned a variety of barriers to screening. In all 15 interviews, key informants identified the cultural and linguistic relevance of the tools as a critical barrier to screening. Parents' fears of their child being labeled or experiencing stigma was also commonly mentioned, in addition to lack of trust in the system, the time required or staff capacity to complete a screening questionnaire, health literacy, and interpreter access (**Figure 2**). While mentioned less frequently, interviewees also identified provider discomfort with not knowing the next steps (especially with ACEs screening), lack of clarity around different points of entry (e.g. When to screen? Who to contact?), and lack of confidence in the validity of the tools as barriers to screening. It's important to mention that providers mostly perceived barriers as responding to families' context and needs, as well as navigating systemic inequities.

Figure 2. Cultural and linguistic relevance of the tools and fears of stigma were the most commonly identified barriers reported during interviews



INTERVIEWEES EMPLOYED DIVERSE STRATEGIES TO ENGAGE THE COMMUNITY IN DEVELOPMENTAL SCREENING EFFORTS

From discussing community engagement, we learned that interviewees engaged communities in a variety of ways, including conducting outreach at community meeting places (e.g. churches, libraries, health fairs, children's museums, and childcare centers), holding community workshops or trainings, using mobile vans to conduct screenings in hard-to-reach and hardly reached communities, and participating on community advisory boards. Some interviewees noted how Child Find's contractual requirements for community engagement served as a catalyst for increased outreach and successful connection with families.

> **"We have a variety of programs to engage the community. [We] provide workshops to parents. We go to libraries [and] provide tip sheets to families. That's also where we tend to find families that may [need] screenings"**
> **—Kinship or foster family support provider**

INTERVIEWEES MOSTLY RECEIVED INFORMAL TRAINING AND WANTED SUPPORT WITH FURTHER DEVELOPING "SOFT SKILLS"

Interviewees and other agency staff were most commonly trained through informal training, which included observations of current staff, practicing with peer support, staff knowledge transfer, and reviewing online resources. Common training barriers included the costs of training, time required for learning to use the tools, and staff turnover.

Since many of the tools come with thorough instructions for administering and scoring the questionnaires, providers primarily reported wanting additional support with further developing their soft skills and meaningful integration of developmental screening into relationships with families. Interviewees expressed a desire to receive training around how to engage families from diverse backgrounds, discuss difficult screening results, adapt screening tools to increase cultural relevance, and support families exposed to high levels of trauma.

> **"Yes, there is a need for ongoing training, especially with regard to being culturally responsive and engaging the family… Training on the soft skills is so necessary—how to implement using best practices."**
> **—Policy/ESIT expert**

PROVIDERS REPORTED REFERRING AND LINKING FAMILIES AS INDICATED, BUT ACKNOWLEDGED EXTERNAL FACTORS OFTEN HINDER SUCCESS

In discussing referrals and linkages, most providers reported referring and linking families as indicated, where families received the supports they needed. This was especially true for kinship or foster family support providers who are guided by legal mandates, and for providers who work in settings with on-site access to specialists. Providers used a variety of tactics to ensure successful linkages to care including using patient **care coordinators** to support families, calling and sending **reminder letters** to families, and having **in-depth conversations** to motivate families to follow-up on referrals.

> **"Families need coaching and support. I believe in empowering parents, so we create action plans where everybody is going to be doing something… Then I see parents feeling more confident about being connected with the services."**
>
> **—Systems navigator or researcher**

Common barriers to successful referral and connection to services included **not knowing** who to refer to, **long waiting times** between referrals and receipt of services, **lack of understanding about next steps**, and **provider discomfort** around uncertainty about eligibility requirements. Some providers mentioned they hesitated to even make a referral when they thought it was unlikely that their clients would qualify for the supports they needed. In addition, maintaining services during transitions between age groups (i.e. when a child aged out of Birth-to-Three services, but was not eligible for public school services) was listed as a challenge.

RELATIONSHIP-BUILDING BETWEEN PROVIDERS AND FAMILIES, AS WELL AS ACROSS SECTORS, IS CRITICAL FOR SUCCESSFUL SCREENING AND CONNECTION TO SERVICES

When asked to think about what factors facilitate successful screening and connection to services, most interviewees described relationship-oriented care. Interviewees emphasized the importance of **relationships** between families and providers, meeting the families **where they are**, showing **empathy**, and creating **shared decision-making** processes in order to cultivate trust in the process. Interviewees also acknowledged the role of cross-sector partnerships in facilitating smooth and efficient transitions from one service to another. In addition to interpersonal factors, interviewees noted how **same-day appointments and easily accessible information** for parents and providers supported families with accessing supportive services.

> **"The magic and gift of primary care and also the responsibility is that providers have a bucket of trust they can spend in different ways. Their ability to support and encourage families has much to do with trust and also makes them careful about how they spend that trust."**
>
> **—Healthcare provider**

INTERVIEWEES PERCEIVED STRONG COORDINATION WITHIN SECTORS, AND POOR COORDINATION ACROSS SECTORS

When asked about systems coordination, most key informants perceived sufficient coordination within sectors, but a lack of coordination across sectors (e.g. social services are well connected to service providers who do similar types of work, but not to other types of providers). Although key informants perceived that providers in different sectors shared common values, they speculated that insufficient resources, staff turnover, lack of communication between providers, and lack of widespread awareness of early intervention and developmental screening were key barriers to successful coordination. Key informants suggested that systems coordination improvements are especially needed to ensure continuous care and provide smoother transitions for children who are transitioning out of Birth-to-Three services.

Cardea specifically asked key informants to describe their familiarity with the *Help Me Grow (HMG)* framework. Most key informants did not know much about the HMG framework by name. However, when asked to describe their top priorities for system improvement, the priorities interviewees identified **aligned with elements of the HMG framework**, particularly the **desire for a centralized access point** or “bridge” among sectors.

> **“Connection between healthcare and social service providers is needed. They are really silo’d. There seems to be a disconnect between mental health and primary health providers and social service providers.”**
>
> **—Early learning provider**

CONSIDERATIONS

Cardea interviewed key informants that were suggested by key stakeholders based on their prominence or excellence in the field or their systems-level knowledge. Therefore, Cardea does not expect that their practices exemplify standard practice in King County. Although many of the interviewees we spoke with hold dual roles as providers and caregivers, Cardea was not successful in hearing from as many caregivers as would have been ideal. Therefore, the interviews and resulting summary primarily reflect provider perspectives on developmental screening and referral. Fortunately, additional forms of stakeholder engagement were used for this body of work that offered additional opportunities for caregivers to share their experiences with developmental screening and connection to services, including a Developmental Screening and Referral Survey, focus groups, and community forums.

KEY FINDINGS FROM FOCUS GROUPS AND COMMUNITY FORUMS

BACKGROUND & APPROACH

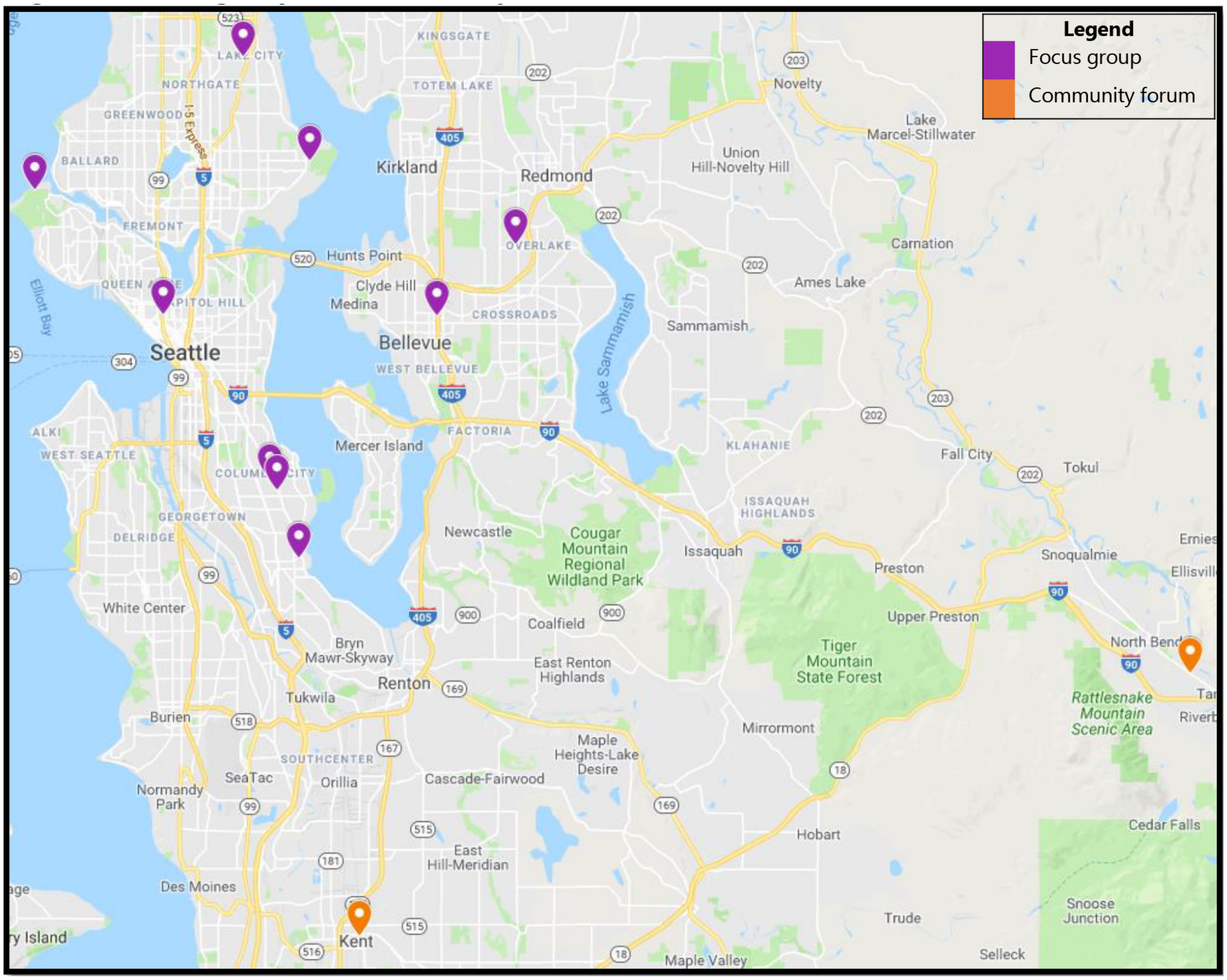
Between January and March 2019, Cardea staff conducted nine focus groups and two community forums, in partnership with community-based organizations to learn about King County families' experiences with developmental screening, referral, and connection to services, and to facilitate connections between local service providers and families. Cardea engaged 55 parents/caregivers through the focus groups. Six of the focus groups were conducted in English and three focus groups were primarily conducted in a non-English language (**Table 1**).

Table 1. Focus group host sites, language, and number of participants

Host Site	Language	# of participants
The Arc of King County	Spanish	5
Atlantic Street Family Resource Center	English	8
Children's Home Society of Washington	Spanish and English	5
Horn of Africa Services	Amharic and Oromo	8
Indian Association of Western Washington	English, Hindi, and Telugu	5
MAIA Midwifery & Fertility Services	English	5
Solid Ground Housing: Santos Place	English	8
United Indians of All Tribes	English	7
Washington State Fathers Network	English	4
		55

The first community forum was held in North Bend in partnership with Encompass, an early learning, pediatric therapy, and family enrichment provider in East King County. Encompass is also one of King County's Early Support for Infants and Toddlers (ESIT) providers. Ten community members attended the forum, of whom three participated in a small group discussion about their experiences with screening, referral, and connection to services. The second community forum happened at the Kent Regional Library, reaching 32 community members. During the event, Cardea staff facilitated four small group discussions with 18 attendees. One discussion group was held in Arabic, with interpretation support provided by a bi-lingual community member. A map documenting the focus group host sites and forum locations is shown in **Figure 1**. Unless specified, the following summary information is the combination of responses from the 97 focus group and community forum participants.

Figure 1. Focus group and community forum locations



DISCUSSION PARTICIPANTS

Prior to participating in a focus group, participants completed a consent form that explained the purpose of the conversation and confirmed their understanding of the voluntary and confidential nature of their participation. As part of the consent process, participants were given the option of answering a few demographic questions about themselves and the child they would be referring to when sharing their experiences with screening, referral, and connection to services. The majority (83%) of participants identified as a parent or caregiver and 13% identified as a relative to the child (i.e. grandmother, aunt, etc.). Among the 36 people who provided information about their family's combined annual income, 44% reported earning less than $25,000 a year. Among the 20 people who answered the question about their sexual orientation or gender identity, 45% identified as bisexual, lesbian, queer, or two-spirit.

> **"Great forum for sharing information and allowing for feedback from parent/caregivers. Thank you!"**
> **—Forum participant**

At the end of each focus group and community forum, participants were given the option of completing a brief evaluation. Fifty-nine people submitted evaluations. Everyone rated their satisfaction with their focus group or forum experience as either "satisfied" or "very satisfied," with 69% reporting that they were "very satisfied." Three out of four (75%) people reported their understanding of developmental screening and referral in King County improved as a result of participating in the conversations. Over four out of five (88%) participants rated Cardea's ability to create space to hear directly from parents and caregivers about their experiences with screening and referral as "very good" or "excellent."

> **"I feel like this discussion was a great door for more community engagement."**
> **—Focus group participant**

KEY FINDINGS

MOST CAREGIVERS WERE DRAWN TO THESE EVENTS TO LEARN MORE ABOUT AVAILABLE RESOURCES AND SHARE THEIR EXPERIENCES WITH SCREENING AND SYSTEMS NAVIGATION

When participants were asked to share why they wanted to participate in the conversation or what they hoped to get out of the event, most expressed a desire to learn about resources that could support their child. Many also wanted to share their stories related to screening, referral, and connection to services, so other families could benefit from their own learnings and experiences. Several participants noted that they also wanted to build connections with other caregivers of children with special health care needs to increase their network of support.

FAMILIES SPEND THEIR TIME IN DIVERSE COMMUNITY SETTINGS, PROVIDING MULTIPLE OPPORTUNITIES FOR ENGAGEMENT AROUND DEVELOPMENTAL SCREENING

When asked to think about places they go with their children in the community, caregivers listed a wide range of settings that provided opportunities for social interaction, learning, and community building. Some common places included,

Community centers

Cultural centers, groups & events

Faith centers

Learning & enrichment groups

Libraries

Nature & hikes

Sport fields, parks & playgrounds

School

Zoo, museums & aquarium

Many caregivers of neurodivergent children (i.e. children experiencing developmental delays) noted that they try to find parks and play spaces that use universal design principles and purposefully avoid busy times in public places to reduce the social stress on their child and mitigate feeling judged by caregivers of neurotypical children (i.e. children experiencing typical development).

When asked how these activities support their child's development, parents talked about benefits of building social skills with other children of similar age as well as an opportunity for caregivers to observe their child's development within a larger group of children. Caregivers noted additional benefits to cognitive development, confidence building, strengthening family relationships and cultural awareness, and creating spaces for caregivers to interact and swap information about child development.

"It's difficult to adapt in places where there are more children, like the Children's Museums. People look at him funny. I feel embarrassed because I cannot explain to them that he has autism, and I think they are somehow judging me. I'm not embarrassed about him having a disability, just the way people look at him. This happens often in all the places we've gone, even at church they have kicked me out."

—Focus group participant

DEVELOPMENTAL SCREENING EXPERIENCES VARIED WIDELY WITHIN AND AMONG DISCUSSION GROUPS

Several caregivers reported never having conversations with any type of professional about their child's development and behavior, especially those who were kinship families.

A few parent/caregivers reported positive screening experiences in a school, daycare, or early learning setting. One caregiver described an impressively efficient screening event at a public school that resulted in an autism diagnosis and transition to a developmental preschool within weeks. A few caregivers described the most positive experiences as screenings that were thoroughly strengths-based from the explanation of the screening through results, allowing enough space for the caregiver to learn about their child's development and how to be a supportive caregiver. Caregivers also had a positive experience when the screening was completed by someone who was aware of how culture relates to the unique ways children display growth and development.

Families whose primary language was not English, families of color, or families that were multi-systems involved, tended to describe negative experiences with screening (i.e. professionals not explaining the purpose of the questionnaire, medical providers dismissing caregivers' concerns or opinion, or screeners delivering the results insensitively). For example, care-

"Conversations were difficult during the screening because I had to watch my child struggle with the screening process. I was told throughout what was happening but it felt so depressing because it was all deficit-based."

—Focus group participant

givers of color talked about a lack of cultural sensitivity leading to false labeling of their children. Other caregivers described feeling depressed when providers exclusively described screening results from a deficit-based perspective (i.e. the provider only noted where the child was behind the expected milestones). Many caregivers also stated they did not know the screening would happen and both the child and parent were surprised by the questions and activities. Caregivers reported that the surprise usually created false results because the child would become uncomfortable and be closed off during the screening.

> **“The conversations were discouraging and very overwhelming...having the practitioner tell you all the different things that need to be done right away now that the child has been screened and concerns identified. There were people coming at you with new services and new things that needed to be done all at once without any time to process or thoughtfully plan next steps”**
>
> **—Focus group participant**

Caregivers of children who were diagnosed prenatally or at birth noted a smoother process from diagnosis to connection to services, whereas those who were caregivers of children with autism, recalled having to continually advocate for their child to receive a diagnosis because providers labeled their child’s behaviors as “normal.” Many caregivers expressed frustrations with continually being asked to complete questionnaires during well-child visits and other points of entry to various social service, education or early learning settings, after their child’s delay had been identified by a provider. Caregivers also expressed a desire for developmental screens or milestones tailored for children with similar diagnoses, rather than neurotypical children.

Most mothers recalled maternal depression screening but expressed concerns with processes following identification of concern

Recollections of maternal depression screening were mixed. Those who identified as mothers reported receiving postnatal depression screening, but expressed concerns that the next steps following a positive screen were often lackluster. Some noted that they did not receive information about supports and resources and one parent shared their frustrations with a three-week delay in starting medication when a friend expressed suicidal ideation. Except for one, most of those who identified as fathers did not recall if their partners received maternal depression screening. Caregivers who stated being involved in multiple social service systems stated they had difficulty accessing services given the number of barriers to getting connected. These caregivers stated they had to make a choice to either pursue screening and services for themselves as the parent or focus on pursuing screening and services for the child because there was not enough time to navigate both.

Screening for Adverse Childhood Experiences (ACEs) appeared to be very rare

Participants rarely recalled professionals asking them about their child’s history of ACEs, with the majority of participants reporting no recollections of ACEs conversations. ACEs “are stressful or traumatic events that children experience before age 18, such as violence at home, neglect, abuse, or having a parent with mental illness or substance dependence. High or frequent exposure to ACEs, without the buffering support of a caring adult, can dysregulate children’s stress response.”[67] One parent who had recently immigrated to the United States and experienced language barriers noted that their pediatrician consistently asked them about stressors the family was experiencing.

EARLY DIAGNOSIS, SKILLS TO NAVIGATE SYSTEMS, PRIVATE INSURANCE, AND ACCESS TO A DEDICATED ADVOCATE FACILITATED REFERRAL AND CONNECTION

Generally, parents of children diagnosed prenatally or at birth tended to report better experiences with getting referred and connected to services than caregivers whose children were diagnosed later in life. One parent whose child was diagnosed prenatally noted that she was immediately connected with specialists that would support her child's development and she was also assigned a social worker to support her with systems navigation.

A limited number of caregivers reported success with self-referral when their primary care provider did not give them a referral. Those who had success with self-referral noted that they had picked up the skills to navigate complex systems through their jobs as social workers. Still, many other participants who were social workers or co-caregiving with a social worker, reported difficulty understanding the process of self-referral and confusion around the best way to access developmental support services.

A few caregivers described efficient connections to service providers and strong communication among specialists; however, these caregivers received services through private-network providers and noted that they could afford to pay the out-of-pocket expenses that many other families might not be able to afford.

> **"Unless a parent or caregiver gets connected to native fluent services, they typically don't get connected to anything."**
> **—Focus group participant**

Several caregivers noted positive experiences when they were assigned an advocate, coordinator, or home visitor dedicated to supporting the family through screening, referral and service connection. Caregivers experienced greater speed of connection to services and felt that there was a larger network of services and resources available.

> **"My daughter has a social worker who has helped me a lot regarding appointments, specialists, and goals to work on with my daughter. This has helped me to have better support. If only we each could have one."**
> **—Focus group participant**

LONG WAITING PERIODS, SYSTEMIC FACTORS, LACK OF CARE COORDINATION, AND INFORMATION OR RESOURCE GATEKEEPING WERE BARRIERS TO REFERRAL AND CONNECTIONS TO SERVICES

When asked to think about what could have been better, many caregivers expressed a desire for shorter waiting periods. Some reported waiting weeks to see a specialist, while others noted it took nearly six months to get an appointment, and one caregiver

> **"It was only three weeks, but it was a very desperate three weeks. When he was born he was in the 95th percentile [for weight] and had gotten down to the 3rd percentile before we were referred."**
> **—Focus group participant**

reported it took 12 months to be connected. Kinship and foster parent caregivers noted that it was sometimes hard to access the services to which they were referred because they had incomplete information about the child's history before the child came under their care that would qualify the child for the service.

> **"There is no safety net for folks who do not have a car, or can't take time off work, or if they do not qualify for home visiting."**
> **—Focus group participant**

Several caregivers also talked about systemic factors, such as racism, immigration status, lack of insurance, and income inequality, which made accessing referrals challenging. Some of these caregivers noted that while receiving a referral felt straightforward, they were unable to connect to services and felt like the family was being mis-directed.

A number of caregivers talked about receiving a large number of referrals without a streamlined way to be connected to services, which made planning and navigation of service connection challenging. Caregivers discussed feeling overwhelmed by options and pressure to get connected without being given a clear idea of how to move forward. Some caregivers also described being sent in circles while trying to follow up on referrals and getting frustrated with the number of repeat screening to referral cycles they experienced without being able to connect to services.

A few parents expressed shock and dismay upon learning that Neonatal Intensive Care Unit (NICU) providers failed to inform them about Early Support for Infants and Toddlers (ESIT) services that could have been delivered within their homes, and instead referred the families to the hospital's attached private service clinics. These parents felt like hospitals and NICUs should be required to share information about the full scope of service options with families, giving families the power of choice to select how they want to receive services and from whom.

Several caregivers identified providers' gatekeeping practices as barriers to getting referred and connected to services. Despite communicating their concerns about their child to their child's primary care provider, many caregivers recalled providers withholding a referral in favor of a "wait-and-see" approach that only delayed care.

> **"When a parent brings up a concern about their child, why do providers tend to err on the "wait and see" side of things and not refer? I don't understand why providers or teachers act as these gatekeepers, in essence deciding who needs services and who does not. The scores from formal evaluations are what should dictate which child gets services — not a singular impression of a doctor or teacher!"**
> **—Focus group participant**

RELATIONSHIP-ORIENTED CARE AND SUPPORT WERE DESCRIBED AS VALUED RESOURCES

Networks of support and supportive services tended to provide caregivers with a sense of community

A few caregivers were able to enroll their children in developmental preschools. These caregivers spoke positively about this resource, noting that they found relief and community among other families with children with delays or disabilities and teachers and staff who embraced them. Similarly, a few caregivers identified in-person or online support groups, such as diagnosis-specific Facebook groups, as deep wells of knowledge and support with navigating care and next steps. Other caregivers described difficulties finding support networks that were a good fit for them and needing to choose between supports for caregivers of children with delays or support networks of parents of similar cultures, languages, or identities.

> **“It’s life-saving for us. I couldn’t do this if I didn’t have the support”**
>
> **—A community forum participant talking about supportive services**

Some caregivers felt unsupported by their service provider. Feelings of judgement when asking questions or discussing the child’s progress led some caregivers to doubt themselves. These caregivers reported that they would stop trying to ask questions of their providers and seek support and information elsewhere.

Caregivers noted relationship building and trust as critical to high-quality service experiences

A few caregivers noted how staff turnover or inconsistency with the professional who is delivering the supportive service can be distressing for their children and can feel like wasted time to the family. Caregivers said whenever they met with a new provider, the beginning of the appointment was spent retelling their story or bringing the new provider up to speed, instead of devoting the full appointment to delivering the service to their child. For some children receiving mental health services, caregivers stated that the time bringing a new provider up to speed was re-traumatizing for their child and would hurt the ability for their child to connect to the new provider. One caregiver noted that when the provider moved to a new clinic, they followed the provider despite the longer more cumbersome travel time to maintain the child’s relationship with the provider.

TRANSITION PERIODS, SYSTEMIC FACTORS, AND LACK OF COMPREHENSIVE CARE COMPROMISED FAMILIES’ CARE EXPERIENCES

Caregivers struggled with transitions into and out of Birth-to-Three services

Caregivers of children who had experienced the transition out of Birth-to-Three/ESIT services described significant challenges with connecting with the next level of care. Some caregivers talked about receiving letters in advance of the transition that warned them the services would be ending without also receiving any information about next steps, which they found very distressing. A few caregivers noted feeling exasperated that while on the waiting list to access ESIT and other services, they received letters about their child approaching the age limit for eligibility and having no way to speed up the process of connecting to services.[1] One parent expressed frustrations with the rigidity of eligibility requirements that prevented their child from directly transitioning to special education services and forced their child to fail before they received additional supports. For

> **“Our oldest was doing too well in Birth-to-Three to automatically qualify for three to five scope of services. He had to transition into a regular preschool environment and fail, which set him back, before screening into the next level up.”**
>
> **—Focus group participant**

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[1] While many caregivers described frustrations with being on a “waitlist,” ESIT does not use a waitlist system. It may take many months from a referral to a scheduled evaluation appointment; thus creating the perception of a waitlist.

caregivers of children with severe developmental delays, it felt “unfair” to have a universal transition point based on age, noting that the Birth-to-Three services were a vitally important aspect of the parents’ network of service support.

Caregivers identified systemic factors as barriers to service accessibility

The ability to access services once connected varied among caregivers. Families with multiple caregivers and financial stability to allow one caregiver to not work, tended to have greater accessibility to a range of services that were geographically, financially, or culturally inaccessible to other caregivers. One caregiver noted that they had to sacrifice their job to be able to support their child with special health care needs because the hours of the job made making appointments with the child impossible.

> **“Racial equity issues are real when trying to utilize the services. There is a feeling that the services are being provided differently to children of color. That prescriptions are more likely to be prescribed over alternative behavioral therapy services”**
>
> **—Focus group participant**

Several caregivers noted that home-based or care coordination services were good experiences for the entire family. Caregivers could ensure the child receiving services was comfortable (child can decide to be anywhere in the home) and resolved any transportation or child care challenges. Some caregivers compared their home-visitor or family resource coordinator to a ‘family therapist’ who supported all aspects of the family’s needs.

> **“Acknowledging that parents/caregivers experiencing poverty/homelessness makes accessing these services so much harder and therefore makes it feel incredibly challenging and demoralizing when trying to get the needed support for our child’s development. There is privilege in being able to find services available in a way that is conducive to things like having a job with uncertain hours and not having reliable transportation or stable housing. It's exhausting trying to navigate all of the service requirements that are piled on top of an already hoop-jumping, barrier-enabled system. When trying to get to all of the services that the whole family needs, it gets overwhelming and easily feels impossible to stay on track and be a good parent to everyone else”**
>
> **—Focus group participant**

Success with Individualized Education Programs (IEPs) varied by school district and family

Experiences with school districts and IEPs were mixed. One parent reported success with getting their child included in a mainstream classroom that was close to their home, whereas another parent reported commuting to a district far from their home because the local school did not have the capacity to support their child’s IEP. The commute became too hard on the family and the child had to opt out of the IEP. Some caregivers struggled getting the IEP that they wanted for their child and were often told they would have to send their child to a school further away from their home to receive the type of school experience they wanted for their child.

Caregivers wanted comprehensive and holistic care when post-screening plans included prescription medication

Many caregivers expressed a desire for co-therapeutic or alternative therapeutic approaches to supporting their child, especially when medication was prescribed. For example, caregivers from a few focus groups spoke about challenges with getting needs met for a child who was exposed to drugs or alcohol *in utero*. These caregivers reported feeling isolated because providers did not take their concerns seriously or provide sufficient medication management guidance. A few caregivers also noted that providers missed the opportunity to provide behavioral co-therapy referrals. As a result, caregivers with the resources to navigate complex systems occasionally had some success with self-referral, but most resorted to their own research to better manage their child's health. Some caregivers reported their providers would not listen to their concerns about prescriptions and the need for co-therapeutic options such as behavioral therapy beyond prescriptions alone or naturopathic therapies. A few caregivers talked about being bullied and feeling shamed by providers threatening or calling child protective services.

Several participants were not connected to services.

> **"We need training around IEPs, your rights, how to advocate well, inclusion in education and what the law states around the child's right to be in the least restrictive environment."**
>
> **—Focus group participant**

FAMILIES RECOMMENDED ENHANCED COORDINATION, EXPANDED ACCESS TO FAMILY-CENTERED, CULTURALLY AND LINGUISTICALY RELEVANT INFORMATION AND SERVICES, AND INCREASED ACCESS TO INCLUSIVE, PUBLIC SPACES

Enhance systems coordination, especially across sectors and during transition periods

When asked to reflect on how the system of developmental screening and referral could be improved, participants wanted 1) more coordinated or centralized access to information and resources to make it easier for families to navigate the system of care; 2) increased provider awareness about developmental delays; and 3) increased education for parents and caregivers about the importance of developmental screening. Participants also wanted a clear process map that provides examples of pathways and outlines high level steps to navigate the system.

> **"When families get their diagnosis, there's no one place you can go to find out all the things you have to do. Each family has to figure it out."**
>
> **—Focus group participant**

Most participants supported enhanced systems coordination and cross-sector communication. A few caregivers noted that large institutions could do a better job coordinating care. Caregivers of children three and older also noted that they wanted the transition between Birth-to-Three and Special Education Services to be seamless. Many noted that maintaining critical care for their children should be accessible to all parents and caregivers, not just those with the time and resources to navigate the system.

Make comprehensive information easily accessible to all families through diverse modes of communication

All focus group and community forum participants talked about wanting more outreach to caregivers about what developmental screening is and where to receive information on how, why, and when to have developmental screening done. Many noted that libraries and community centers are the best place to reach caregivers.

Many caregivers emphasized that it is important to receive information about the screenings before they occur, so caregivers can understand the purpose and prepare their children. A few caregivers suggested that training for caregivers around IEPs, how to advocate well, and why they're good for everyone would also be helpful.

Caregivers also want providers to be more aware of the full scope resources and services available or to provide a more comprehensive source for finding resources that does not limit a caregiver to one service provider.

Increase access to culturally and linguistically relevant resources and services

Several participants noted that the system of screening, referral, and connection to services needs to be more culturally and linguistically relevant. This was especially true among caregivers of color or whose primary language was not English. Caregivers also want to be able to complete a screening and talk with service providers in their primary language or have improved access to interpretive services that can accurately communicate the nuances of the screening questions. Many caregivers said the system needs to provide greater flexibility to families related to defining milestones to ensure culturally relevant results and services. One participant noted that they avoided developmental screening for years because they feared the impact of their child being labeled on top of other identities that made them "different."

> **"As a stay-at-home mother at the time, I had the privilege of time, mobility, ability to pay, and language to navigate the system. Many parents do not. I know personally dozens of parents whose pediatricians dismissed their concerns, only for the delays to become clear to medical professionals when children were no longer eligible for Birth-to-Three services...Stories abound of such children who miss the best time frame for neuroplasticity and valuable early interventions in the birth-to-three period."**
>
> **—Focus group participant**

Expand the quantity of services available, including the hours in which services are delivered

Caregivers also wanted to see an expansion in the number and type of service providers. In particular, caregivers want to see more developmental centers and more feeding therapists, noting that waitlists are currently too long. Expansion of service hours or the ability to create flexibility in scheduling appointments is greatly needed by families interacting with multiple social service systems.

Prioritize continuity of care, parent voice, and interpersonal skill building to elevate service quality

Caregivers noted that it was important for them that their child worked with a consistent provider. A few caregivers suggested that better wages for providers could support increased longevity and minimize provider turnover. Several caregivers also suggested they can better prepare their child for services if the provider does more communication with the caregiver up front about:

- Approximately how long services will be provided
- The type of professional providing services (i.e. an intern, a physician, a licensed social worker, etc.)
- Whether the individual providing services will be the same for each visit or will change based on staffing

Multiple participants suggested that the system would work better if providers listened to caregivers and took their concerns seriously. Many described being held back from moving forward with an evaluation because their child screened “on-track” or the provider labeled the concerns caregivers shared as “normal.” Caregivers want their intuition to carry as much weight as a screening when it comes to connecting with a professional who can further evaluate their child.

Caregivers also recommended providers improve their ‘bedside’ manner to create screening and service environments that are non-judgmental, strengths-based, and non-confrontational. Caregivers would like to feel more comfortable asking any questions that arise and feel supported in their effort to do their best with the resources and time they have available. Many caregivers felt strongly that within the provider community there is a need to remove the concept of ‘bad caregiver’ that conveys to the caregiver that they have done something wrong.

Create inclusive spaces and address stigma associated with developmental screening and delays

Overwhelmingly, participants spoke about the need to reduce stigma around screening, assessment, early intervention, and disability, while also creating more inclusive spaces and services, so families and children with special health care needs feel embraced by the larger community. Suggestions included routinizing developmental screening, public education campaigns, elevating the successes of neurodivergent adolescents and adults, and creating mentorship opportunities for neurodivergent adults to support neurodivergent children.

Some participants were quick to recognize that shifts of this nature would require changes to cultural norms and could not be achieved overnight, but encouraged King County to dream big and create a vision for what a truly inclusive and supportive King County could look like and then create a long-term plan for how the community gets there.

> **“When you start talking about a culture change, you’re talking about something really long-term. I would love to see all the major stakeholders around the county or around the state, come together in some sort of organized conversation to say, in 50 years, if King County was going to be a truly inclusive environment, what would it look like? How do we get there?”**
>
> **—Focus group participant**

KEY FINDINGS FROM THE DEVELOPMENTAL SCREENING & REFERRAL COMMUNITY SURVEY

BACKGROUND & APPROACH

From November 2018 through January 2019, Cardea, in partnership with WithinReach and King County Developmental Disabilities and Early Childhood Supports Division, conducted a survey to learn about developmental screening and connections to services. The Developmental Screening & Referral Community Survey, conducted as part of the Best Starts for Kids initiative, was administered to understand how developmental screening, referrals, and connections to services in King County work and how the system can be improved.

The survey was developed in partnership with local community and national experts and shared with 74 organizations across King County who helped distribute it among primary care providers, specialists, early learning and childcare providers, home-based providers, policy-makers, parents, and caregivers. These key stakeholder groups provided widespread knowledge of the landscape of developmental screening in King County.

The tables included in this document present all data collected from the Developmental Screening & Referral Community Survey, categorized by each participating stakeholder group.

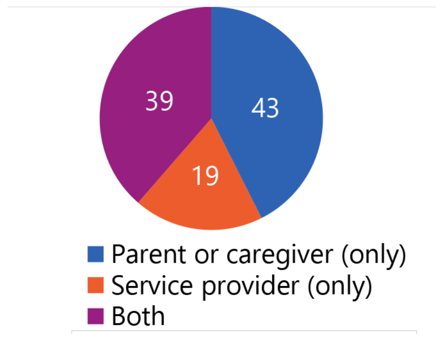
KEY FINDINGS

SURVEY PARTICIPANT DEMOGRAPHICS

Most survey participants were parents or caregivers who lived in Seattle

There were 761 total eligible Developmental Screening & Referral Community Survey respondents. Most lived (96%) and worked (92%) in King County, with the highest proportion of respondents living and working in Seattle (47% and 48%, respectively) (**Figure 1**). Approximately 39% of respondents reported being a parent or caregiver and service provider to pregnant people or families with young children (ages 5 or younger), while 43% were parents or caregivers only, and 19% were providers only (**Figure 2**). Among those who provide services, about one-third work in an early learning, childcare, or school setting, and another third work in a healthcare setting. Approximately one-quarter of service provider-respondents worked in a home-based setting. The largest number of respondents identified as primary care providers (n=84) and early learning or pre-K providers (n=79).[1]

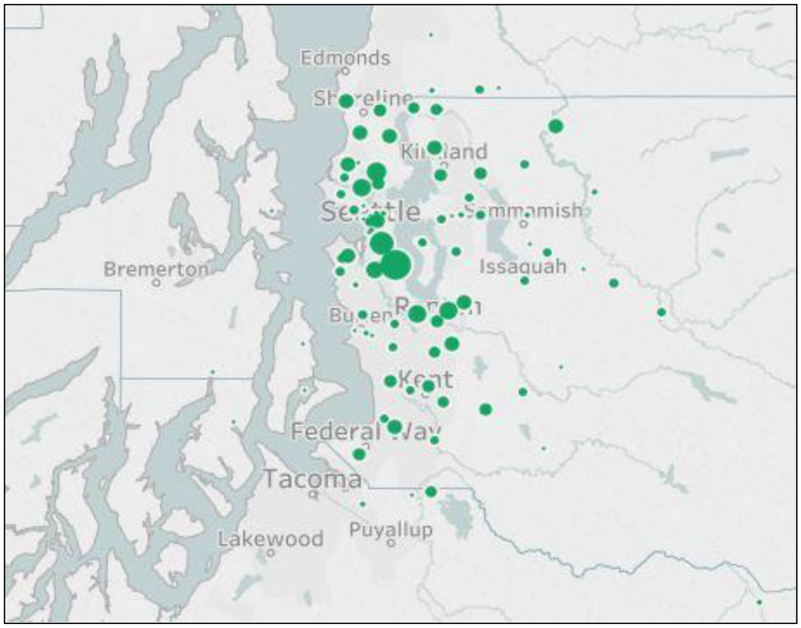
Figure 2: Most participants were parents or caregivers (%, N=761)*



* Adds to over 100% due to rounding

See **Table 1** on page 63 for a complete overview of respondent demographics.

Figure 1: Survey participants lived across King County, with nearly half living in Seattle. (%, n=689)



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[1] The total N for participant types in subsequent sections/tables in this report may be different from those presented on this page for two reasons: (1) Respondents were directed to the survey section that best fit their job type and work setting which increased inclusion for some survey sections. For example, survey logic directed Clinical Social Workers/Mental Health Providers who work in healthcare settings to take the primary care section of the survey; (2) Not all individuals who completed the demographics section of the survey continued taking the survey, leading to smaller sample sizes for some sections.

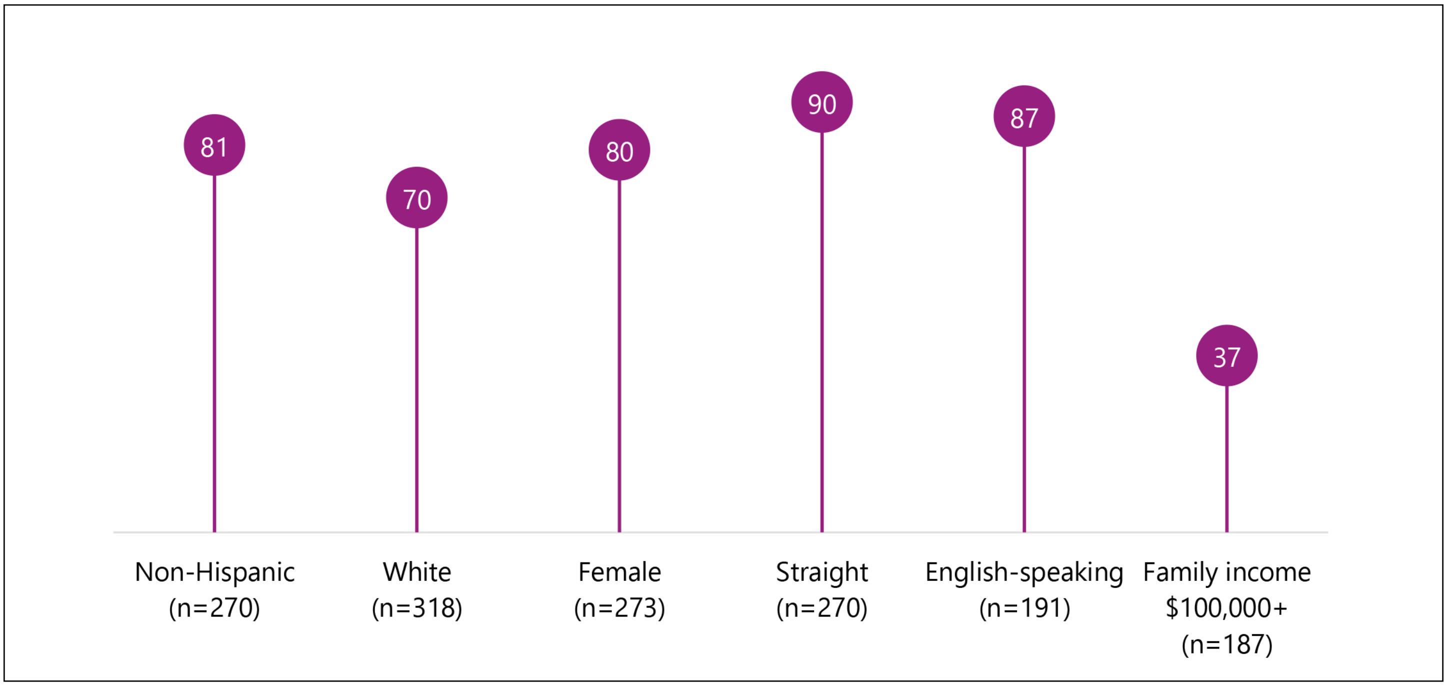
PROVIDER DEMOGRAPHICS

Providers who responded have similar demographics to the families that responded

Among survey participants, 427 (57%) identified as people who provide services to pregnant people or families with young children (ages 5 or younger) in King County. Among those who identified as service-providers, approximately two-thirds also identified as parents or caregivers to a child in King County (**Table 1**). Demographic information was completed for 270 (63%) provider respondents. Most of these providers identified as non-Hispanic (81%), white (70%), female (80%), straight (90%), and English-speaking (87%). The median age among providers was 36 years (IQR: 32-45), and about one-third (37%) reported making a total combined family income of $100,000 or more in the last year (**Figure 3** and **Table 4**). These provider demographics align with the demographics of the non-provider parent/caregiver survey respondents, although provider income is slightly lower than that of the non-provider parent/caregiver respondents (**Table 3**).

See **Table 4** on page 80 for a complete overview of provider demographics.

Figure 3: Most provider participants were non-Hispanic, white, female, straight, and English-speaking (%)



PARENTS & CAREGIVERS

Developmental screening in King County is widespread according to parents/caregivers

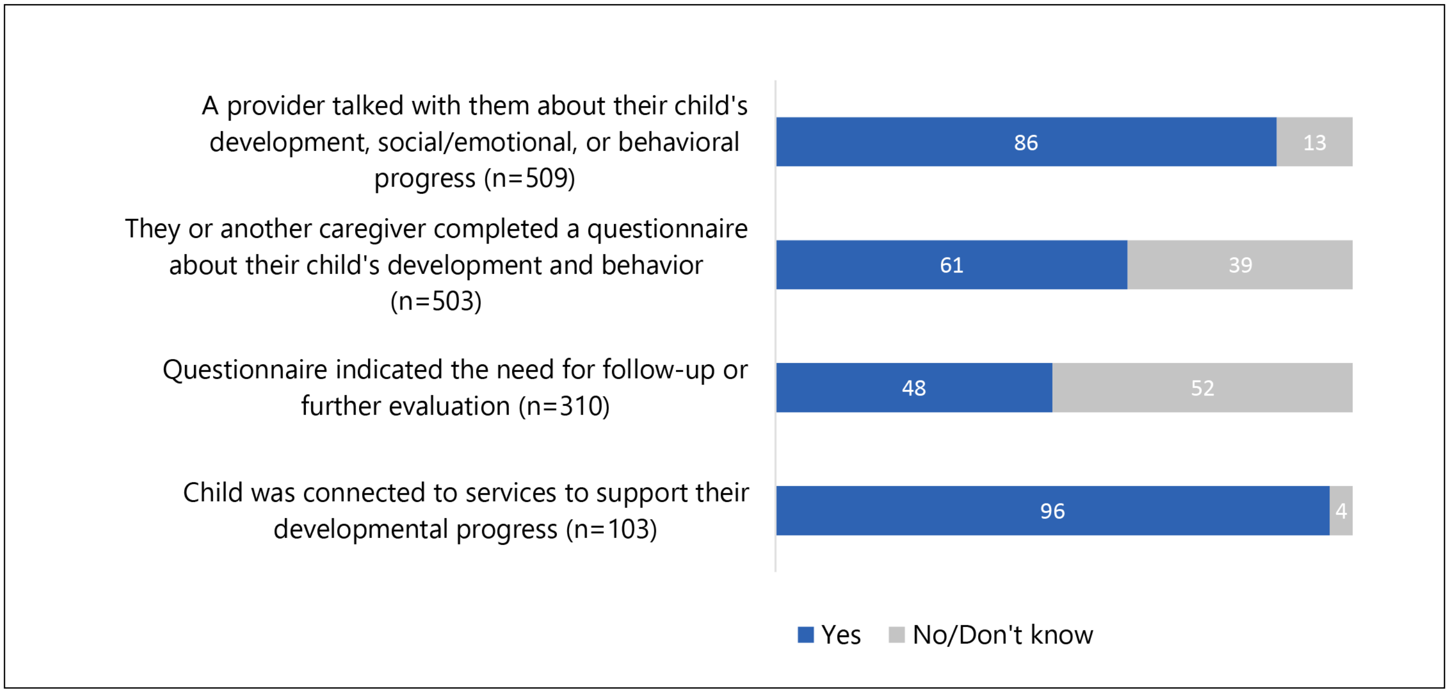
Among survey participants, 620 (81%) identified as parents or caregivers to a child in King County, and 511 (82% of parents/caregivers) were eligible to be included in analysis. Approximately nine out of ten of parent/caregiver respondents were the child's biological or adoptive parent. Most participants (86%) reported that a provider in their child's life has talked with them about their child's developmental, social/emotional, or behavioral progress and that they or another caregiver completed a questionnaire about their child's development (61%). Among those who had completed a questionnaire about their child's development and behavior, 71% completed the questionnaire in a doctor's office.

Most caregivers reported that children were connected to the services needed

About half (48%) reported that the questionnaire indicated the need for follow-up or further evaluation, and nearly all (96%) reported that the child was connected to services to support their developmental progress, if needed (**Figure 4**). Respondents' children were primarily described as white (73%), non-Hispanic (80%), English-speaking (92%), and aged 0 to 3 (60%). Slightly less than half (47%) of parent/caregiver respondents reported making a total combined family income of $100,000 or more in the last year (**Table 2**). Results were similar when parent/caregiver responses were limited to those who were not also service-providers (**Table 3**).

See **Table 2** on page 66 for a complete overview of parent/caregiver responses. See **Table 3** on page 73 for an overview of non-provider parent/caregiver responses.

Figure 4: Most parents/caregivers reported completing developmental screenings and that their child was connected to services, if needed (%)



OVERVIEWS

The following section provides an overview of provider and parent responses on similar topics. Data are overlaid to support interpretation.

Use of Validated or Evidence-Based Screening Tools was common across provider types

A majority of all provider type respondents reported using validated or evidence-based screening tools, with home-based providers most commonly reporting the use of validated or evidence-based tools (87%) and specialists least often using validated or evidence-based tools (61%). **Figure 5** overlays reported use of validated or evidence-based screening tool(s) to screen for developmental progress among different provider types.

Figure 6 shows that the Modified Checklist for Autism in Toddlers (M-CHAT), Ages and Stages Questionnaire (ASQ-3), and Ages and Stages Questionnaire Social and Emotional (ASQ-SE) were the most commonly reported tools used across provider types, with the ASQ-3 being the most frequently reported tool used across provider types. Other tools commonly used were the Developmental Assessment of Young Children (DAYC-2), Learning Accomplishment Profile – Diagnostic (LAP-D), and the Devereux Early Childhood Assessment (DECA).

Figure 5: All provider types commonly reported using validated or evidence based screening tool(s) to screen for developmental progress

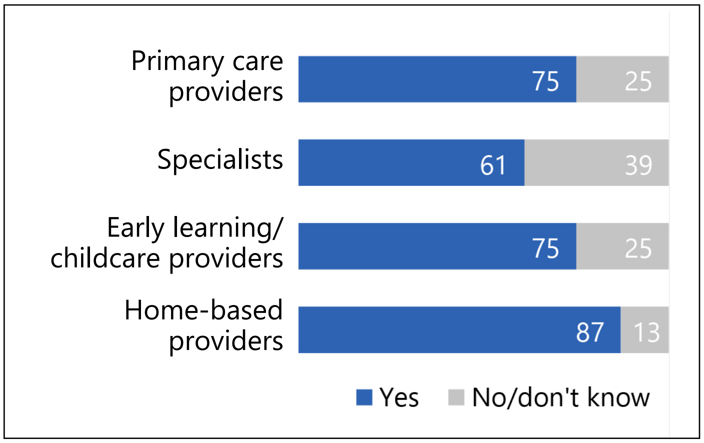
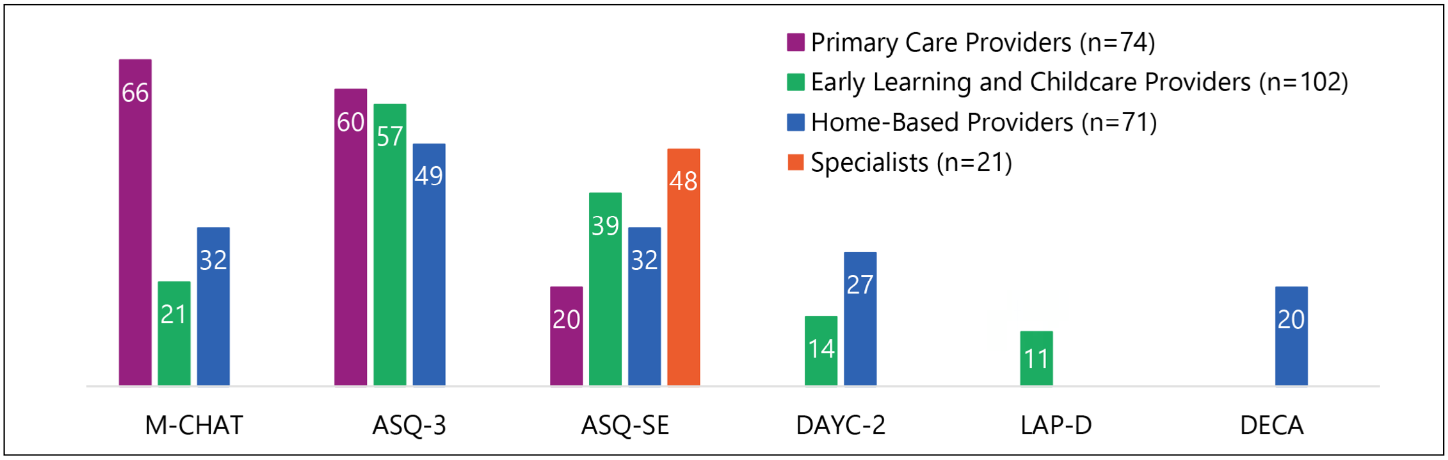


Figure 6: The most commonly reported tools used across providers were the M-CHAT, ASQ-3 and ASQ-SE, by percent



[1] Responses reflected in this visual are only representative of providers who responded to the Developmental Screening and Referral Community Survey and not of all providers who administer validated or evidence-based tools in Seattle and King County

[2] If less than 10% of a provider type reported use of a tool, they were redacted from this visual

[3] Due to the structure of the survey, those who reported adapting tools rather than administering an unmodified validated or evidence-based screening tool are not included in this visual

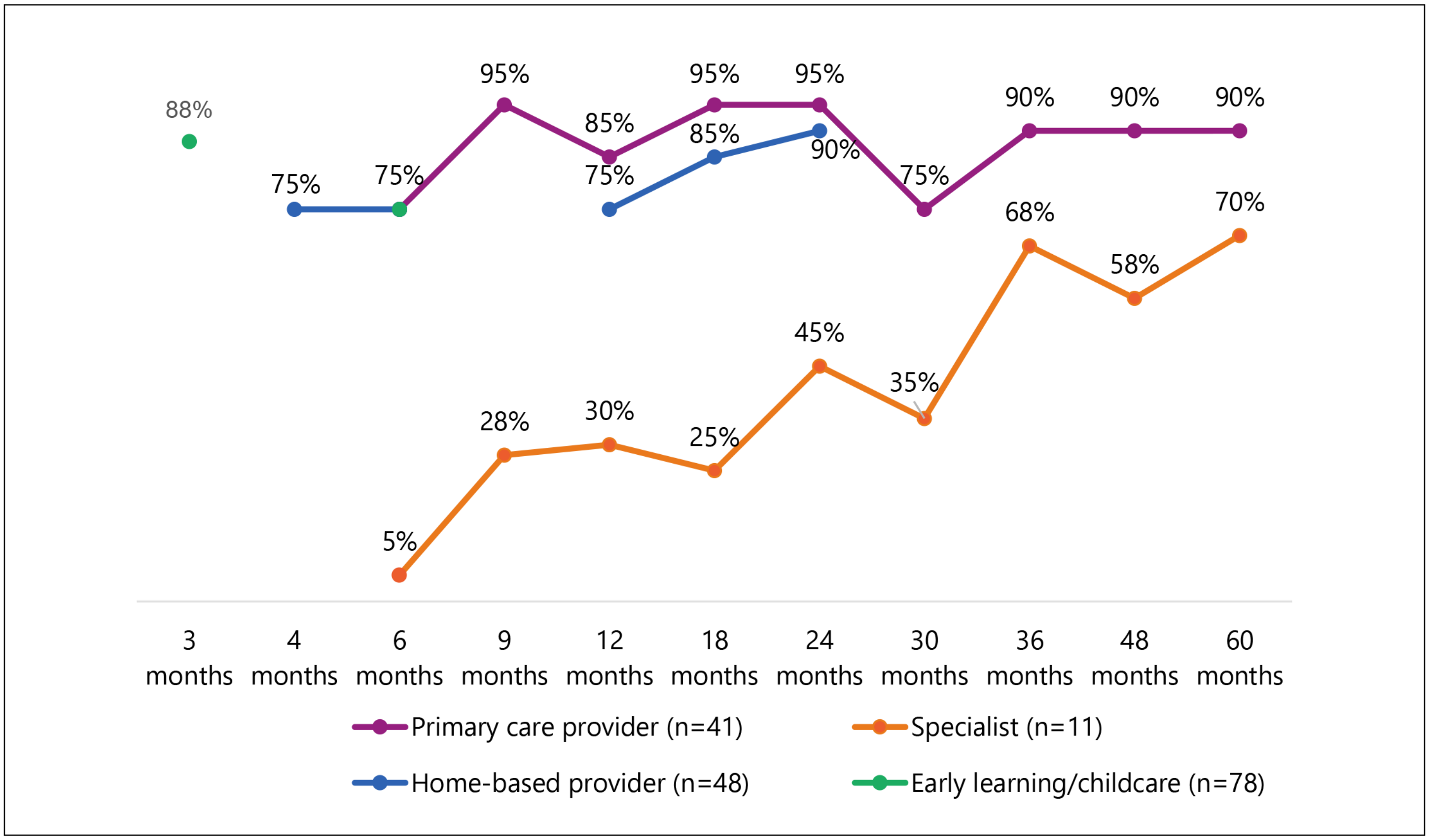
[4] Percentages across provider types do not add to 100% as participants were asked to select all that apply

[5] Due to the role of Specialists as those who deliver services among children who have already been screened and referred, they are not expected to be administering developmental screenings as frequently as other provider types

Primary care providers screen more frequently than other provider types across all child age groups, while specialist screening frequency increases with a child's age

Primary Care Providers (PCPs) reported screening the greatest percentage of children at each time period for which they were asked, when compared with other provider types, and remained fairly constant across age intervals. The percentage of children that specialists screened increased as children's age increased. **Figure 7** overlays the percentage of children that different types of providers reported screening during specific child age intervals.

Figure 7: Time/age when providers screen children for developmental progress varied across provider types, with specialists screening more frequently as children get older and PCPs screening consistently across age groups (%)[1]

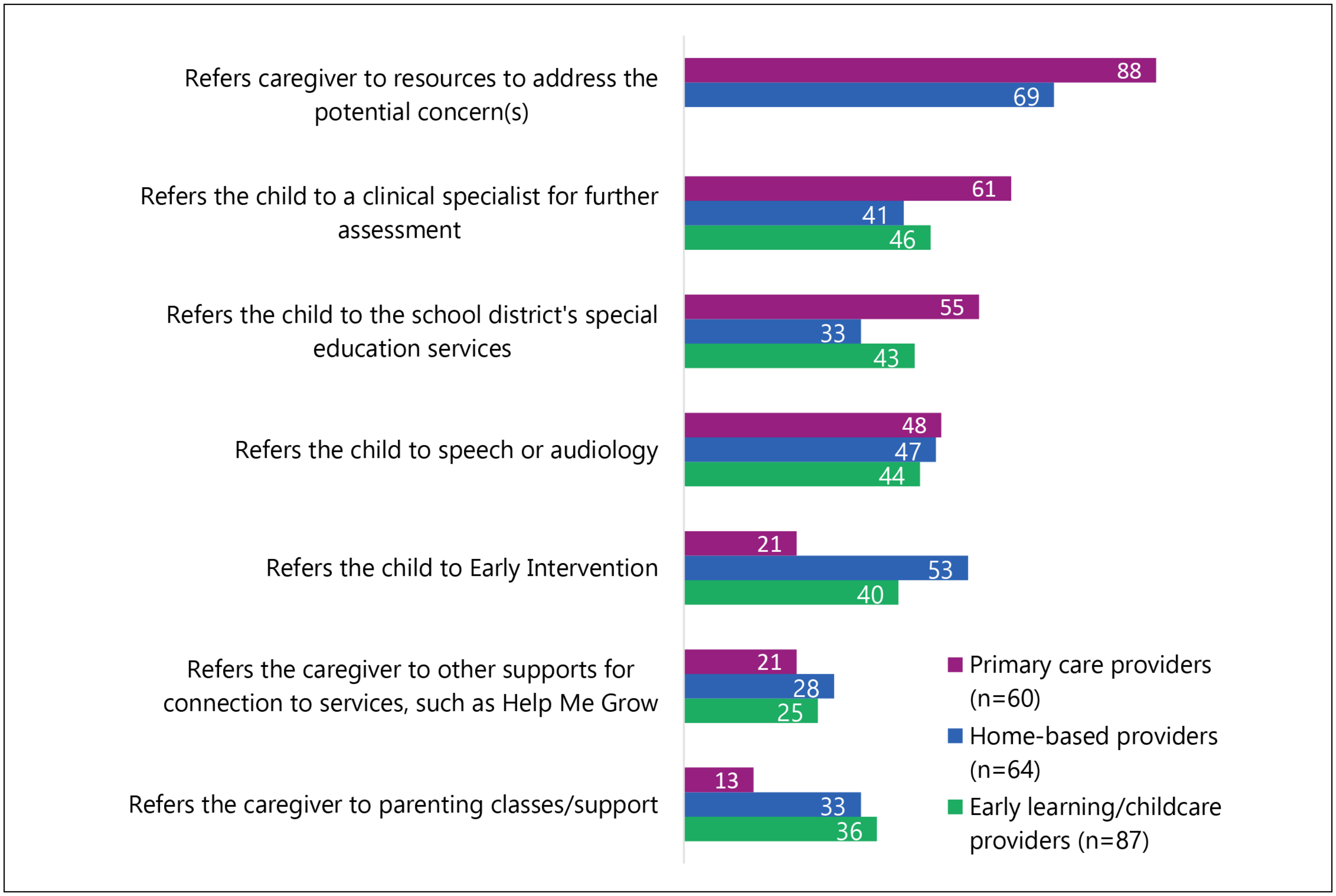


[1] Provider types were asked about screening during different time periods based on what was appropriate for their role. Any gaps in lines between data points exist because data was not collected at a time interval between the two points.

Referral provision varied by provider and referral type, and referrals to Early Intervention, Help Me Grow, and parenting supports were low.

Referring the child to clinical specialists for further assessment, the school district's special education services, and speech and audiology were relatively common across provider types, while referrals to Early Intervention, other supports such as Help Me Grow, and parenting classes or support tended to be less common. **Figure 8** overlays the percentage of respondents of different types of providers who reported routinely making specific types of referrals. PCPs and home-based providers commonly reported referring caregivers to resources to address potential concerns.

Figure 8: The percent (%) of providers who routinely make specific types of referrals varied based on provider and referral type[1-2]



[1] PCPs were asked how often they do the listed activities (Every time, almost every time, almost never, never, or does not apply) when a child's developmental screen indicates a potential delay. The % shown includes "every time" and "almost every time" responses. Early learning and home-based providers were asked to select the steps they routinely take to connect a child/family to supportive services. The % shown includes the providers who selected each option.

[2] Early learning/childcare providers were not asked whether they refer caregivers to resources to address the potential concern(s)

Figure 9 shows the percentage of specialist respondents who reported receiving referrals from the healthcare, early learning, school-based, and childcare providers. The greatest percentage of specialists (85%) reported receiving referrals from healthcare providers, while the smallest percentage of specialists (24%) reported receiving referrals from childcare providers. The percentages in the figure bellow do not add to 100% as specialists were asked to select all stakeholder groups from whom they receive referrals.

Figure 9: Specialists receive referrals from healthcare providers more frequently than other key stakeholder groups (%, n=46)

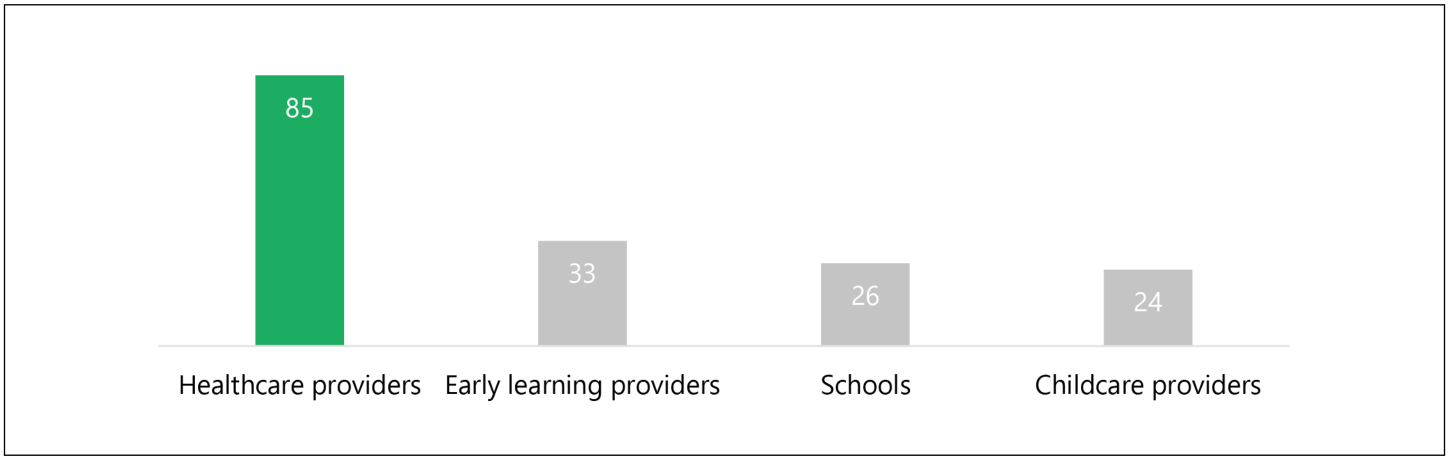


Figure 10 shows the percentage of parent/caregiver respondents who reported receiving a needed referral. Nearly all (96%) parents/caregivers reported that they received a needed referral. Due to a small sample size of parents/caregivers who did not receive a needed referral (n < 5), we were unable to disaggregate this finding to explore differences based on demographic characteristics.

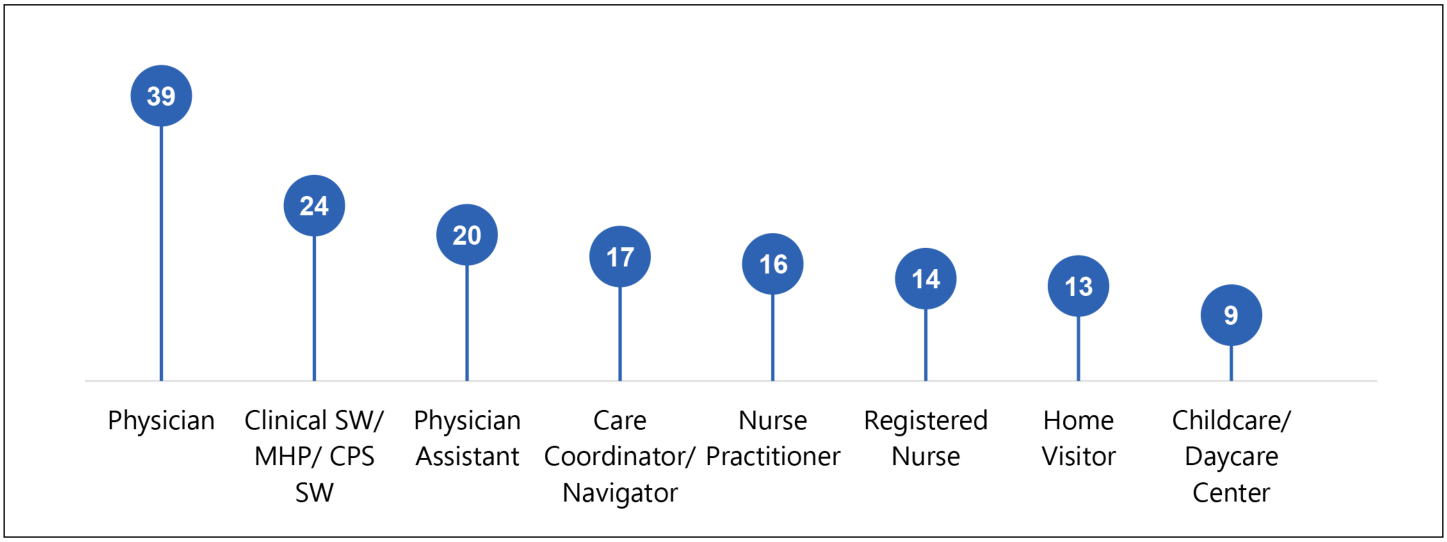
Figure 10: Most (96%) parents/caregivers received the referrals they needed (n=121)

96%

Physicians are the most common provider type involved in connecting caregivers and their children to supportive services

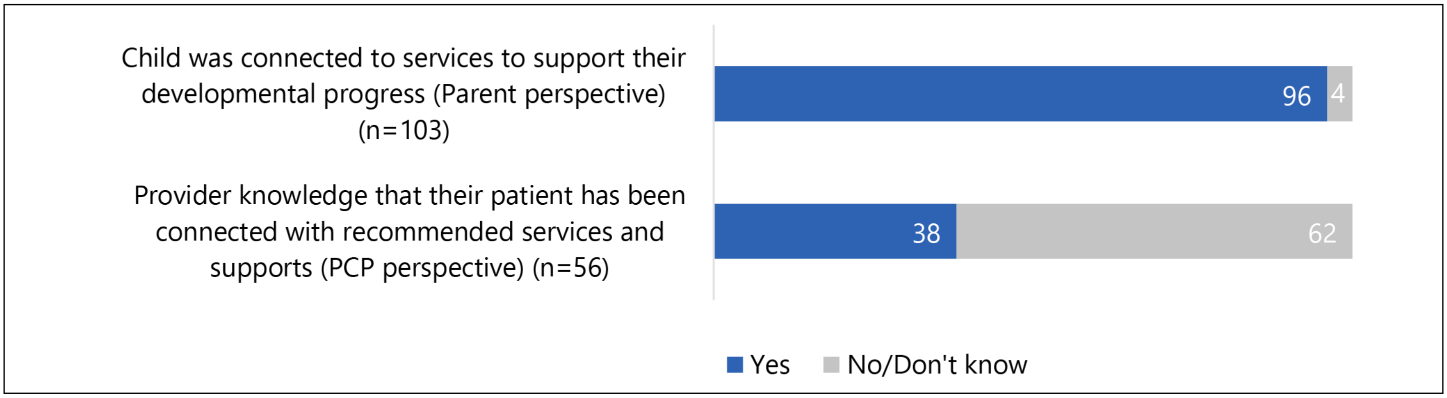
Physicians were the most commonly reported provider type (39%) and childcare/daycare center providers were the least commonly reported provider type involved in connecting parents/caregivers to supportive services. The percentages in the figure below do not add to 100% as parents/caregivers were asked to select all provider types that were involved in their connection to services. **Figure 11** shows the percentage of parent/caregiver respondents who reported that the listed provider types were involved in connecting them and their children to supportive services.

Figure 11: **Parents/caregivers reported that many provider types were involved in connecting them to supportive services, with physicians being most frequently involved in this process (%, n=71)**



Most (96%) of parent/caregiver respondents reported that their child was connected to services to support their developmental progress. However, most PCPs (62%) reported that they do not know if their patients have been connected with recommended services or supports. **Figure 12** compares parent and PCP respondent perspectives regarding patient connection to services.

Figure 12: **Most parents reported that their child was connected to needed services despite only 38% of PCPs reporting that they know when their patients have been connected (%)**

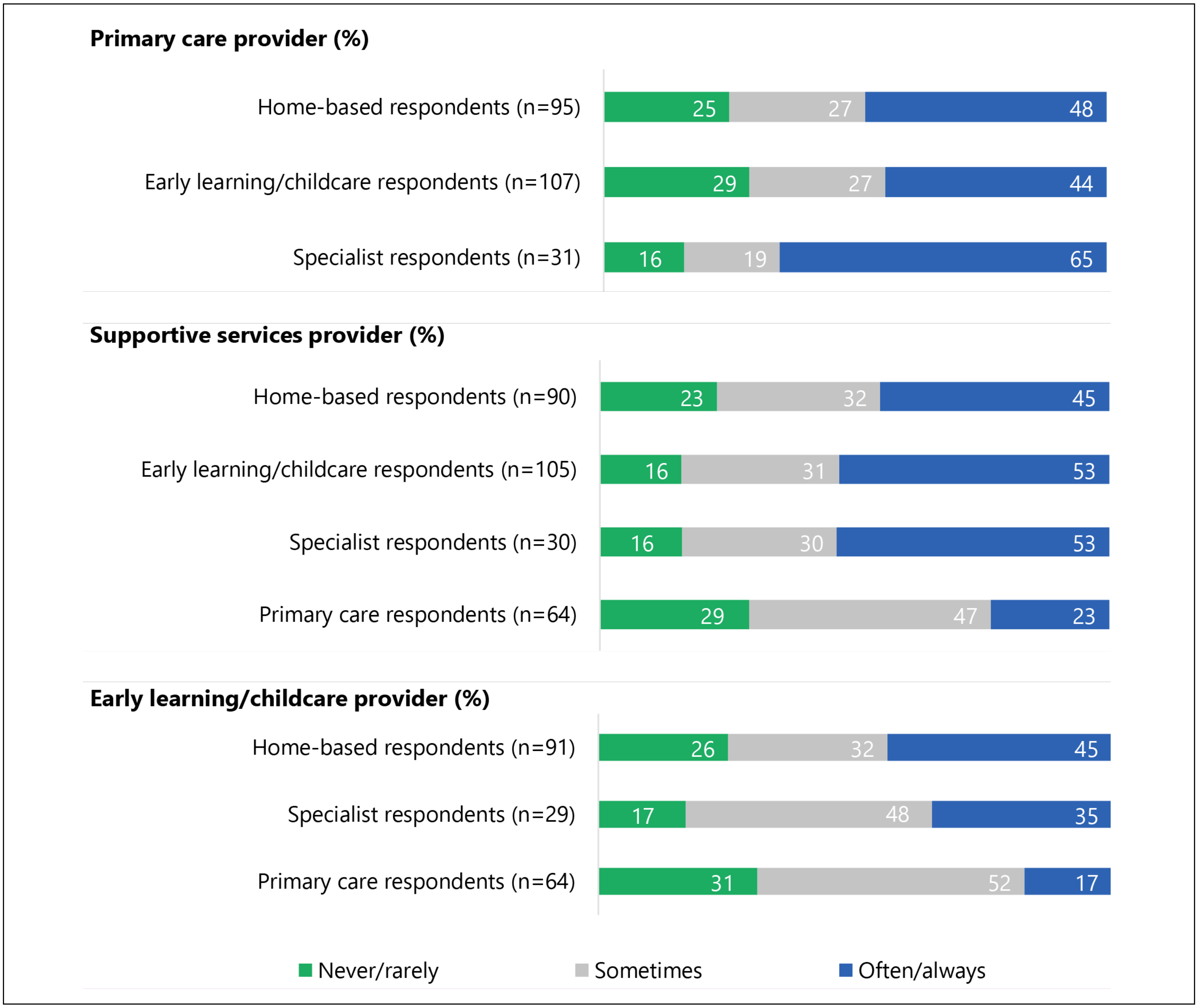


* Parents and PCPs did not have a direct relationship to one another.

Information sharing frequency differed across and between provider types

Overall, the percentage of home-based provider respondents who reported sharing information about a child's development "often or always" remained similar regardless of provider type. However, the percentage of early learning/childcare, specialist, and PCP respondents who shared information about a child's development "often or always" varied based on provider type. Early learning/childcare respondents reported sharing information most frequently with supportive services providers (53% reporting "often or always" sharing information), while specialists reported sharing information most frequently with PCPs (65% reporting "often or always" sharing information). PCPs shared information with other provider types the least frequently. **Figure 13a** illustrates how frequently different provider types reported sharing information about a child's development with the child's other service providers.

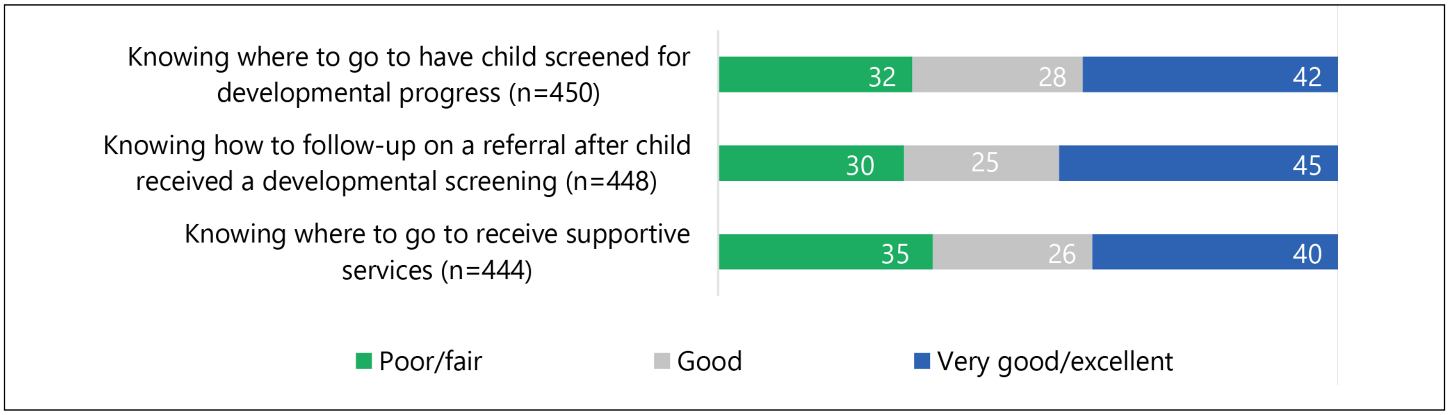
Figure 13a: The frequency with which provider types reported sharing information about a child's development with that child's other types of service providers varied



Less than half of parent/caregiver respondents reported that their knowledge regarding where to go to have their child screened for developmental progress (42%), how to follow-up on a referral after their child received a developmental screening (45%), and where to go to receive supportive services (40%) was "very good or excellent." Responses were similar when disaggregated by race, ethnicity, and income level. **Figure 13b** describes parent/caregiver experiences with systems coordination by their knowledge about how to get the services or supports that they need.

See **Table 10** on page 101 for a complete overview of respondent suggestions to improve the coordination of the developmental and screening referral system.

Figure 13b: Most parents/caregivers reported positive experiences regarding coordination of the developmental screening and referral system



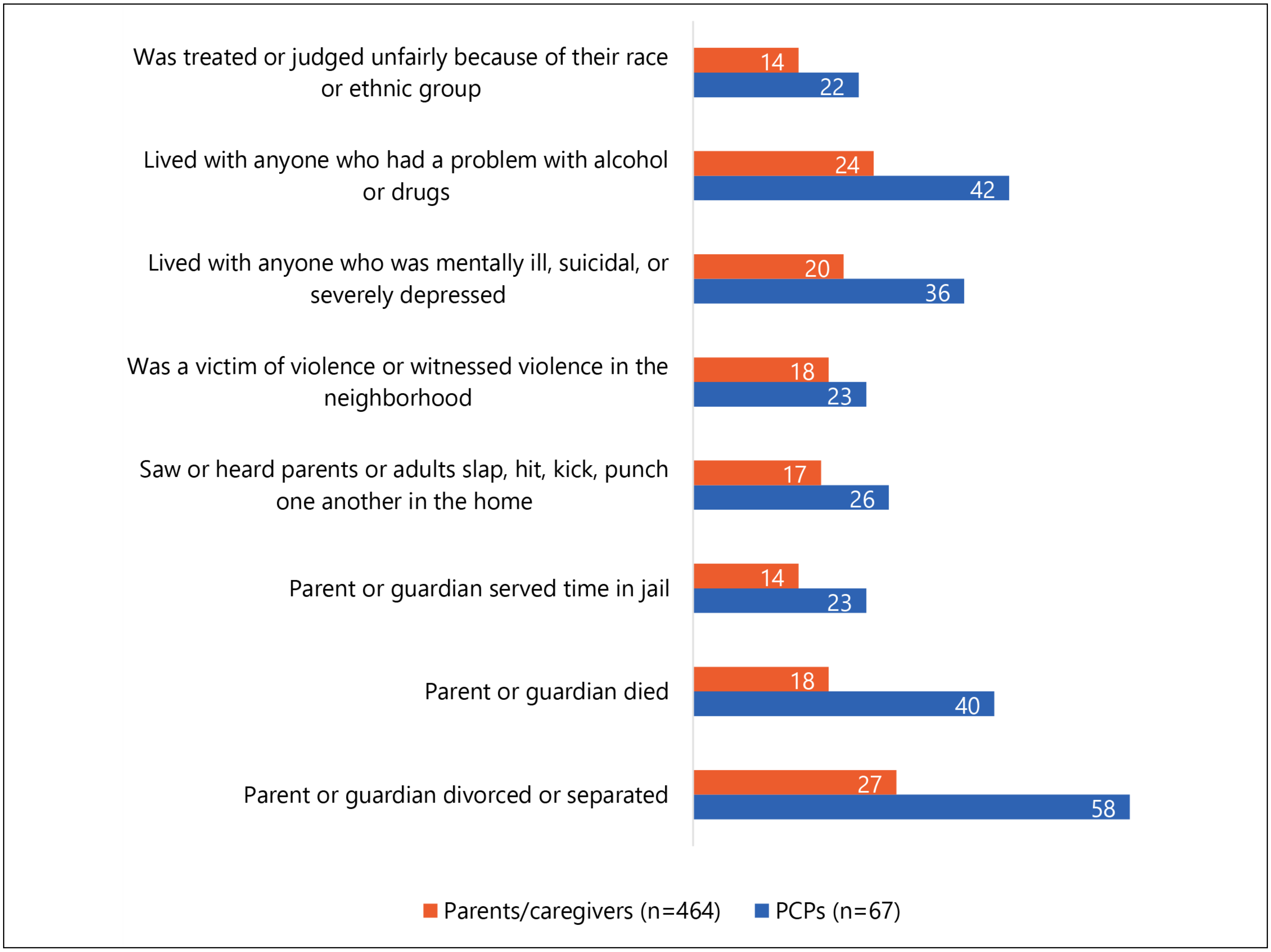
Twenty-eight participants described a "one stop shop" for centralized and accessible screening and referrals as their ideal system to improve coordination of the developmental screening and referral system (n=166) (Table 10)

Twenty-nine participants suggested that improved communication across stakeholder groups would improve the coordination of the developmental screening and referral system (n=166) (Table 10)

Screening for Adverse Childhood Experiences (ACEs) was uncommon

A greater percentage of PCP respondents reported screening for ACEs than parent/caregiver respondents reported being screened for each ACE. **Figure 14** compares the percentage of parent/caregiver respondents who reported that providers have asked them if their child has ever experienced specific adverse childhood experiences (ACEs) with the percentage of PCP respondents who reported that they ask parents/caregivers if their children have experienced the same list of ACEs. The frequency that PCPs reported asking caregivers if their child has ever experienced specific adverse childhood experiences (ACEs) ranged from 22% to 58% depending on the ACE. Most (84%) PCPs reported that their sites did not use a specific tool to screen for ACEs.

Figure 14: More PCP respondents reported screening than parent/caregiver respondents reported being screened for each of the following ACEs, although screening was relatively low across all ACEs (%)[1]



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[1] Responses show the percent of respondents from each group who reported "yes" for each ACE. Only 13% of PCPs reported that their site uses a specific tool to screen for ACEs.

PRIMARY CARE PROVIDERS

Developmental screening was common among primary care providers, while referral provision and support for connection to services were less common

There were 94 primary care provider (PCP) responses[1] to the Developmental Screening & Referral Community Survey, including 62 (66%) physicians among whom 42 (68%) specialized in pediatrics. Three out of four PCPs reported that they used a validated or evidence-based screening tool(s) to screen children for developmental progress. One-third of respondents who reported not using a validated or evidence-based screening tool used an adapted version of a validated or evidence-based tool. Most (79%) PCP respondents reported that their sites use a screening tool or tools to screen for children for developmental progress routinely at specific age intervals. The most commonly administered tools were the Modified Checklist for Autism in Toddlers (M-CHAT) (66%), the Ages and Stages Questionnaire (ASQ-3) (60%), and the Ages and Stages Questionnaire Social and Emotional (ASQ-SE) (20%). The majority of PCP respondents reported that their sites offer developmental screening in English (88%), and a little less than half offer developmental screening in Spanish (46%). **Figure 15** shows PCPs reported referring a median of 50% (Interquartile Range (IQR): 20-90) of children aged zero to five for further assessment when a developmental, social-emotional, or behavioral concern is identified through developmental screening. More than half (55%) of PCPs reported not knowing when their patient has been connected with recommended services and supports. Approximately 75% of PCPs reported that their sites screen for maternal depression.

See **Table 5** on page 81 for a complete overview of PCP responses.

Figure 15: Most PCPs use a validated or evidence-based tool to screen children for developmental progress, while fewer refer children for further assessment

75%

75% of PCPs report using a validated or evidence-based screening tool to screen children for developmental progress (n=94)

50%

PCPs reported referring a median of **50%** of children 0 to 5 for further assessment, when a concern was identified through screening (n=59)

55%

55% of PCPs reported not knowing when their patient has been connected with services and supports (n=56)

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[1] The total N for PCPs is larger than what is presented in the "Participant Demographics" section on Page 45 because survey logic allowed for Clinical Social Workers/Mental Health Providers who work in healthcare settings to take the primary care section of the survey. In this way, 84 PCPs and 10 clinical social workers/mental health providers completed this section.

SPECIALISTS

Specialists reported offering screenings and services that are inclusive of non-English speaking families, although there are opportunities to increase the use of validated or evidence-based screening tools

There were 51 specialist responses[1] to the Developmental Screening & Referral Community Survey, most (73%) of whom provide services to parents/caregivers and their children together. Specialist respondents primarily serve their clients in an individual, rather than group, setting and about half (52%) provide services on an on-going basis. Settings in which the specialists' services are delivered vary, although a little less than half (47%) work in a clinical setting. Specialists reported that children and families are typically referred to them by healthcare providers (85%), self-referrals (44%), other families or word of mouth (41%), and early learning providers (33%) (**Figure 16**). English and Spanish were the most commonly reported languages in which specialist services are offered (83% and 39%, respectively), with nearly two-thirds (63%) reporting that interpreters are available upon request. Slightly less than two out of three specialists (61%) use a validated or evidence-based screening tool or tools to screen children for developmental progress (**Figure 17**). The most commonly administered tools were the Ages and Stages Questionnaire Social and Emotional (ASQ-SE) (48%), the Ages and Stages Questionnaire (ASQ-3) (43%), and the Modified Checklist for Autism in Toddlers (M-CHAT) (29%).

See **Table 6** on page 90 for a complete overview of specialist responses.

Figure 17: More than half (61%) of specialists use validated or evidence-based tools to screen for developmental progress (n=38)

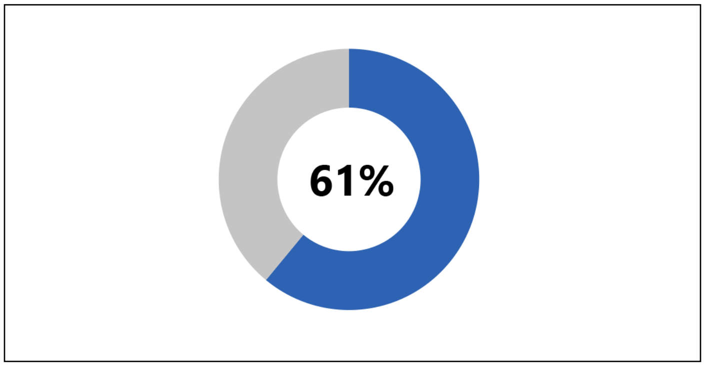
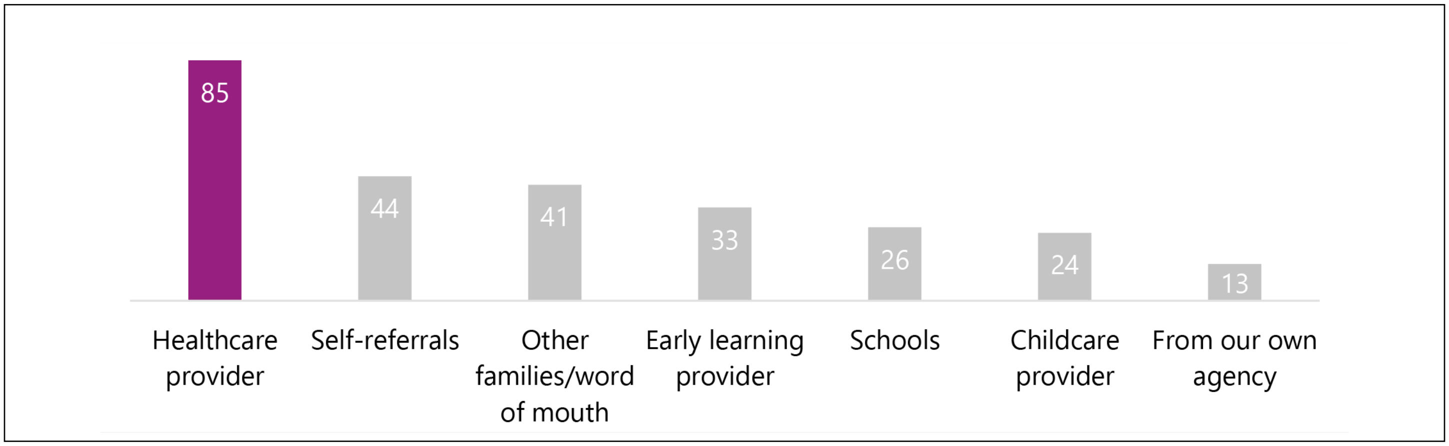


Figure 16: Children and families are most commonly referred to specialist services by healthcare providers (%, n=46, multiple response choices allowed)



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[1] The total N for specialists is larger than what is presented in the "Participant Demographics" section on Page 45 because survey logic allowed for specialists who work in healthcare settings, as well as parenting class providers to take the specialist section of the survey. In this way, 50 specialists who work in healthcare settings and 1 parenting class provider completed this section.

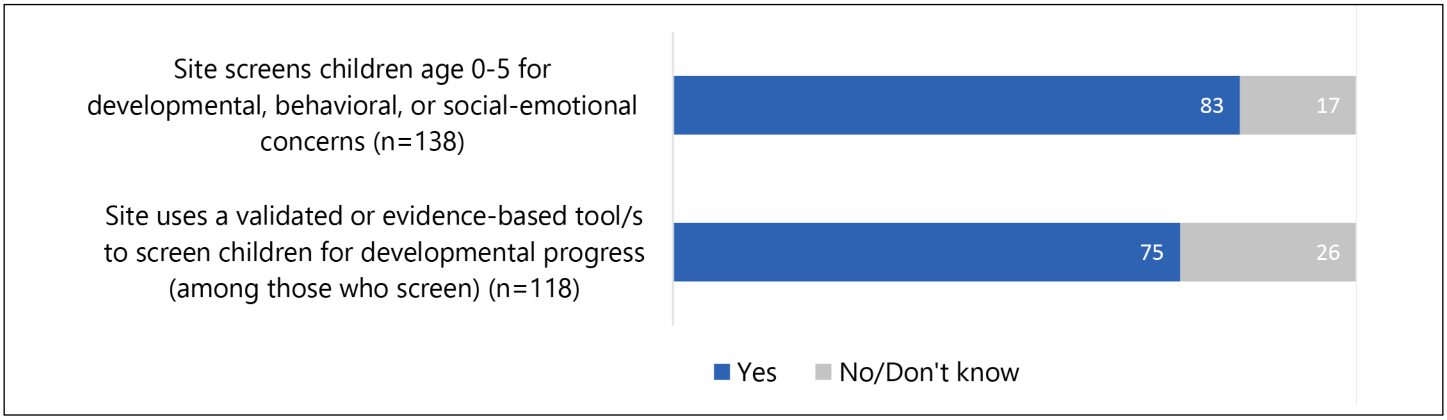
EARLY LEARNING, CHILDCARE AND SCHOOL-BASED PROVIDERS

Most early learning, childcare and school-based providers conduct developmental screening and are comfortable discussing results with the families they serve

There were 138 early learning, childcare, and school-based provider responses to the Developmental Screening & Referral Community Survey.[1] Most (84%) reported that their sites screen children ages zero to five for developmental, behavioral, or social-emotional progress, and 59% reported that their sites screen routinely at specific age intervals. Eighty-eight (75%) early learning providers reported that their site uses a validated or evidence-based screening tool or tools to screen children for developmental progress (**Figure 18**). The most commonly administered tools among early learning providers are the Ages and Stages Questionnaire (ASQ-3) (57%), the Ages and Stages Questionnaire Social and Emotional (ASQ-SE) (39%), and the Modified Checklist for Autism in Toddlers (M-CHAT) (21%). Tools are primarily administered during care or a visit (55%), and most (86%) early learning providers feel either somewhat or very comfortable discussing screening results with a child's caregiver or parent when a screening indicates a potential concern.

See **Table 7** on page 94 for a complete overview of early learning, caregiver, and school-based provider responses.

Figure 18: Developmental screening was common among early learning, childcare, and school-based providers (%)[2]



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[1] The total N for early learning, childcare, and school-based providers is smaller than what is presented in the "Participant Demographics" section on Page 45 because not all individuals who reported working in early learning, childcare, or school-based settings went on to complete the respective survey section.

[2] May add to over 100% due to rounding

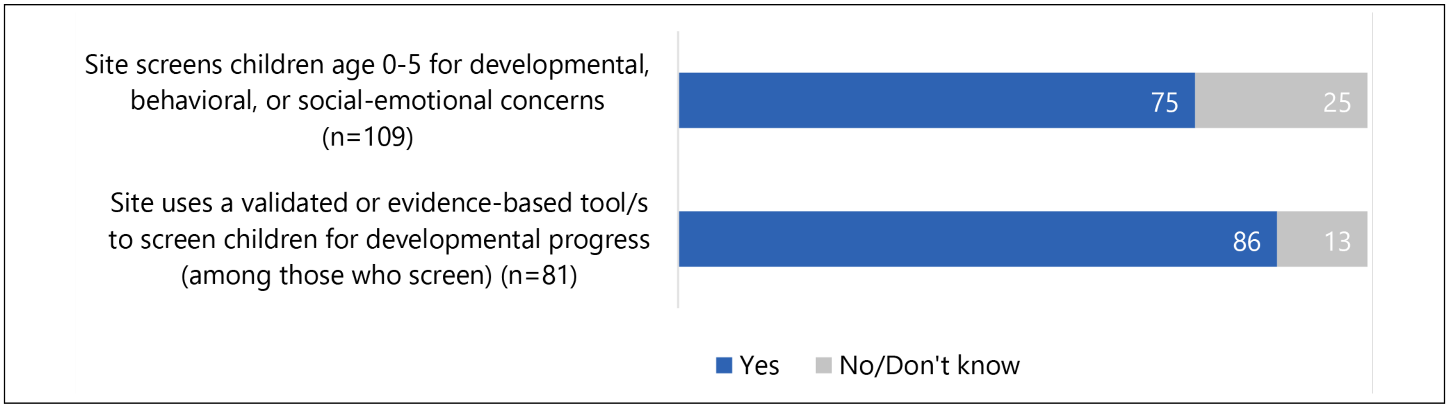
HOME-BASED PROVIDERS

Most home-based providers conduct developmental screening and report high rates of families following up on referrals made

There were 109 home-based provider responses to the Developmental Screening & Referral Community Survey. Home-based providers reported seeing the families they work with a median of three times (IQR: 2-4) per month. Most (75%) reported that their sites screen children ages zero to five for developmental, behavioral, or social-emotional concerns. A little more than half (55%) of home-based provider respondents reported conducting screenings toward the beginning of services, and approximately half (48%) reported screening routinely at specific age intervals. Seventy (86%) early learning providers reported that their site uses a validated or evidence-based screening tool or tools to screen children for developmental progress (**Figure 19**). The most commonly administered tools among early learning providers are the Ages and Stages Questionnaire (ASQ-3) (49%), the Ages and Stages Questionnaire Social and Emotional (ASQ-SE) (32%), and the Modified Checklist for Autism in Toddlers (M-CHAT) (32%). Tools are primarily administered during a visit (81%), and most (86%) home-based providers feel either somewhat or very comfortable discussing screening results with a child's caregiver or parent when a screening indicates a potential concern. Home-based providers reported that a median of 70% (IQR: 44% – 80%) of families in their caseloads follow-up on referrals.

See **Table 8** on page 97 for a complete overview of home-based provider responses.

Figure 19: Most home-based providers reported that their sites screen for developmental concerns using a validated or evidence-based tool (%)



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[1] The total N for home-based providers is smaller than what is presented in the "Participant Demographics" section on Page 45 because not all individuals who reported working in home-based settings went on to complete the respective survey section.

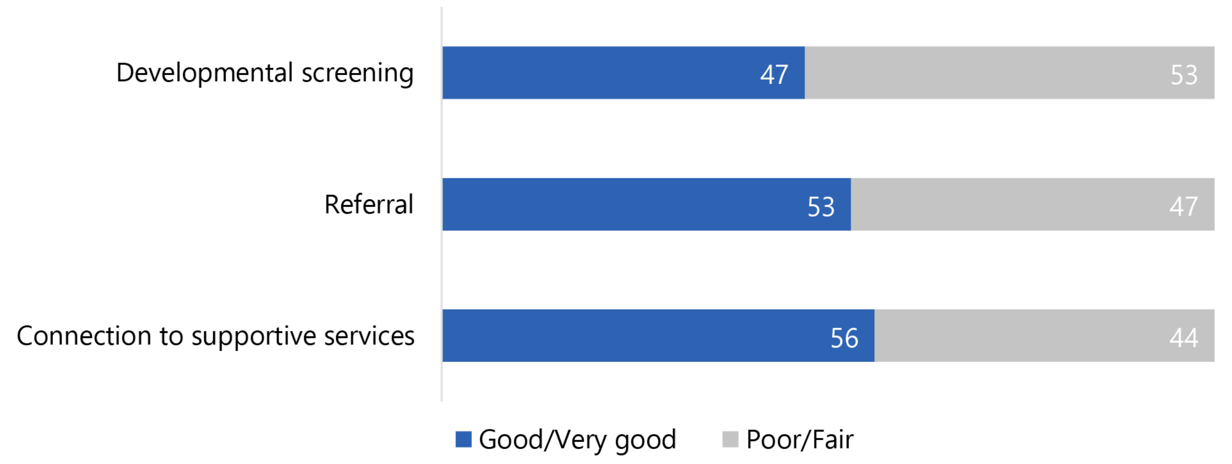
POLICYMAKERS AND CHILDREN'S ADMINISTRATION

Policymakers and Children's Administration officials perceive gaps in coordination of the developmental screening and referral system across King County

There were 34 policymaker or Children's Administration responses to the Developmental Screening & Referral Community Survey. These individuals were only asked questions related to the quality of systems coordination between health care, early learning, childcare, and other sectors that support families in King County. Approximately half (53%) of these respondents reported that the quality of coordination between health care, early learning, childcare, and other sectors that support families in King County was poor or fair in regards to developmental screening. Fewer reported poor or fair coordination in regards to referrals (47%) and connection to services (44%) (**Figure 20**).

See **Table 9** on page 63 for a complete overview of Policymaker and Children's Administration responses.

Figure 20: **Many Policymakers and Children's Administration respondents perceived the quality of coordination between sectors that support families in King County with regard to key areas as "poor" or "fair" (%, n=34)**



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[1] The total N for policymakers and Children's Administration is smaller than what is presented in the "Participant Demographics" section on Page 45 because not all individuals who reported working in policy/advocacy settings or as Children's Administration providers went on to complete the respective survey section.

METHODS & CONSIDERATIONS

STRATEGY

The Developmental Screening & Referral Community Survey was administered online through SurveyGizmo, a robust survey and data platform. The online survey was available from November 1, 2018 through January 21, 2019. It was also administered using paper-based forms during community events upon request. The survey was offered in seven languages, including English, Chinese, Russian, Somali, Spanish, Ukrainian, and Vietnamese, and was voluntary and confidential. Seventy-four organizations supported dissemination of the survey and the survey was posted to the Best Starts for Kids blog in December 2018. Outreach to parents and caregivers focused primarily on those connected to the developmental screening and referral system to avoid impacts on other population-based child health surveys that were launching in close proximity.

The survey included a total of 146 questions, but participants were asked to respond only to questions that aligned with the stakeholder group(s) they selected in the first section of the survey. In this way, the greatest number of questions asked of any one group was 48 questions among primary care providers.

Respondents who completed the parent/caregiver section or childcare and early learning provider section were eligible for a $5 electronic gift card to Starbucks.

INCLUSION CRITERIA

The primary population of interest for this survey were parents or caregivers to children in King County and those who provide services to pregnant people or families with young children in King County. Specifically, we hoped to reach families, primary care providers, specialists, early learning and childcare providers, home-based providers, policy-makers.

For this reason, to be included in this summary of survey results participants needed to have marked that they either live or work in King County, they are a parent or caregiver to a child in King County, or provide services to pregnant people or families with young children (ages five or younger) in King County. Provider respondents also had to have answered at least one question that informed us whether or not they conducted any sort of developmental screening, the first question in their respective survey sections, in order to be included in analysis.

Initial survey results included 956 respondents. After applying the inclusion criteria, there were 761 respondents who were eligible for analysis.

ANALYSIS

Responses to categorical questions were described using counts and proportions. Responses to numeric questions were described using medians and IQRs. IQRs are meaures that describe the middle 50 percent of survey responses. Percentages do not always add up to 100% because of rounding, redaction and the ability for respondents to select multiple answers for many survey questions. Select key trends were summarized using graphs and figures.

LIMITATIONS

This survey was based on a convenience sample of people who volunteered to participate, therefore findings might not be representative of all King County families and early care and education providers. Although the survey was distributed widely across King County, respondents tended to be white, non-Hispanic, female, straight, English-speaking and with a relatively high combined family income (above the area median income). Seattle is the largest city in King County and the majority of respondents also resided in Seattle. For this reason, it was difficult to assess differences in experiences with developmental screening and connection to services across individuals with different demographic backgrounds or who live across different regions in King County.

Although this survey intended to provide baseline data to document the current state of developmental screening and referral and support strategic planning, the developmental screening and referral system is dynamic and several improvement efforts were already underway at the time of this survey. However, this survey was conducted in parallel with qualitative data collection activities, including interviews, focus groups, and community forums, which provide insight into experiences of groups that were less represented in this survey. Please see the Prenatal to Five Developmental Screening and Connection to Services Key Findings from Key Informant Interviews and Key Findings from Focus Groups and Community Forums for additional detail.

TABLES

Table 1: Survey participant demographics

Participant Characteristics N=761	n or Median	% or IQR
Lives in King County [1]	**755**	
Yes	723	96
No	32	4
Primary city or town of residence	**716**	
Seattle	338	48
Renton	68	10
Kent	33	5
Kirkland	26	4
Auburn	25	4
Bellevue	22	3
Federal Way	18	3
Duvall	16	2
Shoreline	16	2
Other [2]	154	22
5-digit zip code of residence [3]	**707**	
98118	64	9
98144	38	5
98115	26	4
98103	23	3
98178	23	3
98056	21	3
98108	20	3
98117	16	2
98059	15	2
98125	15	2
98177	15	2
98001	14	2
98034	14	2
98058	14	2
98122	14	2
98126	14	2
98133	14	2
98019	13	2
98033	12	2
98042	12	2
98031	11	2
98105	11	2

Participant Characteristics N=761	n or Median	% or IQR
98155	11	2
98198	11	2
Other	266	36
Works in King County	**746**	
Yes	689	92
No [4]	57	8
Primary city or town of work location	**689**	
Seattle	329	48
Renton	45	7
Bellevue	44	6
Kent	34	5
Redmond	19	3
Kirkland	18	3
Bothell	17	3
Duvall	17	3
Shoreline	17	3
Auburn	15	2
Federal Way	15	2
Other [5]	123	18
5-digit zip code where of work location [3]	**659**	
98118	34	5
98144	31	5
98104	30	5
98108	30	5
98101	22	3
98105	20	3
98032	19	3
98052	18	3
98057	17	3
98109	16	2
98115	16	2
98195	16	3
98008	15	2
98122	14	2
98125	13	2
98004	12	2
98011	12	2
98019	12	2
98126	11	2
98177	11	2
Other	290	46

Participant Characteristics N=761	n or Median	% or IQR
Caregiver or parent to a child in King County	**761**	
Yes	620	81
No	141	19
Provides services to pregnant people or families with young children (ages 5 or younger) in King County	**761**	
Yes	427	56
No	334	44
Caregiver or parent & service provider to pregnant people or families with young children in King County?	**761**	
No – Parent only	324	43
Yes – Parent/caregiver & service provider	296	39
No – Provider only	141	19
Setting where service provider respondents work with pregnant people or families with young children [6]	**436**	
Early learning, childcare, or school setting	142	33
Early learning or pre-K provider	79	57
Childcare provider	42	30
Special education provider	21	15
Home-based setting	115	26
Specialty care provider	37	33
Home visiting early learning provider	34	30
Doula	18	16
Home visiting nurse	10	9
Other [7]	14	12
Healthcare setting	148	33
Primary care provider (e.g. Family Practice, Internal Medicine, Pediatrics, OB/GYN)	84	57
Specialty care provider (e.g. Behavioral Health, Infant and Early Childhood Mental Health, PT, OT, Speech and Language Therapy, and Early Support for Infants and Toddlers (ESIT))	50	34
Clinical Social Worker/Mental Health Provider (MHP)	11	7
Other	3	2
Out-of-home-care setting (e.g. foster care)	10	2
Policy/advocacy setting	30	6
Community-based non-profit organization	16	53
Other	14	47

[1] The majority of participants that did not live in King County reported living in Snohomish County (n = 23)

[2] Other includes Algona, Beaux Arts Village, Black Diamond, Bothell, Burien, Carnation, Clyde Hill, Covington, Des Moines, Enumclaw, Hunts Point, Issaquah, Kenmore, Lake Forest Park, Maple Valley, Mercer Island, Newcastle, North Bend, Pacific, Redmond, Sammamish, SeaTac, Skykomish, Snoqualmie, Tukwila, Woodinville, Yarrow Point

[3] Any zip codes where there were less than 10 respondents were marked as other

[4] Among those who said they do not live in King County, 19.4% (n=12) said they are not currently working or are a stay at home caregiver

[5] Other includes Algona, Beaux Arts Village, Black Diamond, Burien, Carnation, Clyde Hill, Covington, Des Moines, Enumclaw, Issaquah, Kenmore, Maple Valley, Mercer Island, North bend, Pacific, Sammamish, SeaTac, Shoreline, Skykomish, Snoqualmie, Tukwila, Woodinville, Yarrow Point

[6] The number of respondents for provider type for each setting do not necessarily add to the total number of individuals who selected the setting as provider type and setting were asked separately

[7] Other includes Children's Administration, parenting class provider, and social worker (outside of Children's Administration)

Table 2: Parent and caregiver survey responses, including service providers

Characteristics & Experiences N=511	n or Median	% or IQR
Relationship to child	**511**	
Biological or adoptive parent	458	90
Grandparent	20	4
Aunt or uncle	10	2
Other [1]	23	5
A provider in their child's life has talked with them about their child's developmental, social/emotional, or behavioral progress	**509**	
Yes	440	86
No	63	12
Don't know	6	1
They or another caregiver completed a questionnaire about their child's development and behavior	**503**	
Yes	308	61
No	186	37
Don't know	9	2
Setting in which the questionnaire was completed [2, 3]	**308**	
Doctor's office	220	71
Childcare/daycare center	78	25
Our Home	72	23
School	67	22
Online	29	9
Other [4]	23	7
Offered the opportunity to complete the questionnaire in another language, if needed [3]	**303**	
Yes	123	41
Don't know	101	33
No	79	26
Challenges experienced filling out the questionnaire [2, 3]	**308**	
None of the provided options	155	50
Fears of my child being labeled	45	15
Understanding what the questionnaire was assessing	41	13
Understanding why my child was being screened	35	11
Cultural relevance of the questionnaire	34	11
Language of the questionnaire	24	8
Other [5]	27	9

Characteristics & Experiences N=511	n or Median	% or IQR
How questionnaire results were communicated to parent [2,3]	**320**	
In person	223	70
By mail	69	22
Over the phone	38	12
Don't know	20	6
Through an online portal/Email	18	6
Not Communicated	16	5
Other	7	2
Parent understood what the results of the questionnaire indicated for their child [3]	**309**	
Yes	274	89
No	35	11
Questionnaire indicated the need for follow-up or further evaluation (i.e. the possibility of a concern) [3]	**310**	
Yes	149	48
No	143	46
Don't know	18	6
Child needed a referral to see any doctors or receive any services after completing this task [3]	**164**	
Yes	122	74
No	37	23
Don't recall	5	3
If yes, did parent/caregiver receive the needed referral	121	
Yes	116	96
If yes, how much of a challenge was it to get the needed referrals	**122**	
Not at all	52	43
Small challenge	49	40
Big challenge	21	17
If anyone helped respondent connect with additional resources or supportive services after the referral was made [3]	**116**	
Yes	71	61
No	34	29
Don't recall	11	10
Individuals involved in connecting child to additional resources or supportive services [2,3]	**71**	
Physician	28	39
Clinical Social Worker/Mental Health Provider/CPS Social Worker	17	24
Physician Assistant	14	20
Care coordinator/navigator	12	17
Nurse Practitioner	11	16
Registered Nurse	10	14
Other [6]	40	56

Characteristics & Experiences N=511	n or Median	% or IQR
Child was connected to services to support their developmental progress [3] (yes) (n=103)	**99**	**96**
Services the child was connected to in order to support their developmental progress [2,3]	**96**	
Birth-to-Three Services with Early Support for Infants and Toddlers	55	57
Feeding support	45	47
Special Education	35	37
Speech and language therapy	35	37
Respite services	25	26
Applied Behavior Analysis (ABA)	22	23
Audiology	22	23
Developmental-Behavioral Pediatrics	17	18
Parent education classes	13	14
Physical therapy	12	13
Children with Special Health Care Needs (CSHCN) program	11	11
Psychology	10	10
Other [7]	41	41
How supported the respondent felt during their child's transition out of Birth-to-Three services [3]	**62**	
Very supported	25	40
Somewhat supported	19	31
Other [8]	18	30
Challenges experienced during the referral process [2, 3]	**110**	
Long wait lists	50	46
Scheduling/time conflicts	35	32
Trust that the system could meet my child's needs	22	20
Cost of services	21	19
Lack of resources available for referral and linkage	20	18
None of the above	18	16
Language of the services available	14	13
Fears of my child being labeled	12	11
Other [9]	29	26
How strongly participant agreed or disagreed that they experienced the following, once they were clear about what their child needed [2]		
I was connected to the services I needed	110	
Strongly agree	38	35
Agree	53	48
Disagree/strongly disagree	17	15
I was connected to the services I needed in a timely manner	110	
Strongly agree	28	26
Agree	46	42
Disagree/strongly disagree	32	29

Characteristics & Experiences N=511	n or Median	% or IQR
I was treated with respect by staff at the supportive services agency	109	
Strongly agree	55	51
Agree	41	38
Disagree/strongly disagree	10	9
I was provided with a translator and/or the translated materials I needed	109	
Strongly agree	14	13
Agree	18	17
Disagree/strongly disagree	9	9
Does not apply	68	62
My needs as a caregiver were supported as a result of the services received	110	
Strongly agree	31	28
Agree	51	46
Disagree/strongly disagree	24	22
I felt that the support I received was culturally appropriate	110	
Strongly agree	31	28
Agree	49	45
Disagree/strongly disagree	14	13
Does not apply	16	15
My child gained new skills or abilities as a result of the services received	110	
Strongly agree	46	41
Agree	41	37
Disagree/strongly disagree	15	14
Questions I had about my child's needs were answered appropriately	109	
Strongly agree	37	34
Agree	56	51
Disagree/strongly disagree	12	11
Whether their child's provider asked them whether their child has EVER experienced any of the following [1, 2]		
Parent or guardian divorced or separated	463	
No	265	57
Yes	125	27
Unsure	73	16
Parent or guardian died	463	
No, the provider did not ask me if my child ever experienced	330	71
Yes, the provider asked me if my child ever experienced	81	18
Unsure if the provider asked me if my child ever experienced	52	11
Parent or guardian served time in jail	463	
No, the provider did not ask me if my child ever experienced	340	73
Yes, the provider asked me if my child ever experienced	63	14
Unsure if the provider asked me if my child ever experienced	60	13

Characteristics & Experiences N=511	n or Median	% or IQR
Saw or heard parents or adults slap, hit, kick, punch one another in the home	464	
No, the provider did not ask me if my child ever experienced	318	69
Yes, the provider asked me if my child ever experienced	80	17
Unsure if the provider asked me if my child ever experienced	66	14
Was a victim of violence or witnessed violence in the neighborhood	464	
No, the provider did not ask me if my child ever experienced	331	71
Yes, the provider asked me if my child ever experienced	84	18
Unsure if the provider asked me if my child experienced	49	11
Lived with anyone who was mentally ill, suicidal, or severely depressed	463	
No, the provider did not ask me if my child ever experienced	317	69
Yes, the provider asked me if my child ever experienced	93	20
Unsure if the provider asked if my child ever experienced	53	11
Lived with anyone who had a problem with alcohol or drugs	462	
No, the provider did not ask me if my child ever experienced	297	64
Yes, the provider asked me if my child ever experienced	109	24
Unsure if the provider asked me if my child ever experienced	56	12
Was treated or judged unfairly because of their race or ethnic group	460	
No, the provider did not ask me if my child ever experienced	340	74
Yes, the provider asked me if my child experienced	63	14
Unsure if the provider asked me if my child ever experienced	57	12
Whether child is of Hispanic, Latino(a)(x), or Spanish origin	**463**	
No, not of Hispanic, Latin(x), or Spanish origin	372	80
Yes, Mexican, Mexican American, Chicano	68	15
Yes, Cuban or Puerto Rican	12	3
Yes, another Hispanic, Latin(x), or Spanish origin (specify)	11	2
Description of child [1]	**506**	
White	370	73
Black or African American	50	10
Multiracial	45	9
Chinese	27	5
Mexican, Mexican American, Chicano	25	5
American Indian or Alaska Native	18	4
Filipino	16	3
Japanese	16	3
Somali	10	2
Other [10]	68	12

Characteristics & Experiences N=511	n or Median	% or IQR
Child's age	**509**	
0-3	303	60
4-5	100	20
6-11	73	14
12+	33	7
Sex recorded at birth on child's original birth certificate	**463**	
Female	237	51
Male	226	49
How child currently identifies	**462**	
Female	225	49
Male	212	46
Other	25	5
Child's primary language	**463**	
English	427	92
Spanish	10	2
Other	31	7
Respondent's Hispanic, Latino(a)(x), or Spanish origin	**546**	
No, not of Hispanic, Latin(x), or Spanish origin	471	86
Yes, Mexican, Mexican American, Chicano	56	10
Yes, another Hispanic, Latin(x), or Spanish origin (specify)	19	3
Description of respondent	**501**	
White	447	75
Black or African American	33	6
Chinese	23	4
Multiracial	22	4
Mexican, Mexican American, Chicano	19	3
Japanese	15	3
American Indian or Alaska Native	14	2
Filipino	12	2
Other [10]	55	11
Respondent age (years)	**36**	**(33-41)**
How respondent currently identifies	**553**	
Female	478	86
Male	69	13
Other	6	1
Respondent sexual orientation	**548**	
Straight	495	90
Bisexual	24	4
Queer	16	3
Lesbian or gay	13	2

Characteristics & Experiences N=511	n or Median	% or IQR
Language spoken most often at home	**469**	
English	431	92
Other	38	8
Total combined family income in the last calendar year, before taxes	**464**	
$150,000 or more	115	25
$100,000 – $149,999	104	22
$75,000 – $99,999	90	19
$50,00 – $74,999	75	16
$35,000 – $49,999	42	9
Less than $35,000	38	8
Rating of the quality of their experiences with knowing where to go to have child screened for developmental progress	**450**	
Poor	52	12
Fair	89	20
Good	124	28
Very good	115	26
Excellent	70	16
Rating of the quality of their experiences with knowing how to follow-up on a referral after child received a developmental screening	**448**	
Poor	48	11
Fair	87	19
Good	114	25
Very good	137	31
Excellent	62	14
Rating of the quality of their experiences with knowing where to go to receive supportive services	**444**	
Poor	65	15
Fair	90	20
Good	113	26
Very good	116	26
Excellent	60	14

[1] Other includes foster parent, other guardian (non-relative), and other relative
[2] Percentages do not add to 100% as participants were asked to select all that apply
[3] Only includes respondents who had experience completing a questionnaire
[4] Other includes Birth to 3, ESIT, and research study
[5] Other includes process not relevant to child circumstance, time/questionnaire length, and unfamiliar jargon
[6] Other includes home visitor, childcare/daycare, teacher, medical assistant, peer support/coach, midwife, doula
[7] Other includes parent-child therapy, occupational therapy, psychiatry, play groups, pediatric neurology, peer support
[8] Other includes not very supported, not at all supported, and not applicable. Categories were grouped together because those who selected not very supported or not at all supported added to less than 10 individuals.
[9] Other includes "understanding why my child was being referred", "cultural relevance of services", and "transportation to services"
[10] Other includes Asian Indian, Korean, Cuban, Puerto Rican, Vietnamese, Ethiopian, Middle Eastern, North African, Samoan, Native Hawaiian

Table 3: **Parent and caregiver survey responses, excluding service providers**

Characteristics & Experiences N=323	n or Median	% or IQR
Relationship to child	**323**	
Biological or adoptive parent	305	94
Other [1]	18	6
A provider in their child's life has talked with them about their child's developmental, social/emotional, or behavioral progress	**320**	
Yes	283	88
No	32	10
Don't know	5	2
They or another caregiver completed a questionnaire about their child's development and behavior	**317**	
Yes	195	62
No	117	37
Don't know	5	2
Setting in which the questionnaire was completed [2, 3]	**195**	
Doctor's office	156	80
Our home	55	28
School	42	22
Childcare/daycare center	36	19
Online	19	10
Other	12	6
Offered the opportunity to complete the questionnaire in another language, if needed [3]	**192**	
Don't know	79	41
Yes	74	39
No	39	20
Challenges experienced filling out the questionnaire [2, 3]	**195**	
None of the provided options	109	56
Understanding what the questionnaire was assessing	33	17
Fears of my child being labeled	27	14
Language of the questionnaire	11	6
Not applicable to child's situation	11	6
Other [4]	28	14
How questionnaire results were communicated to parent [2, 3]	**200**	
In person	155	78
By mail	34	17
Over the phone	17	9
Through an online portal/email	13	7
Not communicated	11	6
Other/don't know	19	10

Characteristics & Experiences **N=323**	**n or Median**	**% or IQR**
Parent understood what the results of the questionnaire indicated for their child [3]	**193**	
Yes	170	88
No	23	12
Questionnaire indicated the need for follow-up or further evaluation (i.e. the possibility of a concern) [3]	**193**	
No	98	51
Yes	84	44
Don't know	11	6
Child needed a referral to see any doctors or receive any services after completing this task [3]	**93**	
Yes	72	77
No/don't recall	21	22
If yes, did parent/caregiver receive the needed referral (yes) (n=71)	70	99
If yes, how much of a challenge was it to get the needed referrals	72	
Not at all	41	60
Small challenge	22	31
Other	9	13
If anyone helped respondent connect with additional resources or supportive services after the referral was made [3]	**70**	
Yes	39	56
No/don't recall	31	44
Individuals involved in connecting child to additional resources or supportive services [2]	**39**	
Physician	17	44
Care coordinator/navigator	10	26
Clinical Social Worker/Mental Health Provider/CPS Social Worker	9	23
Home visitor	9	23
Other [5]	28	72
Child was connected to services to support their developmental progress [3] (yes) (n=58)	**57**	**98**
Services the child was connected to in order to support their developmental progress [2, 3]	**57**	
Birth-to-Three services with Early Support for Infants and Toddlers	38	67
Occupational therapy	30	53
Speech and language therapy	29	51
Special Education	20	35
Physical therapy	18	32
Audiology	15	26
Feeding support	15	26
Applied Behavior Analysis (ABA)	14	25
Other [6]	54	95

Characteristics & Experiences N=323	n or Median	% or IQR
How supported the respondent felt during their child's transition out of Birth to Three services [3]	**38**	
Very supported	20	53
Somewhat/not very/not at all supported	10	26
Not applicable	8	21
Challenges experienced during the referral process [2, 3]	**61**	
Long wait lists	30	49
Scheduling/time conflicts	24	39
Cost of services	17	28
Trust that the system could meet my child's needs	16	26
None of the above	12	20
Lack of resources available for referral and linkage	11	18
Other	19	31
How strongly participants agreed or disagreed that they experienced the following, once they were clear about what their child needed [3]		
I was connected to the services I needed	61	
Strongly agree	24	39
Agree	30	49
Disagree/strongly disagree/does not apply	7	11
I was connected to the services I needed in a timely manner	61	
Strongly agree	15	25
Agree	28	46
Disagree/strongly disagree/does not apply	18	30
I was treated with respect by staff at the supportive services agency	60	
Strongly agree	33	55
Agree	23	38
Disagree/strongly disagree/does not apply	4	7
I was provided with a translator and/or the translated materials I needed	61	
Does not apply	53	87
Other	8	13
My needs as a caregiver were supported as a result of the services received	61	
Strongly agree	15	25
Agree	30	49
Disagree/strongly disagree	12	20
Does not apply	4	7
I felt that the support I received was culturally appropriate	61	
Strongly agree	14	23
Agree	30	49
Disagree/strongly disagree/does not apply	17	28

Characteristics & Experiences N=323	n or Median	% or IQR
My child gained new skills or abilities as a result of the services received	61	
Strongly agree	18	30
Agree	34	57
Disagree/strongly disagree/does not apply	8	13
Questions I had about my child's needs were answered appropriately	60	
Strongly agree	18	30
Agree	34	57
Disagree/strongly disagree/does not apply	8	13
Whether their child's provider asked them whether their child has EVER experienced any of the following [2, 3]		
Parent or guardian divorced or separated	285	
No	173	61
Yes	67	24
Unsure	45	16
Parent or guardian died	286	
No, the provider did not ask me if my child ever experienced	222	78
Yes, the provider asked me if my child ever experienced	40	14
Unsure if the provider asked me if my child ever experienced	24	8
Parent or guardian served time in jail	286	
No, the provider did not ask me if my child ever experienced	228	80
Yes, the provider asked me if my child ever experienced	32	11
Unsure if the provider asked me if my child ever experienced	26	9
Saw or heard parents or adults slap, hit, kick, punch one another in the home	286	
No, the provider did not ask me if my child ever experienced	217	76
Yes, the provider asked me if my child ever experienced	35	12
Unsure if the provider asked me if my child ever experienced	34	12
Was a victim of violence or witnessed violence in the neighborhood	286	
No, the provider did not ask me if my child ever experienced	223	78
Yes, the provider asked me if my child ever experienced	35	12
Unsure if the provider asked me if my child experienced	28	10
Lived with anyone who was mentally ill, suicidal, or severely depressed	285	
No, the provider did not ask me if my child ever experienced	216	76
Yes, the provider asked me if my child ever experienced	37	13
Unsure if the provider asked if my child ever experienced	32	11
Lived with anyone who had a problem with alcohol or drugs	285	
No, the provider did not ask me if my child ever experienced	203	71
Yes, the provider asked me if my child ever experienced	50	18
Unsure if the provider asked me if my child ever experienced	32	11

Characteristics & Experiences N=323	n or Median	% or IQR
Was treated or judged unfairly because of their race or ethnic group	284	
No, the provider did not ask me if my child ever experienced	233	82
Unsure if the provider asked me if my child ever experienced	29	10
Yes, the provider asked me if my child experienced	22	8
Whether child is of Hispanic, Latino(a)(x), or Spanish origin	**282**	
No, not of Hispanic, Latin(x), or Spanish origin	245	87
Yes, Mexican, Mexican American, Chicano	25	9
Yes, another Hispanic, Latin(x), or Spanish origin	12	4
Description of child [2]	**286**	
White	229	80
Black or African American	30	11
Multiracial	29	14
Mexican, Mexican American, Chicano	18	6
Chinese	14	5
Filipino	13	5
Japanese	13	5
American Indian or Alaska Native	10	4
Other [7]	35	12
Child's age	**323**	
0-3	215	67
4-5	53	16
6-11	38	12
12+	17	5
Sex recorded at birth on child's original birth certificate	**285**	
Male	146	51
Female	139	49
How child currently identifies	**283**	
Female	131	46
Male	133	47
I'm not sure/other	19	7
Child's primary language	**284**	
English	270	95
Other	14	5

Characteristics & Experiences N=323	n or Median	% or IQR
Whether respondent is of Hispanic, Latino(a)(x), or Spanish origin	**276**	
No, not of Hispanic, Latin(x), or Spanish origin	253	92
Yes, Mexican, Mexican American, Chicano	14	5
Yes, another Hispanic, Latin(x), or Spanish origin	9	4
Description of respondent [2]	**282**	
White	224	79
Black or African American	18	6
Multiracial	14	5
Chinese	11	4
Japanese	10	4
Other [8]	47	17
Respondent age (years)	**36**	**(33-40)**
How respondent currently identifies	**280**	
Female	261	93
Male	16	6
Other	3	1
Respondent sexual orientation	**278**	
Straight	251	90
Bisexual	13	5
Other	14	5
Language spoken most often at home	**278**	
English	264	95
Other	14	5
Total combined family income in the last calendar year, before taxes	**277**	
$150,000 or more	76	27
$100,000 – $149,999	74	27
$75,000 – $99,999	46	17
$50,00 – $74,999	39	14
$35,000 – $49,999	14	5
Less than $35,000	28	10
Rate of the quality of their experiences with knowing where to go to have child screened for developmental progress	**267**	
Poor	47	18
Fair	62	23
Good	70	26
Very good	54	20
Excellent	34	13

Characteristics & Experiences N=323	n or Median	% or IQR
Rate of the quality of their experiences with knowing how to follow-up on a referral after child received a developmental screening	**265**	
Poor	35	13
Fair	66	25
Good	72	27
Very good	69	26
Excellent	23	9
Rate of the quality of their experiences with knowing where to go to receive supportive services	**264**	
Poor	54	21
Fair	65	25
Good	69	26
Very good	51	19
Excellent	25	10

[1] Other includes grandparents, foster parents, other relatives and guardians

[2] Percentages do not add to 100% as participants were asked to select all that apply

[3] Only includes respondents who had experience completing a questionnaire

[4] Other includes cultural relevance of the questionnaire, understanding why the child was being screened, jargon, and time/questionnaire length

[5] Other includes clinical social worker/mental health provider/cps social worker, home visitor, childcare/daycare center, physician assistant, and nurses

[6] Other includes developmental-behavioral pediatrics, play groups, respite services, pediatric neurology, parent-child therapy, psychology, psychiatry, parent education classes and peer support

[7] Other includes Asian Indian, Korean, Cuban, Puerto Rican, Vietnamese, Middle Eastern, North African, Ethiopian, Somali, Native Hawaiian, Samoan

[8] Other includes Mexican, Mexican American, Chicano, Filipino, Vietnamese, American Indian, Alaska Native, Asian Indian, Korean, Cuban, Puerto Rican, Middle Eastern, North African, Somali, Kenyan

Table 4: Provider participant demographics

Characteristics & Experiences N=318	n or Median	% or IQR
Whether provider is of Hispanic, Latino(a)(x), or Spanish origin	**270**	
No, not of Hispanic, Latin(x), or Spanish origin	218	81
Yes, Mexican, Mexican American, Chicano	42	16
Yes, another Hispanic, Latin(x), or Spanish origin (specify)	10	4
Description of provider [1]	**318**	
White	223	70
Black or African American	15	5
Chinese	12	4
American Indian or Alaska Native	10	3
Mexican, Mexican American, Chicano	10	3
Other [2]	46	14
Provider age (years)	36	(32-45)
How provider currently identifies	**273**	
Female	217	80
Male	53	19
Other	3	1
Provider sexual orientation	**270**	
Straight	244	90
Bisexual	11	4
Other	15	6
Language spoken most often at home	**191**	
English	167	87
Other	24	13
Total combined family income in the last calendar year, before taxes	**187**	
$75,000 – $99,999	44	24
$150,000 or more	39	21
$50,00 – $74,999	36	19
$100,000 – $149,999	30	16
$35,000 – $49,999	28	15
Less than $35,000	10	6

[1] Percentages do not add to 100% as participants were asked to select all that apply

[2] Other includes Multiracial, Somali, Japanese, Filipino, Asian Indian, Kenyan, Cuban, Puerto Rican, Ethiopian, Native Hawaiian, Samoan, Vietnamese, Korean, Middle Eastern, North African

Table 5: Primary care provider survey responses

Characteristics & Experiences N=94	n or Median	% or IQR
Healthcare provider type	**94**	
Physician	62	66
Other [1]	32	34
Healthcare specialty	**62**	
Pediatrics	42	68
Family Medicine	19	31
Person who conducts developmental surveillance most often at site	**94**	
Physician	63	67
Other [2]	31	33
Site use of a validated or evidence-based screening tool(s) to screen children for developmental progress	**94**	
Yes	70	75
No	15	16
Don't know	9	10
Site use of an adapted validated or evidence-based screening tool(s) to screen children for developmental progress [3]	**15**	
No	10	67
Yes	5	33
How often site uses a screening tool(s) to screen children for developmental progress [4]	**84**	
Routinely at specific age intervals	66	79
Only when there is a concern	12	14
Don't know	6	7
Approximate % of children screened by provider or their staff with a standardized tool during each of the following well-child visit:	**41**	
6 months	75	(15-100)
9 months	95	(46-100)
12 months	85	(31-100)
18 months	95	(80-100)
24 months	95	(75-100)
30 months	75	(25-100)
36 months	90	(43-100)
48 months	90	(41-100)
60 months	90	(40-100)
Screening tools administered to identify children age 0 to 5 at-risk for developmental, social-emotional, or behavioral delays [4, 5]	**74**	
Modified Checklist for Autism in Toddlers (M-CHAT)	49	66
Ages and Stages Questionnaire (ASQ-3)	44	60
Ages and Stages Questionnaire Social and Emotional (ASQ-SE)	15	20
Other [6]	43	58

Characteristics & Experiences N=94	n or Median	% or IQR
Languages respondent's site offers developmental screening questionnaires [4, 5]	**73**	
English	65	88
Spanish	34	46
Other	14	19
Languages respondent's site offers developmental screening interpretative services [4, 5]	**74**	
English	45	61
Spanish	42	57
Vietnamese	28	38
Somali	27	27
Chinese	26	35
Russian	22	30
Ukrainian	17	23
Don't know	11	15
Other	19	26
When developmental screening tools are administered [4, 5]	**70**	
During the well-child visit	43	61
While waiting for the well-child visit to begin	29	56
Before the day of the well-child visit	16	23
Other	14	20
How developmental screening tools are administered at site [4, 5]	**70**	
Parents complete a paper-based questionnaire	52	74
Questions are asked of parents orally	46	66
Clinicians conduct observation	42	60
Other	9	13
How staff were trained to administer the developmental screening tool(s) at site [4, 5]	**70**	
Residency or clinical training	33	47
Self-taught	26	37
Attended a training	18	26
In-service training	12	17
Not trained	10	14
Don't know/other	13	18
Person who is primarily responsible for the interpretation of developmental screening results at site [4]	**70**	
Physician	56	80
Other	14	20

Characteristics & Experiences N=94	n or Median	% or IQR
How site documents results of each developmental screen [4, 5]	**69**	
We record that a screening was completed in the child's health record	48	70
We scan and attach the completed tool and/or summary sheet to the child's health record	40	58
We enter the summary score into the child's health record	38	55
We enter each domain score into the child's health record	26	38
Don't know/other	5	7
How screening results are communicated to a child's caregiver/parent (When there is a concern) [4, 5]	**69**	
We discuss the results with the caregiver/parent in-person	61	88
We notify the caregiver/parent by phone	12	17
We mail a letter to the caregiver/parent	10	15
Other	15	22
How screening results are communicated to a child's caregiver/parent (When the child is on track) [4, 5]	**69**	
We discuss the results with the caregiver/parent in-person	60	87
Other [7]	28	41
Approximate % of children age 0-5 that provider has referred for further assessment when a developmental, social-emotional, or behavioral concern was identified through developmental screening (n=59) [4]	**50**	**(20-90)**
When a child's developmental screen indicates a potential delay, how often the provider does the following [4]		
Discusses next steps and results with the child's caregiver/parent(s)	60	
Every time	48	80
Other	12	20
Informs the caregiver/parent(s) about the potential concern(s)	60	
Every time	53	88
Other	7	12
Makes a note in the child's record to re-screen at the next visit	60	
Every time	35	58
Almost every time	16	27
Other	9	16
Provides the caregiver/parent(s) with some activities they can do with their child	60	
Every time	23	38
Almost every time	20	33
Other	17	29
Refers the caregiver/parent(s) to resources to address the potential concern(s)	60	
Every time	34	57
Almost every time	19	32
Other	7	12

Characteristics & Experiences N=94	n or Median	% or IQR
Refers the caregiver/parent(s) to parenting classes/support	60	
Some of the time	28	47
Almost never/never	23	38
Other	9	16
Refers the child to a clinical specialist for further assessment	59	
Every time	16	27
Almost every time	20	34
Some of the time	19	32
Other	4	7
Refers the child to speech or audiology	60	
Every time	12	20
Almost every time	17	28
Some of the time	28	47
Other	3	5
Refers the caregiver/parent(s) to other supports for connection to services, such as Help Me Grow	57	
Every time/almost every time	12	21
Some of the time	16	28
Almost never	15	26
Never	13	23
Does not apply	1	2
Refers the child to Early Intervention (i.e. Early Support for Infants and Toddlers)	60	
Every time	16	27
Almost every time	23	38
Some of the time	14	23
Other	7	12
Refers the child to their school district's special education services	60	
Every time	14	23
Almost every time	19	32
Some of the time	24	40
Other	3	5
Refers the caregiver/parent(s) to a Family Resources Coordinator	60	
Some of the time	14	23
Almost never	13	22
Never	21	35
Other	12	20
Provider's level of agreement with the following statements regarding developmental screening of children age 0-5 [4]		
I have the clinical expertise to identify most children with developmental delays in my site setting without the use of a formal screening instrument	68	
Strongly agree/agree	42	62
Strongly disagree/disagree	26	38

Characteristics & Experiences N=94	n or Median	% or IQR
It is important to use a validated or evidence-based screening tool at the recommended intervals	67	
Strongly agree	49	73
Agree	17	25
Other	1	2
Using a validated or evidence-based tool makes it easier to identify developmental delays	67	
Strongly agree	49	73
Agree	17	25
Other	1	2
During a typical well-care visit, there is adequate time to perform developmental screening	68	
Strongly agree	11	16
Agree	28	41
Strongly disagree/disagree	29	42
Once I identify developmental delays in a child, I feel confident in how to care for the child, including managing consultations for referrals for therapy and/or further assessment	68	
Strongly agree	24	35
Agree	28	41
Strongly disagree/disagree	16	24
Reimbursement for well-child visits is sufficient to cover time spent on developmental screening	67	
Strongly agree/agree	27	41
Disagree	28	42
Strongly disagree	12	18
There are sufficient resources in my community to provide services to children with developmental problems	67	
Strongly agree/agree	39	58
Strongly disagree/disagree	28	42
Communication between organizations that support children with developmental problems in my community is sufficiently coordinated	68	
Strongly agree/agree	26	38
Strongly disagree/disagree	42	62
Providers' level of agreement that the following are barriers to screening children for developmental delays [4]		
Lack of time to perform developmental screenings during a typical well-care visit	67	
Strongly agree	22	33
Agree	29	43
Disagree	16	24
Insufficient staffing	69	
Strongly agree	16	23
Agree	29	42
Strongly disagree/disagree	24	35

Characteristics & Experiences N=94	n or Median	% or IQR
Lack of EHR integration	67	
Strongly agree	20	30
Agree	29	43
Strongly disagree/disagree	18	27
Lack of resources	67	
Strongly agree	14	21
Agree	33	49
Disagree	20	30
Lack of interpretative services	68	
Strongly agree	16	24
Agree	28	41
Strongly disagree/disagree	24	35
Caregiver/parent literacy	68	
Strongly agree	15	22
Agree	30	44
Strongly disagree/disagree	23	34
Caregiver/parent health literacy	68	
Strongly agree	16	24
Agree	33	49
Strongly disagree/disagree	19	29
Validity of screening tools	66	
Strongly agree/agree	19	29
Strongly disagree/disagree	47	71
Lack of training on how to administer the tool	68	
Strongly agree/agree	33	49
Strongly disagree/disagree	35	51
Lack of training on how to interpret the results	68	
Strongly agree/agree	31	45
Strongly disagree/disagree	37	55
Cultural and linguistic relevance of tools	68	
Strongly agree	27	40
Agree	30	44
Strongly disagree/disagree	11	16
Insufficient reimbursement	66	
Strongly agree	12	18
Agree	33	50
Disagree	18	27
Uncertainty of resources available for referral/linkage	68	
Strongly agree	12	18
Agree	34	50
Disagree	22	32

Characteristics & Experiences N=94	n or Median	% or IQR
Lack of available programs to refer children with developmental and social-emotional/behavior problems	68	
Strongly agree	15	22
Agree	35	52
Disagree	18	27
Appointment scheduling constraints	67	
Strongly agree	14	21
Agree	31	46
Strongly disagree/disagree	22	33
Whether provider knows when their patient has been connected with recommended services and supports [4]	**56**	
No	31	55
Yes	21	38
Don't know	4	7
Process for following up on patient referrals for developmental, social-emotional, or behavioral concerns [4, 5]	**56**	
Contacting patients to schedule referral appointments	22	39
Contacting referral agencies/providers to coordinate scheduling of patient referral appointments	21	38
Sharing educational materials with patients	20	36
No established process	15	27
Using referral reports for internal accountability	14	25
Using appointment notifications	12	21
Other	3	5
Person who is primarily responsible for following up with the patient's caregiver/parent at site [4]	**56**	
Physician	26	46
No established responsibility for follow-up	10	18
Other	20	36
How provider engages the community in developmental screening [4, 5]	**55**	
Recommends developmental screening during appointments	40	73
Shares educational materials with parents/caregivers during appointments	32	58
Utilizes translators during appointments for non-English speakers	31	56
Displays developmental screening educational materials in office/waiting room	14	26
Translates educational materials for non-English speakers	11	20
Participates as a member in community groups	10	18
Other	12	22
Site screening for maternal depression	**67**	
Yes	50	75
No	15	22
Don't know	2	3

Characteristics & Experiences N=94	n or Median	% or IQR
Tool(s) site uses to screen for maternal depression [5]	**50**	
Edinburgh Postnatal Depression Screen (EPDS)	43	86
Patient Health Questionaire-9 (PHQ-9)	20	40
Patient Health Questionnair-2 (PHQ-2)	18	36
Generalized Anxiety Disorder Scale (GAD-7)	17	34
Other	1	2
Approximate % of caregivers screened for maternal depression at the following visits	**15**	
Prenatal visit	60	(20-75)
Second trimester visit	50	(37-74)
Third trimester visit	55	(35-83)
First postpartum visit	90	(55-100)
3-month pediatric visit	80	(50-100)
9-month pediatric visit	50	(25-90)
12-month pediatric visit	43	(10-80)
Whether provider asks caregivers if their child has EVER experienced any of the following		
Parent or guardian divorced or separated	67	
Yes	29	58
No	24	36
Don’t know	4	6
Parent or guardian died	67	
No	36	54
Yes	27	40
Don’t know	4	6
Parent or guardian served time in jail	64	
No	45	70
Yes	15	23
Don’t know	4	6
Saw or heard parents or adults slap, hit, kick, punch one another in the home	66	
No	46	70
Yes	17	26
Don’t know	3	5
Was a victim of violence or witnessed violence in the neighborhood	66	
No	48	73
Yes	15	23
Don’t know	3	5
Lived with anyone who was mentally ill, suicidal, or severely depressed	67	
No	41	61
Yes	24	36
Don’t know	2	3

Characteristics & Experiences N=94	n or Median	% or IQR
Lived with anyone who had a problem with alcohol or drugs	67	
No	37	55
Yes	28	42
Don't know	2	3
Was treated or judged unfairly because of their race or ethnic group	65	
No	47	72
Yes	14	22
Don't know	4	6
Site use of a specific tool to screen for Adverse Childhood Experiences (ACEs)	**67**	
No	56	84
Yes [8]	9	13
Don't know	2	3
Frequency that provider shares information about a child's development with a child's supportive services providers	**64**	
Never/rarely	19	29
Sometimes	30	47
Often/always	15	23
Frequency that provider shares information about a child's development with a child's early learning/childcare providers	**64**	
Never/rarely	20	31
Sometimes	33	52
Often/always	11	17

[1] Other includes clinical social worker/mental health provider, physician assistant, nurse, dentist, dietician, administrative professional, and naturopathic doctor

[2] Other includes clinical social worker/mental health provider, physician assistant, nurse, no developmental screening takes place, and multiple provider types involved in screenings

[3] Only asked if reported that site is not using a validated or evidence-based screening tool(s) to screen children for developmental progress

[4] Only asked among those who reported using a validated or evidence-based screening tool(s) to screen children for developmental progress

[5] Percentages do not add to 100% as participants were asked to select all that apply

[6] Other includes Survey of Wellbeing of Young Children, Early Screening Profiles, Learning Accomplishment Profile — Diagnostic Screens (LAP-D), ASQ-9, Capute Scales, Eyberg Child Behavior Inventory (ECBI), and Edinburgh Postnatal Depression Scale, Kaiser Specific Screening Tool, Modified Checklist for Autism in Toddlers Revised (MCHAT-R)

[7] Other includes "We notify the caregiver/parent by email or online patient portal," "We notify the caregiver/parent by phone," "We mail a letter to the caregiver/parent," and "Don't know"

[8] Types of tools used include Adverse Childhood Experiences (ACE) Questionnaire and Child and Adolescent Trauma Screen (CATS). Respondents screen children at varied points in time

Table 6: Specialist survey responses

Characteristics & experiences N=51	n or Median	% or IQR
Primary clients who respondents are working with for developmental delays/ concerns?	**51**	
Parents/caregivers and children together	37	73
Other	14	27
How respondents serve pregnant people or families with young children	**51**	
Individual (child or family)	40	78
Other	11	22
Format of respondents' service or program?	**50**	
On-going basis	26	52
A series of sessions	15	30
Other	9	18
Frequency that clients receive the service	**50**	
Weekly	15	30
Varies based on client	13	26
Other [1]	22	44
Setting in which services are delivered [2]	**45**	
Clinic	21	47
Hospital	14	31
Family's home	11	24
At our agency	10	22
Other	16	36
Secondary area(s) targeted through respondent's service [2, 3]	**47**	
Parent knowledge of child's development	20	43
Emotional or self-regulation	16	34
Family support (e.g. systems navigation, cultural, and linguistic support)	14	30
Social or play skills	14	30
Attachment/relationships	13	28
Speech and language skills	11	23
Adaptive skills	10	21
Other [4]	33	70
How children and families are typically referred to respondent's service [2]	**46**	
Healthcare provider	39	85
Self-referrals	20	44
Other families/word of mouth	19	41
Early learning provider	15	33
Schools	12	26
Childcare provider	11	24
Other [5]	17	37

Characteristics & experiences N=51	n or Median	% or IQR
Criteria used to determine eligibility for respondent's specialty service [2]	**46**	
Diagnosed condition	17	37
None - any family can access our services	14	30
Informed clinical opinion	13	28
Percentage of delay determined by further assessment/evaluation	12	26
Other [6]	20	43
How service providers at the agency tailor or match services to a child or family's particular level of developmental, behavioral, or social/emotional need [2]	**46**	
Services are provided on an individualized basis by a specialist and are tailored accordingly	27	59
Services are intended to meet varying needs of children, but not formal matching system is used	17	37
Other [7]	18	39
Specific population(s) in which respondent services focus [2]	**41**	
Families with children with special health care needs	22	54
Families experiencing homelessness	12	29
Foster and adoptive families	12	29
Low-income families	10	24
Other [8]	39	95
Language(s) in which services are delivered [2]	**41**	
English	34	83
Interpreters available for other languages upon request	26	63
Spanish	16	39
Russian	10	7
Other	12	29
How respondents deliver culturally and linguistically appropriate services [2]	**41**	
Contract with interpretative services	31	76
Employ bilingual or multilingual staff	20	49
Employ staff from the cultural groups that we serve	16	39
Other	6	15
Level of agreement that the following are barriers to providing quality services to their clients:		
Lack of time to perform developmental screenings	37	
Strongly agree/agree	18	49
Strongly disagree/disagree	19	51
Insufficient staffing	39	
Strongly agree/agree	28	72
Strongly disagree/disagree	11	28
Lack of EHR integration	37	
Strongly agree/agree	16	43
Strongly disagree/disagree	21	57

Characteristics & experiences N=51	n or Median	% or IQR
Lack of resources	39	
Strongly agree/agree	25	64
Strongly disagree/disagree	14	36
Lack of interpretative services	39	
Strongly agree/agree	14	36
Strongly disagree/disagree	25	64
Caregiver/parent literacy	40	
Strongly agree/agree	23	57
Strongly disagree/disagree	17	43
Caregiver/parent health literacy	40	
Strongly agree/agree	26	65
Strongly disagree/disagree	14	35
Validity of screening tools	38	
Strongly disagree/disagree	29	76
Other	9	24
Lack of training on how to administer the tool	39	
Strongly disagree/disagree	30	77
Other	9	23
Lack of training on how to interpret the results	39	
Strongly agree/agree	11	28
Strongly disagree/disagree	28	72
Cultural and linguistic relevance of the tools	39	
Strongly agree/agree	23	59
Strongly disagree/disagree	16	41
Insufficient reimbursement	39	
Strongly agree	14	36
Agree	17	44
Other	8	20
Appointment scheduling constraints	38	
Strongly agree	12	32
Agree	13	34
Strongly disagree/disagree	13	34
Whether staff providing the service to families and children with developmental delays or social-emotional/behavioral concerns have on-going training or professional development opportunities	**41**	
Yes	31	76
No/unsure	10	24
Person who conducts developmental surveillance most often at site[2]	**41**	
Clinical Social Worker/Mental Health Provider	14	34
Child Development Specialist	12	29
Other [9]	61	---

Characteristics & experiences N=51	n or Median	% or IQR
Site use of a validated or evidence-based screening tool(s) to screen children for developmental progress	**38**	
Yes [10]	23	61
No/don't know	15	39
Developmental screening tools administered through respondent services [2, 6]	**21**	
Ages and Stages Questionnaire Social and Emotional (ASQ-SE)	10	48
Other [11]	31	---
Approximate % of children screened with a standardized developmental screening tool during each of the following supportive service visits: [12]	**11**	
6-months	5	(5-50)
9-months	28	(5-69)
12-months	30	(5-80)
18-months	25	(5-55)
24-months	45	(5-85)
30-months	35	(5-75)
36-months	68	(9-91)
48-months	58	(13-96)
60-months	70	(16-96)
Languages in which site offers developmental screening [2, 12]	**21**	
English	13	62
Other	13	62
How respondents engage the community in developmental screening [2, 12]	**21**	
Share educational materials with parents/caregivers during appointments	10	48
Other [13]	38	181
Frequency in which respondents share information about a child's development with a child's primary care provider	**31**	
Often/always	20	65
Never/rarely/sometimes	11	35
Frequency in which respondents share information about a child's development with a child's early learning/childcare providers	**29**	
Never/rarely/sometimes	19	66
Often/always	10	34
Frequency in which respondents share information about a child's development with a child's other supportive services provider	**30**	
Never/rarely/sometimes	14	47
Often/always	16	53

[1] Other includes monthly, once at diagnosis, daily, and twice a month

[2] Percentages do not add to 100% as participants were asked to select all that apply

[3] Due to sample sizes less than ten in every category, responses regarding the primary areas targeted through respondent services were redacted

[4] Other includes cognitive development, fine motor skills, gross motor skills, and infants exposed to drugs/alcohol, and multiple areas at the same time

[5] Other includes "From our own agency," "Help Me Grow/WithinReach/ParentHelp123," and "Don't know"

[6] Other includes geographic location, income, and others

[7] Other includes "curriculum is adjusted based on needs of the child," and "small group sizes are designed to accommodate varying needs of clients"

[8] Other includes: Families experiencing domestic violence, immigrant or refugee families, single-parent families, families of color, LGBTQ families, families who are a part of tribal groups, linguistic and spiritual communities

[9] Other includes Occupational Therapist, Registered Nurse, Speech and Hearing Pathologist, Educator, Family Resource Coordinator, Intake Staff, Social Worker, Nurse Practitioner, and others

[10] Developmental screening tools were delivered in a variety of ways. Due to small sample sizes, data regarding how tools are delivered was redacted

[11] Other includes Ages and Stages Questionnaire (ASQ-3), Modified Checklist for Autism in Toddlers (M-CHAT), Developmental Assessment of Young Children (DAYC-2), Achenbach Child Behavior Checklist, Children Adolescents Needs Strengths (CANS), Function Emotional Assessment Scale, Behavior Assessment System for Children (BASC), Bayley Scales of Infant and Toddler Development, NICHQ Vanderbilt Assessment Scales

[12] Among respondents who reported using a validated or evidence-based screening tool(s) to screen children for developmental progress

[13] Other includes "utilize translators during appointments for non-English speakers," "display developmental screening educational materials in office/waiting," "participate at a community events/health fairs," "recommend developmental screening during appointments"

Table 7: Early learning and childcare provider survey responses

Characteristics & Experiences N=138	n or Median	% or IQR
Site screening of children age 0-5 for developmental, behavioral, or social-emotional concerns	**138**	
Yes, routinely at specific age intervals	81	59
Yes, but only when there is a concern	34	25
No/don't know	23	17
Site use of a validated or evidence-based screening tool(s) to screen children for developmental progress	**118**	
Yes	88	75
No	16	14
Don't know	14	12
Screening tools administered to identify children age 0 to 5 at-risk for developmental, social-emotional, or behavioral delays [1, 2]	**102**	
Ages and Stages Questionnaire (ASQ-3)	58	57
Ages and Stages Questionnaire Social and Emotional (ASQ-SE)	40	39
Modified Checklist for Autism in Toddlers (M-CHAT)	21	21
Developmental Assessment of Young Children (DAYC-2)	14	14
Learning Accomplishment Profile = Diagnostic Screens (LAP-D)	11	11
Don't know	10	10
Other [3]	47	46
When developmental screening tools are administered at site [2]	**95**	
Before arriving on site	27	28
While waiting for the care or visit to begin	23	24
During care or visit	52	55
Other [1]	14	15
Approximate % of children screened by staff with a standardized tool at: [2]	**78**	
3 months	88	(50-100)
6 months	75	(40-95)

Characteristics & Experiences N=138	n or Median	% or IQR
How developmental screening tools are administered at site [1, 2]	**95**	
Questions are asked of parents orally	57	60
Professionals conduct observation	55	58
Parents complete a paper-based questionnaire	50	53
Parents complete an electronic questionnaire	12	13
Other	7	7
How respondents were trained to administer screening tool(s) [2]	**90**	
Attended a training, but no continuing education credits were offered	33	37
Attended a training that offered continuing education credits	19	21
In-service training	18	20
Other [4]	20	22
How respondents were trained to interpret screening results [2]	**90**	
Attended a training, but no continuing education credits were offered	27	30
Attended a training that offered continuing education credits	24	27
In-service training	15	17
Other [4]	24	27
How respondents or their colleagues record the results of each developmental, behavioral, or social-emotional screening [1, 2]	**93**	
We keep a hard copy of the results on file	49	53
We record that a screening was completed on the child's record in our program database	44	47
We enter the summary score into the child's record in our program database	29	31
We enter each domain score into the child's record in our program database	27	29
We record the screening results in a screening-specific databased (e.g. ASQ Online)	13	14
We scan and attach the completed tool and/or summary sheet to the child's record in our program database	11	12
Other	9	10
How screening results are communicated to the child's caregiver/parent (When there is a concern) [1, 2]	**87**	
We discuss the results with the caregiver/parent in-person	62	71
We notify the caregiver/parent by phone	22	25
We mail a letter to the caregiver/parent	18	21
We do not notify the caregiver/parent of the screening results	14	16
Don't know	9	10
How screening results are communicated to the child's caregiver/parent (When the child is on track) [1, 2]	**87**	
We discuss the results with the caregiver/parent in-person	59	68
We mail a letter to the caregiver/parent	33	38
We notify the caregiver/parent by phone	17	20
Don't know	14	16
We do not notify the caregiver/parent of the screening results	12	14

Characteristics & Experiences N=138	n or Median	% or IQR
Level of comfort discussing screening results with a child's caregiver/parent when screening indicates a potential concern [2]	**79**	
Very comfortable	35	44
Somewhat comfortable	33	42
Somewhat/very uncomfortable	11	14
Steps respondents routinely take to connect a child/family to supportive services [1]	**87**	
Inform the parents about the potential concern(s)	57	66
Discuss next steps and results with the child's caregiver/parent(s)	55	63
Refer the child to a clinical specialist for further assessment	40	46
Refer the child to speech and audiology services	38	44
Refer the child to their school district's special education services	37	43
Refer the child to Early Intervention (i.e. Early Support for Infants and Toddlers)	35	40
Refer the caregiver/parent to parenting classes/support	31	36
Refer the caregiver/parent to other supports for connection to services, such as Help Me Grow	22	25
Other	4	5
How respondents engage the community in developmental screening [1, 2]	**87**	
Share educational materials with parents/caregivers	53	61
Recommend developmental screening to parents	39	45
Display developmental screening educational materials	32	37
Utilize translators during screenings for non-English speakers	32	37
Participate as a member in community groups	19	22
Participate at community events/health fairs	15	17
Other	5	5
How often respondents experience hesitance to complete developmental screening from the families they work with [2]	**80**	
Never	10	13
Rarely	22	28
Occasionally	40	50
Other	8	10
Factors that support the screening process when parents/caregivers are hesitant about developmental screening [2]	**78**	
Conversations about developmental screening	58	74
Providing written information about developmental screening	17	22
Other	3	4
Frequency that respondents share information about a child's development with the child's primary care provider	**107**	
Never	13	12
Rarely	18	17
Sometimes	29	27
Often	32	30
Very often	15	14

Characteristics & Experiences N=138	n or Median	% or IQR
Frequency that respondents share information about a child's development with the child's supportive services provider	**105**	
Never/rarely	16	16
Sometimes	33	31
Often	38	36
Very often	18	17

[1] Percentages do not add to 100% as participants were asked to select all that apply

[2] Among respondents who reported using a validated or evidence-based screening tool(s) to screen children for developmental progress

[3] Other includes Devereux Early Childhood Assessment, Early Screening Profiles, Parents Evaluation of Developmental Status – Developmental Milestones (PEDS-DM), Brigance Screens, Infant Development (IDI), Hawaii Early Learning Profile (HELP), and others

[4] Other includes: Self-taught, formal education, and not trained

Table 8: Home-Based Provider Survey Responses

Characteristics & Experiences N=109	n or Median	% or IQR
# of times per month respondent typically sees the families they work with	3	(2-4)
Site screening of children age 0-5 for developmental, behavioral, or social-emotional concerns	**109**	
Yes	82	75
No/don't know	27	25
When screenings among children age 0-5 for developmental, behavioral, or social-emotional concerns are administered [1]	**83**	
Toward the beginning of services	46	55
Routinely at specific age intervals	40	48
When there is a concern	29	35
Toward the end of services	20	24
Use of a validated or evidence-based screening tool(s) to screen for developmental progress?	**81**	
Yes	70	86
No/don't know	11	13
Screening tools administered to identify children age 0 to 5 at-risk for developmental, social-emotional, or behavioral delays [1, 2]	**71**	
Ages and Stages Questionnaire (ASQ-3)	35	49
Ages and Stages Questionnaire Social and Emotional (ASQ-SE)	23	32
Modified Checklist for Autism in Toddlers (M-CHAT)	23	32
Developmental Assessment of Young Children (DAYC-2)	19	27
Devereux Early Childhood Assessment	14	20
Other [3]	28	39
When developmental screening tools are administered [1, 2]	**68**	
During the visit	55	81
Before the day of the visit	14	21
Other	4	6

Characteristics & Experiences N=109	n or Median	% or IQR
Approximate % of children in caseload who are screened with a standardized tool...[2]	**48**	
Within 3 months of program entry	80	(45-100)
Within 6 months of program entry	65	(50-85)
At 4 months	75	(50-100)
At 6 months	75	(25-100)
At 12 months	75	(50-100)
At 18 months	85	(59-100)
At 24 months	90	(66-100)
How developmental screening tools are administered [1, 2]	**68**	
Questions are asked of parents orally	60	88
Home visit provider conducts observation	54	79
Parents complete a paper-based questionnaire	23	34
Other	5	8
How respondents were trained to administer screening tool(s) [2]	**66**	
In-service training	24	36
Attended a training, but no continuing education credits were offered	23	35
Attended a training that offered continuing education credits	12	18
Other	7	11
How respondents were trained to interpret screening results [2]	**66**	
In-service training	23	35
Attended a training, but no continuing education credits were offered	21	32
Attended a training that offered continuing education credits	13	20
Other	9	14
How results of each developmental, behavioral, or social-emotional screening are recorded [1, 2]	**67**	
We keep a hard copy of the results on file	45	67
We enter each domain score into the child's record in our program database	41	61
We record that the screening was completed on the child's record in our program database	41	61
We enter the summary score into the child's record in our program database	33	49
We record the screening results in a screening-specific database (e.g. ASQ Online)	10	15
Other	5	8
How often respondents experience hesitance to complete developmental screening from the families they work with [2]	**64**	
Never	20	31
Rarely	22	34
Occasionally	17	27
Other	5	8

Characteristics & Experiences N=109	n or Median	% or IQR
Factors that support the screening process when parents/caregivers are hesitant about developmental screening [2]	**62**	
Conversations about developmental screening	52	84
Other	10	16
How screening results are communicated to the child's caregiver/parent (For children that are on track) [1, 2]	**64**	
We discuss the results with the caregiver/parent in-person	53	83
We mail a letter to the caregiver/parent	18	28
We notify the caregiver/parent by phone	11	17
Other	9	14
How screening results are communicated to the child's caregiver/parent (When screening results indicate a concern) [1, 2]	**64**	
We discuss the results with the caregiver/parent in-person	49	77
We notify the caregiver/parent by phone	13	20
We mail a letter to the caregiver/parent	11	17
Other	5	8
Level of comfort discussing screening results with the child's caregiver/parent when screening indicates a potential concern [2]	**63**	
Very comfortable	33	52
Somewhat comfortable	21	33
Other	9	14
Approximate % of families in caseload who follow up on referrals [2]	**70**	**(44-80)**
Steps respondents routinely take to connect the child/family to supportive services [1]	**64**	
Inform the parents about the potential concern(s)	45	70
Refer the caregiver/parent to resources to address the potential concern(s)	44	69
Discuss next steps and results with the child's caregiver/parent(s)	43	67
Refer the child to Early Intervention (i.e. Early Support for Infants and Toddlers)	34	53
Refer the child to speech and audiology services	30	47
Support the caregiver/parent in in being a self-advocate (ex: making calls together)	27	42
Refer the child to a clinical specialist for further assessment	26	41
Refer the caregiver/parent to parenting classes/support	21	33
Refer the child to their school district's special education services	21	33
Refer the caregiver/parent to other supports for connection to services, such as Help Me Grow/WithinReach/ParentHelp123	18	28
Other	1	2
How respondents engage the community in developmental screening [1, 2]	**64**	
Participate at community events/health fairs	19	30
Participate as a member in community groups	14	22
Share educational materials with parents/caregivers	47	73
Utilize translators during screenings for non-English families	29	45
Other	4	7

Characteristics & Experiences N=109	n or Median	% or IQR
Frequency that respondents share information about a child's development with a child's primary care provider	**95**	
Never	11	12
Rarely	12	13
Sometimes	26	27
Often	22	23
Always	24	25
Frequency that respondents share information about a child's development with a child's supportive services providers	**90**	
Never	11	12
Rarely	10	11
Sometimes	29	32
Often/always	40	44
Frequency that respondents share information about a child's development with a child's early learning/childcare providers	**91**	
Never	14	15
Rarely	10	11
Sometimes	29	32
Often/always	40	44

[1] Percentages do not add to 100% as participants were asked to select all that apply

[2] Among respondents who reported using a validated or evidence-based screening tool(s) to screen children for developmental progress

[3] Other includes Bayley Scales of Infant Toddler Development, Learning Accomplishment Profile — Diagnostic Screens (LAP-D), Early Screening Profiles, Hawaii Early Learning Profile (HELP), Infant Development (IDI), and others

Table 9: Policymaker and Children's Administration Survey Responses

Characteristics & experiences N=34	n	%
Rate of the quality of coordination between health care, early learning, child-care and other sectors that support families in King County with regard to…		
Developmental screening	34	
Poor/fair	18	53
Good/very good	16	47
Referral	34	
Poor/fair	16	47
Good/very good	18	53
Connection to supportive services	34	
Poor/fair	15	44
Good/very good	19	56

Table 10: Respondent suggestions to improve the coordination of the developmental screening and referral system [1]

Theme N=166	n
Improved communication/coordination across stakeholder groups (i.e.: Provider willingness/knowledge to refer outside of their own institution; shared EHR systems)	29
"One stop shop" for centralized and accessible screening & referrals. The ideal system would: • Be community-centered/accessible to all (regardless of geographic location) • Not discriminate based on insurance coverage • Have universal tools that are used consistently • Include patient navigators/care coordinators • Utilize a confidential database • Be sufficiently funded • Be flexible to meet parent needs (i.e.: flexible appointment times)	28
Improved referral process (i.e.: One that is consistent, simple to navigate, transparent, and friendly)	13
Better provider training/supervision to increase availability of qualified providers. Specific provider training requests included: • Reducing stigma/provider biases • Conducting screenings consistently • Referral processes and next steps for parents/caregivers • Resources available for parents and where they can find them • Common developmental concerns and how they look different in different kids	13
Increased parent knowledge/awareness of screening and evaluation (i.e.: Through community outreach; phone applications, etc.)	12
Increased service availability to reduce waitlists/time between evaluation and service receipt	10
Other, including: • More informational resources, including those targeting key stakeholder groups • Culturally appropriate tools/services • Increased variety of languages of tools/screenings • More comprehensive, widespread, and consistent screening • Increased parent/caregiver support (i.e.: support groups, navigators, extra support for parents/caregivers that "fall through the cracks" such as kinship caregivers) • Increased funding to support staff capacity for screening and follow-up • More knowledgeable and better trained interpreters • Better, more comprehensive services (i.e.: More specific services for autistic children including social skills groups) • Accessible evaluation and services for children older than birth to five • Improving transition periods (i.e.: Transition from: Birth to Three, Three to Five) • Increased provider trust in parent/caregiver concerns	55

[1] This table is a summary of responses from 166 respondents who answered an open-ended question asking for one suggestion to improve the coordination of the developmental screening and referral system. Many respondents provided more than one suggestion; many also provided one word answers which were not included in this table.

GLOSSARY OF TERMS

Academic detailing — refers to face-to-face structured educational outreach visits that are used to support healthcare professionals in their practices.

Adverse Childhood Experiences — stressful or traumatic events (e.g. violence, abuse, neglect, etc.) that children experience before age 18.

Anticipatory guidance — advice, specific to the age of the patient, given by a provider to prepare families for what to expect next in their child's growth and development.

Birth-to-Three services — a range of targeted services designed to help children birth to age three who have a developmental delay or specific health condition associated with delays. Sometimes this is referred to as "ESIT services."

Child Find — requires states to identify, locate, and screen all children with disabilities, between the ages of birth to 21, who are in need of Early Intervention or special education services.

Community supports — a range of services available to the families that support a child's healthy development, that may include quality child care and early learning, parent education, nurse home visiting, and developmentally appropriate play.

Cultural humility — an approach that acknowledges and responds to the complexity of cultural identity; recognizes the dynamics of power, avoids reinforcing cultural stereotypes and prejudice in the work; is thoughtful and deliberate in the use of language and other social relations to reduce bias when conducting evaluations; uses culturally appropriate theories and methods, recognizes the many ways data can be collected, analyzed, interpreted, and disseminated in order to produce work that is honest, accurate, respectful and valid. [68]

Developmental domains — a term used to describe common areas of childhood development. Domains frequently included in developmental screening tools include, communication (i.e. how kids use language), gross motor (i.e. how kids move their bodies), fine motor (i.e. how kids use their hands), problem-solving (i.e. how kids interact with their world), and personal-social (i.e. how kids calm themselves down).

Developmental screening — is defined as screening children's development and/or behavior through the use of validated tools for the purpose of identifying children who may need more comprehensive evaluation.

Developmental delay — a term used to describe when child does not reach developmental milestones at the expected times. A temporary or short lived lag is not considered a delay; rather, it is an ongoing major or minor delay in the process of development.

Developmental evaluation or assessment — a formal evaluation, following a developmental screening, that provides a more in-depth look at a child's development, and is usually conducted by a trained specialist (e.g., pediatrician, child psychologist, speech-language pathologist, occupational therapist, or other specialist). Results of this formal evaluation determines whether a child needs special treatments or Early Intervention services or both.

Developmental surveillance — the process of documenting a child's developmental history, asking parents about their child's development, and observing the child's development in addition to the physical exam without the use of a standardized screening tool, in order to identify children at risk for developmental delays.

Early care and education — health care, home visiting, child care, early learning, and related fields that provide supports to pregnant people and children under the age of six.

Early childhood special education (ECSE) services — special education services provided to children age three and older through the Individuals with Disabilities Education Act Part B.

Early intervention — a term that describes the services and supports available to babies and young children with developmental delays and disabilities and their families, including ECSE and ESIT services.

Early Support for Infants and Toddlers (ESIT) services — a range of targeted services designed to help children birth to age three who have a developmental delay or specific health condition associated with delays. Sometimes this is referred to as "Birth-to-Three services."

Individuals with Disabilities Education Act (IDEA) — federal law mandating policies and procedures that state and local education agencies must follow to ensure students with a disability receive free appropriate public education. Infants and toddlers (i.e., birth through age two) with disabilities and their families receive Early Intervention services under Part C. Youth ages three through 21 years receive special education and related services under Part B.

Intellectual and/or developmental disability — a group of conditions caused by impairment(s) in intellectual, physical, language or behavioral areas. These conditions usually begin early in life, may impact day-to-day functioning, and tend to last through a person's lifetime.

Interquartile range (IQR) — a measure that describes the middle 50 percent of responses in a set of survey responses or other data.

Neurodiverse — a term that describes the diversity of human brains, recognizing that neurological differences are to be respected as any other human variation.

Neurodivergent — a broad term that describes a person whose brain functions in ways that diverge significantly from what society has termed 'typical' or 'average.'

Neurotypical — a term that describes a person whose brain functions in ways that align with what society has termed 'typical' or 'average.'

Referral — concrete action to connect families to the next appropriate service (e.g. further assessment, community resources) that can provide a comprehensive evaluation.

Soft skills — a term that describes interpersonal skills that enable people to relate to others.

Specialist — a term that describes service providers with advanced knowledge and skills who provide developmental support services to young children and their families. Examples include behavioral health providers, speech and language therapists, physical therapists, occupational therapists, infant and early childhood mental health providers, and others.

Supportive services — a term that describes a wide range of services and programs that support children's healthy development, including ESIT/Birth-to-Three services, medical care, specialized early learning programs, and Early Intervention programs.

Universal design principles — a framework for the design and composition of an environment that is accessible, understood and used to the greatest extent possible by all people, regardless of their age, size, ability, or disability.[69]

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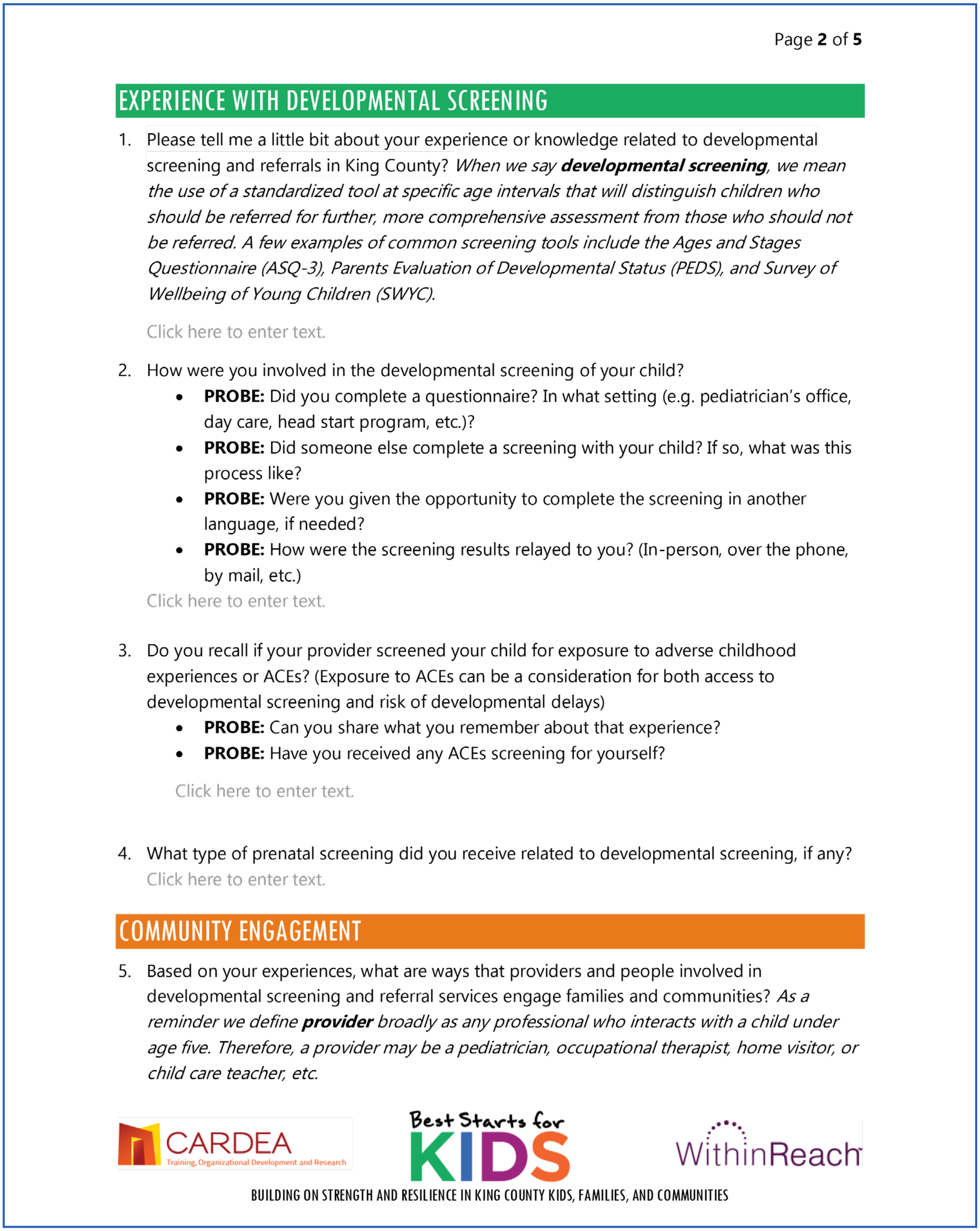
SEMI-STRUCTURED KEY INFORMANT INTERVIEW GUIDE EXCERPT (PARENT)



EXPERIENCE WITH DEVELOPMENTAL SCREENING

1. Please tell me a little bit about your experience or knowledge related to developmental screening and referrals in King County? *When we say **developmental screening**, we mean the use of a standardized tool at specific age intervals that will distinguish children who should be referred for further, more comprehensive assessment from those who should not be referred. A few examples of common screening tools include the Ages and Stages Questionnaire (ASQ-3), Parents Evaluation of Developmental Status (PEDS), and Survey of Wellbeing of Young Children (SWYC).*

   Click here to enter text.

2. How were you involved in the developmental screening of your child?
   - **PROBE:** Did you complete a questionnaire? In what setting (e.g. pediatrician's office, day care, head start program, etc.)?
   - **PROBE:** Did someone else complete a screening with your child? If so, what was this process like?
   - **PROBE:** Were you given the opportunity to complete the screening in another language, if needed?
   - **PROBE:** How were the screening results relayed to you? (In-person, over the phone, by mail, etc.)

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3. Do you recall if your provider screened your child for exposure to adverse childhood experiences or ACEs? (Exposure to ACEs can be a consideration for both access to developmental screening and risk of developmental delays)
   - **PROBE:** Can you share what you remember about that experience?
   - **PROBE:** Have you received any ACEs screening for yourself?

   Click here to enter text.

4. What type of prenatal screening did you receive related to developmental screening, if any?
   Click here to enter text.

COMMUNITY ENGAGEMENT

5. Based on your experiences, what are ways that providers and people involved in developmental screening and referral services engage families and communities? *As a reminder we define **provider** broadly as any professional who interacts with a child under age five. Therefore, a provider may be a pediatrician, occupational therapist, home visitor, or child care teacher, etc.*

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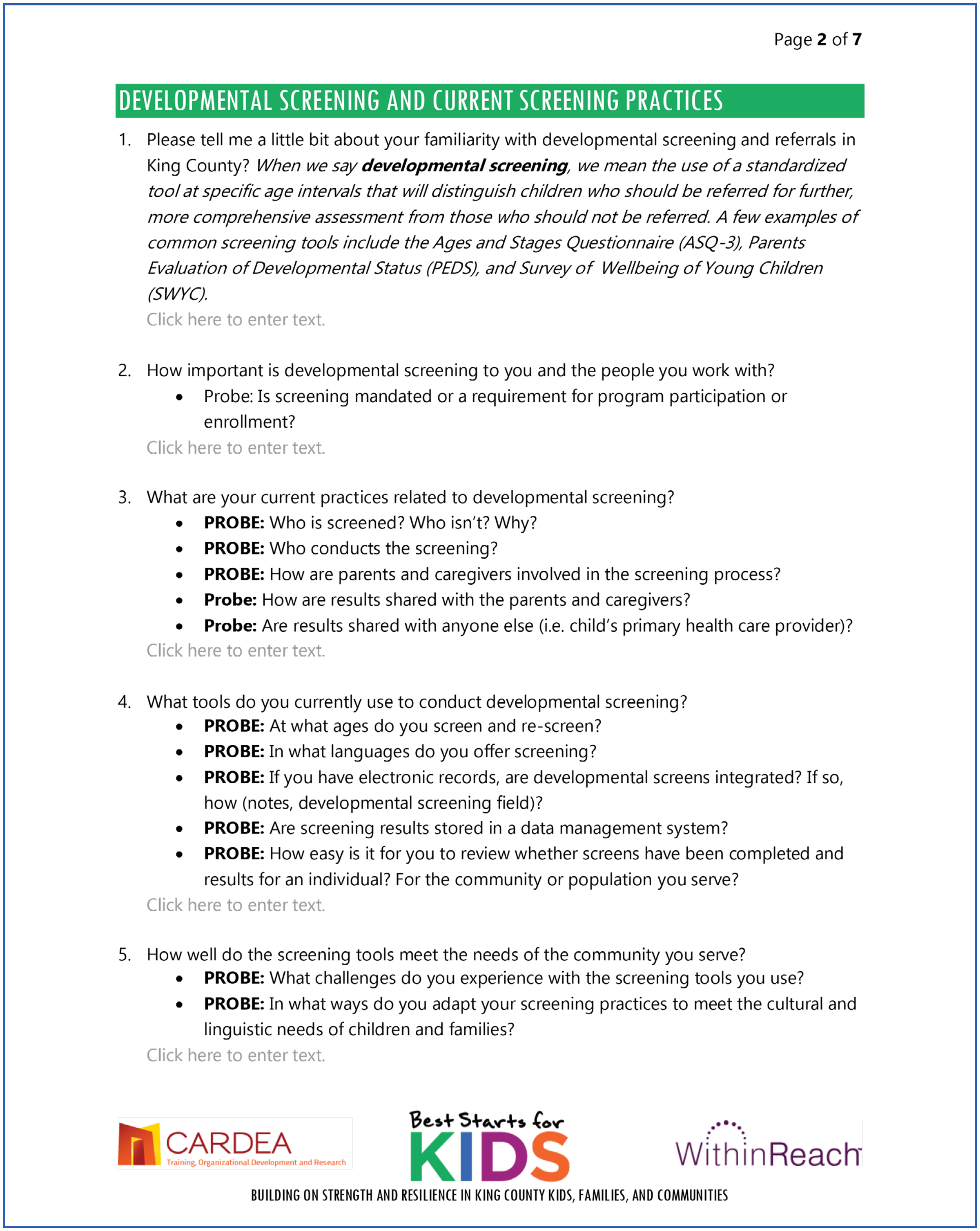
SEMI-STRUCTURED KEY INFORMANT INTERVIEW GUIDE EXCERPT (PROVIDER)



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DEVELOPMENTAL SCREENING AND CURRENT SCREENING PRACTICES

1. Please tell me a little bit about your familiarity with developmental screening and referrals in King County? *When we say **developmental screening**, we mean the use of a standardized tool at specific age intervals that will distinguish children who should be referred for further, more comprehensive assessment from those who should not be referred. A few examples of common screening tools include the Ages and Stages Questionnaire (ASQ-3), Parents Evaluation of Developmental Status (PEDS), and Survey of Wellbeing of Young Children (SWYC).*

   Click here to enter text.

2. How important is developmental screening to you and the people you work with?
   - Probe: Is screening mandated or a requirement for program participation or enrollment?

   Click here to enter text.

3. What are your current practices related to developmental screening?
   - **PROBE:** Who is screened? Who isn't? Why?
   - **PROBE:** Who conducts the screening?
   - **PROBE:** How are parents and caregivers involved in the screening process?
   - **Probe:** How are results shared with the parents and caregivers?
   - **Probe:** Are results shared with anyone else (i.e. child's primary health care provider)?

   Click here to enter text.

4. What tools do you currently use to conduct developmental screening?
   - **PROBE:** At what ages do you screen and re-screen?
   - **PROBE:** In what languages do you offer screening?
   - **PROBE:** If you have electronic records, are developmental screens integrated? If so, how (notes, developmental screening field)?
   - **PROBE:** Are screening results stored in a data management system?
   - **PROBE:** How easy is it for you to review whether screens have been completed and results for an individual? For the community or population you serve?

   Click here to enter text.

5. How well do the screening tools meet the needs of the community you serve?
   - **PROBE:** What challenges do you experience with the screening tools you use?
   - **PROBE:** In what ways do you adapt your screening practices to meet the cultural and linguistic needs of children and families?

   Click here to enter text.

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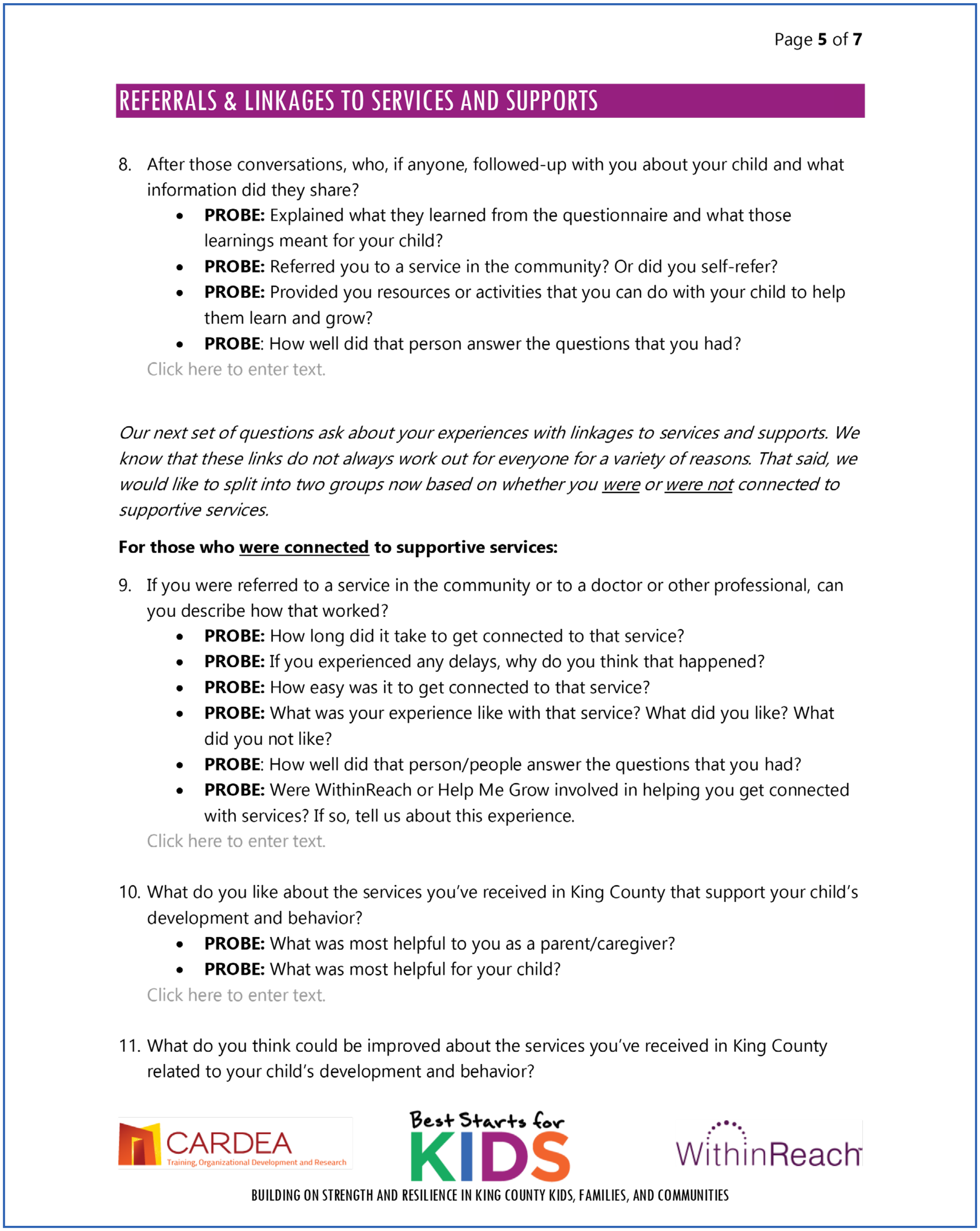
FOCUS GROUP GUIDE EXCERPT



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REFERRALS & LINKAGES TO SERVICES AND SUPPORTS

8. After those conversations, who, if anyone, followed-up with you about your child and what information did they share?
    - **PROBE:** Explained what they learned from the questionnaire and what those learnings meant for your child?
    - **PROBE:** Referred you to a service in the community? Or did you self-refer?
    - **PROBE:** Provided you resources or activities that you can do with your child to help them learn and grow?
    - **PROBE**: How well did that person answer the questions that you had?

    Click here to enter text.

Our next set of questions ask about your experiences with linkages to services and supports. We know that these links do not always work out for everyone for a variety of reasons. That said, we would like to split into two groups now based on whether you were or were not connected to supportive services.

For those who were connected to supportive services:

9. If you were referred to a service in the community or to a doctor or other professional, can you describe how that worked?
    - **PROBE:** How long did it take to get connected to that service?
    - **PROBE:** If you experienced any delays, why do you think that happened?
    - **PROBE:** How easy was it to get connected to that service?
    - **PROBE:** What was your experience like with that service? What did you like? What did you not like?
    - **PROBE**: How well did that person/people answer the questions that you had?
    - **PROBE:** Were WithinReach or Help Me Grow involved in helping you get connected with services? If so, tell us about this experience.

    Click here to enter text.

10. What do you like about the services you've received in King County that support your child's development and behavior?
    - **PROBE:** What was most helpful to you as a parent/caregiver?
    - **PROBE:** What was most helpful for your child?

    Click here to enter text.

11. What do you think could be improved about the services you've received in King County related to your child's development and behavior?

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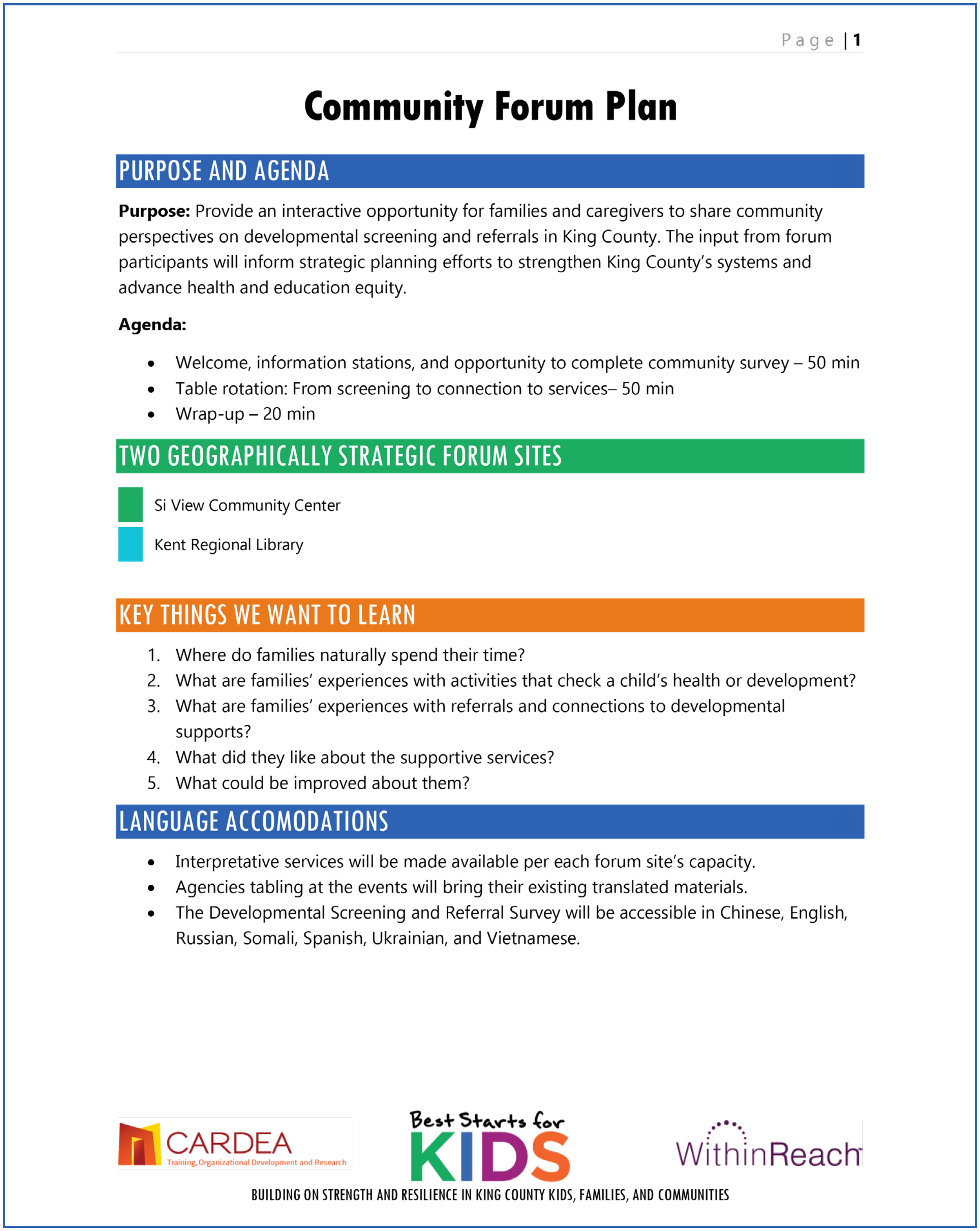
COMMUNITY FORUM PLAN EXCERPT



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Community Forum Plan

PURPOSE AND AGENDA

Purpose: Provide an interactive opportunity for families and caregivers to share community perspectives on developmental screening and referrals in King County. The input from forum participants will inform strategic planning efforts to strengthen King County's systems and advance health and education equity.

Agenda:

- Welcome, information stations, and opportunity to complete community survey – 50 min
- Table rotation: From screening to connection to services– 50 min
- Wrap-up – 20 min

TWO GEOGRAPHICALLY STRATEGIC FORUM SITES

🟩 Si View Community Center

🟦 Kent Regional Library

KEY THINGS WE WANT TO LEARN

1. Where do families naturally spend their time?
2. What are families' experiences with activities that check a child's health or development?
3. What are families' experiences with referrals and connections to developmental supports?
4. What did they like about the supportive services?
5. What could be improved about them?

LANGUAGE ACCOMODATIONS

- Interpretative services will be made available per each forum site's capacity.
- Agencies tabling at the events will bring their existing translated materials.
- The Developmental Screening and Referral Survey will be accessible in Chinese, English, Russian, Somali, Spanish, Ukrainian, and Vietnamese.

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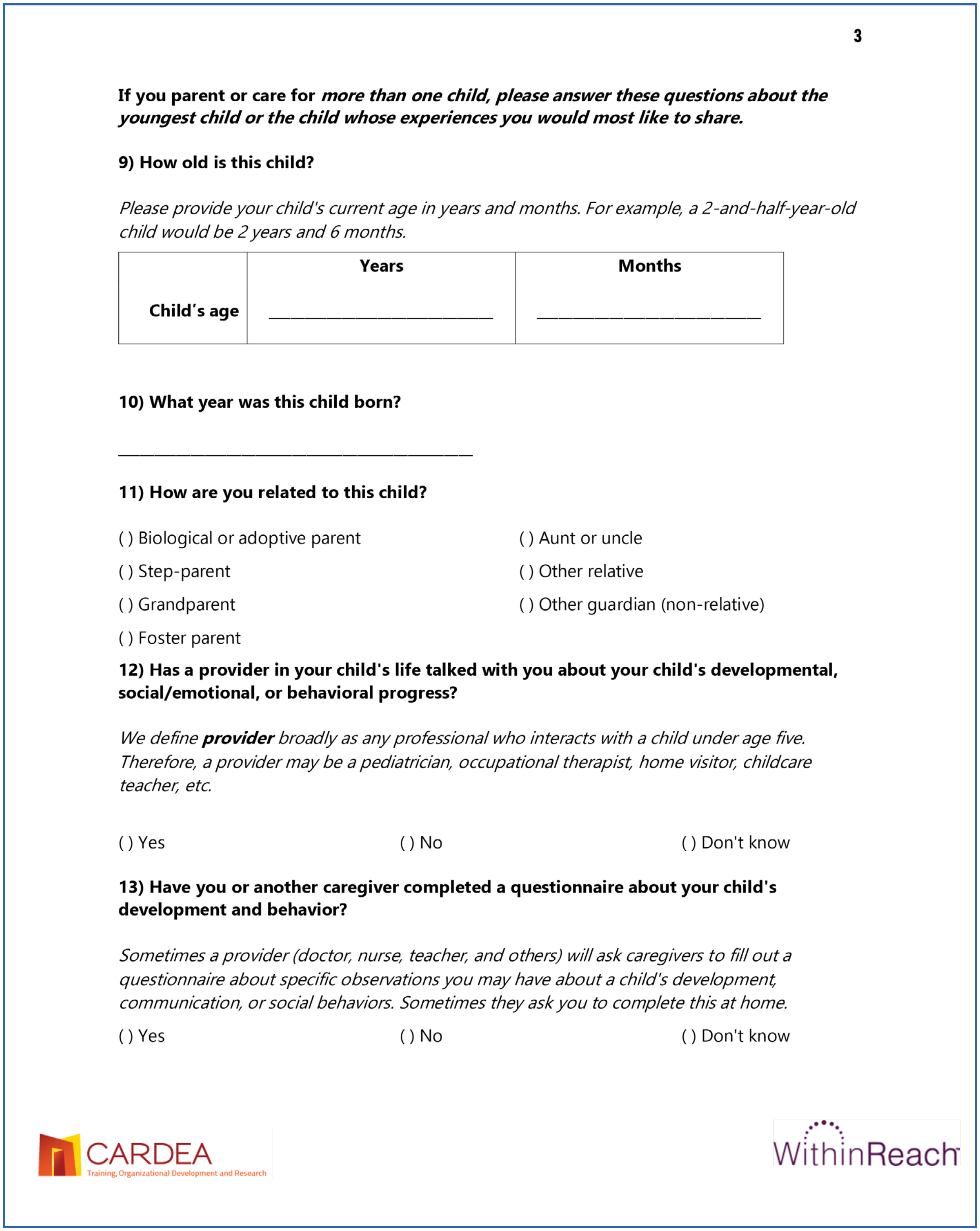
DEVELOPMENTAL SCREENING AND REFERRAL COMMUNITY SURVEY EXCERPT



3

If you parent or care for *more than one child, please answer these questions about the youngest child or the child whose experiences you would most like to share.*

9) How old is this child?

Please provide your child's current age in years and months. For example, a 2-and-half-year-old child would be 2 years and 6 months.

	Years	**Months**
Child's age	______________________	______________________

10) What year was this child born?

____

11) How are you related to this child?

( ) Biological or adoptive parent
( ) Step-parent
( ) Grandparent
( ) Foster parent
( ) Aunt or uncle
( ) Other relative
( ) Other guardian (non-relative)

12) Has a provider in your child's life talked with you about your child's developmental, social/emotional, or behavioral progress?

*We define **provider** broadly as any professional who interacts with a child under age five. Therefore, a provider may be a pediatrician, occupational therapist, home visitor, childcare teacher, etc.*

( ) Yes ( ) No ( ) Don't know

13) Have you or another caregiver completed a questionnaire about your child's development and behavior?

Sometimes a provider (doctor, nurse, teacher, and others) will ask caregivers to fill out a questionnaire about specific observations you may have about a child's development, communication, or social behaviors. Sometimes they ask you to complete this at home.

( ) Yes ( ) No ( ) Don't know

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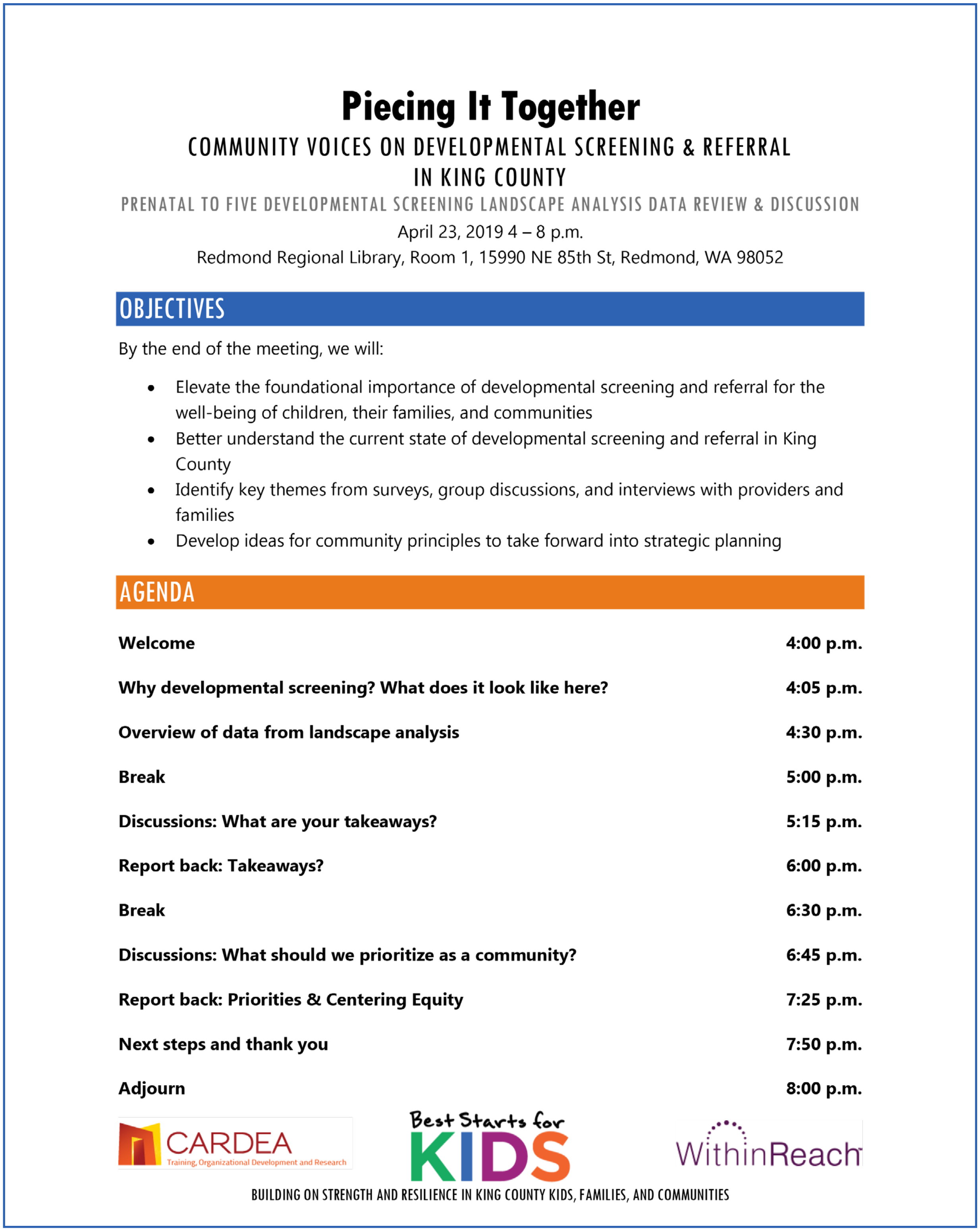
SAMPLE DATA DISCUSSIOIN AGENDA



Piecing It Together

COMMUNITY VOICES ON DEVELOPMENTAL SCREENING & REFERRAL IN KING COUNTY

PRENATAL TO FIVE DEVELOPMENTAL SCREENING LANDSCAPE ANALYSIS DATA REVIEW & DISCUSSION

April 23, 2019 4 – 8 p.m.
Redmond Regional Library, Room 1, 15990 NE 85th St, Redmond, WA 98052

OBJECTIVES

By the end of the meeting, we will:

- Elevate the foundational importance of developmental screening and referral for the well-being of children, their families, and communities
- Better understand the current state of developmental screening and referral in King County
- Identify key themes from surveys, group discussions, and interviews with providers and families
- Develop ideas for community principles to take forward into strategic planning

AGENDA

Welcome	**4:00 p.m.**
Why developmental screening? What does it look like here?	**4:05 p.m.**
Overview of data from landscape analysis	**4:30 p.m.**
Break	**5:00 p.m.**
Discussions: What are your takeaways?	**5:15 p.m.**
Report back: Takeaways?	**6:00 p.m.**
Break	**6:30 p.m.**
Discussions: What should we prioritize as a community?	**6:45 p.m.**
Report back: Priorities & Centering Equity	**7:25 p.m.**
Next steps and thank you	**7:50 p.m.**
Adjourn	**8:00 p.m.**

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COMMUNITY PRINCIPLES

The following principles summarize input received through three community discussions and a public sector discussion with stakeholders across King County. The term early care and education refers health care, home visiting, child care, early learning, and related fields that provide supports to pregnant people and children up to the age of five.

Brief principles are outlined below with more detailed approaches outlined on pages 2-3.

THE IDEAL KING COUNTY DEVELOPMENTAL SCREENING, REFERRAL, AND CONNECTION TO SERVICES SYSTEM WILL SUPPORT EFFORTS TO...

1. Build trusting relationships between families and providers that support shared decision making
2. Be inclusive of and center children and families who are most underserved or at greatest risk of developmental delays
3. Develop a highly skilled early care and education workforce that reflects the communities they work with
4. Improve cross-sector communication and information sharing
5. Address stigma associated with screening and developmental delays
6. Build structures that center equity and are continually responsive to the needs of families

1 **Build trusting relationships between families and providers that support shared decision making by**

a. Elevating the expertise and strengths of families, including primary caregivers as integral members of each child's care team;

b. Focusing on the whole family, respecting the diversity of family structures;

c. Using or adapting evidence-based screening instruments, creating resources, and providing services that are culturally and linguistically relevant;

d. Providing comprehensive, accessible information about available services and resources and how to get connected to them for all families and providers;

e. Applying a "no wrong door" approach to screening and connection to services that are the right fit for families and strengthening the role of community-based organizations that have established trust with local communities;

f. Ensuring interpreters and cultural and linguistic liaisons have content knowledge related to childhood development and behavior;

g. Eliminating referral gatekeepers and the "wait and see approach" wherever it originates.

2 **Be inclusive of and center children and families who are most underserved or at greatest risk of developmental delays by**

a. Co-creating services and systems in partnership with communities that are most impacted and marginalized, making sure these families are prioritized at every step;

b. Balancing screening and referral centralization with the need for tailored approaches;

c. Identifying and bridging gaps in the fragmented policy and protocol landscape to eliminate barriers to care, including the transition out of Birth to Three services;

d. Ensuring the supply of supportive service providers can meet any increased demand for services, including taking steps to improve reimbursements for services provided;

e. Addressing barriers to services (i.e. insurance coverage and reimbursement, immigration status, etc.);

f. Creating navigator networks to support families to access resources, information, and services.

3 **Develop a highly skilled early care and education workforce that reflects the communities they work with by**

a. Supporting the evolution of the early care and education field to better reflect the King County community, remediating systemic disparities that affect the field;

b. Supporting early care and education agencies in recruiting and retaining staff that reflect the diversity of the community, including addressing workplace inequities that drive turnover;

c. Providing soft skills training to providers to support delivery of high-quality services (cultural humility, strengths-based counseling, motivational interviewing, etc.);

d. Regularly training, coaching, and evaluating providers on unconscious bias and cultural models that perpetuate stigma;

e. Integrating a trauma-informed approach within early care and education settings;

f. Promoting cultural humility among early care and education settings and providers.

4 Improve cross-sector communication and information sharing by

a. Cultivating trusting and respectful relationships among early care and education providers;

b. Enabling information sharing across sectors to support holistic, coordinated care for the whole family, supporting families who desire privacy and empathy and enabling providers to focus on active listening when families to choose to share traumatic histories;

c. Strengthening or establishing feedback loops so providers across the early care and education field know whether the families they work with have been connected to supportive services.

5 Address stigma associated with screening and developmental delays by

a. Amplifying a strengths-based approach to screening;

b. Reaffirming that all children are unique, develop uniquely, and have unlimited potential;

c. Celebrating early childhood's milestones and supporting developmental promotion approaches;

d. Normalizing developmental screening by making it routine and common;

e. Engaging communities through culturally sensitive education and forums to routinize conversations regarding screening and delays;

f. Elevating the successes of adolescents and adults with disabilities and involving them in shaping the system.

6 Build structures that center equity and are continually responsive to the needs of families

a. Involving communities most impacted in determining what data are collected, how the data are analyzed, and how they are interpreted;

b. Committing to ongoing learning among early care and education providers and community advocates that continually centers family voices;

c. Assessing and addressing disproportionalities within the developmental screening and referral system;

d. Accepting and embracing the iterative process of systems building and improvement;

e. Creating space for fluidity and responsiveness to shifting needs and priorities.