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## Developmental Service Referrals and Utilization Among Young Children in Protective Custody

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### Abstract

Children in foster care are at high risk for developmental delay. In this retrospective cohort study of young children presenting to a foster care clinic, 77% were not receiving developmental services and 75% failed developmental screening. Of those potentially eligible, 60% were not referred for developmental services.

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Nationally, there are approximately 440 000 children in child protective custody (ie, foster care), of which 24% (~104 000) are under the age of 3 years.<sup>1</sup> Young children in foster care usually have 2 placement options while in protective custody: (1) nonrelative foster caregivers—individuals who are recruited, trained, and credentialed to provide full-time care to the child in their home and receive a monetary stipend for this role or (2) kinship caregivers—relatives or family friends who agree to provide full-time care to the child in their home, with oversight from the child protection agency. Kinship caregivers tend to be older and are more likely to experience poverty.<sup>2</sup> Child protection agencies give preference to kinship caregivers when placing a child in out-of-home care.<sup>3</sup> As a result, the number of children placed with kinship caregivers has increased over the past decade,<sup>1</sup> and the number of children placed with nonrelative foster caregivers has remained stable.

Most children enter foster care as a result of maltreatment, including neglect and abuse.<sup>4,5</sup> This history of maltreatment, along with other risks, places them at higher risk for developmental delay compared with nonabused children,<sup>6</sup> with prevalence of developmental delay as high as 45%–62%<sup>7–11</sup> vs 13%–15%, respectively.<sup>12–15</sup> Early identification of developmental delay is important because of the opportunity for early developmental interventions, such as Early Intervention and private therapy including speech therapy (ST),

physical therapy (PT), and occupational therapy (OT) to yield developmental catch-up. The importance of identifying developmental delay among children in foster care is reflected in both federal legislation (Child Abuse Prevention and Treatment Act) and in American Academy of Pediatrics guidelines.<sup>16</sup> Despite the presence of Child Abuse Prevention and Treatment Act and American Academy of Pediatrics guidelines, many children in foster care with developmental delay are not adequately identified<sup>8,17,18</sup> nor do they successfully access early intervention or other developmental services.<sup>7,19</sup> This study sought to better understand developmental screening, service referral, and service completion rates for young children in foster care to identify opportunities for intervention to improve developmental outcomes in this population.

## Methods

We performed a retrospective cohort study from 2012 to 2017, with approval from the Institutional Review Board at Cincinnati Children's Hospital Medical Center. A waiver of consent was granted. Subjects were included if they were less than 36 months old, in the custody of the local county child welfare system, seen at the Cincinnati Children's Hospital Medical Center CHECK Foster Care Center, and received developmental screening as part of that visit.

### Setting of Screening

The Cincinnati Children's Hospital Medical Center CHECK Foster Care Center (CHECK Center) is an evaluation model clinic,<sup>20</sup> designed in collaboration with the local county child welfare agency to consult on every child entering foster care in a single county in Ohio before referring back to primary care. Children are seen within 5 business days of entering foster care and again in 1–2 months for follow-up if still in care. The process repeats with every placement change. Children receive a developmental screening as part of the follow-up visit, 1–2 months after the placement visit, to allow the child a period of transition and the caregiver a period for observation.

### Measures

Developmental screening at the CHECK Center is completed with the Ages and Stages Questionnaire (ASQ). Seventeen age-appropriate paper questionnaires are available, ranging from 0 to 36 months. The caregiver responds “yes,” “sometimes,” or “not yet” to 30 questions capturing 5 domains of development, including communication, gross motor, fine motor, problem solving, and adaptive behavior. These responses are then converted to scores of 10, 5, and 0 respectively. The total scores for each domain are compared with established screening cut-offs. If a score falls below this set cut-off, the child is considered to be at risk for developmental delay and warrants further assessment or intervention. For the purposes of this study, ASQ results were divided into “fail,” when the child was borderline or failed at least 1 domain, and “pass,” when the child passed all domains. The ASQ takes 10–15 minutes to complete and 5 minutes to score. Concurrent validity ranges from 76% to 91% in general pediatric population.<sup>21</sup> There were children who received more than 1 ASQ over the study period due to multiple CHECK Center follow-up visits with different placement changes. For these children, we included the first administered ASQ.

## Data Collection

The hospital has an enterprise electronic health record installed in 2009. All order entries and referrals are electronic. We extracted demographic data, including age, sex, race, and placement type (nonrelative foster family or kinship foster family), ASQ results, and data on enrollment in developmental services at baseline (ie, the time of ASQ screening), referrals for developmental services (including early intervention referrals and private PT, OT, and ST referrals), and completed referrals, defined as receiving a full evaluation from the referral service.

## Results

### Developmental Screening Results

From 2012 to 2017, there were 235 children (42% female, 25% White, 42% with kinship caregivers, mean age = 1.57, SD = 0.79) seen at the CHECK Center who were eligible for inclusion, indicating they were <36 months of age and completed developmental screening with an ASQ (Figure). Thirty-four children received more than 1 ASQ (range 2–3) over the study period because of rescreening for changes in placement and only had their first ASQ included in the data set.

Of this group of 235 children, 59 (25%) passed their ASQ in all domains. The remaining 176 children (75%) had at least 1 borderline or failing score. The most commonly passed domain was gross motor, which was passed by 152 children (65%). Among those who failed the screening, the most commonly failed domain was problem-solving, which was borderline or failed by 129 children (55%). Among those who failed the screening, 39 (22%) failed 1 domain, 35 (20%) failed 2 domains, and 102 (58%) failed 3 or more domains (Table I; available at [www.jpeds.com](http://www.jpeds.com)). In multivariate logistic regression model 1 predicting whether or not a child failed any ASQ domain, children (n = 235) were more likely to fail an ASQ when they were male (Table II). There were no other significant demographic differences. Children in kinship placements and nonrelative placements were equally likely to fail the ASQ.

### Established Developmental Services

The majority (77%) of the 235 children in this study were not receiving developmental services at the time of their CHECK Center visit and developmental screening. Among children who passed the ASQ (n = 59), only 3 (5%) were already receiving developmental services at the time of screening. Among children who failed the ASQ (n = 176), 52 (30%) were already receiving developmental services at the time of screening. In multivariate logistic regression model 2 predicting enrollment into developmental services at baseline, children (n = 235) receiving developmental services at the time of screening were more likely to be in nonrelative placement (Table II).

### Referrals

Among the 124 children who failed the ASQ and were not receiving services, 38 (30.6%) were referred to developmental services, including early intervention or private therapies (PT, OT, and/or ST). In multivariate logistic regression model 3 predicting referral to

services, children (n = 176) with multiple failed domains were more likely to get a referral to developmental services and children already enrolled in services were less likely to get a referral (Table II). Children referred to developmental services were otherwise not demographically different than children who were not referred to developmental services, and there was no variation by placement type. Younger children and children failing fewer ASQ domains were more likely to be referred to Early Intervention when compared with private therapy (OT, PT, ST), regardless of placement type (model 4, Table II).

### Referral Completion

Among children referred to services who failed at least 1 domain on the ASQ (n = 49), 22% were already receiving developmental services. Thirty-two completed a referral, including 10 who were already enrolled in services. Seventeen did not complete a referral. In multivariate logistic regression model 5 predicting whether or not a child completed a referral for developmental services, children's (n = 49) demographic characteristics and placement type were not associated with the completed referrals (Table II). Of those completing a referral, 7 were seen for evaluation for private therapy and 26 completed a referral to Early Intervention; 1 completed a referral to both service types. In multivariate logistic regression model 6 predicting whether or not a child completed an Early Intervention referral, licensed nonrelative caregivers were 4.3 times more likely to complete a referral to Early Intervention than kinship caregivers; no other demographic characteristics were significant. The most common reason for not completing a referral was "unknown" regardless of placement type. Other common reasons for not completing the Early Intervention referral for kinship families included caregiver declined (24%) and unable to contact family (18%). Other common reasons for not completing the Early Intervention referral for nonrelative foster families included unable to contact family (15%) and caregiver declined (7%). Finally, among those receiving an Early Intervention evaluation, 12 (46%) met criteria for enrollment and were engaged in Early Intervention services, and 14 were determined ineligible for Early Intervention services.

### Discussion

In this study, we identified that a majority of young children in foster care failed development screening and were not referred for further developmental evaluation, regardless of placement type. This is particularly concerning as children in foster care are identified as a particularly vulnerable group for developmental delay and academic challenges.<sup>7,11</sup> Seventy-five percent of foster children in this study had a borderline or failing ASQ. However, only 51% of this group were either already in services or referred to services. This means that almost one-half of the children had concerns on the ASQ did not receive further evaluation to determine if developmental delays were present. The most commonly failed domain in our population was problem-solving. Previous report of ASQ utilization in a general pediatrics clinic found communication as the most commonly failed domain. Further study is warranted to evaluate this as a meaningful difference for this population.<sup>22</sup>

Among the characteristics we examined, there were no trends associated with whether a child was referred to developmental services, and importantly, children in kinship placements and nonrelative foster placements were equally likely to need a referral and be referred for services. Our study did not collect how often developmental services were discussed and declined, or it did not allow us to delve into the qualitative aspects of the referral process. We also did not examine medical decision-making on referrals to private therapy vs Early Intervention.

We did find, however, that despite equal referral rates and rates of referral completion overall, foster caregivers were 4.3 times more likely to complete referrals to Early Intervention than kinship caregivers. Further, percentage of declined services was higher in kinship caregivers compared with nonrelative foster families. Nonrelative foster families had higher percentages of referrals closed because of being unable to contact the family, and these may represent passively declined services. More research is needed to inform implementation of intervention services and how to engage nonrelative foster and kinship caregivers in services.

In previous studies of kinship caregivers compared with nonrelative foster caregivers, kinship caregivers were more likely to be single, older, unemployed, and to have more health problems, in addition to being significantly more likely to have incomes below 100% of the federal poverty line.<sup>2,23,24</sup> Yet, they generally received fewer services and less help from their local child welfare agency, in addition to little or no training.<sup>23–25</sup> Further, past research has found that kinship caregivers have a more positive attitude toward the child's behaviors and are more inclined to deny behavior problems.<sup>23,24</sup> If a similar phenomenon is happening with their impression of the child's developmental needs, they may be less inclined to follow through on a referral when made by the health care provider. Given the different trend in referral completion rates for private therapy referrals, which occurred less frequently and was high in both kinship caregivers and nonrelative licensed caregivers, it is also possible that some kinship families are uncomfortable with the home-based delivery method for Early Intervention and do not want service providers coming to their homes. Nonrelative foster caregivers may be more used to professionals coming to their homes because of their experiences with the nonrelative foster care system, which sets home visitation as a norm. It could also be that children referred to private therapies had higher developmental needs which were more concerning to the caregivers.

Our findings suggest that a different approach may be required to manage possible developmental delays with licensed and kinship caregivers. This may include partnering with the local child welfare and early intervention agencies to address barriers to getting evaluations completed and services in place. It may be that giving caregivers a choice between home-based therapies or nonhome-based therapies may increase referral completion rates. A lower threshold for referral to developmental services after a failed developmental screening may be needed. Watchful waiting may be an effective approach for children in traditional families, but placement changes and other challenges make children in foster care difficult to follow.

The strengths of this study include being able to utilize clinical data from a well-established consultative foster care clinic that has standard practices around use of developmental screeners. There are several limitations to this study. ASQs, especially completed by foster caregivers who are generally unfamiliar with children when they are first placed with them, may or may not accurately reflect likelihood of diagnosed developmental delay. Our data did not include when developmental service referrals were offered but declined or reasons a provider may have chosen watchful waiting for an individual child rather than referral or one referral type over another. Finally, this data set only included referrals from our hospital system. Although most caregivers seek referrals for these services through our foster care clinic, others may seek such referrals from private agencies in the area and not be reflected in our data. Finally, other systems may have automated referral processes in place and these results may not be generalizable to those settings.

Research in this area should focus on the qualitative aspects of why there may be hesitancy to refer to developmental services and why foster and kinship caregivers are not completing developmental evaluations despite identifying concerns on standardized screening and receiving referrals for developmental services, in particular for home-based Early Intervention services. The emerging role for telehealth will also need to be evaluated. This deeper understanding will facilitate development of concrete interventions to improve developmental outcomes in this high-risk population. More research is also needed on the efficacy of watchful waiting to follow development in young children in foster care.

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## Glossary

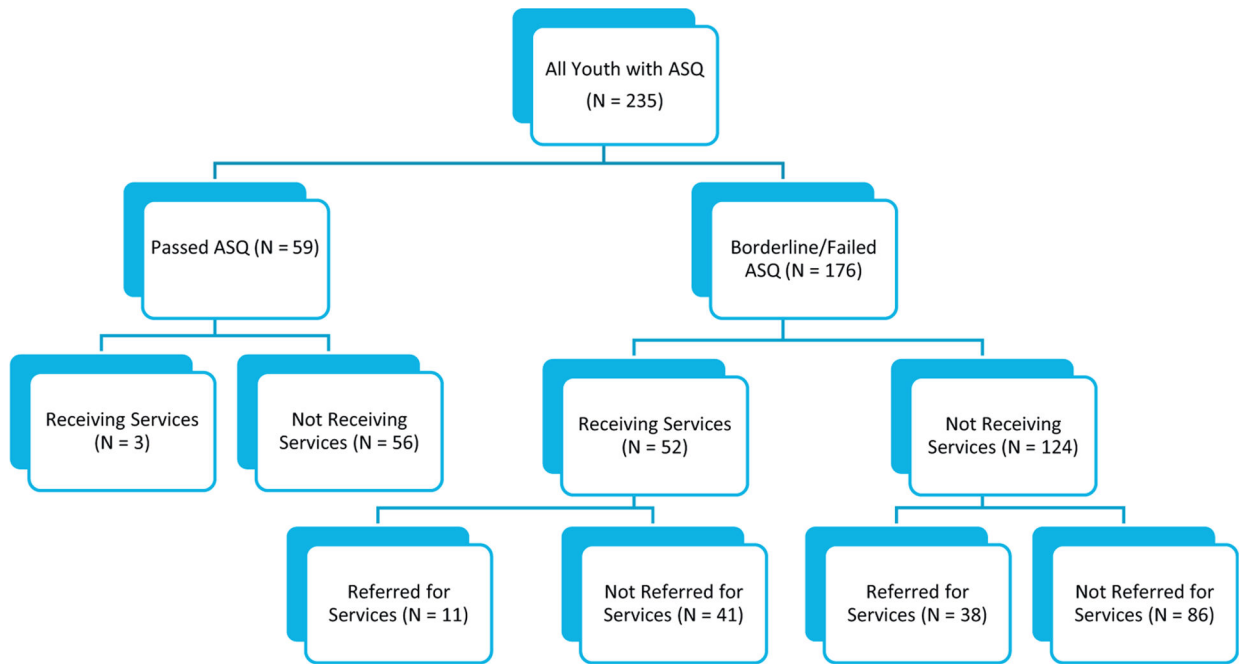
<b>ASQ</b>	Ages and Stages Questionnaire
<b>OT</b>	Occupational therapy
<b>PT</b>	Physical therapy
<b>ST</b>	Speech therapy

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**Figure.** Breakdown of ASQ results and referrals for young children presenting to foster care clinic.



Descriptive statistics for children who failed the ASQ, by number of domains and which domains were failed

**Table 1.**

Variables	Passed all domains (n = 59)	Failed any domain (n = 176)	Failed more than 1 domain (n = 137)	Failed communication (n = 97)	Failed fine motor (n = 113)	Failed gross motor (n = 81)	Failed personal-social (n = 114)	Failed problem-solving (n = 129)
Mean age (SD)	1.52 (0.81)	1.59 (0.78)	1.62 (0.82)	1.66 (0.76)	1.59 (0.83)	1.46 (0.77)	1.56 (0.81)	1.55 (0.79)
% Female	32 (54%)	67 (38%)	54 (39%)	39 (40%)	45 (40%)	32 (40%)	41 (36%)	51 (40%)
% White	15 (25%)	44 (25%)	34 (25%)	24 (25%)	25 (22%)	18 (22%)	27 (24%)	29 (22%)
% Kinship placement	31 (53%)	67 (38%)	51 (37%)	33 (34%)	38 (34%)	24 (30%)	42 (37%)	50 (39%)

**Table II.**

Results of multiple regression models examining ASQ screening results, referrals for developmental services, and completion of referrals

Variables	ASQ failure (model 1)		Enrollment in any developmental services at baseline (model 2)		Number of failed domains	Referred to any developmental services (model 3)		Referred for EI (model 4)		Completed any developmental service referral (model 5)		Completed EI referral (model 6)		
	OR	CI	OR	CI		B	SE	OR	CI	OR	CI	OR	CI	
Intercept	-	-	-	-	2.13	0.35	-	-	-	-	-	-	-	
Age	1.03	0.69-1.54	1.41	0.95-2.09	-0.11	0.14	1.17	0.76-1.79	0.01*	0.00-0.61	1.41	0.61-3.27	0.75	0.28-2.03
Race	0.99	0.69-1.41	0.91	0.63-1.31	-0.13	0.13	0.95	0.64-1.40	0.33	0.07-1.65	1.04	0.50-2.18	0.86	0.37-1.96
Sex	0.53*	0.29-0.99	0.83	0.44-1.57	-0.22	0.22	1.01	0.51-1.99	0.15	0.01-3.61	1.36	0.35-5.27	0.84	0.17-4.05
Placement type	1.45	0.78-2.71	2.55**	1.30-5.04	0.35	0.23	0.87	0.44-1.73	7.70	0.31-194.05	2.97	0.84-10.53	4.30	1.09-16.88
Service enrollment	7.19**	2.12-24.30	-	-	1.74**	0.27	0.40*	0.17-0.92	0.95	0.06-16.40	-	-	-	-
Failed ASQ	-	-	-	-	-	-	4.63	0.90-23.96	-	-	-	-	-	-
Number of failed domain	-	-	-	-	-	-	1.42**	1.11-1.82	0.21*	0.04-0.97	0.97	0.58-1.57	0.84	0.49-1.43

B, regression coefficient; CI, ±95% confidence interval; EI, Early Intervention; OR, odds ratio.

Age was entered into all regression models as a continuous variable. Race was coded as White (3), Black (1), or Other (2). Sex was coded as female (1) or male (0). Placement type was coded as kinship (0) or nonrelative caregiver (1). Enrollment in any developmental services at baseline refers whether the child was already receiving EI or private therapy (OT, PT, or ST) at the time the ASQ was completed (1) or not (0). Failed ASQ refers to whether the child failed any domains (1) or passed all domains (0). Number of failed domains refers to a count of ASQ domains failed. Referral to any developmental services refers to whether a child received a referral to either EI or private therapy (1) or no referral (0). Referral to EI specifically compares receiving a EI referral (2) vs a private therapy referral (1). Completed developmental referral refers to whether the child engaged with either EI or private therapy (1) or failed to engage in services (0). Completed EI referral refers to whether the child engaged with EI specifically (1) or not (0). Number of failed domains was examined as an outcome using multiple linear regression; all other outcomes were evaluated in logistic regression models.

\*  $P < .05$ .

\*\*  $P < .01$ .