

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

A REPORT FROM A PARTICIPATORY LANDSCAPE ANALYSIS



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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).

EXECUTIVE SUMMARY

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 conversations 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.

Contact DevelopmentalScreening@cardeaservices.org for a copy of the full report.