**APPENDICES: Equity and Inclusion for Children with Disabilities**

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**Appendix A: Literature Review**

**Adequate & Robust Funding**

* The cost of services for community-based providers disincentivizes enrollment of infants and toddlers who may require additional supports (Weglarz-Ward, Santos, & Hayslip, 2020).
* **“**The majority of Part C funding is provided by the state (55%); slightly over a quarter is provided through federal sources (31%); and the remaining 14% is derived from local funds (Hebbeler, Greer, & Hutton, 2011). Regulations dictate that federal funds supporting Part C be used as payer of last resort by which other funding sources for specific ser- vices cannot be supplanted. In general, Part C federal funds cover EI administrative costs while many services are funded through state funds and other sources such as Medicaid, insurance, and parental fees for services. This merging of funds between EI and Medicaid can be difficult due to the diverse policies and funding mechanisms associated with each program (Heider, 2016)” (Vail, Lieberman-Betz, McCorkle, 2018, p. 230). Additionally, challenges include funding variability in each state and decreasing per child expenditures budgeted for Part C because states are required to have a balanced budget (Ibid.)
* A survey completed by ITCA in 2016 found that none of the Part C programs had systems collecting data about program costs (Derrington, Spiker, Hebbeler, & Diefendorf, 2013).  States are required to pull together multiple sources of funding to coordinate services with many using 2 to 15 funding sources (Ibid.).
* To compensate for insufficient funds, states have increased family fees, reduced provider reimbursement, required prior approval before families receive services beyond a predetermined amount, altered state Medicaid plans to increase Part C coverage, and covering services specific to an Autism diagnosis (Vail, Lieberman-Betz, McCorkle, 2018, p. 230).
* Additionally states have resorted to state required personnel furloughs, hiring freezes, reduced funding for public awareness and child find, and narrowed definitions of eligibility to reduce caseloads. (Vail, Lieberman-Betz, McCorkle, 2018)
* In a study of 32 Part C Early Intervention Coordinators for states and territories, respondents identified three “ideal” solutions including 1) increased or full funding from the Federal government; 2) funding for Part C based on the number of children served, 3) funding for Part C through multiple sources including Medicaid, state funds, and federal funds. (Vail, Lieberman-Betz, McCorkle, 2018)

**Stable & Diverse Workforce**

* State systems present issues in differing qualifications for providers with little or no special education preparation requirements for child care workers, leaving them feeling unprepared to support infants and toddlers with disabilities and their families (Weglarz-Ward, Santos, & Hayslip, 2020).
* “Enduring and chronic shortages and uneven distribution of high-quality special education teachers continue to be a challenge, especially in schools and community-based settings serving high proportions of low-income and racially/ethnically minoritized students (Cook & Yang, 2016; Mason-Williams, 2015; Ondrasek et al., 2020). Highly specialized, separate schools providing intensive and individualized services also struggle with staffing needs (Mason-Williams & Gagnon, 2016; Mason-Williams et al., 2017). Such challenges potentially undermine efforts to fully meet the promise of IDEA. Moreover, a lack of qualified special education teachers (SETs) and other related service providers all but ensures inequitable access and outcomes for low-income and racially/ethnically minoritized students (Gilmour, 2020; Schochet et al., 2020).” (Council for Exceptional Children, 2021)
* “Research evidence suggesting that SETs with less experience, who work in high poverty schools, or who teach students with emotional/behavioral disorders are more likely to leave suggests a need for targeted supports to more effectively retain SETs (Bettini et al., 2019; Billingsley, 2004; Gilmour, 2020)” (Council for Exceptional Children, 2021)
* “Rigorous, high quality SET preparation increases the learning of children and youth with exceptionalities; and strong preparation leads to retention (Bettini et al., 2020; Gilmour & Wehby, 2020).” (Council for Exceptional Children, 2021)
* “Effective administrators play a critical role in creating a collegial culture in school and community-based settings that can help retain racially, culturally, and linguistically diverse SETs (Scott et al., 2020)” (Council for Exceptional Children, 2021)
* 2020 Bureau of Labor Statistics (Bureau of Labor, 2022)
* 463,200 in special education Pre-K-12th grade
* 20,800 in preschool settings
* 2019 report from Early Childhood Personnel Center and CEC (Early Childhood Personnel Center and Council for Exceptional Children, 2020)
* “42 states report a shortage of Early Intervention professionals”
* “Teacher preparation enrollment was down 35% over 5 years”
* “Loss of faculty in higher education”
* “Increase in retirements”

**Governance that Enhances Coordination & Collaboration**

* Research shows the critical nature of the relationship between Early Intervention and teachers in community-based programming (Weglarz-Ward, Santos, & Hayslip, 2020; Dinnebeil, et al., 2008).
* Policies that create frameworks for collaboration and compensate for challenges in philosophical and practical implementation require better data to support professional development for teachers and early intervention staff to promote collaboration *(*Weglarz-Ward, Santos, & Hayslip, 2020; Bose and Hinojosa 2008; Cameron and Tveit 2019; Dinnebeil et al. 2006; Hong and Shaffer 2015; Rens and Joosten 2014; Wesley et al. 2001; Wolery et al. 2002)
* The Interagency Coordinating Councils (ICCs) were intended to create and support planning for service delivery that “fully involved all stakeholders, from agency members to practitioners to policymakers to parents.” (Baker & Stahl, 2004, 169)
* The ICCs collaborative governance structures were critical to ensuring the multitude of stakeholders serving children with disabilities could cohesively plan, implement, and evaluate services in concrete ways. Yet, insufficient guidance and funding has led to significant challenges in ICC implementation. Information sharing occurs during meetings, yet actionable work is difficult without agreed upon goals and direction for the group and clear roles and responsibilities that build on member strengths (Baker & Stahl, 2004, 169).
* “There is almost constant enthusiasm and a willingness to work for the cause reflected in the examined documents. The overarching challenge in interagency or interorganizational collaboration is to operationalize this willingness and enthusiasm without relying on traditional signals of commitment within a bureaucratic setting (such as regular meeting attendance). Collaborative efforts may be— or become—the full-time job of the individuals involved in interagency or interorganization groups, but the collaboration exercise itself is not (Thompson, Socolar, Brown, & Haggerty, 2002).” (Baker & Stahl, 2004, 175)

**Family- and Child-Centered Screening, Eligibility & Evaluation**

* “A key tool for identifying young children with a developmental delay is developmental screening, which often takes the form of checklists or questionnaires given to families by professionals in health care, child care, and other community settings.” (Gillespie, 2021)
* “One-quarter of children under age 5 are at risk of having a developmental delay, and so all children should be screened in their first three years. Yet only 30% of children ages 9 months through 35 months are screened for developmental delays using a standardized measure, and less than one-quarter of children who are eligible for EI services actually access them”. (Ashley H. Hirai, Michael D. Kogan, Veni Kandasamy, Colleen Reuland, and Christina Bethell. 2018 in Gillespie, 2021)
* “Our current systems often focus on screening, yet neglect to document the needs of the families, the services rendered, or the improvements made in family and child wellbeing.” (Prenatal-to-3 Policy Impact Center, 2020, 43).
* According to Prenatal-to-3 Policy Impact Center’s analysis of state policies, “Nearly 3 out of 4 children in the five worst states do not receive a developmental screening assessment prior to age 3; but even in the five best states, up to half of children do not receive this important assessment for early detection of developmental delays. Black and Hispanic children are substantially less likely than White children to be screened at an early age for developmental delays” (Prenatal-to-3 Policy Impact Center, 2020, 47).
* National data suggests that the prevalence of children under age 3 with delays and disabilities who can benefit from Early Intervention services is between 13% and 20%. In 2018, Part C served only 3.5% of the US population under age 3. A lack of awareness of EI and the full range of eligibility criteria, even among early childhood and health providers, also leads to many children not ever accessing the services that can make a difference in their lifelong trajectory. (Office of Special Education Programs, 2021)
* Early childhood programs help build strong foundations for vulnerable children. Given this, the joint statement from the U.S. Department of Education and Health and Human Services (HHS) set a vision to establish stronger partnerships between Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) and the Individuals with Disabilities Education Act, Part C Program (IDEA Part C Program). This specific statement identified effective collaboration and coordination across MIECHV and IDEA Part C Program can yield high quality system of services and supports for infants and toddlers with disabilities, including those in vulnerable populations (US Departments of Education & Health and Human Services, 2017).
* Approximately 11 percent of newborns have prenatal substance abuse exposure; however, 95 percent of these infants are sent home from the hospital without being identified or referred for early intervention services (Young, Gardner, Otero, Dennis, Change, Earle, & Amatetti, 2009).
* Given that between 2000 and 2012, health officials identified a steep increase in the number of infants exposed prenatally, identifying a coordinated system of prevention and intervention supports can improve outcomes for this population (US Departments of Education & Health and Human Services, 2017).
* Child maltreatment is connected to increased risk in a child’s development, including physical injuries, delayed physical growth, and behavioral issues (Gross, 2016). The Child Abuse Prevention and Treatment Reauthorization Act of 2010 (CAPTA) requires States that receive CAPTA funds to establish policies and procedures for the referral of children under the age of three involved in a substantiated case of abuse or neglect to the IDEA Part C state program.
* Children under the age of five are the most likely age group to experience homelessness, with children under the age of one being the most common age group to enter shelters and transitional housing programs (US Departments of Education & Health and Human Services,2017).
* Low birth weight, developmental delays, and emotional and behavioral challenges are more common in infants and toddlers experiencing homelessness than other children; however, they are underrepresented in early childhood and home visiting programs (McCoy-Roth, Mackintosh & Murphey, 2012).
* The joint HHS/Department of Housing and Urban Development/ED *Policy Statement on Metting the Needs of Families with Young Children Experiencing and at Risk of Homelessness* identifies the need for cross-system collaboration across all programs and systems that interact with families during early childhood because no single system or program can meet all the needs of young children and families experiencing homelessness (US Departments of Education & Health and Human Services, 2017).
* "Black and Latino children tend to be identified as eligible for these crucial services later than their White peers, and too often, fail to receive the evaluations and services for which they are eligible, according to studies conducted in cities and states across the country.This inequitable access reflects the fact that early intervention services are at the nexus of health care, education, and other systems pervaded by systemic racism.” (Gillespie, 2021, 7)
* “A large, nationally representative study found that Black and White children who are eligible for early intervention services received them at the same (albeit low) rate of 9% at 9 months of age, but at 24 months of age, Black children were five times less likely to receive early intervention services than White children.” (Feinberg, Silverstein, Donahue, & Bliss, 2011 in Gillespie, 2021, 8)
* “States are required by the federal government to collect, report, and publish some information about children who are found eligible for early intervention services, as well as recipients of those services, including the number and percentage of children participating, the settings in which they participate, and information about exiting Part C services and about dispute resolution.5 Some of this data is disaggregated by race, ethnicity, and gender, but it is not disaggregated by income level or dual language learner status.6 Information pertaining to children who are not enrolled in Part C services, but who are identified, referred, and evaluated, is collected by states, but there is wide variation in the public accessibility of that data.” (Gillespie, 2021, 7)

**Equitable & Inclusive Service Delivery**

* “Data currently collected are based on the actual number of days between parental consent or the date specified on the IFSP for the initiation of services and the provision of services... although not all states collect and report delays attributable to family circumstances.” (ECTA, 2022)
* The *State of Babies Yearbook* identifies race, ethnicity, and racism as critical factors on the quality of care that parents and babies receive. A baby who is born healthy depends on their mother’s/birthing person’s well-being, not just before birth but also prior to conception. Mother’s require access to appropriate health care services before, during, and after pregnancy. (Keating, Heinemeier, et al., 2022)
* For women of color and their babies the connection between maternal and child well-being is especially important given the intergenerational effects of and lived experiences with institutional and interpersonal racism (Wilkerson et al., 2021).
* The United States (U.S.) is the only high-income country in the world where the maternal mortality rate has risen over the past two decades (1) and the infant mortality rate is twice the rate in the European Union and for Black infants in the U.S. the mortality rate is nearly four times that of the EU (Infant Mortality by Race in the United States, 2020; Mortality Rate, Infant, per 1,000 live births, n.d). These differences in maternal and child health outcomes by race/ethnicity in the U.S. are caused by ongoing experiences of institutional and interpersonal racism. (Keating, Heinemeier, et al., 2022)
* Inequities by race/ethnicity in education, high-quality health care, and safe neighborhoods which in turn impact maternal and child health outcomes are examples of institutionalized racism. Socioeconomic status (SES) can also impact these social determinants of health; however, research identifies disparities in health outcomes by race/ethnicity persist even after accounting for SES (Brown, Richardson, Hargrove, & Thomas, 2016).
* Interpersonal racism, or societal racism, also influences the racial/ethnic disparities in maternal and child health. The *State of Babies Yearbook* identifies three ways in which racism drives disparities in maternal and child health: 1) it increases stress and weathering, 2) it limits access to high-quality health care, and 3) it reduces the quality of care received (Wilkerson, et al., 2021).
* The *State of Babies Yearbook* goes on to further identify inequities for the mother during preconception, pregnancy, and birth and in their babies’ first months of life. These include: lack of health insurance, prenatal care, preterm births, low birth weight, infant mortality, maternal mortality and morbidity, and breastfeeding (Wilkerson, et al., 2021).
* The human right to equal opportunity and the scientific basis for inclusion are reflected in the IDEA law, which calls for young children with delays and disabilities to receive special education and related services in the least restrictive environment (LRE), alongside their typically developing peers (Early Choices, ND). The LRE is the language in the law that defines the environment in which services are received, and is foundational to the legal framework that ensures that children receive their special education and related services in the LRE across a continuum of settings. Under Part B of the Individuals with Disabilities Education Act (IDEA), special education and related services are to be made available to all children with disabilities ages three through 21, to the maximum extent appropriate, in the least restrictive environment factoring in an individual child’s unique strengths and needs.
* As clarification of the requirements under Part B of the IDEA, in 2015, the U.S. Departments of Education (ED) and Health and Human Services (HHS) jointly released a Policy Statement on Inclusion in Early Childhood Programsthat specifies IDEA’s free appropriate public education (FAPE) and LRE requirements to non-public school settings, such as community-based child care and Head Start. Under this framework, Local Education Agencies (LEAs) must ensure that a free appropriate public education (FAPE) is provided in the LRE to every child with a disability in its jurisdiction. (US Department of Health and Human Services and Department of Education, 2015)
* Children with disabilities, including those with the most significant disabilities and the highest needs, are able to make significant developmental and learning process in an inclusive setting (Green, Terry, & Gallager, 2014; Strain & Bovey, 2011; Rafferty, Piscitelli, & Boettcher, 2003).
* Some studies have identified that for children with disabilities an inclusive setting leads to greater cognitive and communication development compared to those children with disabilities in a separate setting (Nahmias, Kase, & Mandell, 2014; Rafferty, Piscitelli, Y Boettcher, 2003).
* Levels of engagement is similar across children with disabilities and those neurotypically developing peers (Odom, et al., 2004; Brown, Odom, Li, & Zercher, 1999).
* Along these lines, given that children’s growth and learning can be related to their peers’ skills, this impact are most pronounced for children with disabilities (Justice, Logan, Lin, & Kaderavek, 2014).
* An inclusive setting can also positively impact a child with a disabilities social-emotional development. Research identified that children with disabilities in inclusive settings demonstrated more social emotional growth compared to children in separate settings (Guralnick, Conner, Hammond, Gottman, & Kinnish, 1996; Fryxell & Kennedy, 1995; Freeman & Alkin, 2000; Cole, & Meyer, 1991; Katz & Mirenda, 2002).
* Most importantly, these gains are achieved when young children with disabilities are included several days per week in social and learning opportunities with typically developing peers (Freeman & Alkin, 2000) and specialized instructional strategies are utilized to meet children’s individual needs (Strain, Bovey, Wilson, & Roybal, 2009).
* To ensure programs and individuals can fully meet the needs of children with disabilities, supports, including professional development, ongoing coaching and collaboration, and time for communication and planning are an essential component (Odom, Buysse & Soukakou, 2011).
* Strain and Hoyson (2000) found that these developmental benefits of early childhood inclusion continue to grow when paired with inclusion at the preschool, kindergarten, and elementary level.
* When supported by classroom teachers, compassion and empathy in addition to a more positive perception of children with disabilities (Frazeur Cross, Traub, Hutter-Pishgahi, & Shelton, 2004; Diamond & Huang, 2005).
* When programs and teachers have an understanding and capacity for individualizing learning, all children can benefit (US Departments of Health and Human Services and Education, 2015).
* Colorado, Nebraska, Wyoming, Vermont, Ohio, Connecticut and Kentucky are the states with the highest rates of inclusion in early childhood programs, while, Louisiana, Alaska, South Dakota, Washington and Idaho are the states with the lowest rates. For Idaho, Ohio, Mississippi, Virginia, Indiana, New Hampshire, Texas, Connecticut, Alaska, Missouri, New Jersey and Kentucky the percentage of children of color receiving services in an inclusive setting is lower than the average state inclusion rate (Meek et al., 2019).
* According to Start with Equity (2019), public pre-K is an underused lever to increase inclusion. Given the greater number of student slots, strong public Pre-K systems should have a greater percentage of students with disabilities receiving services in inclusive, early learning settings. Despite this, Start with Equity (2019) found this access to be disproportionate in relation to the number of children with disabilities receiving their services within an inclusive setting Meek et al., 2019).
* With a recent push in strengthening support for infants and toddlers with social-emotional (SE) delays and mental health conditions, State Systemic Improvement Plans (SSIPs) identified 31 states as identifying a goal to improve outcomes in the SE domain, including a child’s capacity to form strong social relationships and SE skills (Smith, et al., 2020).
* While nationally a delay in social and emotional development is a qualifier for Part C services, what and how this looks like varies from state-to-state (i.e., the definition and criteria for establishing social and emotional delay vary across states). Infant-toddler mental health has been identified as a core goal to ensure a positive developmental trajectory with subsequently improved chances to succeed educationally and across life (Smith, et. al., 2020).
* The National Center for Children in Poverty (NCCP) and Georgetown University Center for Children and Families (CCF) led a 50-state survey exploring state Part C policies and procedures related to the screening, evaluation, eligibility, services, and financing of the programs capacity to meet infant-toddler social and emotional and mental health needs. Results identified 30 states promote (either via promotional materials or online information) providing screening and services to children with social and emotional concerns. Thirty states offer in-person training on social and emotional screenings and referrals, while 24 states offer this training virtually; however, only eight states require the use of a social and emotional screener by both EI and outside providers. While 30 states recommend the use of an social and emotional tool, the extent the tool is implemented has the potential of impacting whether or not children with social and emotional concerns are identified and referred. Furthermore, only 13-states require an experienced mental health professional to be part of the eligibility evaluation team. With 31-states referring children with possible social and emotional concerns who are found ineligible for Part C services to outside programs for support, only five states have written policies in place requiring Part C to offer an additional social and emotional screener after a period of time (Smith, et. al., 2020).
* For those children eligible for Part C services, 24-states offer dyadic (parent-child) treatment with only six requiring the use of an evidence-based model. Thirty-four states offer parenting programs to support social and emotional outcomes; however, only 14 use an evidence-based model. While five-states offer screenings for maternal depression, the majority (30) do not. In regards to consultation between mental health specialists and EI providers, 29-states provide this level of support. A shortage of available and qualified providers who offer social and emotional-related services was identified as a barrier for 30-states with 16-states reporting low reimbursement rates. Only 10-states identified maximizing federal Medicaid for reimbursement purposes for social and emotional services (Smith, et. al., 2020).
* “States reported 1.27 million cases of young children enrolled in public schools being disciplined through exclusionary practices in the 2015-2016 school year.A national parent survey found that approximately 50,000 children under five were suspended, and 17,000 were expelled, in a single year.” (Meek, 2020).

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**Appendix B: National Survey Results**

The following survey was disseminated through national partners in early childhood and special education services in Marcy 2022. Results included responses from 1,528 individuals including families, practitioners in early childhood, early intervention/preschool special education, health providers and administrators, state and local administrators, and advocates from 48/50 states. Please note that the survey respondents are disproportionately white, non-Hispanic, English-speaking, and hold Master’s degrees or above.

We recognize that this is not representative of families with children with disabilities/delays and the providers who serve them. Policy priorities should be informed by data that is more reflective of the communities that are impacted, and gathering this data must be a key next step as others consider these policy recommendations, prioritize and pursue them. The following summarizes findings from survey results and align with the categories of federal policy recommendations developed through the Alliance for IDEA Policy project. To see detailed data tables of survey results, click [here](https://docs.google.com/document/d/1rcTr_0zri_9KLGNdCu_GgosuGj74Mr0W/edit?usp=sharing&ouid=114127591642816470327&rtpof=true&sd=true).

**Respondent Demographics**

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| --- |
| **Respondent Role**  |
| I am a family member of a young child with disabilities/delays or a suspected disability/delay.  | 16.72% (253)  |
| I teach, manage, or provide technical assistance for a local program for young children with disabilities/delays and their families (for example, early intervention or preschool education).  | 26.04% (394)  |
| I teach, manage, or provide technical technical asstance for a local early childhood program (for example, child care, state preschool, Head Start or Early Head Start).  | 38.73% (586)  |
| I provide or manage health services for young children with disabilities/delays and their families in my community (for example, medical homes, public health, home visiting, et.).  | 8.33% (126)  |
| I am a state or federal administrator, policymaker or advocate.  | 10.18% (154)  |
| **TOTAL**  | 1,513  |

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| --- |
| **Respondent Race**  |
|   | **Family**  | **Provider**  | **Policymaker or Advocate**  |
| American Indian and Alaska Native  | 2.99% (5)  | 1.62% (10)  | 4.26% (2)  |
| Asian  | 0.60% (1)  | 1.13% (7)  | 6.38% (3)  |
| Black or African American  | 10.78% (18)  | 6.32% (39)  | 8.51% (4)  |
| Native Hawaiian and Other Pacific Islands  | 0.60% (1)  | 0  | 2.13% (1)  |
| White  | 77.25% (129)  | 79.09% (488)  | 87.23% (41)  |
| Two or more races  | 5.39% (9)  | 2.92% (18)  | 4.26% (2)  |
| Prefer not to specify  | 4.79% (8)  | 7.29% (45)  | 0  |
| Other  | 4.79% (8)  | 2.76% (17)  | 0  |
| **TOTAL**  | Answered: 167 Skipped: 86  | Answered: 617 Skipped: 489  | Answered: 47 Skipped: 107  |

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| **Family Respondent Ethnicity**  |
|   | **Family**  | **Provider**  | **Policymaker or Advocate**  |
| Hispanic/Latine  | 18.93% (32)  | 7.59% (46)  | 6.67% (3)  |
| Not Hispanic/Latine  | 81.07% (137)  | 92.41% (560)  | 93.33% (42)  |
| **TOTAL**  | Answered: 169 Skipped: 84  | Answered: 606 Skipped: 500  | Answered: 45 Skipped: 109  |

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| **Family Respondent Home Language**  |
|   | **Family**  | **Provider**  | **Policymaker or Advocate**  |
| English  | 95.88 (163)  | 97.06% (595)  | 97.92% (47)  |
| Spanish  | 8.82% (15)  | 4.57% (28)  | 6.25% (3)  |
| Arabic  | 0  | 0.16% (1)  | 0  |
| French  | 0  | 0.49% (3)  | 0  |
| Mandarin/Cantonese  | 0  | 0.33% (2)  | 0  |
| Other  | 5.29% (9)  | 1.31% (8)  | 2.08% (10)  |
| **TOTAL**  | Answered: 170 Skipped: 83  | Answered: 613 Skipped: 493  | Answered: 48 Skipped: 106  |

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| **Family Respondent Educational Background**  |
|   | **Family**  | **Provider**  | **Policymaker or Advocate**  |
| Some high school  | 1.18% (2)  | 0.16% (1)  | 0  |
| High school diploma/GED  | 17.06% (29)  | 3.08 (19)  | 0  |
| Child Development Associate (CDA) credential or other professional certificate  | 1.76% (3)  | 5.36% (33)  | 2.04% (1)  |
| Associate’s degree  | 5.88% (10)  | 7.95% (49)  | 4.08% (2)  |
| Some college  | 15.29% (26)  | 3.25% (20)  | 6.12% (3)  |
| Bachelor’s degree  | 24.71% (42)  | 26.30% (162)  | 12.24% (6)  |
| Master’s degree or above  | 34.12% (58)  | 53.90% (332)  | 75.51% (37)  |
| **TOTAL**  | Answered: 170 Skipped: 83  | Answered: 616 Skipped: 490  | Answered: 49 Skipped: 105  |

**Adequate & Robust Funding**

* State and Federal administrators and advocates indicated the following resources **exist but need improvement:**
* Specific funding in the state budget for
* Part C (58% or 41 respondents)
* Part B, Section 619 (58% or 42 respondents)
* 14% or 3 Section 619 administrators indicated having federal or state clarification on blended or braided funding strategies, while 40% or 8 respondents wanted it.
* 56% or 69 Early Intervention Providers, Case Management Services, Related Services for Infants & Toddlers indicated that families they work with have financial constraints related to early intervention services. Challenges included:
* Navigating health insurance systems: 85% or 45 respondents
* Finding alternative systems to pay for services (health insurance is not an option): 62% or 33 respondents
* Needing supplementary financial support regardless of sliding scare fee structures: 35% or 35 respondents
* Other:
* Getting TEFRA
* Eliminated family fees; HMO insurance through EI system
* Child care, housing, transportation, access to Medical waivers through regional centers; no access to respite care
* Lack of transportation to access services
* Time off from work; difficulty finding child care
* Private insurance does not always cover needs and is extremely expensive; loopholed to access Medicaid based on disability not income.
* Assisted family care- students with complex medical needs, nursing staff, etc.
* Access to equipment means making difficult choices
* Availability of services
* Offering pediatric services
* Scheduling conflicts
* Insurance covering no or limited sessions
* All medical home administrator respondents (2) indicated equal billing for developmental screening with Medicaid, SCHIP, private insurance, and no separate funding.
* Administrators indicated that funding reconciliation due state and federal regulations decreases fiscal supports for services when services are combined.
* State and federal administrators and advocates ranked the following funding and budgetary supports:
* Streamlined funding sources from the state and federal government (2.93 out of 4)
* Expert guidance on the true cost of services for children with disabilities within each of the settings in the mixed delivery system (2.67 out of 4)
* Support for blended/braided funding (2.33 out of 4)
* Coordinated requirements for each funding stream (2.09 out of 4)
* State and Federal administrators and advocates indicated the following resources **exist but need improvement:**
* Specific funding in the state budget for
* Part C (58% or 41 respondents)
* Part B, Section 619 (58% or 42 respondents)
* Support for blended/braided funding through coordinated requirements among funding streams (52% or 38 respondents)

**Stable & Diverse Workforce**

* EI professionals and Section 619 administrators specify challenges to their work including:
* Significant/burdensome paperwork requirements (74% or 89 EI professionals, 59% or 13 Section 619 administrators)
* Large caseloads (63% or 76 EI professionals, 45% or 10 Section 619 administrators)
* Insufficient planning time and accessing supports from well-trained paraprofessionals (55% or 12 Section 619 administrators)
* EC educators specify challenges to their work including
* Lack of professional development on effectively supporting children with disabilities/delays and their families (71% or 5 FCC providers)
* Insufficient connections to other professionals who work with children with disabilities and their families (37% or 46 EC teachers, 43% or 3 FCC providers, 37% or 10 home visitors)
* Connecting state and/or local early learning standards with children’s IFSP, IEP, or ISP goals (43% or 3 FCC providers)
* Lack of support from special education or early intervention partners (39% or 49 EC teachers)
* A Family Child Care (FCC) respondent commented that the only support received is through a Facebook group.
* EI/ECSE professionals indicated a wide range of preferred professional development supports including:
* Opportunities for promotion or professional growth within the program (71% or 15 Section 619 administrators)
* Staffing to make manageable caseloads for everyone (69% or 77 EI professionals)
* Coaching supports to provide ongoing feedback and guidance on supporting children with disabilities/delays (in various settings) (67% or 14 Section 619 administrators)
* Certification or degree programs to further your own/staff members’ career(s) (67% or 14 Section 619 administrators)
* Co-training with (early childhood/ special education) partners so everyone is learning the same approaches and messages (63% or 70 EI professionals)
* Other:
* Early Intervention Provider, Case Management Services, Related Services for Infants & Toddlers:
* Mental health for children, parents, and family members
* Funding for programs to hire highly qualified and credentialed staff
* Educate other stakeholders about EI clinical expertise, higher pay and level of coaches to train coaches
* True coaching practice – some reported poor coaching experiences
* Time for regular meetings
* Increase EI workforce and EI workforce preparation programs
* Higher financial compensation
* Increased opportunities to promote child socialization
* Section 619 Administrator
* None of the professional development is reimbursable so the program does less than needed.
* Most frequent reasons that professional development is not used are:
* Not requested by staff (35% or 6 Section 619 administrators)
* Not available within our community (29% or 5 Section 619 administrators)
* EC professionals indicated a wide range of preferred professional development supports including:
* Certification or degree programs to further career(s) (86% or 6 FCC providers and 67% or 116 EC administrators)
* Mental health and wellness activities to support and retain staff (73% or 126 EC administrators)
* Co-training with early intervention/special education partners so everyone is learning the same approaches and messages (71% or 5 FCC providers and 69% or 20 home visitors)
* Training on services for children with disabilities (71% or 5 FCC providers and 68% or 105 EC teachers)
* Coaching supports to provide ongoing feedback and guidance on supporting children with disabilities/delays (in various settings) (69% or 119 EC administrators)
* Opportunities for promotion or professional growth within the program (68% or 117 EC administrators)
* Staffing teaching teams to support adult-child ratios (67% or 115 EC administrators)
* Recruitment of professionals who reflect the race, languages, and/or cultures of the families you serve (62% or 107 EC administrators)
* Other:
* ECE Teachers
* Access to Education and Behavior Specialist
* Extra support for children with challenging behaviors
* Smaller class size
* More staff
* Family Child Care
* Should be offered but not required – people will leave the field if these are required.
* Most frequent reasons that professional development is not used are:
* Not available within the community (33% or 49 EC administrators)
* Too expensive (30% or 45 EC administrators)
* Not requested by staff (29% or 43 EC administrators)
* EC administrators indicated using the following for their own PD supports:
* general PD including workshops, coaching, mentoring
* Wellness supports
* Compensation analysis
* Technical assistance through state QRIS, CCR&Rs, NAEYC
* Supervision supports including reflective supervision
* T.E.A.C.H. scholarships
* Section 619 administrators indicated using the following for their own PD supports:
* Online support
* Peer-to-Peer support
* Public school Human Resources supports
* Staffing impacts capacity
* Statewide professional development and meetings
* Wellness opportunities
* TA providers working with
* EI (75% or 6 respondents), ECSE (78% or 7 respondents), and EC (75% or 3 respondents) programs indicate hiring and retaining staff is a significant challenge.
* EI (75% or 6 respondents) and ECSE (56% or 5 respondents) programs indicate challenges in managing large caseloads.
* EI (63% or 9 respondents) and ECSE (56% or 5 respondents) programs indicate hiring and retaining staff is a significant challenge.
* TA providers (67% or 2 EC programs, 57% or 4 EI programs, and 50% or 4 ECSE programs) indicate professional development registries to support staff in progressing on career ladders **should be improved.**
* State and Federal administrators indicated the following
* **exist but need improvement**
* Requirements that ensure staffing structures provide appropriate adult-child ratios (44% or 22 respondents)
* Legislation or initiatives to support personnel preparation programs to increase the workforce (42% or 21 respondents)
* Public/private partnerships to incentivize workforce recruitment/retention (37% or 18 respondents)
* Focus on recruitment/retention of a diverse workforce to represent the children with disabilities and their families receiving services (34% or 17 respondents)
* **doesn’t exist but should be created**
* Focus on recruitment/retention of a diverse workforce to represent the children with disabilities and their families receiving services (38% or 19 respondents)
* Legislation or initiatives to support personnel preparation programs to increase the workforce (34% or 17 respondents)

* **Governance that Enhances Coordination and Collaboration**
* When asked about perceptions of referrals to partners, health providers indicated they were “very easy” when working with early intervention:
* 67% or 10 Direct health services providers,
* 50% or 1 Medical home administrator,
* 73% or 8 local health services administrators)
* Direct health providers indicated the most difficult referrals were to early childhood special education (19% or 3 respondents selecting “moderately difficult” and 13% or 2 respondents selecting “very difficult”)
* Health providers indicate varying degrees of ease in collaborating with special education partners:
* “moderately easy” collaborations with preschool special education and other specialists who diagnose children with a disability/delay (43% or 6 direct health services providers)
* “very easy” collaborations with early intervention (82% or 9 local health services administrators) and preschool special education (45% or 5 local health services providers
* Medical home administrators and local health services administrators indicated the most difficult referrals were to other specialists who diagnose children with a disability/delay.
* EI professionals indicated partnering with:
* Early childhood educators: 94% or 103 respondents
* Health providers: 75% or 83 respondents
* Social workers or other family service supports: 73% or 80 respondents
* Mental health providers: 44% or 48 respondents
* Most (24 or 77%) home visitors indicated conducting home visits with early intervention or special education.
* EI Professionals and Section 619 administrators specify challenges to their work including:
* Caseloads that require significant collaboration with partners (58% or 69 EI professionals)
* Planning with the EC teacher (57% or 12 Section 619 administrators)
* Scheduling with the EC teacher (52% or 11 Section 619 administrators)
* Clearly defining roles and responsibilities in the setting (52% or 11 Section 619 administrators)
* Challenges to collaboration reported by EC administrators include:
* Planning with the early intervention, special education, or related services: 60% or 101 responses
* Scheduling services with the early intervention, special education, or related services providers: 58% or 97 responses
* Lack of professional development for effectively supporting children with disabilities/delays (57% or 95 responses)
* EC professionals indicate needing **more access** to:
* Connections to community partners who support children with IEPs, IFSPs, and ISPs and their families (67% of 91 EC administrators)
* Early intervention and preschool special education collaboration supports include:
* Planning and problem solving together: 81% or 88 EI professionals
* Meeting and communication regularly: 69% or 75 EI professionals and 67% or 14 Section 619 administrators
* Sharing child and family data (with FERPA and HIPAA compliance): 62% or 68 EI professionals
* Participation in community-wide organizations like the LICC (57% or 12 Section 619 administrators)
* Of desired collaboration supports selected by Section 619 administrators, only two were areas where administrators indicated wanting more than they currently had:
* Shared data systems that support partners in gathering and using data jointly (43% or 9 currently have these and 50% or 10 would like to have them)
* Connections to local Parent Training and Information Centers (19% or 4 currently have these and 40% or 8 would like to have them)
* TA providers identified collaborating as a challenge for EI (75% or 6 responses) and preschool special education (56% or 5 responses). They identified several resources that should be improved including:
* Community wide systems that support coordination including the LICC, CCR&Rs or Head Start HSACs (71% or 5 EI responses and 86% or 6 ECSE responses)
* State or local support to address topics like racial equity, social determinants of health, and mental health (57% or 4 EI responses, 50% or 4 ECSE responses, and 75% or 3 EC responses)
* Data systems are used for program improvement and mandatory reporting requirements.
* Most EI professionals indicated using a program-wide system that all staff use to gather comprehensive data (beyond what is gathered by the state) (46% or 50 respondents)
* Most Section 619 administrators indicated using statewide K-12 systems (43% or 9 respondents)
* About 2/3 of Section 619 and EC administrators indicated their reports offered sufficient detail. Recommendations for improvements included:
* Funding to support time for data and paperwork
* Enhanced data collection systems that support data disaggregation and analysis
* Better connections between data systems
* Enhanced data collection for mental health/trauma, dosage, and progress monitoring
* Outcomes driven data collection systems that support analysis at multiple levels
* Simplified reporting requirement and clearer connections to program improvement measures
* TA providers working in EI and ECSE thought simple data systems that provide child outcomes data from various partners for quality improvement efforts and reporting to families and state/federal administrators should be
* created (43% or 3 EI TA providers, 38% or 3 ECSE TA providers)
* improved (43% or 3 EI TA providers, 50% or 4 ECSE TA providers)
* State and federal administrators and advocates indicated the following **don’t exist but should be created**:
* Coordination of continuity between data system providing information from birth through 12th grade (46% or 23 respondents)
* Data systems that track and assess the programmatic quality for disability services across the mixed delivery system (42% or 20 respondents)
* Other:
* Periodic and systemic assessment of data systems to ensure effectiveness
* Creation of hubs for services and continuity between systems
* Statewide consistency
* Better systems for home-based services
* Systems that integrate qualitative data (which will support racial and thnic equity)
* Streamlined system rather than separate systems
* More data on timeliness of services
* Parent voice in data systems
* Section 619 Administrators indicated several ways in which state and federal regulations impact collaborations:
* State rates for EI, special educators, and related service providers offer disparities in incomes for providers making collaborations more difficult
* Transitions at the age of three causing disruptions in services
* Some state laws inhibit full day services through paperwork and fee structures
* State and Federal administrators and advocates indicated funded initiatives to promote partnership among community partners to identify and support children with disabilities and their families **exist but need improvement** (58% or 42 respondents)
* 66% or 48 state and federal administrators and advocates indicated birth to five programming and collaborations to support continuity of care **exist but need improvement.**
* Most families indicated **not** being aware of opportunities to participate in leadership or advocacy to improve early intervention and special education services (40% or 29 EI families, 30% or 30 ECSE families)
* State and Federal administrators and advocates indicated that leadership opportunities within the local and state/territory/district for families of children with disabilities **exist but need improvement** (66% or 48 respondents)
* State and Federal administrators and advocates ranked family engagement activities including:
* Ongoing stakeholder engagement activities which provide feedback opportunities (2.5 out of 4)
* Leadership opportunities within the local and state/territory/district level (2.04 out of 4)
* Most state and federal administrators or advocates participate in the state Early Childhood Advisory Council, Early Childhood Commission, or other Interagency Collaboration but vary depending on the organizations they are aligned with.
* Preschool Development Grant (100% or 9 respondents)
* Child welfare services (100% or 4 responses)
* Maternal Infant and Early Childhood Home Visiting Program 89% or 8 responses)
* Head Start (94% or 15 responses)
* Child care (74% or 14 responses)
* Early intervention (72% or 23 responses)
* Public preschool (71% or 10 responses)
* Preschool special education (64% or 16 responses)
* Child and family services (63% or 5 respondents)
* Public health (50% or 2 responses)
* Thirty (59%) of state and federal administrator and advocates indicated representatives from disability services participate in state, territory, or district councils, commissions, and collaborations, while 5 or 10% indicated disability service providers are not represented and 16 or 31% indicated they were not sure.
* State and federal administrators and advocates indicated coordination of continuity and providing information with K-12 **exists but need improvement** (57% or 17 respondents)

**Family- and Child-Centered Screening, Eligibility & Evaluation**

* All direct health services providers and medical home administrators indicated awareness of the automatic eligibility for early intervention. 82% or 9 local health program administrators were aware.
* All direct health services providers and medical home administrators indicated awareness of eligibility through medical diagnosis while 91% or 10 local health program administrators were aware.
* The majority of respondents indicated that their program is responsible for conducting screening:
* 100% or 3 of medical home administrators
* 88% or 45 of home visitors (most often the responsibility of the home visitor [71% or 25], educational consultants [23% or 8], or other professionals [20% or 7])
* 87% or 245 of early childhood program administrators
* 86% or 19 of local health program administrators
* 84% or 222 of early childhood teacher respondents (most often the responsibility of the lead teacher [79% or 162], assistant teachers [38% or 77], educational consultants [23% or 47], or other professionals [44 or 22%])
* 79% or 26 of direct health providers
* 67% or 10 family child care providers
* Respondents from health and early childhood education indicated screening children when:
* they have developmental concerns (64% or 333 responses)
* a child is newly enrolled (60% or 311 responses).
* Approximately two-thirds of respondents indicated screening within 45 days of enrollment which aligns with Head Start requirements (148 or 93% of early childhood administrators who indicated receiving funding from Head Start responded that they meet this requirement).
* Slightly less than half (49% or 253) of the responses indicated screening all children annually.
* Most screening occurred at either the child’s doctor’s office or early childhood program.
* Most (41% or 302 family respondents) indicated these screenings occurred in the doctor’s office, followed by 237 or 32% who were screened by an early childhood program.
* Most (71 or 24% in the doctor’s office and 54 or 23% at the early childhood program) of these evaluations occurred when the child was 2 years old but the screenings were delivered from infancy until the child reached 5 years old.
* Most Section 619 Administrators indicated that
* “yes”, they received screening results (48% or 16 responses) or
* “sometimes” (40% or 13) they received screening results.
* Most (43% or 65) child find providers indicated receiving screening results “sometimes”
* Only one third indicated “yes” they received screening results.
* When asked if their children received screening, 90% or 217 families indicated that their children were screened.
* Section 619 administrators collect demographic data including:
* Eligibility: 90% or 19 respondents
* Referral: 81% or 17 respondents
* There is variability in families’ understanding of eligibility:
* Of families who want(ed) EI Services, 21 or 64% indicated they were provided resources to understand eligibility criteria, while 7 (21%) did not and 5 (15%) were unsure.
* For families who want(ed) ECSE services, 7 or 47% reported they were provided resources to understand eligibility criteria, while 6 (40%) did not and 2 (13%) were unsure.
* When disaggregating data regarding family perspectives of the ease of understanding eligibility criteria, few indicated that it was “very easy”.
* Families who want(ed) EI services with 2 year old found it “somewhat easy” (83%) yet families of 3 year old most often found it “somewhat hard” (60%).
* Families who want(ed) ECSE services were most likely to find it “somewhat hard” to understand eligibility criteria regardless of age.
* There were no significant discrepancies in race or ethnicity.
* The majority of families felt they were able to share at least some information during the eligibility process
* 55% or 16 Families who want[ed] EI indicated “yes”
* 21% or 6 Families who want[ed] EI indicated “somewhat”
* 38% or 6 Families who want[ed] ECSE indicated “yes”
* 23% or 3 Families who want[ed] ECSE indicated “somewhat”
* Responses from early intervention, special education, and early childhood professionals reflected on the availability of specific resources to support families through the referral and evaluation process, indicating **less** availability of:
* Evaluations that integrate the culture of the family (responses between 31% to 53%)
* Easy-to-understand information about eligibility under the medical condition and diagnosis category (responses of 50%)
* Resources written in all of the home languages represented within your service area (responses between 30% and 41%)
* A single application that parents can fill in to apply for multiple early childhood programs (responses between 18 and 32%)
* Other themes that arose in requests to support families through the referral process included:
* Access to community resources including affordable ECE
* Clearer understanding of the process and options by ECE providers and health providers
* Clear and slow description of rights and process (including insurance and billing); easy-to-understand, culturally responsive, multi-lingual handouts; clarifications on EI and other services with contact and eligibility information; one-stop shop for information
* Coordination between all agencies serving the family
* Decreased paperwork
* Flexible scheduling including weekend, evening, and summer options
* Funding
* Smaller caseloads
* Staffing including enrollment staff and parent liaisons, reliable, well-trained itinerant service and related service providers, multi-lingual speakers, and inclusion, intake, and eligibility specialist
* Translation/ Interpretation
* The majority of early childhood education and health respondents indicated
* supporting families through the referral process (77% or 399 responses),
* conducting follow up on screening results (75% or 790 responses), and
* coordinating with early intervention or special education providers (71% or 371).
* Most early childhood respondents participation during the eligibility process included:
* All early childhood respondents talked with the family about their child’s developmental strengths and challenges **most often** (87% or 150 EC teachers, 92% or 12 FCC providers, 87% or 27 home visitors)
* Early childhood teachers developed and used an individualization plan during the eligibility process **least often** (51% or 99 respondents)
* Family child care participated in eligibility meetings, talked with family about the eligibility process, and developed and used an individualization plan during the eligibility process **least often** (31% or 4 respondents)
* Home visitors developed and used an individualization plan for the child before the referral **least often** (35% or 11 respondents)
* When asked about challenges within the referral process,
* Early childhood teachers and family child care providers indicated that:
* Families complain that they don’t understand the eligibility process (33% or 57 EC teachers and 69% or 7 FCC providers)
* The early intervention or special education partner requests more child data specific to individualization for the child before launching the eligibility process (34% or 59 EC Teachers)
* The overall referral process is unclear (62% or 8 FCC providers)
* It’s unclear what makes a child eligible for services (62% or 8 FCC providers)
* Health providers indicated that:
* Utilizing a social determinants of health and racial equity lens in providing health services was **extremely helpful** for 53% or 8 direct health services providers
* Collaborating with the eligibility team to share medical findings was **extremely helpful** for 56% or 5 local health services administrators
* The majority of EC administrators (73% of 108 respondents) reported receiving pre-referral consultants while 78% or 21 Section 619 administrators reported offering pre-referral consultation. Supports included:
* Teacher consultants, technical assistance, coaching
* Response to Intervention/Multi-tiered systems of support
* Behavioral assessment and intervention, supports for challenging behaviors
* Child and family resources
* Classroom accommodations including assistive technology
* EC professionals indicate needing more access to:
* Coaching in ways to include children with disabilities in program activities (67% or 104 EC administrators)
* Access to mental health consultants to support staff in creating positive learning environments and integrating social emotional learning (62% or 98 EC administrators)
* Coaching from mental health professionals to support children with challenging behaviors (58% or 57 EC teachers and 64% or 14 home visitors)
* Strategies to individualize for specific child needs (68% or 107 EC administrators)
* Connections to community partners who support children with delays and their families (62% or 98 EC administrators)
* EC professionals commented on the culturally responsive referral and eligibility process
* Early childhood teachers (62% or 107) and home visitors (81% or 26) reported access to translators/interpreters, while 77% or 10 FCC providers indicated not being sure.
* Early childhood teachers (51% or 89) and home visitors (53% or 17) reported integration of family culture, while 62% or 8 FCC providers indicated not being sure.
* Challenges include:
* Lack of translators
* Incongruence between culture and social emotional evaluation tools
* Recognizing cultural differences
* When presented with results,
* Families most often agree when their child is found eligible and disagree when found ineligible.
* 59% or 10 families who want(ed) EI selected “strongly agree” and 7 or 41% selected “agree”
* 60% or 3 families who want(ed) EI selected “strongly disagree” and 2 or 40% selected “disagree”
* 43% or 3 families who want(ed) EI selected “strongly agree” and 4 or 57% selected “agree”
* 100% or 1 families who want(ed) EI selected “strongly disagree”
* EC professionals varied in their responses to eligibility determination
* 67% or 117 EC Teachers generally **agreed**
* 53% or 17 home visitors generally **agreed**
* 54% or 7 FCC providers generally **disagreed**
* Trends in factors cited included:
* Age
* Family refusal
* Lack of funding
* Language barriers
* Strict eligibility definitions
* Families responded to questions about alternative services
* Of the families who want(ed) early intervention who reported not being able to get EI services,
* 16 or 57% reported looking elsewhere for services to support child development, while 7 or 25% indicated not looking and 5 or 19% were unsure if they looked for services elsewhere.
* Twelve or 71% were able to get services elsewhere, while 5 or 29% were not.
* There was a moderate correlation between those who sought and received services elsewhere.
* Of the families who want(ed) early childhood special education who reported not being able to get ECSE services,
* 9 or 64% indicated looking elsewhere to support their child’s development, while 1 or 7% indicated not looking and 4 or 29% indicated not being sure if they looked.
* Seven or 78% were able to get services elsewhere, while 2 or 22% were not.
* There is a very strong correlation (r = .92) between whether individuals sought services and were able to get them elsewhere.
* Families overall commented about
* What worked:
* Clarity about eligibility, expectations, and the process
* Using an advocate
* Challenges:
* Lack of timely identification or drawn out evaluation process
* Insufficient supports for families to understand the requirements and process
* Recommended changes:
* Improve family-centered practices
* Simplify referral, evaluation, and re-evaluation process
* Earlier screening
* Faster timelines
* Child find professionals selected factors that influence services and placement including availability within settings (25 responses), child’s eligibility classification (24 responses), and family preferences (23 responses). Quality within settings (11 responses) and cultural and linguistic appropriateness (12 responses) are the least common responses.
* Additionally, Child Find respondents reported screenings of children referred to them occurred most frequently (77 or 72%) at early childhood programs, followed by 47 or 44% reporting receiving screening results from doctor’s offices.
* Health providers indicate needing more access to:
* State and Federally funded initiatives to promote developmental screening and monitoring (64% or 7 medical home administrators)
* Guidance regarding Medicaid requirements for children at risk for or diagnosed with disabilities/delays (75% or 6 local health program administrators)
* State and local collaborations on early identification of children with disabilities/delays 64% or 5 local health program administrators)
* Resources and training on development screening tools (73% or 8 direct service provider)
* TA providers indicated activities, policies & procedures, and plans to promote development before or during referral **should be improved** (86% or 6 in ECSE programs)
* State and Federal administrators and advocates indicated the following family engagement initiatives to promote awareness of  the following **exist but need improvement:**
* EC programs (73% or 55 respondents)
* EI programs (66% or 49 respondents)
* ECSE programs (64% or 46 respondents)
* State and Federal administrators and advocates ranked family engagement activities including:
* Streamlined enrollment systems (3.03 out of 4)
* Multi-lingual, multi-cultural training for staff to support conversations with families (2.41 out of 4)
* State and Federal administrators and advocates ranked:
* Prioritizing universal screening for all young children ages birth to five as a priority with a score of 3.99 out of 5.
* Standards or guidance for valid & reliable screening and evaluation tools for children who are culturally and/or linguistically diverse: 3.01 out of 5
* Initiatives to address disproportionate representation within early childhood special education services: 2.89 out of 5
* Clearly defined eligibility criteria: 2.83 out of 5
* Integration and enforcement of the use of developmental screening as part of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program nationally: 2.38 out of 5
* Most state and federal administrators and advocates (41% or 30 respondents) indicated that streamlined recruitment and enrollment systems **exist** to simplify screening, referral, and enrollment process for families exist **but need improvement**. 38% (28 respondents) indicated these systems **did not exist but should be created**.
* Most state and federal administrators and advocates (42% or 30 respondents) also indicated that the use of local “hubs” for referrals to comprehensive services for children with disabilities and their families **exist but need improvement**. 27% (19 respondents) indicated these **do not exist but should**.
* Health providers indicated that EPSDT requirements help promote early diagnosis and treatment during the well child check or regular health visits.

**Equitable & Inclusive Service Delivery**

* Most families viewed IFSP/IEP creation as very easy or somewhat easy
* 37% or 29 “very easy” and 38% or 30 “somewhat easy” IFSP creation
* 30% or 34 “very easy” and 29% or 32 “somewhat easy” IEP creation
* More families felt they co-created their IFSP than their IEP.
* 67% or 53 co-created the IFSP, while 22% or 17 felt they could have been more involved
* 40% or 44 co-created the IEP, while 33% or 36 felt they could have been more involved
* Section 619 administrators collect demographic data including:
* Timeliness including: date of referral, evaluation completion, eligibility determination, and service start date: 90% or 19 responses
* Hours delivered by type of service: 76% or 16 respondents
* Hours delivered by family outcome: 5% or 1 respondent
* Families receiving early intervention indicated slightly faster services than families receiving early childhood special education services
* The majority of families report receiving an EI evaluation within 4 – 6 weeks (76% or 60 respondents)
* The majority of families report receiving a preschool special education evaluation within 2 months (67% or 75 respondents)
* The majority of families report having a fully created IFSP within 4-6 weeks (81% or 63 respondents)
* The majority of families report having a fully created IEP within 2 months (65% or 73 respondents)
* The majority of families indicated receiving IFSP services within a month (70% or 52 respondents)
* The majority of families indicated receiving IEP services within a month (54% or 58 respondents)
* EI, case management, and infant toddler related services providers indicate accessing timely services often (48% or 59 responses). Barriers to new services include:
* Communicating with families: 82 (66%)
* Shortage/lack of availability of staff to provide the services: 74 (60%)
* Determining a schedule for services: 61 (49%)
* Language barriers for non-English speakers: 52 (42%)
* Coordinating with other providers in the IFSP: 43 (35%)
* Determining location for services: 21 (17%)
* Other (please specify): 24 (19%)
* TA providers indicated guidance on timeline requirements should be improved (46% or 31 in EI programs; 71% or 5 in ECSE programs)
* Families were more satisfied with IFSP services than IEP services
* 41% or 32 families were “very satisfied” with their IFSP services versus 26% or 26 families who were “very satisfied” with IEP services.
* 22% or 22 families were “very dissatisfied” with their IEP services versus 7% or 6 families who were “very dissatisfied”
* About two thirds of families were satisfied with their EI dosage, while the other third wanted more.
* 60% or 45 families indicated receiving EI services as often as needed, while 36% or 27 families desire more services.
* 61% or 45 families indicated receiving EI services as long as needed, while 34% or 25 families wanted services for a longer period of time.
* Section 619 administrators collect demographic data including:
* Hours delivered by type of service: 76% or 16 respondents
* Hours delivered by outcome: 5% or 1 respondent
* Location of service delivery: 57% or 12 responses
* Families of children in Early Intervention were more likely to access services where they wanted them than parents of children in preschool special education:
* Correlations between parent reported and desired services for early intervention in home visiting (r = .85) and child care (r = .78) were very strong.
* Correlations between parent reported and desired services in preschool special education services with children do not have disabilities the majority of the time (r = .59) and in a separate classroom with other children with disabilities (r = .50) were moderate.
* Most (60 or 61%) family respondents indicated they were able to send their child where they wanted to send them, and they were still able to receive their special education services. 24 or 24% of family respondents indicated they were not able to send their child where they wanted to send them because of where they needed to receive their special education services. 15 other respondents indicated challenges included:
* Covid complications
* Financial constraints
* Health insurance coverage
* Lack of placement options
* Lack of transportation
* Length of day/times for services
* Out of district placement
* Required parental case coordination
* Still waiting
* Additional programs reported by Part C, Section 619, and early childhood administrators include:
* Most often
* Head Start/Early Head Start (57% - 64%)
* WIC (47% - 70%)
* Maternal, Infant, and Early Childhood Home Visiting (6% - 67%)
* Child care subsidy (37% - 55%)
* Least often
* Title I (3% - 30%)
* None (6% - 20%)
* Most providers indicated families requested a different setting for their child (50% to 100%)
* EI, case management, and infant toddler related service providers indicated the desired setting is not a location where services can be provided (66% or 33 respondents)
* Home visitors indicated the desired program had no room for enrollment (71% or 25 respondents)
* EC administrators defined natural environments as:
* Resources and accommodations similar to home
* Homes and places within the community
* Same classroom/settings with all other children
* Different for each child to support access
* Where the child is comfortable and learning
* Places where they spend time
* “Calming colors, natural fibers and textures, outdoor environments that encourage investigation with nature”
* Developmentally appropriate practice and culturally appropriate
* Most (127 or 67%) Early Childhood Administrators indicated wanting more clarity of the Natural Environment definition from the Federal government.
* Services reported by Early Intervention professionals are delivered
* Most often in family homes through home visiting (84% or 122 Part C providers and 79% or 26 Part C administrators), telehealth/virtual visits (48% or 70 Part C providers and 45% or 15 Part C administrators), and child care centers (41% or 60 Part C providers and 55% or 18 Part C administrators)
* Least often in medical environment (4% or 6 Part C providers), self-contained special education classroom (19% or 28 Part C providers and 6% or 2 Part C administrators), and parent-child centers (13% or 19 Part C providers and 15% or 5 Part C administrators)
* Most (19 or 73%) Section 619 Administrators did not indicate wanting more clarity of the LRE definition from the Federal government. Section 619 administrators offered definitions of LRE including
* “Meeting a child’s needs with the least amount of extra support”
* “Includes students with disabilities having the same access to general education programs as their non-disabled peers.”
* “To the maximum extent appropriate” with nondisabled peers and where special education students are not removed.
* “Consider supplementary aides and services to support prior to a more restrictive setting”
* Most (107 or 56%) EC administrators indicated wanting more clarity of the Least Restrictive Environment definition from the Federal government. EC Administrators included definitions of LRE including:
* Same classroom with all other children
* Environment where children receive necessary services
* “To the maximum extent appropriate, with nondisabled peers and that special education students are not removed from regular classes, unless, even with supplemental aids and services, education in regular classes cannot be achieved satisfactorily.”
* Place children would attend if they did not have disabilities
* Children feel part of the classroom community
* “Reggio inspired, open play, open ended invitations to play”
* EC professionals indicated wanting **more** access to
* inclusion specialists to learn ideas and solutions (46% or 31 EC teachers)
* mental health consultants to support staff in creating positive learning environments and integrating social emotional learning (59% or 79 EC administrators)
* guidance from medical professionals about children with medical or health concerns (62% or 82 EC administrators)
* training for staff in inclusive practices (71% or 94 EC administrators)
* Most EI, Case Management, and Infant Toddler Related Services Providers report
* not offering services in settings with nondisabled peers: 93% or 34 providers
* Providing services in their setting: 78% or 73 respondents.
* State and Federal administrators indicated that the availability of high-quality infant toddler programs within the mixed delivery system **needs improvement** (63% or 45 respondents)
* Virtual services or telehealth are available.
* 92% of 111 EI respondents offered virtual services with 59% or 64 requiring parent responsibility for technology.
* 43 or 59% of state and federal administrators and advocates indicated approved telehealth and/or virtual learning opportunities exist but need improvement
* 31 or 44% of EI families indicated not having access to an extended IFSP but wishing it was available.
* Services reported by special education professionals are delivered:
* Most often in school based preschool (46% or 32 Section 619 providers and 77% or 23 Section 619 administrators) and self-contained special education classroom (50% or 35 Section 619 providers and 53% or 16 Section 619 administrators)
* Least often in telehealth/virtual visits (4% or 4 Section 619 providers and 3% or 10 Section 619 administrators), family child care/home day care (9% or 6 Section 619 providers and 17% or 5 Section 619 administrators), and child care center (13% or 9 Section 619 providers and 40% or 12 Section 619 administrators)
* Most EC Teachers (47% or 62 respondents) and administrators (46% or 87 respondents) report children are “sometimes” removed from their classrooms. They receive services:
* **Most often** in the same building: 63% or 70 respondents
* **Least often** in a community setting: 13% or 15 respondents
* Transported **most often** by a parent or approved adult’s vehicle (46% or 51 respondents) and in a bus provided by general education program (43% or 48 respondents)
* Transported **least often** by a bus provided by the special education program (8% or 9 respondents) or other transportation (8% or 9 respondents)
* Most families felt like the provider is/was respectful of the family culture (92% or 65 EI families; 80% or 79 ECSE families)
* Most early intervention providers, case management services, and related service providers for infants and toddlers (49 or 43%) indicate accessing translators and/or interpreters is an issue for the program. Forty-one (36%) respondents did not indicate trouble accessing translators and/or interpreters while 24 or 21% of respondents indicated not knowing.
* Section 619 and EC administrators collect demographic data including:
* Race (81% or 17 619 respondents and 62% or 87 EC administrators)
* Gender (81% or 17 619 respondents and 61% or 86 EC administrators)
* Home language (76% or 16 619 respondents and 59% or 83 EC administrators)
* Ethnicity (76% or 16 619 respondents and 60% or 84 EC administrators)
* Homelessness (62% or 13 619 respondents and 56% or 70 EC administrators)
* When looking at data collected, Section 619 administrators identified some areas where over- or under-representation may exist:
* Poverty or income level (32% or 6 respondents)
* Race (26% or 5 respondents) *(there is a moderate connection between those who indicated that they collected this data also indicated this as an area of over-/under-representation)*
* Comments from respondents focus on:
* Socio-economic disparities and gaps in services by socioeconomic level (the donut hole)
* Services for multi-lingual children
* Generalized services which do not differentiate for children’s individual culture, preferences, or needs
* Smaller early learning programs don’t have resources for inclusive settings
* Parental stigmas about disability and delays, particularly behavior
* Child care deserts, particularly after COVID-19
* Age – as children turn three they often lose services
* Geographical disparities (access to transportation)
* Lack of staff who represent the population served
* Telecommunications/technology gaps
* Cultural value of education for families
* Language barriers
* Education gaps for families
* Teachers and addressing implicit/explicit bias
* Discrepancies in identification of challenging behaviors by race
* Over-/under-identification of children with developmental delay by race
* District size and access to resources (tax base)
* When families were asked about negative experiences, they responded:
* Families of children in EI (43% or 17 respondents), ECSE (61% or 46 respondents), families who want(ed) EI (30% or 8 respondents), and ECSE (33% or 4 respondents) felt they were not taken seriously **most often**
* Families of children in ECSE also reported interactions that made them feel uncomfortable (47% or 35 respondents)
* Language barriers (8% or 3 EI families, 4% or 3 ECSE families) and racial bias (3% or 1 EI families, 9% or 7 ECSE families, 4% or 1 families who want EI) were least often selected as negative experiences
* Most families indicated being “very satisfied” with EI services (43% or 33 respondents) and “somewhat satisfied” with ECSE services (30% or 29 respondents)
* Early intervention providers, case management services, and related service providers for infants and toddlers support families who disengage or are non-responsive to attempts made by:
* Individual communication with families: 77 or 68% respondents
* Connections with other service providers to re-engage families: 17 or 15% respondents
* Relationships with trusted community organizations that support follow-up and re-engagement: 9 or 8% respondents
* Other: 10 or 9% respondents
* Families are dropped if no response after 3 attempts.
* All of the above
* EC professionals indicating wanting **more access** to guidance from EI/ECSE partners on program discipline and short-term exclusion policies and procedures (63% or 81 EC administrators)
* 75% or 128 EC teachers indicated their program has policies and procedures for challenging behaviors. 77% or 99 also indicated including considerations or adaptations for children with disabilities/delays in these policies and procedures.
* Families overall commented about
* What worked:
* Interventionists adapting to the individual family needs
* Services at a location the family prefers
* Specialized parent training
* Ongoing, open communication
* Strong connections with knowledgeable, experienced, nurturing practitioners
* Inclusive, nurturing placement setting
* Well-coordinated, family-centered transitions
* Self confidence in parental ability
* Challenges:
* Not enough or inconsistent services
* Lack of integration between systems
* Lack of inclusive programs
* Insufficient open and ongoing communication
* Conflicting approaches from multiple providers
* Insufficient social emotional learning
* Transitions
* Providers with lack of experience and knowledge
* Disconnect/lack of trust between families and providers
* COVID
* Staff turnover
* Managing childhood behaviors
* Bias and segregation
* Disagreement within the IEP team
* Exclusionary practices
* Transportation
* Recommended changes:
* Improve family-centered practices
* Communication systems
* Transition planning
* More inclusive settings
* Individualize intensity of dosage to the child and family’s needs
* Improve quality of staff
* Extended IFSP
* More supplementary supports and services, particularly assistive technology
* More educational to support parental advocacy
* Use of professional advocates
* Training for all staff regarding inclusion and collaboration
* Address segregation and bias
* Earlier screening
* Faster timelines
* Integration of ACEs and trauma informed practices
* Families of children in EI indicated that 47 or 69% also had IEPs, while 21 or 30% did not. Families who want(ed) EI services indicated that 12 or 44% also tried (or are currently trying) to get ECSE services, while 15 or 56% indicated they did not.
* EI professionals believe transitions are either “somewhat easy” or “somewhat challenging” (36% or 41 respondents for each option). Families also are equally split with 17% or 11 indicating it was “somewhat difficult” and 15% or 10 indicating it was “somewhat easy”.
* Transition challenges include:
* Coordinating with the preschool special education partners (75% or 33 EI professionals)
* Coordinating with the receiving program or school’s staff (70% or 109 EC administrators and 61% and 11 Section 619 administrators)
* The timeline/timing of transitioning from EL to preschool special education (68% or 30 EI professionals
* Helping the family understand the IEP and preschool special education (61% or 27 EI professionals)
* Helping families through the eligibility or enrollment process (56% or 10 Section 619 administrators and 45% or 70 EC administrators)
* Coordinating with multiple partners is a challenge (52% or 14 home visitors)
* Families do not understand the requirements (48% or 13 home visitors and 67% or 4 FCC providers)
* Transferring data about child progress (48% or 75 EC administrator)
* TA providers working with EC programs indicate promoting school readiness for children with disabilities/delays (75% or 3 respondents). Recommendations included creating crosswalks from federal and state programs defining similarities and differences in regulations (57% or 4 ECSE TA providers)
* TA providers in ECSE settings indicate accessing the LRE is a challenge (67% or 6 respondents) or promoting access to the general education curriculum (78% or 7 respondents)
* TA providers indicated that guidance from state and federal administrators on inclusive policies and practices should be improved (71% or 5 TA in EI; 75% or 6 TA in ECSE; or 100% or 3 ECE)
* State and Federal administrators indicated that the availability of high quality preschool programs within the mixed delivery system needs improvement (76% or 55 respondents)
* Section 619 administrators collect demographic data including progress towards IEP goals: 71% or 15 responses
* State and federal administrators indicate the following exist but need improvement:
* Early education program policies (including Head Start, child care, public pre-K and K-12) regarding transitions for children with disabilities between early intervention, preschool special education, and kindergarten (84% or 43 respondents)
* Family-centered initiatives to ensure children with disabilities receive continuity of services during transitions (65% or 33 respondents)
* High level collaborations regarding enrollment and eligibility transitions and data transfer during transitions (56% or 28 respondents)
* Monitoring and enforcement systems to ensure children with disabilities have access to natural environments and the least restrictive environments (61% or 31 respondents)
* Section 619 Administrators described the following strategies to support families in understanding the complaint procedures
* Offer printed information at eligibility meetings: 17 or 81% respondents
* Offer verbal information at eligibility meetings: 8 or 38% respondents
* Offer printed information at IEP/IFSP meetings: 10 or 48% respondents
* Offer verbal information at IEP/IFSP meetings: 7 or 33% respondents
* Include in the parent handbook or other parent publications: 14 or 67% respondents
* Other: 4 or 19% respondents
* Regular conversations
* Parent orientation
* Referral
* PAC meetings, website, and social media posts
* Families of children in ECSE indicated clear and easy ways to provide feedback (45% or 45 respondents) and feedback or concerns would be
* Addressed (39& or 39 respondents)
* taken into consideration but not necessarily addressed (38% or 27 respondents)

**Appendix C: Feedback Session Summary Results**

**Adequate & Robust Funding**

* When blended funding models exist, general education teachers feel like they are less responsible
* Supporting young children with disabilities or developmental delay works when
* Families have financial support
* Challenges include:
* Funding issues that lead to grouping children with different needs
* Families are dropping out earlier because of funding issues
* Improvements suggested:
* Work with providers and insurers to expand coverage
* Adequate funding for programs including Medicaid and IDEA
* Incentivize programs to provide services for at-risk children

**Stable & Diverse Workforce**

* Use of CLASS observations to determine teacher effectiveness
* Needs to be stronger teacher preparation and partnerships with institutes of higher education
* Set aside for Early Intervention Workforce within the Federal budget
* Supporting young children with disabilities or developmental delay works when
* Teachers work with strategies and have a good disposition to work with children
* Provider education to implement in the classroom to add enrichment
* More of all types of staff to support children and families
* Challenges include:
* Teachers who do not have deep knowledge on
* disabilities or ADHD/Autism
* supporting families in times of crisis
* understanding and managing behavior
* Teachers who do not read or learn the IEP/IFSP
* Misinformation from school staff
* Varying levels of understanding within different placements
* Paraprofessional engagement in work
* Insufficient supports for classroom teachers to promote inclusion
* High caseloads that leads to high turnover
* Implicit and explicit bias in working with parents and children
* Improvements suggested:
* Invest in staff to be more capable to know about disabilities, especially staff (security/kitchen, etc.)
* Provision of time and resources to communicate with families
* Career pathways that allow people to fill immediate gap in services but that have room for advancement through experience and on-the-job training
* Flexibility for providers to select their own caseloads/service areas

**Governance that Enhances Coordination & Collaboration**

* Supporting young children with disabilities or developmental delay works when
* The teacher work with the therapist
* Communication with directors and teachers
* Offering communication and team effort to support interventions
* The communication between all the team members and meeting to support the child in early intervention
* Joining a parent network
* Streamlined partnerships where space and time allow for collaboration
* Challenges include:
* Learning communication avenues with teachers and families to make sure everyone is on the same page
* Working with agencies that have different policies
* Giving recommendations for child and having it followed through with teachers/parents
* Trying different styles of communication to see what works and what doesn’t
* Consultation with families, therapists, school staff when creating curriculums/programs
* Communication between professionals and families
* Improvements Suggested:
* Enhanced data to understand what is happening and make changes
* Supports for interdisciplinary collaboration across health care, early intervention, special education, etc.
* More standardization across Part C
* Better integration of families in the Interagency Coordinating Council (ICC)
* Data collection from the Parent Information Training Centers on parents concerns
* Providing families with information to promote self-education, sufficiency, and advocacy
* Ongoing feedback loops within states to provide monitoring of service delivery from provider and parent perspectives

**Family- and Child-Centered Screening, Eligibility & Evaluation**

* The continuum of services should also include at-risk behaviors
* Supporting young children with disabilities or developmental delay works when
* Having a mental health consultant working with the teacher and family early on in the school year
* Having a home-based program addressing the families with children and serving as a referral source as needed
* Family knowledge of rights and role as well as confidence in their expertise regarding their child
* Bringing the child to meetings so that professionals are focused on the child
* Challenges include:
* Getting in touch with families – initiation of communication is challenging
* Getting on the same page with parents to understand the different viewpoints concerning the child
* Misperceptions of child age or development
* Listening to and valuing parents within the process
* Difficulty with early identification of learning disabilities such as dyslexia
* Identification as children age
* More access to screening and evaluation in various locations within communities to address equity issues
* Integration of questions about family legal status or child social security numbers in the process
* Improvements suggested:
* More attention to assessment of infant toddlers
* Making the process easier
* Assessments that better identify behaviors that warrant referral
* Roundtables with mental health consultants every 60 days to address concerns
* Awareness for parents on timelines
* Efforts to decrease timelines
* Improve responsiveness within the referral and evaluation process
* More access to multi-lingual culturally responsive information and resources for families
* Developmental screenings in AAP Bright Futures
* Make developmental screening billable
* Providing interpreters
* Improved access to screeners, resources to complete them, and tracking tools
* Addressing stigmas associated with services
* Bilingual developmental screening tools
* Community ambassadors to support families through the process

**Equitable & Inclusive Service Delivery**

* Supporting young children with disabilities or developmental delay works when
* Disabilities coordinator works with families to provide holistic support
* Connections with early interventionists, home visitor, social worker, and others
* Family members are involved in therapy to help with children
* Social emotional facilitators-observations are in place
* No judgement zone which makes it comfortable for parents to be part of the system
* Sending pictures and communication throughout the day
* Family voice in the IEP development process
* Family engagement in program-wide activities and leadership
* Knowing placement and service options and family advocacy for each child
* Flexibility on timing
* Individualization in placements based on needs
* Challenges include:
* Providing services as quickly as possible
* Waiting on authorizations
* Language barriers and cultural issues
* Bumpy transitions
* Time to services
* Insufficient educational tools for families
* Supports for children with 504 plans
* Lack of individualization
* Lack of placements
* Refusal to initiate services until school aged
* Misinformation about placements
* Waitlists for services
* Medication administration and tracking side-effects
* Medication for behavioral concerns
* Lack of clear policies and procedures to support children with developmental delay in early childhood or community-based settings
* Transportation
* Improvements suggested:
* Education for new families in parenting and strategies (including an electronic library of resources)
* IFSP/IEP in families’ home languages using culturally relevant strategies
* Special attention/program to treat the social skills for the child instead of academic
* Smoother transitions
* More parental choice within systems
* Guidance co-created with families that focuses on family needs
* Removing preschool special education classrooms and serving children in community early childhood settings
* Tension between increasing access when not enough settings exist
* End the removal of children from Pre-K to attend ECSE settings
* Addressing access disparities
* Providing interpreters
* Parents identifying forms of service delivery that works best for them and their child
* Transportation services
* Policies to support services for minorities, immigrants, refugees, and Latinx families
* Requirements for translation with the resources to meet them
* Verify availability of services in each community and offer resources to families to improve access and choice

**Organizations that Held Feedback Sessions**

* Community Organizing and Family Issues (COFI), Chicago, IL
* Educare Miami-Dade, Florida
* Jack Be Nimble, Kentucky Youth Advocates, and Play Cousins Collaborative
* La Casita Center, Louisville, Kentucky
* MomsRising Parent Voices Townhall
* Parents Leading for Educational Equity and Rhode Island Kids Count
* Start Early through multiple opportunities including:
* The 2021 Division for Early Childhood Conference
* The 2022 International Inclusion Institute
* The 2022 National Head Start Association Conference
* Alliance for IDEA Policy State and National Partners Table
* Head Start Disability Coordinators in Chicago, Illinois
* United Parent Leaders Action Network – Parent Leaders Advisory Group to the Alliance for IDEA Policy