

Life Course Indicator: Early Intervention

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the [W.K. Kellogg Foundation](#).

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Early Intervention (LC-17)

Brief description: Proportion of children aged zero to three years who received EI services of all children aged zero to three years

Indicator category: Early Life Services

Indicator domain: Service/Capacity

Numerator: Children aged zero to three years receiving Early Intervention services in a given state

Denominator: All children aged zero to three years

Potential modifiers: Race/ethnicity, age of referral, sex, type of eligibility

Data source: IDEA 618 Child Count

Notes on calculation: None

Similar measures in other indicator sets: Healthy People 2020 Maternal, Infant and Child Health (MICH) 29.1 – Proportion of Children (10-35 months) Who Have Been Screened for an Autism Spectrum Disorder (ASD) and Other Developmental Delays

Life Course Criteria

Introduction

Children from birth to three who are identified as having, or being at risk for, developmental delays are eligible for services under the Early Intervention Program for Infants and Toddlers with Disabilities under Part C of the *Individuals with Disabilities Educational Act* (IDEA) (Federal Registrar, 2011). Congress established the Part C Early Intervention program (hereafter referred to as EI) in 1986. Consistent with life course theory, EI is intended to affect the future needs and development of the children it serves. The goals of the program are to: 1) enhance the development of infant and toddlers with disabilities, 2) reduce educational costs by minimizing the need for special education, 3) minimize the likelihood of institutionalization, and maximize independent living, and 4) enhance the capacity of families to meet the needs of their children (ETAC, 2014).

All states, eligible territories (American Samoa, Guam, Northern Mariana Islands, Puerto Rico and the Virgin Islands) and the District of Columbia (hereafter referred to as the states) participate in EI. Because EI is a federal entitlement program, a condition of participation is that the states must ensure access to the program to all eligible children and their families. This is accomplished through EI Child Find programs, which require school districts to identify, locate, and evaluate eligible children. Although the states are required to provide EI services to eligible children and families, they have flexibility in how they define developmental delay, whether they include children who are “at risk” for developmental delay in their eligibility criteria, and what state agency leads the program (e.g., public health or education department). This flexibility results in variability in the numbers of children covered and how the EI programs operate across the states. In federal fiscal year (FFY) 2013, almost 340,000 children, representing about 3 percent of the total child population, were served by the EI program. The EI appropriation for FFY 2013 was \$438,500,000 (ECTAC, 2014).

Implications for equity

Although about 3 percent of children in the United States overall are served by the EI program, the percent of children enrolled in the program vary across the states. For example, the proportion of children enrolled in EI ranged from 1.5 percent in Georgia to 7.0 percent in Massachusetts in 2010 (U.S. Department of Education, 2010). This variability may be explained, in part, by the different state policies related to EI eligibility, including the state definition of developmental delay, but the enrollment differences also raise questions about whether all eligible children in a state are enrolled in EI.

There is some evidence that there are disparities in enrollment related to individual-related characteristics, but the research is equivocal, and more research is needed. Factors found to be associated with lower EI enrollment include poverty, lack of insurance, and race/ethnicity (Shapiro and Derrington, 2004, Feinberg et al., 2001). Additionally, children without diagnoses, or mild delays or conditions have been found to be more likely to have lower EI enrollment compared to those with diagnoses, or moderate or severe delays or conditions (McManus et al., 2009). A Massachusetts analysis also found that children born to older mothers, and those of higher income were more likely to be referred to EI, compared to younger and lower income mothers; and that children born to Asian, foreign-born and non-English speaking mothers were less likely to be referred than children born to White, American-born and English-speaking mothers (Clements, 2006, 2008).

Environmental factors and stressors may play a role in determining who receives and continues EI services. EI is a voluntary program for families, and ongoing involvement can be difficult for families experiencing multiple stressors. Families dealing with homelessness; domestic violence; substance abuse; or lack of social support, adequate shelter and clothing often have difficulty accessing services. Family beliefs and cultures about child development, and sensitivity on the part of families to identify developmental delays in their children may also be contributing factors in low EI enrollment. Research has identified parents’ concerns about diagnoses of developmental delays as a factor in using services (Glascoe, 2003, 2006). There also is some evidence that clinicians may respond differently to patients based on gender, clinical training and the child’s behavior, which could influence decision-making about possible diagnoses and EI referrals (Glascoe, 1993; Sices et al., 2004).

Public health impact

EI services are designed to identify and meet the needs of the child in five developmental areas including: physical development, cognitive development, social or emotional development, adaptive development and communications. EI services may be provided in many settings, but are required to be provided in the child’s natural environment (e.g., home)

as possible. Referrals to EI may be made from multiple sources, including physicians, parents or other family members, social workers and others working with the family. All children receiving EI have an Individualized Family Service Plan (IFSP) that specifies the child's outcomes and services, based on an assessment by a multidisciplinary team. The services most often received by children enrolled in EI include: speech, occupational and physical therapy, as well as early childhood education (Raspa et al., 2010). Family members are critical participants in the EI process, and receive service coordination to support their children's development.

EI involvement reduces the number of children referred to special education at the age of three years as well as after a child enters school. This impact provides significant cost avoidance to states. For example, in Massachusetts during fiscal year 2010, EI services resulted in a cost avoidance of more than \$25 million (MDPH Budget Office, personal communication, Feb. 25, 2011). Although this amount refers to the cost of EI services in Massachusetts, similar savings may be seen across other states. The future savings from investment in EI services are becoming more important as the number of children enrolled nationally continues to rise.

Family-centered EI services can lead to improved developmental, social and educational outcomes. Children who are enabled to reach their fullest potential for school readiness are likely to have a more successful experience in school. Successful achievement, which is tied to academic performance, is a deterrent to juvenile delinquency and school drop-out, which are both associated with negative socioeconomic and health outcomes. Schools that are prepared for these children during the transition process from EI to special education are positioned to help maximize the learning experience.

Leverage or realign resources

There are many opportunities for EI to leverage or realign resources. Per the 2011 regulations, states are required to coordinate their Child Find systems with specific agencies responsible for such programs as the early hearing detection and intervention, child abuse prevention and treatment, and the maternal and child health home visiting programs (Federal Register 2011). Additionally, the EI program works closely with educators to transition EI enrollees to Part C of the IDEA at the age of three, including Head Start, Early Start and Early Child Education programs, as appropriate. EI programs also coordinate with their Title V and Children with Special Health Care Need programs, as well as the Special Nutrition Supplement Program for Women and Infants and Children (WIC) and the Children's Health Insurance Program (CHIP).

One of the major opportunities that states are exploring now is working with private and public insurers to cover EI services. This alignment may free up EI funds to potentially support more families (e.g., through expanded eligibility), but also can provide stronger coordination of care for the children and their families. Currently several states have legislation for coverage of EI services by private insurances, and other states are exploring this possibility (Benham 2014).

The Medicaid Program is a particularly important partner for EI. Medicaid covers about one third of the children in the United States, but the program also mandates Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) services for children. These services closely align with EI services. Additionally most Medicaid programs have implemented care coordination activities, including medical homes that also align well with EI services. The majority of the states work with their Medicaid Programs. The Affordable Care Act also presents an opportunity for coverage of EI services in states' essential benefits packages. Of 31 reporting states, 19 percent have included EI services in their benefits packages, and another 32 percent are still working through the inclusion of EI in their packages (Benham, 2014).

Predict an individual's health and wellness and/or that of their offspring

The National Early Intervention Longitudinal Study found that overall infants and toddlers who participated in EI experienced increased motor, social and cognitive functioning; acquired age-appropriate skills and had reduced negative impacts of their disabilities (Hebbeler et al., 2007). Data for 2011-12 collected from the states showed more than two thirds of the children with greater than expected growth across three areas – social relations, use of knowledge and skills and taking action to meet needs (The Early Child Outcome Center). For this same period, more than 50 percent of the children left the program within age expectations for knowledge; and about 60 percent left within age expectations for social relationships.

Children who function within age expectations are more likely than their peers who do not function within age expectations to have positive life course outcomes. In addition, families who have learned to be better advocates for their children in EI will more than likely continue to do so with other systems and networks, providing more opportunities to improve the child's health. Their children, in turn, may well become better advocates for themselves and their children, tying EI services into the life course.

Data Criteria

Data availability

Data collection for EI is outlined in the Federal Register notices. Each state must include a system for compiling and reporting timely and accurate EI data that meets the requirements of the federal regulations of Part C of IDEA. The data system required must include a description of the process that the State uses, or will use, to compile data on infants or toddlers with disabilities receiving early intervention services, including a description of the State's sampling methods, if sampling is used, for reporting the data required by the Secretary under sections 616 and 618 of the Act and §§303.700 through 303.707. Each State must collect valid and reliable information as needed to report annually to the Secretary on the indicators established by the Secretary for the State Performance Plans and Annual Reports.

For the purposes of the annual report required by section 618 of the Act and §303.720, the lead agency must count and report the number of infants and toddlers receiving early intervention services on any date between Oct. 1 and Dec. 1 of each year. The report must include: 1) The number and percentage of infants and toddlers with disabilities in the state, by race, gender and ethnicity, who are receiving early intervention services (and include in this number any children reported to it by tribes, tribal organizations, etc.); 2) The number and percentage of infants and toddlers with disabilities, by race, gender, and ethnicity, who, from birth through age two, stopped receiving services from the EI program because of program completion or for other reasons; and 3) The number and percentage of at-risk infants and toddlers (as defined in section 632(1) of the Act), by race and ethnicity, who are receiving early intervention services under Part C of the Act.

Every state EI program reports annual Child Count data to the Department of Education, Office of Special Education Programs through the Annual Performance Report. This report includes the percentage of children birth to one and percentage of children birth to three with IFSPs compared to other states.

Data quality

The annual number of children served in Early Intervention by a given state as reported in the State's Annual Performance Report is accurate and reliable. States have been reporting these data for more than 20 years, and there is a verification process in place with local EIs to ensure the accuracy of the data. Each state must establish procedures to be used by the local EI in counting the number of children with disabilities receiving early intervention services. Each state must establish dates by which those EIs must report to the lead agency to ensure that the state data are accurate, and obtain certification from the local EIP provider that an unduplicated and accurate count has been made. The state must maintain data for the purposes of audits on the child count.

Simplicity of indicator

The level of complexity in calculating and explaining this indicator is low. The numerator and the denominator are simple and straightforward. The numerator is the number of children birth to age three years receiving early intervention services as of a given date. The denominator is provided through census data of the population birth through three years.

Eligibility criteria for EI may vary from state to state; however, there is enough comparability among states for this indicator to be meaningful. For example, the Infant Toddlers Coordinators Association (OSEP DANS, 2012) has established categories of eligibility to include the following:

Category A: At Risk, Any Delay, Atypical Development, one standard deviation in one domain, 20 percent delay in two or more domains, 22 percent delay in two or more domains, 25 percent delay in one or more domains.

Category B: 25 percent delay in two or more domains, 30 percent delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, 33 percent delay in one domain.

Category C: 33 percent delay in two or more domains, 40 percent delay in one domain, 50 percent delay in one domain, 1.5 standard deviations in two or more domains, 1.75 standard deviations in one domain, two standard deviations in one domain, two standard deviations in two or more domains. Historical Child Count data and cumulative number of children served by each state are available on the ITCA website at ideainfanttoddler.org/pdf/2011-Child-Count-Data-Charts.pdf.

References

Benham, R. (June 2014) Finance Webinar Series – Utilizing Private Insurance in Supporting Part C Services. Available at: <http://ectacenter.org/~calls/2014/financepartc/financepartc.asp#session3>

Clements K. (2008). Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Maternal and Child Health Journal*. 12:708-17.

Clements K. (2006, September). Referral to and Participation in Massachusetts Early Intervention among children born January 1998 to September 2000. Boston, MA: Massachusetts Department of Public Health. Data Brief No. 1. pp. 1-5.

The Early Childhood Outcomes Center. Funded by the Office of Special Education Programs, U.S. Department of Health. Funded by the Outcomes for Children Served through IDEA's Early Childhood Program. 2011-2012. Received from the Massachusetts Early Intervention Program, September 4, 2014.

The Early Childhood Technical Assistance Center (ECTAC). Annual Appropriations and Number of Children served Under Part C of IDEA Federal Fiscal Years 1987-2012. Available at: <http://ectacenter.org/partc/partodata.asp>. Accessed September 2, 2014.

Federal Register. (2011). Early Intervention Program for Infants and Toddlers with Disabilities; Final Regulations. U.S. Department of Education: 34 CFR Part 303. Available from: <http://www.gpo.gov/fdsys/pkg/FR-2011-09-28/pdf/2011-22783.pdf>.

Feinberg, E., Silverstein, M., Donahue, S., Bliss, R. (2011). The impact of race on participation in Part C Early Intervention services. *Journal of Developmental and Behavioral Pediatrics*. 32(4): 284-291.

Glascoe, F.P. (1997). Obstacles to effective developmental surveillance: errors in clinical reasoning. *Journal of Developmental and Behavioral Pediatrics*. 14(5): 344-349.

Glascoe, F.P. (2003) Parent's evaluation of developmental status: how well do parents' concerns identify children with behavioral and emotional problems? *Clinical Pediatrics*. 42(9): 133-138.

Glascoe, F.P. (2006). If you don't ask, parents may not tell: noticing problems vs. expressing concerns. *Archives of Pediatric Adolescent Medicine*. 160(2) 220.

Hebbeler K., Spiker, D., Bailey, D., Scarborough, A., Mallik, S., Simeonsson, R., Singer, M. (2007) Early intervention for toddlers and infants with disabilities and their families; participants, services and outcomes. Final Report of the National Early Intervention Longitudinal Study (NEILS). Available at: http://www.sri.com/sites/default/files/publications/neils_finalreport_200702.pdf

McManus, B., McCormick, M.C., Acevedo-Garcia, D., Ganz, M., Hauser-Cram, P. (2009). The Effects of State Early Intervention Eligibility Policy on Participation among a Cohort of Young CSHCN. *Pediatrics*. 124:s638-s674.

Raspa, M., Hebbeler, K., Bailey, D.B., Scarborough, A.A. (2010) Service provider combinations and the delivery of early intervention services to children and families. *Infants Young Children*. 23(2): 132-144.

Rosenberg, S.A., Zhang, D., Robinson, C.C. (2008) Prevalence of Developmental Delays and Participation in Early Intervention Services for Young Children. *Pediatrics*. 122(6): e15003-e1509.

Shapiro, B.J., Derrington, T.M. (2004). Equity and Disparity in Access to Services: An Outcome-Based Evaluation of Early Intervention in Child Find in Hawaii. *Topics in early Childhood Special Education*. 24(4): 199-212.

Sica, L., Feudtner, C., McLaughlin, J., Drotar D., Williams, M. (2004). How Do Primary Care Physicians Manage Children with Possible Developmental Delays? A National Survey with an Experimental Design. *Pediatrics*. 113(4): 274-282.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS). (2011). Infants and Toddlers Receiving Early Intervention Services in Accordance with Part C. U.S. Department of Education: OMB #1820-0557. Available from: <http://www.ideainfanttoddler.org/pdf/2010-Child-Count-Data-Charts.pdf>

This publication was supported by a grant from the W.K. Kellogg Foundation. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the W.K. Kellogg Foundation.

To learn more, please contact Caroline Stampfel, senior epidemiologist at cstampfel@amchp.org or (202) 775-0436.

Association of Maternal & Child Health Programs

2030 M Street, NW, Suite 350

Washington, DC 20036

(202) 775-0436 • www.amchp.org

