

IDEA INFANT TODDLER COORDINATORS ASSOCIATION EARLY INTERVENTION BIRTH COHORT STUDY

An Alternative Approach to Measuring Child & Family
Participation in Part C of IDEA

Abstract

Child and family participation in the national Part C Early Intervention Program is an important issue for ITCA and its constituencies. This report describes the recently completed birth cohort study conducted by ITCA with member states to answer the question: what percent of the birth-to-three population *ever* receive services available under Part C to families and their children before they turn three? According to the U.S. Department of Education annual count of children with an individualized family service plan on a single day, 3% of infants and toddlers ages birth to three years received early intervention services in 2017. Using a birth cohort analysis with data available from state administrative data systems, ITCA found that on average, 15% of children in nine consecutive birth cohorts were referred, 11% were evaluated, and 8% were found eligible for state Early Intervention Programs. Our findings demonstrate that states and territories are reaching significant numbers of infants and toddlers and their families in need of early intervention services.

Individuals with Disabilities Education Act (IDEA) Infant Toddler Coordinators Association (ITCA)

ITCA (ideainfanttoddler.org) is organized as a not-for-profit corporation to promote mutual assistance, cooperation, and exchange of information and ideas in the administration of the Part C Early Intervention (EI) Program under the Individuals with Disabilities Education Act (IDEA), and to provide support to state and territory Part C coordinators. The association identifies and represents the interests of state and territory infant and toddler early intervention programs at the state and national level; develops and recommends models, standards, policies, and programs that promote quality services to eligible infants and toddlers and their families; and strengthens current leadership and fosters new leadership in early intervention programs at the local, state or territory, and national levels.

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Contract Staff

Maureen Greer, Executive Director

6545 Olney Street
Indianapolis, IN 46220
Phone: (317) 251-1510; Cell: (317) 281-9834;
Fax: (317) 251-1510

Sharon Walsh, Governmental Relations

6129 Calico Pool Lane
Burke, VA 22015
Phone: (703) 250-2564; Cell: (703) 850-1187;
Fax: (703) 250-4935

Consultant for the Birth Cohort Study Report

Donna M. Noyes-Grosser, Ph.D.
Donna_Noyes_Grosser@alumni.umass.edu

The ITCA Board and staff wish to acknowledge the following expert reviewers: Richard Adams, M.D., Batya Elbaum, Ph.D., Kathleen Hebbeler, Ph.D., Christina Kasprzak, Ph.D., and Donna Spiker, Ph.D. We thank them for their time, knowledge, insight, and valuable contributions made to this report.

Executive Summary

Child and family participation in the federal IDEA Part C Early Intervention Program is an important issue for ITCA and its constituency. The annual point-in-time and cumulative child counts reported by states to the US Department of Education, Office of Special Education Programs (OSEP) under Section 618 of IDEA describe the number of children and their families with an IFSP on a single day or a twelve-month period. These data, while providing useful information, have limitations and do not address the question of primary concern to policymakers, public officials, and their EI constituencies: what percent of the birth-to-three population *ever* receive services available under Part C to families and their children before they turn three?

To address this important question and in response to reported estimates of under-utilization of the Part C program (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013; Grant & Isakson, 2013; Rosenberg, Zhang, & Robinson, 2008), ITCA completed a large birth cohort study with member states to examine the extent to which children and families participate in state Part C Early Intervention Programs (state EI programs) during the formative period from birth to age three.

Cohort methodologies are frequently used by developmental scientists and epidemiologists in observational research to study developmental or health outcomes in populations. In a cohort methodology, a population is identified and followed as it ages through time and can be especially useful in establishing a sequence of events or outcomes in the population of interest (Mann, 2003). These studies can be either prospective (a sample is followed prospectively over time) or retrospective (data already collected for another purpose are analyzed post-hoc) (Euser, Jager, Zoccali, & Dekker, 2009). In population-based birth cohort studies, data for all individuals born in a specified timeframe form the basis of analysis for the outcome(s) of interest. Cohort analyses can be designed to measure service events (e.g., screenings, diagnostic examinations)(Pearce, 2012).

ITCA employed a retrospective, population-based methodology for this birth cohort study. For purposes of this study, birth cohorts were defined as consisting of all resident births in the state for a specified calendar year and for which state EI program data were available through children's third birthdays (e.g., 2009 for the 2006 birth cohort, 2010 for the 2007 birth cohort, etc.).

States participating in the study were asked to report data on the following key Part C service system events: (1) *referred* (the number of children born in a given calendar year ever referred to the state EI program); (2) *evaluated* (the number of children born in a given calendar year ever evaluated by the state EI program to determine eligibility); (3) *eligible* (the number of children born in given calendar year ever found eligible for the state EI program); and (4) *enrolled* (the number of children born in a given calendar year who receive an IFSP and whose parents chose to participate in Part C early intervention services).

Over the course of the study, data were collected for nine successive birth cohorts. Participation in the study required that member states have data management systems with the requisite data capture and staff resources available to complete data analyses. The total number of member states and the group of member states for which data were available therefore varied for each

birth cohort.

Thirty-five states reported data for one or more birth cohorts, with a range of 11 to 28 states across the nine birth cohorts. State participants reported service system event measures for more than 16 million resident births. On average across the combined nine birth cohorts, states reported data on referrals, evaluations, and eligibility determinations for more than 3 million and on enrollment for more than 2.5 million children in Part C service delivery systems.

Analyses of data aggregated across all reported cohorts revealed that on average, 15% of children in birth cohorts (i.e., all resident births in specified calendar years) were referred, 11% were evaluated, and 8% were found eligible for Part C. Enrollment in Part C was available for only a subset of five birth cohorts (2006, 2011 through 2014). On average, 9% of children and their families in this subset of birth cohorts were enrolled in Part C.

Complete data for both OSEP child counts (single day “point-in-time” and 12-month “cumulative” counts) and Part C service system events collected for this study were available for 30 states. Analyses were completed on data from these states to compare OSEP child counts with the percent of children in birth cohorts reported as eligible for their EI programs. Results showed that on average, 10% of children in birth cohorts were found eligible for state EI programs. By comparison, these states reported to OSEP that 7% of children received EI services in a 12-month period (cumulative count) and only 4% were reported to have an IFSP on a single day (point-in-time count).

ITCA acknowledges the difference between the birth cohort metric “eligible” and OSEP child counts, which only include eligible children and their families who develop and agree to an IFSP. Due to revisions in data collection procedures and variability in participation of member states in this multi-year, multi-cohort study, birth cohort data on the eligible metric were available both for a larger number of states (35 versus 26) and more birth cohorts (9 versus 5 birth cohorts across participating states). Analyses of trend data available from a subset of states with complete data all birth cohort measures (referrals, evaluations, eligibility and enrollment) found that nearly all children found eligible for Part C and their families (95% on average) continued on to an IFSP. Thus, the birth cohort metric “eligible” is an appropriate basis of comparison with OSEP child counts required to be reported by states.

A subset of states reported all service system event measures and one or both OSEP child count measures for all birth cohorts from 2007 through 2014. Trend analyses completed for these states showed that across successive birth cohorts, greater percentages of children were referred, evaluated, found eligible, and enrolled in state EI programs than indicated by either of the OSEP child count measures.

The ITCA birth cohort data demonstrate that Part C early intervention service delivery systems managed by states are reaching significant numbers of infants and toddlers in need of early intervention services. When considering the full opportunity to participate in Part C during the period from birth through their third birthdays, sizable percentages of young children and their families are being referred, evaluated, found eligible for, and enrolled in Part C state EI

programs. These data show that OSEP child count reports, while useful indicators of the extent to which children are receiving early intervention services at a given point or during a specific period, cannot and should not be interpreted as measures of the extent to which children and families are receiving services through their state EI programs.

All fifty states and six territories participate in Part C at their discretion, contributing significant investments of state and local resources toward ensuring the availability of a full complement of early intervention services for young children and their families and meeting all federal requirements, rights, and entitlements for the service delivery system. In a 2018 finance survey of member states (N=47), ITCA found that states reported a total financial contribution of more than 2.1 billion to their Part C systems (52.2% of total funding for Part C across all funding sources), with an additional \$517.6 million reported in local funds by 23 states. The ITCA Finance Report found that state EI programs are significantly challenged by lack of sufficient funding to meet mandated federal requirements and the increasing need for early intervention services among young children and their families (IDEA Infant Toddlers Coordinators Association, 2019). Local flexibility in program implementation is essential to preserving the current system.

The ITCA birth cohort study demonstrates the tremendous potential of Part C state EI program information management systems as a valuable data resource for program evaluation and quality improvement efforts. The birth cohort approach offers state and local governments and EI stakeholders an alternative model for establishing benchmarks and monitoring the success of EI programs in reaching eligible infants and toddlers and their families with needed early intervention services.

Introduction

Decades worth of scholarly research have shown the benefits of early intervention services for infants and toddlers with developmental delays and disabilities and their families, and there is widespread agreement across all constituencies about the need to ensure access to Part C early intervention services for eligible children and their families (Shonkoff & Phillips, 2001; Guralnick, 2011; Bruder, 2010; Kavanagh, Gerdes, Sell, & Jiminez, 2012; Twardzik, Cotto-Negron, & MacDonald, 2017). Child and family participation in the federal IDEA Part C EI Program is therefore an important issue for ITCA and its constituency.

The annual point-in-time child counts reported by states under Section 618 of IDEA describe the number of children and their families with an IFSP on a single day in a given year. These data, while providing useful information, have limitations and do not address the question of primary concern to policymakers, public officials, and their EI constituencies: what percent of the birth-to-three population *ever* receive services available to families and their children under Part C?

To address this important question and in response to reported estimates of under-utilization of the Part C program (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013; Grant & Isakson, 2013; Rosenberg, Zhang, & Robinson, 2008), ITCA recently completed a large birth cohort study with member states to examine the extent to which children and families, during the formative period from birth to age three years:

- Are referred to state EI programs.
- Receive a multidisciplinary evaluation to determine eligibility for EI.
- Are found eligible for EI.
- Enroll in EI and receive an IFSP.

Using the birth cohort measures collected through this study, ITCA asked the following questions:

- How do the birth cohort measures compare with federal child counts?
- What do these metrics tell us about child and family participation in state EI programs, including trends over time and across states?

This report reviews current issues related to measuring child and family participation in early intervention programs administered by states and US territories (referred to throughout as “states”), including a review of relevant research and federal reporting requirements. The ITCA’s birth cohort methodology and data are presented, offering an alternative way of measuring child and family engagement in Part C based on the experience of member states. ITCA’s findings from this birth cohort study clearly demonstrate that states are reaching and providing Part C services to significant numbers of infants and toddlers and their families in need of early intervention services.

Federal EI Program

The federal EI program for infants and toddlers with disabilities ages birth to three years and

Individuals with Disabilities Education Act

Accords specific rights, procedural safeguards to children and families and requires states to ensure families receive the rights and entitlements accorded to them by the law.

Provides that participation in the Part C EI program is voluntary to families

Requires that infants and toddlers and their families referred to EI receive service coordination, multidisciplinary child evaluations and assessments, and optional family assessments

Requires development of a comprehensive Individualized Family Services Plan (IFSP) for eligible children and their families.

Requires services contained in an IFSP be provided by the state EI program.

Provides that states establish eligibility criteria for their EI programs, which must include a definition of developmental delay and diagnosed physical or mental conditions with a high probability of resulting in developmental delay.

Provides states the option to include and define “at-risk” infants and toddlers as eligible for the EI program.

Requires states have system of payments for EI services approved by the federal Office of Special Education Programs (OSEP) that includes the use of public and private insurance and may include parent financial participation through sliding fee scales.

their families is established in Part C of IDEA. Part C is a discretionary grant-funded program available to states, all of which currently participate in the program. States participating in Part C must comply with IDEA law and regulations in administration of their EI programs, including sixteen required service delivery system components, and provide assurances that requirements will be met in their annual applications to the US Department of Education, Office of Special Education Programs (OSEP) for federal funding. Under IDEA, Part C formula grants are allocated to states based on the annual federal appropriation and the number of children under age three years residing in the state as a proportion of the total US population of children ages birth to three years.

IDEA envisions Part C as a multidisciplinary, coordinated, statewide system of services for infants and toddlers and their families, funded through a variety of both public and private sources. Federal funds were intended to be “glue money” to assist states in administering their service delivery systems and fill in gaps in availability of services. In reality, over the course of more than three decades of implementation, states have experienced significant increases in costs incurred for early intervention services.

In a 2018 finance survey of member states, ITCA found that states (N=46) reported a total financial contribution of more than \$2.1 billion to their Part C systems (52.2% of total funding for Part C across all funding sources)(N=46), with an additional \$517.6 million reported in local funds by 31 states. The ITCA Finance Report showed that state EI programs are significantly challenged by lack of sufficient funding to meet mandated federal requirements and the increasing need for early intervention services among young children and their families (IDEA Infant Toddlers Coordinators Association, 2019).

These realities for states – substantial federal program mandates, the growing demand for early intervention services for vulnerable children and their families, and level or constrained funding on multiple levels (federal, state, and local) impact financing for early intervention services and provide an important context for the question: what percent of the birth-to-three population ever

receive services available under Part C to families and their children before they turn three?

For more than a decade, there has been substantive national discussion and debate on the extent to which infants, toddlers and their families are being referred, evaluated, and found eligible to receive services under Part C. The issue is complex and multifaceted, requiring consideration of (1) Part C child find, multidisciplinary evaluation, and eligibility requirements; (2) methods for estimating the prevalence of developmental delays and disabilities among young children; (3) eligibility criteria used by state EI programs; and, importantly, (4) methodologies used for collecting, analyzing and reporting data on child and family participation in state EI programs.

Child Find and Multidisciplinary Evaluation Policies for the Part C Early Intervention Program

Section 303.302 of Part C of IDEA and federal regulations require state lead agencies to maintain and comprehensive child find systems to ensure that all infants and toddlers who are eligible for early intervention services are identified, located, and evaluated (US Department of Education, 2011; US Department of Education, 2011). IDEA further requires that states, with parental consent, provide a timely, comprehensive, multidisciplinary evaluation of children referred to their EI programs to determine whether the child is eligible for the program (unless the child is referred with a documented diagnosed condition or established level of developmental delay that meets state eligibility requirements) (US Department of Education, 2011). Children who are found eligible for state EI programs must receive a multidisciplinary assessment at no cost to their parents to identify their unique developmental strengths and needs, and services necessary to meet those needs (US Department of Education, 2011). Families may choose to participate in a family-directed assessment of their resources, priorities and concerns related to their children's development and the supports and services needed to enhance the family's capacity to meet their child's developmental needs (US Department of Education, 2011).

Estimated Prevalence of Developmental Disabilities in US Children

Estimating the prevalence of developmental delays and disabilities in the population of infants and toddlers less than three years of age is challenging. Developmental delays and disabilities can be difficult to recognize or diagnosis in children under three years of age (Boyle, et al., 2011) and many national estimates rely on parent-reported developmental problems rather than direct child assessments (Rosenberg, Zhang, & Robinson, 2008). While prevalence data are increasingly available for a number of diagnosed conditions that impact young children's development (e.g., autism spectrum disorder, cerebral palsy, and hearing loss) through scientific research such as the Metropolitan Atlanta Developmental Disabilities Surveillance Network (US Department of Health and Human Services, 2019), there is wide variation in definition and measurement of developmental delay in young children both in research and clinical practice. Thus, there currently is no universal agreement on the extent of developmental delays and disabilities in the infant-toddler population.

Despite these challenges, there are some important studies that have made contributions in estimating the prevalence of developmental delays and disabilities in young children. A recent study based on the National Health Survey interviews concluded that 13.2% of children under

age 17 experienced one or more developmental disabilities from 1997-2005 (Boyle, et al., 2011). Studies based on the national survey of children with special health care needs in 2001 found that 12.8% of US children under 18 years of age, and 7.8% of children ages 0-5, experienced a special health care need (Van Dyck, Kogan, McPherson, & Weissman, 2004). While these studies are based on parent report data and include children over the age of three years, they nonetheless provide a context within which to consider the extent to which state EI programs are delivering services to infants and toddlers with developmental concerns and their families.

The paucity of prevalence data on developmental disabilities in very young children also highlights the need for additional research on developmental problems in the birth-to-three population, including family access to services and supports to promote their children’s development. The need for and importance of such data was one rationale for ITCA’s initiation of the birth cohort study.

Eligibility Policies for the Part C Early Intervention Program

Under the IDEA, states must establish eligibility criteria for their EI programs, including use of a rigorous definition of developmental delay and the types of diagnosed physical and mental conditions with a high probability of resulting in developmental delay that constitute eligibility for program enrollment (US Department of Education, n.d.). States are required to include these eligibility criteria in their policies and procedures for their EI programs and must seek and consider public comment and receive the approval of the US Department of Education, Office of Special Education Programs (OSEP), when establishing or revising them.

IDEA and federal regulations provide states with latitude in both in defining developmental delay and determining the diagnosed conditions that constitute eligibility for EI program enrollment. As such, states have established a range of eligibility criteria for their EI programs that are responsive to their local circumstances, both in terms of state-specific definition of developmental delay and types of diagnosed physical and mental conditions with a high probability of resulting in developmental delay. State eligibility policies for their EI Programs are widely available, and several efforts have been made to describe and catalogue states’ eligibility criteria for Part C (IDEA Infant Toddler Coordinators Association, 2018; Barger, et al., 2015; Shackelford, 2006). ITCA works with its member states on an annual basis to organize states into three categories of eligibility for the EI program. The number of states for each category for the most recent year is as follows (IDEA Infant Toddler Coordinators Association, 2018):

Category	N of States	Level of Developmental Delay included in state eligibility criteria	Standard Deviations (SD) Below Mean in state eligibility criteria
A	15	- At-risk, any delay, atypical development - 25% delay in one domain - 20% or 22% delay in two/more domains	- 1 SD in one domain
B	20	- 25% delay in two/more domains - 30% or 33% delay in one or more domains	- 1.3 SD two/more domains - 1.5 SD in one domain
C	16	- 33% delay in two/more domains - 40% delay in one domain - 50% delay in one domain	- 1.5 SD in 2 domains - 1.75 or 2 SD in one domain - 2 SD in two/more domains

These categories illustrate the range in state eligibility policies and consequently range in the level of developmental delay young children must be experiencing to be eligible for EI programs in their resident states. Likewise, the range in state eligibility policies should be considered and can help inform efforts to evaluate the extent to which states are successfully reaching their eligible population of infants and toddlers with EI program services.

Estimating the EI Eligible Child Population - Referrals and Evaluations

States are not required to report the number of children referred and evaluated for the EI programs to the U.S. Department of Education. However, the extent to which all potentially eligible children and their families are referred and evaluated for state EI programs are meaningful metrics of child and family participation in Part C. Data on child referrals and evaluations are important indicators of the scope child find systems and level of resources (personnel, funding, etc.) invested by states in administering and delivering Part C services.

Most research related to participation in the Part C EI program has focused on the population of children found eligible for state EI programs. A recently completed systematic review of factors related to enrollment in Part C programs included five studies on referrals to EI which met quality indicators established by the authors (Twardzik, Cotto-Negron, & MacDonald, 2017). In a comprehensive review of published studies capturing data on model approaches to early identification and referral of children to Part C programs, Barger et al. (Barger, Rice, & Simmons, 2018) identified 43 studies which followed cohorts of children from identification of a potential developmental problem to referral to Part C programs by community-based specialized or primary care settings. They concluded that the relative lack of available data on Part C Child Find makes it difficult to evaluate the effectiveness of current systems aimed at ensuring the early identification and referral of children to Part C program (Barger, Rice, & Simmons, 2018).

While there is a dearth of studies which employ a population-based approach to analyzing the number and percent of children referred to and evaluated by state EI programs, many states routinely capture data on referrals and multidisciplinary evaluations as part of information management systems for their EI programs. As such, state administrative data on EI programs are a valuable source of information on the extent to which children in the birth-to-three population are being identified, referred, and evaluated to determine eligibility for state EI programs.

Eligibility

A recent study used child assessment data for nine- and twenty-four-month-old participants in the Early Childhood Longitudinal Study Birth Cohort (ECLS-B) study to estimate that 13% of children birth to age three experienced developmental delays that would make them potentially eligible for Part C early intervention programs (Rosenberg, Zhang, & Robinson, 2008). Rosenberg and colleagues (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013) have expanded upon this earlier work to develop a methodology to estimate the proportion of children who may be eligible for state EI programs based on a developmental delay in one or more areas of development. By applying the criteria of a developmental delay of 1.5 to 2 standard deviations below the mean to the ECLS-B assessment data, Rosenberg et al. estimated that, when

considering all five developmental domains (physical, cognitive, communication, social-emotional, and adaptive), an estimated 12% of children may be potentially eligible for Part C early intervention programs in states that use definitions of developmental delay comparable to those used by the study for EI program eligibility (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013).

In addition to the work of Rosenberg and his colleagues, a number of other studies and policy statements have been published related to child and family access to Part C state EI program services by examining issues such as: regional variations in enrollment of children with developmental delays and their families in state EI programs (Grant & Isakson, 2012); factors associated with early intervention referral and evaluations (Jiminez, et al., 2014) and enrollment in Part C (Twardzik, Cotto-Negron, & MacDonald, 2017); relationships between type of state lead agency and enrollment in state EI programs (Twardzki, MacDonald, & Dixon-Ibarra, 2017); ways to improve access to early intervention for children with behavioral and developmental concerns (Marks, et al., 2015); and, implications of narrowing of eligibility criteria for enrollment in Part C (Elbaum, Celimli-Askoy, Marshall, & Berkovits, 2017). To a large degree, the scholarly research and policy reviews on access to early intervention rely on the U.S. Department of Education, Office of Special Education Programs (OSEP) published Part C Section 618 child count data (U.S. Department of Education, 2018) as the standard or benchmark for determining the level of child and family participation in state EI programs from a national perspective.

Section 618 Data on Part C Enrollment

Section 618 of the IDEA requires states to submit data on infants and toddlers, ages birth through two years, receiving early intervention services under Part C of the Act, including Child Count, Settings, Exiting, and Dispute Resolution (U.S. Department of Education, 2018). OSEP issues data documentation requirements guidance to states for use of state-level data files to meet these reporting requirements each year. States report Child Count and Settings data on the first Wednesday in April and Exiting and Dispute Resolution data on the first Wednesday in November. The Child Count data reports, relevant to this report, are as follows:

1. **Child Count Birth thru 2 – Total:** The number of infants and toddlers with disabilities birth through two (receiving early intervention services according to an active IFSP in place on the count date). The count date is a State-designated date between October 1st and December 1st of a given calendar year, inclusive.
2. **Cumulative Count – Gender Total:** The total cumulative number of infants and toddlers with disabilities of both genders who received early intervention services during the most recent 12-month period for which data are available (U.S. Department of Education, 2017).

States also submit the above data delineated by race and gender. The U.S. Department of Education makes state-level data files available to the public on their website,

<https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html> (U.S. Department of Education, 2018).

In colloquial terms, the OSEP Part C Child Count report is generally referred to as the “point in time” count and is consistent with the epidemiologic concept of point prevalence (i.e., the number of individuals with an existing condition at a given point in time, divided by the number of a defined population at the same point in time), while the OSEP Part C Cumulative Count report is consistent with the concept of period prevalence (the number of individuals with the condition, for example, the number of individuals who have the flu in a given flu season divided by total number of people in that population).

The U.S. Department of Education uses the point in time child counts reported by states to calculate and report the proportion of infants and toddlers receiving Part C services as a percentage of the total national population of children in this age group. For the years 2006 through 2015, the percentage of infants and toddlers receiving Part C services, as reported by the U.S. Department of Education, increased from 2.5% (304,510 infants and toddlers ages birth through age 2 in 2006) to 3.0 percent (357,715 infants and toddlers ages birth through age 2 in 2017) (U.S. Department of Education, 2017). For the 2014-15 reporting period, the cumulative count of children in 50 states and DC receiving early intervention services was 681,149 (5.7% of the total birth to three population – referred to as a “risk index”) (U.S. Department of Education, 2017).

While the federal child count reports provide valuable information regarding infant, toddler and family participation in the national Part C program, these data present a limited picture of the scope and reach of state EI programs for some important reasons. First, the number of children who are referred and/or evaluated to determine eligibility for state EI programs is not reported at the national level. Thus, the number of children with an IFSP on a single day or in a twelve-month period underestimates the extent to which children and families are accessing services available from state EI programs (i.e., children and families receiving service coordination services, screening, and multidisciplinary services prior to an IFSP and children found ineligible for EI programs).

Second, the relatively short period of time children and families participate in state EI programs renders the child count and cumulative counts susceptible to undercounting the number of children who access these programs. The average length of stay in state EI programs as reported by states (N=32) participating in the most recent ITCA annual *State Challenges Survey* was 13.9 months, with a range of 8 to 19 months (IDEA Infant Toddler Coordinators Association, 2018). As a result, the volume of children and families entering and exiting state EI programs on an ongoing basis is high.

The point in time count is particularly likely to underestimate the number of children and their families receiving EI services because of the amount of entry and exit experienced in state EI programs. Even when assuming a one-to-one correspondence between children entering and exiting the program on the same day (e.g., a child with an IFSP exits and is replaced by another child and family with a new IFSP), the total number of children receiving services over a period

of time will be greater than the number served on any given day. The extent of the difference between the point in time count and other metrics will be dependent on the amount of “turnover” in the EI population. Similarly, the amount of turnover on any given day may be influenced by a variety of factors, including seasonal variations, policies on transition to preschool special education, eligibility criteria, etc. Thus, children and their families may enter and exit a state EI program and not be included the point in time child count (or conceivably, in the cumulative count).

Third, states are required to exclude children over the age of three from annual and cumulative federal child counts who, based on state requirements, continue to participate in state EI programs until they transition to Part B preschool special education services (only states exercising the Birth to Six Option for their state EI programs report the number of children three years of age and older to OSEP).

Finally, the number and percent of children and families with an IFSP on a given day, or in a specified 12-month period, underestimates the population of infants, toddlers and families accessing the broad array of Part C services (including service coordination and evaluations) at some point in the three-year period during which children meet age-eligibility criteria (i.e., from birth to a child’s third birthday) for state EI programs.

Methodology

ITCA Birth Cohort Analyses

Recognizing the limitations of federal data reports, and in response to reported estimates of underutilization of the Part C program (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013; Grant & Isakson, 2012; Rosenberg, Zhang, & Robinson, 2008), the ITCA initiated a retrospective birth cohort study with member states and territories to analyze child and family participation in state EI programs using states’ administrative data (Noyes & MacLeod, 2013a) (Noyes & MacLeod, 2013b). ITCA executive staff worked with members of the ITCA Data Committee, comprised of member-state Part C Coordinators and Data Managers, to design and implement this study. Cohort methodologies (longitudinal studies that involve repeated observations of study participants over time) are frequently used by developmental scientists and epidemiologists in observational research to study developmental or health outcomes in typical or at-risk populations. In a cohort methodology, a population is identified and followed as it ages through time to study the emergence of one or more characteristics (Mann, 2003). A cohort approach can be especially useful in establishing a sequence of events and examining multiple characteristics or outcomes in the population of interest (Mann, 2003). These studies can be either prospective (i.e., a sample is identified at the initiation of a study and followed prospectively over a defined period) or retrospective (i.e., data already collected for another purpose are analyzed post-hoc) (Euser, Jager, Zoccali, & Dekker, 2009). In population-based birth cohort studies, data for all individuals born in a specified timeframe form the basis of analysis for the outcome(s) of interest. Cohort analyses can be designed to measure service events (e.g., screenings, diagnostic examinations) as well as outcomes interest (Pearce, 2012).

Participants

A retrospective, population-based methodology was used for this birth cohort study. For purposes of this study, birth cohorts were defined as consisting of all resident births in the state for a specified calendar year (e.g., all children with birthdates in calendar year 2006, 2007, 2008, etc.) and for which state EI program data were available through children’s third birthdays (e.g., 2009 for the 2006 birth cohort, 2010 for the 2007 birth cohort, etc.).

No personally identifiable child data were collected or used by ITCA for the study. Data collected for the study from member states were aggregate, de-identified data available from states’ Part C data maintained for program management and reporting purposes. The study was initiated in 2009 with collection of data for the 2006 birth cohort and continued through 2018. Data were collected from member states for each successive birth cohort as complete data became for the cohort. During the course of the study, data were collected for nine consecutive birth cohorts (i.e., data for all resident births for the 2006, 2007, 2008, 2009, 2010, 2011, 2012, 2013, and 2014 cohorts).

Participation in the study required that member states have data management systems with both the requisite data capture and staff resources available to complete data analyses (i.e., capacity to aggregate and submit de-identified child data for each measure by year of birth and calculate unduplicated child counts for the birth cohorts). Therefore, both the total number of member states, and the group of member states for which data were available, varied for each birth cohort.

Over the course of the study, a combined total of 35 states reported data for one or more birth cohorts. The number of member states for which data were available ranged from 28 states for the 2010 birth cohort to 11 states for the 2012, 2013, and 2014 birth cohorts. Table 1 shows the number of states that contributed data to each birth cohort.

Table 1.

Birth Cohort Year	N of States
2006	19
2007	23
2008	23
2009	25
2010	28
2011	21
2012	11
2013	11
2014	11

Procedures

Data on specific Part C service system events from referral to enrollment in state EI programs were considered to be complete for birth cohorts at the end of the three-year period from the

birth year for that cohort.

Member states received a data request from the ITCA Executive Director each calendar year from 2009 through 2018 for the relevant birth cohort (e.g., for 2009, Part C Coordinators were asked to submit service system events data for children born in calendar year 2006, etc.), followed by periodic reminders until data collection for the birth cohort closed. The annual and periodic follow-up requests for birth cohort were sent to Part C Coordinators via email, accompanied by a data collection table for completion and submission to ITCA. Data requests made to Part C Coordinators each year were only for the relevant birth cohort (a sample data collection form for 2012-2014 is included in Appendix A). Part C coordinators were not asked for data on prior birth cohorts once data collection was closed. Data collection for each birth cohort closed no later than the end of the calendar year in which the request was made.

Part C Service System Event Measures

The Part C service system event measures used for this study were as follows:

- (1) *Referred*: the number of children born in that year ever referred to the state EI program.
- (2) *Evaluated*: the number of children born in that year ever evaluated by the state EI program to determine eligibility.
- (3) *Eligible*: the number of children born in that year ever found eligible for the state EI program.
- (4) *Enrolled*: the number of children born in that year who receive an IFSP and whose parents chose to participate in Part C services (collected for a subset of cohorts).

The Part C service system events collected by ITCA were modified during the course of the study. Data collected for the first birth cohort (2006) did not include the service system event “eligible” but did include the service system event “enrolled” measure. Data for all subsequent birth cohorts (2007 through 2014 cohorts) included the “eligible” measure. For the 2011 through 2014 birth cohorts, the service system event “enrolled” measure was also included. In addition to the variation in collection of the “eligible” and “enrolled” measures, there was some variation across participating member states in the extent to which all measures were available for any given cohort.

Table 2 summarizes the total number of state birth cohorts reported to ITCA by respective birth cohort year and reported child and family participation measures (see Appendix B for the number of birth cohorts and measures reported to ITCA by individual states).

Table 2. Summary of Service System Event Measures Reported by States for Birth Cohorts

Year	N of Birth Cohorts	N of States Reporting Number Referred	N of States Reporting Number Evaluated	N of States Reporting Number Eligible	N of States Reporting Number Enrolled
2006	19	19	16	Not collected	19
2007	23	23	23	23	Not collected
2008	23	23	23	23	Not collected
2009	25	25	25	25	Not collected
2010	28	28	28	28	Not collected
2011	21	21	21	21	21
2012	11	11	11	10	10
2013	11	11	11	10	10
2014	11	11	11	10	10

Table 3 summarizes birth cohort data reported by states over the course of this study for service system events, including the average and range in the number of birth cohorts reported by states (data for individual states are presented in Appendix B).

Table 3. Summary of Service System Event Measures Reported

	Referred	Evaluated	Eligible	Enrolled
N of States	35	35	35	26
Average N of Birth Cohorts	5	5	2	8
Range in N Birth Cohorts	1 to 9	1 to 9	1-9	1-5

In addition to the above measures, OSEP annual point-in-time and cumulative child count data were also requested from member states, corresponding to the last possible year of Part C participation for each birth cohort (for example, OSEP 2009 child count data were for the 2006 birth cohort, etc.), based on the rationale that this would be the last year children from the cohort could be included in OSEP child counts. Appendix C shows the availability of OSEP data by state. Data submitted by member states were verified by ITCA using published OSEP Part C child count tables.

The official number of resident births for each birth cohort was reported to ITCA by participating states. Corrected resident birth data were obtained from state vital statistic reports for two states whose data were inconsistent with submissions in previous years.

Data on the population of children ages birth through two years (i.e., the birth to three population) residing in participating states were retrieved from the U.S. Bureau of the Census for state birth cohorts for 2007, 2008, 2009, 2010, 2011, 2012, and 2013. These data were obtained to derive the percentage of children in birth cohorts with an IFSP in a twelve-month period from the cumulative count reported by states to OSEP.

Data Analyses

All birth cohort data submitted by states were used for this study, regardless of the number of birth cohorts and the service system event measures available for analysis. Data for 35 states that submitted data for birth cohorts at some time during the course of the study were combined into a single data set using Microsoft Excel for purposes of this analysis.

Calculation of Service System Event Measures Across State Participants' Reported Birth Cohorts

Data for states that submitted data for two or more birth cohorts (N=29) were averaged for all measures to obtain single representative values for these states on measures across their birth cohorts. The single representative values for states with multiple birth cohorts and values for states with data for only one birth cohort (N=6) were summed across participating states for resident births, birth-to-three population and each service system measure (referred, evaluated, eligible, and enrolled). The total percent of children for the combined birth cohorts was then calculated for the service system measures (referred, evaluated, eligible, enrolled) using the sum of states' resident births (i.e., sum of the mean births across multiple birth cohorts or total resident births for a single birth cohort, as applicable) as the denominator.

Summation of OSEP Point-in-Time and Cumulative Child Count Measures Across State Participants' Reported Birth Cohorts

The OSEP annual point-in-time and cumulative child count data obtained for states were analyzed using similar procedures as described above.

OSEP point-in-time child count data (the percent infants and toddlers with an IFSP *on a single day*) for state participants that submitted data for two or more birth cohorts (N=29) were averaged across each state's birth cohorts to obtain a single mean percent value for each state. The mean values for OSEP point-in-time counts for states with multiple birth cohorts and OSEP point-in-time child count for states with data for only one birth cohort (N=6) were then summed across participating states to obtain the mean percent of infants and toddlers with an IFSP on a single day for the birth cohorts, combined across states.

Data for the OSEP cumulative count (the number of children with an IFSP at some point *during a 12-month period*) for states that submitted data for two or more birth cohorts (N=29) were averaged for all measures to obtain single representative cumulative count mean values for each state across their birth cohorts. The single representative values for states with multiple birth cohorts and the values for states with data for only one birth cohort (N=6) were then summed across all states to obtain a mean value for the OSEP cumulative count. The total percent of children for combined birth cohorts was then calculated for the OSEP cumulative count using the sum of states' birth-to-three population (i.e., the single representative mean for states with multiple birth cohorts or the state's birth-to-three population for a single birth cohort) as the denominator.

Comparison of OSEP Child Counts and Birth Cohort Eligibility Across States

The values derived for the combined birth cohorts reported by states, as described above, were used to compare OSEP child counts with birth cohort eligibility using the service system

“eligible” event measure.

Comparison of OSEP Child Counts and Birth Cohort Service System Eligible Event Measure for Individual States

Data on both OSEP child counts (point-in-time and cumulative counts) and birth cohort eligibility (service system event “eligible”) were available for 30 individual states. Measures on all three child counts were compared across individual states using the single representative values calculated for states with multiple birth cohorts (N= 24) and data for states with only a single cohort (N=6). As previously discussed, due to revisions to data collection procedures over the course of this multiyear study, the service system event “enrolled” was available for only a subset of birth cohorts reported by states. The service system event “eligible” was available for all birth cohorts and all states participating in the study. Analyses completed on birth cohorts for whom both service system events (“eligible” and “enrolled”) were available showed that on average, 95% of children found “eligible” for state EI programs and their families continued on to receive an IFSP. Therefore, ITCA determined the service system event “eligible” is an appropriate metric to use as a basis for comparison with OSEP child counts.

Analysis of Trends for Individual States with Multiple Birth Cohorts

Complete data for all service system event measures (referred, evaluated, eligible, enrolled) and both OSEP child counts (point-in-time and cumulative counts) were available for seven states for eight consecutive birth cohorts (2007-2014). Complete data were available for all service system event measures and the OSEP point-in-time count for 15 states for eight consecutive child counts. Data for these two groups of states were used to compare trends over time across birth cohorts.

Results

Service System Event Measures Across State Participants’ Reported Birth Cohorts

States participating in this study reported service system event measures for 16,167,500 resident births during the period January 1, 2006 through December 31, 2014. Across all birth cohorts combined, data were reported on unduplicated counts of 2,369,933 child referral events; 2,067,448 child evaluation events; 1,351,296 child eligibility events; and, 664,238 child and family enrollments in state EI programs. As described above, these data were used to derive single representative mean values for states reporting multiple birth cohorts (N=29), and then summed with states reporting a single birth cohort to derive means for resident births, birth to three population, and referred, evaluated, eligible, and enrolled service system events.

Table 4 presents the mean resident births, and mean number and percent of children for each service system event measures for all birth cohorts combined reported by participating states.

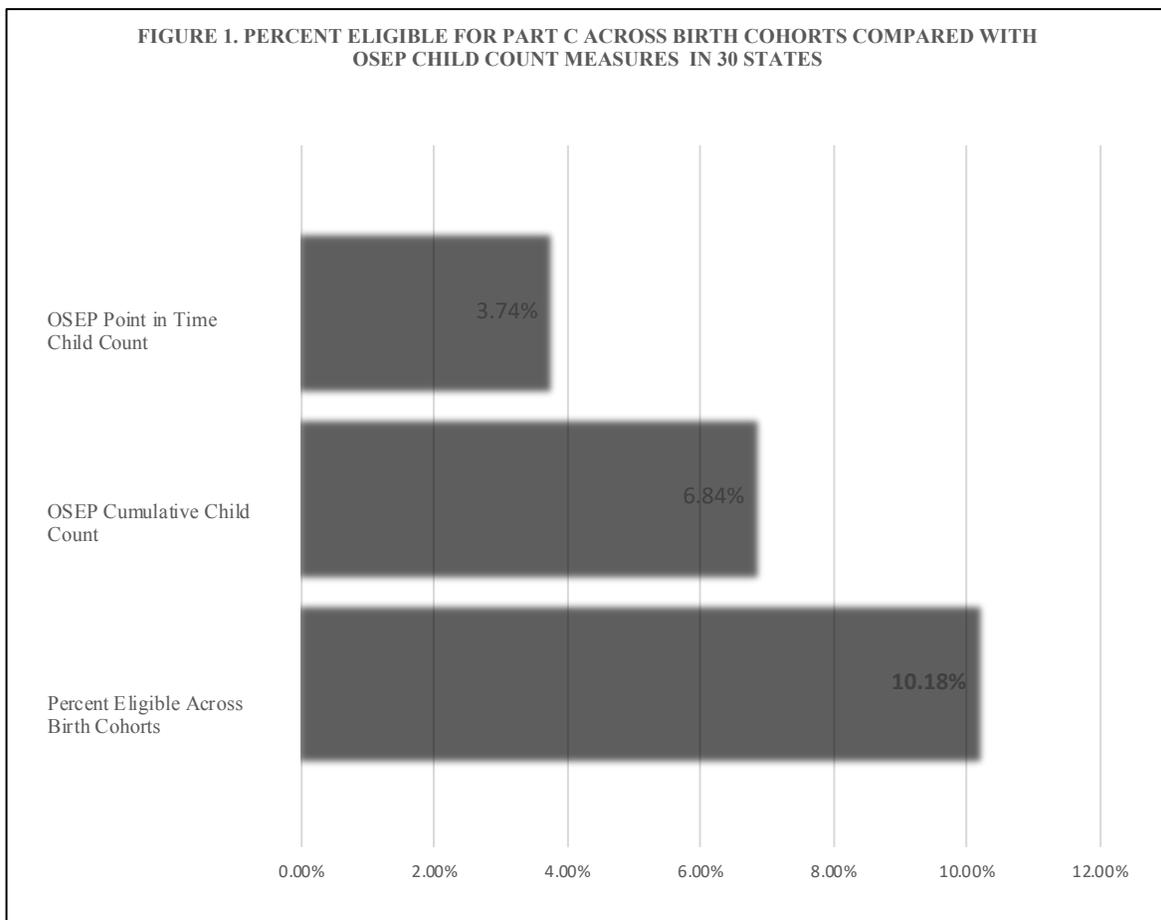
Table 4. Mean Resident Births and Service System Event Measures for Combined Birth Cohorts

	Referred (2006-2014)	Evaluated (2006-2014)	Eligible (2007-2014)	Enrolled (2006, 2011-2014)*
Mean N of Children for Service System Event	487,071	369,965	276,603	237,137
Mean N of Resident Births	3,324,957	3,324,397	3,301,412	2,546,647
Mean Percent and Range of Children with Service System Events	15% (7%-30%)	11% (5%-29%)	8% (5%-23%)	9% (2%-22%)

*Note: The larger percentage of children enrolled compared with eligible is a function of the use of different cohorts for calculation of the eligible and enrolled service system event measures. Data were only available for five of the nine birth cohorts.

Comparison of Part C Eligibility in Birth Cohorts and OSEP Child Counts Across Birth Cohorts

Figure 1 presents a comparison of eligibility as measured for birth cohorts in this study compared with OSEP child counts collected in the last year of each birth cohort period.



As shown in Figure 1, data on Part C eligibility in combined birth cohorts reported by states combined revealed a substantially greater percentage of children were found eligible in states participating in the study than was evidenced by either of the child counts reported to OSEP. On average, 10.18% of children in birth cohorts were reported as eligible for state EI programs participating in our study, compared with 6.8% of children reported to have an IFSP in a 12-month period and 3.74% of children reported to have an IFSP by these states in the last year of each birth cohort period.

Trends for States Reporting Multiple Birth Cohorts

Figure 2 presents trend data available for seven states for eight birth cohorts (2007-2014) with complete data reported for service system event measures and OSEP child counts (point in time and cumulative). Across all state birth cohorts, greater percentages of children in birth cohorts were found eligible and enrolled in their state EI programs when compared with OSEP annual child count measures. States' data for their respective cohorts are relatively consistent, with all states showing small increases in referrals, evaluations, eligibility, and enrollment in their Part C programs across consecutive birth cohorts. Resident births in these states generally declined over time in these states (from a total of 692,292 in 2007 to 651,273 in 2014), suggesting that any increase in service system events for children in these states is not attributable to an increase in resident births.

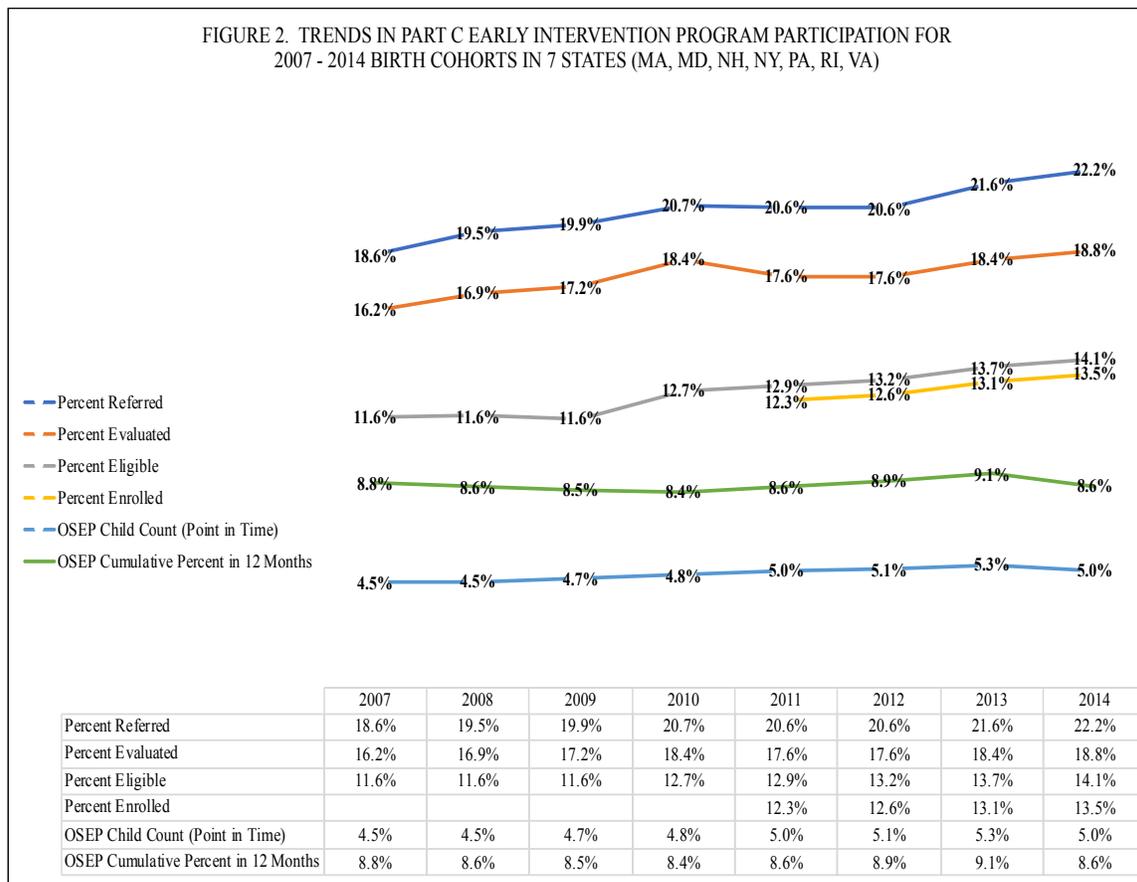
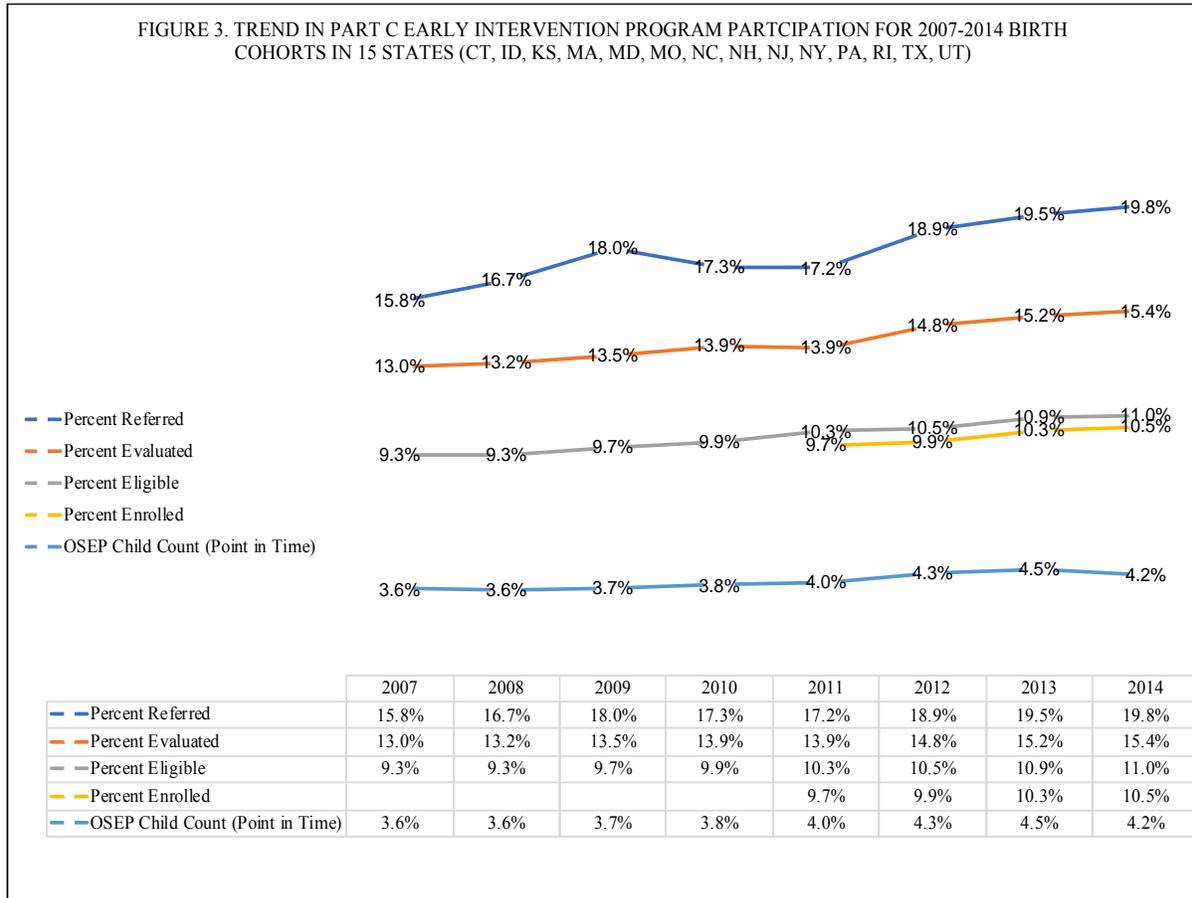


Figure 3 presents data on service system event measures and OSEP point in time annual child counts for eight birth cohorts (2007-2014) in 15 states. These data also show consistently higher percentages for birth cohort eligibility and enrollment data when compared with annual child counts reported to OSEP. States' data for their respective cohorts are relatively consistent, with all states showing small increases in referrals, evaluations, eligibility, and enrollment in their Part C programs across consecutive birth cohorts.



Resident births in these also states generally declined over time (from a total of 1,568,715 in 2007 to 1,148, 531 in 2014), again suggesting that any increase in service system events for children in these states is not attributable to an increase in birth rates.

Discussion

The extent to which state EI programs under Part C of IDEA are finding and reaching potentially eligible children and their families with early intervention services is an important and widely debated question (Rosenberg, Robinson, Shaw, & C.Ellison, 2013). Typically, when examining this question, researchers and advocates use annual point-in-time child count data as a benchmark for determining the extent to which children and families are participating in Part C early intervention services. However, both the OSEP point-in-time and cumulative child count data present a limited view of child and family participation in state EI programs, by including only those children with an active IFSP on a single day or during a twelve-month period.

ITCA recognized that states have a unique contribution to make, through use of longitudinal administrative data for their Part C programs, toward evaluating the extent to which children and families are accessing state EI programs. Using a retrospective birth cohort approach and working with 35 states over a period of nine years, ITCA collected and analyzed data on Part C service system events reported by states participating in this study for more than 16 million births across consecutive birth cohorts from 2006 through 2014. On average across combined birth cohorts, states reported data on referrals, evaluations, and eligibility determinations for more than 3 million and enrollment data for more than 2.5 million children in Part C service delivery systems. On average, 15% of children in birth cohorts were referred, 11% were evaluated, and 8% were found eligible for Part C.

Data analyses on birth cohort eligibility for thirty states with complete data for both OSEP child counts revealed that on average, 10% of children in birth cohorts were found eligible for state EI programs, compared with approximately 7% of children receiving EI services in a 12-month period (OSEP cumulative count) and 4% of children with an IFSP on a specific day (point in time count). Enrollment in Part C was available for only a subset of birth cohorts (2006, 2011, 2012, 2013, and 2014). On average, 9% of children and their families in these birth cohorts (i.e., all resident births) were enrolled in Part C.

ITCA acknowledges the difference between the birth cohort service system event “eligible” and OSEP child counts, which only include eligible children and their families who develop and agree to an IFSP. Due to revisions in data collection procedures and variability in participation of member states in this multi-year, multi-cohort study, birth cohort data on the service system event “eligible” were available both for a larger number of states (35 versus 26) and more birth cohorts (maximum of 9 versus 5 birth cohorts across participating states). Analyses completed on birth cohorts for whom both service system events (“eligible” and “enrolled”) were available showed that on average, 95% of children found “eligible” for state EI programs and their families continued on to receive an IFSP. Thus, the birth cohort service system event “eligible” is an appropriate basis of comparison with OSEP child counts required to be reported by states.

The metric “eligible” is arguably a better basis of comparison when considering data available on the prevalence of developmental problems in young children and theoretical estimates of the Part C eligible population. Compellingly, the percentage of children found eligible for state EI programs across all birth cohorts reported for this study approximate both available prevalence data and theoretical estimates developed through scholarly research. Van Dyck et al. estimated

that 7.8% of children ages birth to 5 years of age experienced a special health care need (Van Dyck, Kogan, McPherson, & Weissman, 2004). Rosenberg et al. estimated 12% (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013) or 13% of children (Rosenberg, Zhang, & Robinson, 2008) birth to age three years may have developmental delays that qualify them for Part C EI programs.

Data for all ITCA measures (referrals, evaluations, eligibility, and enrollment) and one or both OSEP child count measures for eight successive birth cohorts (2007-2014) were reported by a subset of states. Trend analyses of these data revealed that high percentages of children were referred and evaluated by state EI programs across consecutive birth cohorts. Across each successive birth cohort, the percent of children found eligible and enrolled in state EI programs was consistently much greater than indicated by either of the OSEP child count measures.

Taken together, the ITCA birth cohort data demonstrate that Part C early intervention service delivery systems managed by states are reaching significant numbers of infants and toddlers in need of early intervention systems. When considering the full opportunity to participate in Part C during the period from birth through their third birthdays, sizable percentages of young children and their families are being referred, evaluated, found eligible for, and enrolled in Part C state EI programs. These data show that OSEP child count reports, while useful indicators of the extent to which children are receiving early intervention services at a given point or during a specific period, cannot and should not be interpreted as measures of the extent to which children and families are receiving services through their state EI programs.

ITCA recognizes that although high percentages of children and families in birth cohorts are engaged in state EI programs, more children may be eligible for Part C services than are being reached by state systems. Scholarly research examining the pathways from early identification of developmental concerns to participation in Part C programs have identified a number of factors influencing child referrals and evaluations, including level of risk/developmental delay (children at greater risk and with delays in more areas were more likely to be referred) (Jimenez, et al., 2014; Twardzik, Cotto-Negron, & MacDonald, 2017), family receptivity to EI services (Jimenez, et al., 2014; Little, Kamholz, Corwin, Barrero-Castillero, & Wang, 2015; Twardzik, Cotto-Negron, & MacDonald, 2017), and referral method (faxing a referral to EI was more effective than providing contact information to families) (Jimenez, et al., 2014). Such studies provide important information for all Part C constituents that can help guide quality improvement efforts related to child find systems.

Participation in the Part C early intervention system of services is voluntary for families and their infants and toddlers, and some families choose not to participate in state EI programs for a variety of reasons. Part C is one of many early childhood service delivery systems for infants and toddlers and their families and is a vibrant contributor to the broader early childhood community. Specialty services will always be needed for some very young children and their families. Likewise, all young children and their families, including those with delays and disabilities should be supported to participate in a variety of early childhood programs and services. A rich array of services, such as home visiting, early education programs, child care services, and children's health homes is available for young children who may not qualify for state EI

programs.

ITCA recognizes that a baseline estimate is needed for the population of children under age three who are potentially eligible for early intervention services under Part C of IDEA, and has an ongoing, active collaboration with the US Department of Education, Centers for Prevention and Control, National Center for Birth Defects and Developmental Disabilities (CDC), Association of Centers for University Centers of Excellence in Developmental Disabilities (AUCD), and the National Early Childhood Technical Assistance Center on methods that may be used to achieve this goal (Elie, Barger, Shaw, & Greer, 2016; Barger, et al., 2015). Such estimates fluctuate over time and should be refined and revised to consider emerging and changing populations in need of early intervention services, such as children affected by neonatal abstinence syndrome and ASD. In the context of this work, ITCA has promoted the need for research on early identification practices and strategies to strengthen relationships between Part C state EI programs and community partners, including health care providers, particularly focusing on children with diagnosed physical and mental conditions with a high probability of resulting in developmental delay.

Conclusion

The Part C EI program under IDEA is a vital resource for infants and toddlers with special needs and their families. Nationally, Part C is a complex system of state-operated early intervention programs. As such, it is important to recognize, understand, and acknowledge the extent to which states and territories are currently reaching significant numbers of infants and toddlers and their families in need of early intervention services. All fifty states and six territories participate in Part C at their discretion, contributing significant investments of state and local resources toward ensuring the availability of a full complement of early intervention services for young children and their families and meeting all federal requirements, rights and entitlements for the service delivery system. Local flexibility in program implementation is essential to preserving the current system. Likewise, there may be implications for continued participation by all jurisdictions if advocacy efforts and screening initiatives to increase referrals to Part C are not followed by adequate resources to support early intervention services and program administration.

The birth cohort approach offers state and local governments and EI stakeholders an alternative model for establishing benchmarks and monitoring the success of EI programs in reaching eligible infants and toddlers and their families with needed early intervention services. The ITCA birth cohort study further demonstrates the tremendous potential of Part C state EI program information management systems as a valuable data resource for quality improvement and program evaluation efforts.

References

- Barger, B., Rice, C., & Simmons, C. &. (2018). A systematic review of Part C early identification studies. *Topics in Early Childhood Special Education, 38*(1), 4-16.
- Barger, B., Rice, C., Shaw, E., Squires, J., Noyes, D., & Kaculic, C. (2015). Use of diagnosed conditions for Part C Early Intervention (EI) service eligibility. Atlanta, GA: Annual Meeting of the Division For Early Childhood (DEC) of the Council for Exceptional Children (CEC)(October 2015).
- Boyle, C., Boulet, S., Schieve, L., Cohen, R., Blumberg, S., Yeargin-Allsopp, M., . . . Kogan, M. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*(6), 1034-1042.
- Bruder, M. (2010). Early childhood intervention: A promise to children and families for their future. *Exceptional Children, 76*(3), 339-355.
- Elbaum, B., Celimli-Aksoy, S., Marshall, J. T., & Berkovits, M. D. (2017). How does the narrowing of eligibility criteria affect enrollment in Part C early intervention? *Infants & Young Children, 30*(1), 28-40.
- Elie, J., Barger, B., Shaw, E., & Greer, M. (2016). Use of diagnosed conditions for IDEA Part C early intervention program eligibility. New Orleans: 2016 Improving Data, Improving Outcomes Conference (August, 2016).
- Euser, A. M., Jager, K. J., Zoccali, C., & Dekker, F. W. (2009). Cohort studies: prospective versus Retrospective. *Nephron Clinical Practice, 113*(1), c214-c217.
- Grant, R., & Isakson, E. (2013). Regional variations in early intervention utilization for children with developmental delay. *Journal of Maternal and Child Health, 17*(7), 1252-1259.
- Guralnick, M. (2011). Why early intervention works: A systems perspective. *Infants & Young Children, 24*(1), 6-28.
- IDEA Infant Toddler Coordinators Association. (2018). *Association Reports - Child Count Data*. Retrieved November 2018 from IDEA Infant & Toddler Coordinators Association: www.ideainfanttoddler.org.
- IDEA Infant Toddler Coordinators Association. (2018). *Association Reports - State Challenges*. Retrieved November 2018 from IDEA Infant & Toddler Coordinators Association: www.ideainfanttoddler.org.
- IDEA Infant Toddlers Coordinators Association. (2019, January). *Board Approved Surveys - '19 Finance Report*. Retrieved March 2019, from IDEA Infant Toddlers Coordinators Association: www.ideainfanttoddler.org.
- Jimenez, M., Fiks, A., Shah, L., Gerdes, M., Ni, A., Pati, S., & Guevara, J.P. (2014). Factors associated with early intervention referral and evaluation: A mixed methods analysis. *American Pediatrics, 14*(3), 315-323.
- Kavanagh, J., Gerdes, M., Sell, K., & Jiminez, M. G. (2012). SERIES: An Integrated Approach to Supporting Child Development. *Evidence to Action (Summer)*. PolicyLab Center to Bridge Research Practice & Policy: Philadelphia.
- Little, A. A., Kamholz, K., Corwin, B. K., Barrero-Castillero, A., & Wang, J. (2015). Understanding barriers to early intervention services for preterm infants: Lessons from two states. *Academic Pediatrics, 15*(4), 430-438.

- Mann, C. (2003). Observational research methods. Research design II: Cohort, cross sectional, and case control studies. *Emergency Medicine*, 20(1), 54-60.
- Marks, K., Griffen, A., Herrera, P., Macias, M., Rice, C., & Robinson, C. (2015). Statewide solutions to improve early intervention for developmental and behavioral concerns. *Pediatrics*, 136(6) e1492-e1494.
- Noyes, D., & MacLeod, L. (2013a). Expanding the national toolbox for measuring Part C participation Rates: Feasibility and utility of birth cohort methodology. Washington, D.C.: 2013 Improving Data, Improving Outcomes Conference (September, 2013).
- Noyes, D., & MacLeod, L. (2013b). Expanding the national toolbox for measuring Part C participation rates: Feasibility and utility of birth cohort methodology. Washington, D.C.: AUCD Conference: Promoting Inclusion in an Increasingly Diverse World (November, 2013).
- Pearce, N. (2012). Classification of epidemiological study designs. *International Journal of Epidemiology*, 41(2), 393-397.
- Rosenberg, S., Ellison, M., Fast, B., Robinson, C., & Lazar, R. (2013). Computing Theoretical Rates of Part C Eligibility Based on Developmental Delays. *Journal of Maternal Child Health*, 17(2), 384-390.
- Rosenberg, S., Robinson, C., Shaw, E., & C.Ellison, M. (2013). Part C Early Intervention for Infants and Toddlers with Disabilities, Percentage Eligible Versus Served. *Pediatrics*, (131)(1), 38-46.
- Rosenberg, S., Zhang, D., & Robinson, C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*, 121(6), 1503-1509.
- Rotholz, D. A., Kinsman, A. M., Lacy, K. K., & Charles, J. (2017). Improving Early Identification and Screening for Children at Risk for Autism Spectrum Disorder. *Pediatrics*, 139(2),1-7.
- Shackelford, J. (2006). *State and jurisdictional eligibility definitions for infants and toddlers under IDEA. (NECTAC Notes No. 21)*. Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center.
- Shonkoff, J., & Phillips, D. (2001). *From Nuerons to Neighborhoods: The Science of Early Childhood Development*. Washington, D.C.: National Academy Press.
- Twardzik, E., Cotto-Negron, C., & MacDonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal*, 10(4), 467-474.
- US Department of Education. (2017). *39th Annual Report To Congress on Implementation of the Individuals with Disabilities Education Act, 2017*. Washington, D.C.: U.S. Department of Education.
- US Department of Education. (2017). *IDEA Part C child count and settings for the school year 2016-17*. Retrieved November 2018 from ed.gov: <https://www2.ed.gov/programs/osepidea/618-data/collection-documentation/index.html>.
- US Department of Education. (2018). *Sec. 303.21 Infant or toddler with a disability*. Retrieved July 2018 from ed.gov: <https://sites.ed.gov/idea/regs/c/d303.21/a/1>
- US Department of Education. (2018). *IDEA 618 data products: state-level data files*. Retrieved July 2018 from ed.gov: <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html>.
- US Department of Education. (2018). *Sec. 303.302 Comprehensive child find system/Individuals with Disabilities Education Act*. Retrieved July 2018 from Ed.gov: <https://sites.ed.gov/idea/regs/c/d/303.302>.
- US Department of Health and Human Services, Centers for Disease Control and Prevention. (2019). *Research on developmental disabilities*. Retrieved April 2019 from CDC.gov:

<https://www.cdc.gov/ncbddd/developmentaldisabilities/research.html>.

Van Dyck, P., Kogan, M., McPherson, M., & Weissman, M. N. (2004). Prevalence and characteristics of children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, *158*(9) 884-890.

Williams, M., Perrigo, J., Maric, T., & Goldfarb, F. (2018). Barriers to accessing services for young children. *Journal of Early Intervention*, *35*(1), 61-74.

Appendix A

2012-2014 Birth Cohort Study Data Collection Form

Target Population: Children born in 2012, 2013 or 2014 who were referred, evaluated or served at any point during the three years they would have been eligible for Part C. This must be an unduplicated count as much as possible. For children who are exited and re-referred, use the LAST referral.

			Referred to Part C		Evaluated		Eligible for Part C		Eligibility Rate	Enrolled Part C		Enrollment Rate
Year	State	Resident Births in 2012	#	%	#	%	#	%	%	#	%	%
2012												
			Referred to Part C		Evaluated		Eligible for Part C		Eligibility Rate	Enrolled Part C		Enrollment Rate
Year	State	Resident Births in 2013	#	%	#	%	#	%	%	#	%	%
2013		62,476										
			Referred to Part C		Evaluated		Eligible for Part C		Eligibility Rate	Enrolled Part C		Enrollment Rate
Year	State	Resident Births in 2014	#	%	#	%	#	%	%	#	%	%
2014												

Resident Births = Your state's official total number of resident births for the specific year

Referred = A child referred to Part C by a primary referral source, regardless of whether or not an evaluation was completed.

Evaluated = A determination about eligibility was made - eligible or not. This does not include children who were not evaluated due to moving out of state, being unable to locate the family, or other reasons

Eligible for Part C = Children who were evaluated and determined eligible

Enrolled in Part C = children who were determined eligible and had an IFSP

Appendix B

State	N of Cohorts / Resident Births	N of Cohorts / Referrals Reported	N of Cohorts/ Evaluations Reported	N of Cohorts / Eligibility Reported	N of Cohorts / Enrolled Reported	Birth Year Cohorts Reported
AK	4	4	4	4	N/R	2007-10
AR	2	2	2	2	N/R	2009-10
AZ	1	1	1	1	1	2011
CA	1	1	1	1	N/R	2010
CO	1	1	1	1	N/R	2010
CT	6	6	6	5	2	2006-11
DC	2	2	2	2	N/R	2009-10
FL	4	4	4	3	1	2006-09
IA	1	1	1	1	1	2011
ID	8	8	7	7	5	2006-14
IL	2	2	1	1	1	2006-07
KS	6	6	6	5	2	2006-11
KY	1	1	1	1	N/R	2010
LA	9	9	9	5	2	2006-14
MA	9	9	9	8	5	2006-14
MD	8	8	8	8	4	2007-14
MO	9	9	9	8	5	2006-14
MS	3	3	3	3	N/R	2007-09
NC	5	5	5	5	1	2007-11
NH	8	8	8	8	4	2007-14
NJ	5	5	5	5	1	2007-11
NM	5	5	5	4	1	2006-10
NV	4	4	4	3	1	2006, 2008-10
NY	9	9	9	8	5	2006-14
OH	4	4	4	4	1	2007, 2009-11
OR	2	2	2	2	1	2010-11
PA	9	9	9	8	5	2006-14
RI	9	9	9	8	5	2006-14
TX	9	9	9	8	5	2006-14
UT	6	6	6	5	2	2006-11
VA	9	9	9	8	5	2006-14
VT	4	4	4	3	1	2006, 2010-11
WA	3	3	3	2	2	2006, 2010-11
WI	1	1	1	1	N/R	2010
WV	3	3	2	2	1	2006-08

Appendix C

State	N of Cohorts / OSEP Annual Child Count	N of Cohorts / Count of Children OSEP Cumulative Count
AK	4	4
AR	2	2
AZ	1	1
CA	1	1
CO	1	1
CT	6	6
DC	2	2
FL	4	4
IA	1	1
ID	8	8
IL	2	2
KS	6	6
KY	1	1
LA	9	8
MA	9	9
MD	8	8
MO	9	9
MS	3	3
NC	5	5
NH	8	8
NJ	5	5
NM	5	5
NV	4	4
NY	9	9
OH	4	4
OR	2	2
PA	9	9
RI	9	9
TX	9	8
UT	6	6
VA	9	9
VT	4	4
WA	3	3
WI	1	1
WV	3	3