HHS Public Access

Author manuscript

*Infants Young Child*. Author manuscript; available in PMC 2020 December 01.

Published in final edited form as:

*Infants Young Child*. 2019 December ; 32(4): 231–244. doi:10.1097/iyc.0000000000000151.

# State Variability in Diagnosed Conditions for IDEA Part C Eligibility

**Brian Barger, PhD**, **Jane Squires, PhD**, **Maureen Greer, BA**, **Donna Noyes-Grosser, PhD**, **Julia Martin Eile, EdM**, **Catherine Rice, PhD**, **Evelyn Shaw, Med**, **Kala Shah Surprenant, JD**, **Elizabeth Twombly, MS**, **Sarah London, MPH**, **Jennifer Zubler, MD**, **Rebecca B. Wolf, MA**

Center for Leadership in Disability, School of Public Health, Georgia State University, Atlanta (Dr Barger); Disability Research and Dissemination Center, Arnold School of Public Health, University of South Carolina, Columbia (Dr Barger); Center on Human Development, University of Oregon, Eugene (Dr Squires and Ms Twombly); Infant & Toddler Coordinators Association, Indianapolis, Indiana (Ms Greer); Office of Special Education Programs (Dr Noyes-Grosser and Ms Martin Eile) and Office of General Counsel (Dr Surprenant), US Department of Education, Washington, District of Columbia; Department of Psychiatry and Behavioral Sciences (Dr Rice) and Emory School of Public Health (Ms London), Emory University, Atlanta, Georgia; Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill (Ms Shaw); Carter Consulting, Inc, Atlanta, Georgia (Dr Zubler); and National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia (Drs Rice and Zubler and Mss London and Wolf).

## Abstract

An infant or toddler can begin the process of receiving Part C early intervention services by having a diagnosed condition with a high probability of developmental delay (Individuals with Disabilities Education Improvement Act, 2004). How states define those diagnosed conditions that begin the initiation process varies widely. Lists of diagnosed conditions were collected from state Part C websites and Part C coordinators for a descriptive analysis. Across 49 states, the District of Columbia, and 4 territories, a final list of 620 unique conditions was compiled. No single condition was listed by all jurisdictions. Hearing impairment was the condition listed by the most states ($n = 38$), followed by fetal alcohol syndrome ($n = 34$). Of the 620 conditions, 168 (27%) were listed by only 1 state, 554 (89%) were listed by fewer than 10 states, and 66 (11%) were listed by 10 or more states. Of these 66 conditions, 47 (71%) were listed by fewer than 20 states. Most of these 66 conditions ($n = 48$; 72.7%) had a prevalence of "very rare or rare," 8 (12%) were "common," 6 (9%) were "very common," and 4 (6.1%) were "unknown." The wide heterogeneity in the number and type of diagnostic conditions listed across states should be further investigated as it may represent imbalances in children with diagnosed conditions gaining access to Part C evaluations and individualized family service plans and potentially the services themselves across

**Correspondence:** Brian Barger, PhD, Center for Leadership in Disability, School of Public Health, Georgia State University, 75 Piedmont NE, Atlanta, GA 30606 (bbarger1@gsu.edu).

Dr Barger, Dr Squires, and Ms Greer contributed equally to the development of this project.

The authors declare no conflict of interest.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.iycjournal.com).

states. In addition, providing ready access to lists of diagnosed conditions is a simple step that could help states and Part C programs facilitate access to services.

**Keywords**

developmental delay; developmental disability; diagnosed conditions; early intervention; eligibility; IDEA

EARLY INTERVENTION (EI) is critical for improving the developmental and behavioral skills of children at risk of developmental delays and disabilities (Guralnick, 2019; Squires, Bricker, & Twombly, 2015). High-quality services promote improved social-emotional and learning skills in young children and families that make a significant contribution to success in school and later life experiences (Litt, Glymour, Hauser-Cram, Hehir, & McCormick, 2018; Woodman, Demers, Crossman, Warfield, & Hauser-Cram, 2018). Brain development research suggests that high-quality early experiences with caregivers can positively impact brain structure, forming healthier, more robust neural connections and structures in young children, and have been related to improved social, health, and academic outcomes (Bernier et al., 2019; Fox, Levitt, & Nelson, 2010; Gluckman, Hanson, Cooper, & Thornburg, 2008; Wang et al., 2019). In addition, by taking advantage of the brain's plasticity during infancy and toddlerhood, high-quality EI experiences may improve children's developmental and academic outcomes by beneficially altering their neural pathways (Bernier et al., 2019; Meaney, 2010; Wang et al., 2019). Intervening during the early years is considered the most effective means for changing developmental trajectories and facilitating development of critical skills for children with developmental disabilities and delays.

Part C of the Individuals with Disabilities Education Act (IDEA) provides funding to supplement federal, state, territorial, and local funding, both public and private, in order to identify infants and toddlers with disabilities and provide those children with EI services. "Infant or toddler with a disability" is defined in the law as a child younger than 3 years who needs EI because either (1) he or she has a diagnosed condition that has a high probability of resulting in a developmental delay, or (2) he or she has a developmental delay in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development as measured by appropriate instruments and procedures (20 U.S.C. § 1432(5)(a)). Diagnosed conditions likely to result in a developmental delay commonly are referred to as diagnosed conditions or Category 1 conditions. IDEA regulations expand on the law's definition of diagnosed conditions by including some specific examples: chromosomal abnormalities; genetic or congenital disorders; sensory impairments; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; severe attachment disorders; and disorders secondary to exposure to toxic substances, including fetal alcohol syndrome (FAS) (34 C.F.R. § 303.21(a)(2)(ii)).

Although diagnosed conditions and developmental delay are the primary pathways to EI receipt discussed here, there are two other options for serving children rarely exercised by states. Part C allows states, at their discretion, to deem eligible infants and toddlers who would be at risk of experiencing a substantial developmental delay due to biological or

environmental factors if EI services were not provided (34 C.F.R. § 303.21(b) and § 303.5). Part C also allows states to continue providing EI services with the addition of preliteracy, language, and numeracy skills to children with disabilities already eligible beyond 3 years of age, provided that they meet the state's criteria for preschool IDEA services under IDEA Section 619 (34 C.F.R. § 303.21(c)).

## CHALLENGES IN PART C ELIGIBILITY RELATED TO DEVELOPMENTAL DELAY AND DIAGNOSED CONDITIONS

States and territories set their own criteria for eligibility for each of these two major IDEA definitions, but determining those criteria is a challenging endeavor. For example, states can select differing standards or "cutoff" scores for determining whether delay exists. States vary widely in selecting different cut points on standardized tests to define delay (Rosenberg, Zhang, & Robinson, 2008). Furthermore, no clear policies define the number, type, or limitations around state definitions of diagnosed conditions. Theoretically, a state could select as many or as few diagnosed conditions as they see fit, or simply copy a condition or classification of conditions (e.g., chromosomal abnormalities) from the Federal Register.

Aside from the policy considerations, not all categorical diagnosed conditions determinations are necessarily clearly differentiated from dimensional considerations such as delays. Identification of developmental delays and many diagnosed conditions wherein children are developing atypically requires multiple steps and is partially informed by imperfect assessments (Barger, Rice, & Roach, 2018). Assessments are the primary tools used to identify probable delay and diagnoses, but each has its own biases and predictive accuracy metrics (e.g., sensitivity, specificity), often developed in ideal research settings by highly trained faculty and students (Barger, Rice, & Roach, 2018; Doebler, Holling, & BÖhning, 2012). In reality, diagnostic decision-making is done by a wide variety of clinical specialists who may have varying degrees of expertise in the diagnosis/assessment of particular conditions and recommended assessments (Barger, Rice, & Roach, 2018). Although there are single-gene (e.g., Down syndrome) or clear sensory disorders, many diagnosed conditions (e.g., autism spectrum disorder, fetal alcohol spectrum disorder) range from mild to severe, with unclear demarcations on the higher functioning/typical end. Ultimately, diagnostic decisions are determined by trained clinicians using imperfect assessment tools who may not have particular expertise related to a particular condition (Barger, Rice, & Roach, 2018). Thus, the diagnosed conditions policy routing children to Part C is complicated by the reality that categorical diagnosed conditions are often determined via continuous measures of multidimensional underlying symptoms and delays (Beauchaine & Klein, 2017; Scarborough, Hebbeler, Spiker, & Simeonsson, 2007). As such, eligibility under a diagnosed conditions criterion obviates the need for children to undergo extensive assessments in order to show evidence of their need for EI via expression of a significant developmental delay. Instead, the diagnosis itself conveys the need for intervention as soon as possible, receipt of which potentially leads to better outcomes.

## RESEARCH ON DEVELOPMENTAL DELAY AND DIAGNOSED CONDITIONS

Currently, there is little research on the processes by which children are identified as eligible for Part C services in their communities (Barger, Rice, Simmons, & Wolf, 2018; Bricker, Macy, Squires, & Marks, 2013; Macy, Marks, & Towle, 2014; Twardzik, CottoNegron, & Macdonald, 2017). Most research focuses on early identification via screening and monitoring (Barger, Rice, Simmons, et al., 2018; Bricker et al., 2013; Hirai, Kogan, Kandasamy, Reuland, & Bethell, 2018), specific instruments used for eligibility evaluations (e.g., Mullen Scale of Early Learning), state definitions of developmental delay (McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009; Rosenberg et al., 2008; Schneider, Smith, Walters, & Cooper, 2010), and continuity of EI services as children leave Part C and enter preschool special education services (Danaher, Shackelford, & Harbin, 2004).

The few reports investigating diagnosed conditions either focus on single conditions (e.g., autism; Stahmer and Mandell, 2007) or report on broad eligibility categories (Mott & Dunst, 2006; Scarborough, Hebbeler, & Spiker, 2006); little research exists on how children with diagnosed conditions are identified for Part C services (Silverstein et al., 2006). In addition, no data exist on the variability of diagnosed conditions across states. This is surprising because of a national longitudinal study of Part C estimated that 21% of children in EI have a known diagnosed condition (Scarborough et al., 2006). These children are in EI longer and their services are costlier than children routed to EI for developmental delay (Hebbeler, Levin, Perez, Lam, & Chambers, 2009). In a survey conducted on referral practices of pediatricians, 64% ($n = 894$) of respondents thought that diagnosed conditions were an important consideration for EI referrals (Silverstein et al., 2006). Elucidating the diagnosed conditions included in states' and territories' Part C eligibility criteria may be important to help the field understand the scope of conditions served and lead to research improving our understanding of the differential effects of diagnosed conditions policies across states.

The prevalence of diagnosed conditions and their association with delays warranting EI is an important consideration as states determine which conditions they should cover. This is underscored by the fact that up to one in five children receiving Part C services has a diagnosed condition (Scarborough et al., 2006) and there is likely a great diversity of conditions covered across states. For example, some conditions, such as autism, are more prevalent and others (e.g., Angelman syndrome) less so. Currently, no data exist linking the receipt of Part C services with the prevalence of diagnosed conditions broadly, though some research exists on particular conditions (see Barger, Rice, Simmons, et al., 2018). Such explicit linkages would facilitate planning for legislators and Part C administrators when expanding diagnosed conditions lists to consider for inclusion. Furthermore, not all conditions are strongly associated with delays warranting EI. For example, some groups argue that low birth weight should universally be on all diagnosed conditions lists, as developmental delays are frequently comorbid (Division for Early Childhood, 2018). On the contrary, although anxiety is more frequent in children with developmental disabilities or delays (White, Oswald, Ollendick, & Scahill, 2009), having an anxiety disorder in early childhood does not necessarily coincide with developmental delays. Thus, some states may be including diagnosed conditions that do not typically lead to delays warranting Part C

services. A final side benefit of co-considering prevalence rates with diagnosed conditions is that it could lead to collaborative opportunities between public health organizations and Part C systems that lead to improved prevalence estimates for rare or very rare conditions. Ultimately, considering prevalence of data in relation to diagnosed conditions may aid Part C services in determining which conditions to include on state lists.

Despite the understood role that the diagnosed conditions policy plays in helping identify children in need of EI services, there is no published research on how many different conditions are served across states, which conditions are commonly served by Part C, or variability in condition types served by Part C across states. Thus, the purpose of this study was to document current state lists of diagnosed conditions for EI eligibility, analyze their frequency of occurrence, and summarize the estimated relative prevalence of the most commonly covered conditions. Understanding this variability is an essential part of investigating how children with diagnosed conditions are identified and referred from community settings to Part C EI services. Furthermore, investigating variability of diagnosed conditions may help set the stage for studies elucidating the sources of differences in EI receipt seen across states and territories (McManus et al., 2009). For example, if some states accept a wide range of diverse conditions and others do not, this could potentially influence the number of children receiving services in one state over another. In addition, some states may include a high number of common conditions but other states could only include a lower number of rare conditions, which could theoretically impact the number of children ultimately routed to EI services via the diagnosed conditions route. Differential acceptance of diagnosed conditions across states may impact the financial and caseload burden of Part C systems experience across states and territories.

## METHODS

### Condition identification

Data came from two sources: state Part C websites (Squires, 2012) and a special study conducted in 2014 by the Infant and Toddler Coordinators Association (ITCA) with 37 member states on conditions included in states' eligibility criteria for Part C (M. Greer, personal communication). For the list compiled from Part C websites, conditions that were listed on official state policy documents were included.

**ITCA data—**For the ITCA data, state Part C coordinators were asked to submit the list of medical conditions that were in their official OSEP-approved eligibility criteria. Submissions ranged from highly detailed lists of medical diagnoses to language that simply reflected the regulatory language. The full compilation was then sent back to states to confirm the accuracy of their information and to make any corrections needed. A third wave of data collection was performed in 2018 from 17 states without data identified in the 2014 search.

**Part C website data—**An environmental scan of state Part C websites was conducted by J.S. and two research assistants, wherein the assistants identified relevant diagnosed conditions lists and policy documents. When such data were unavailable online, they reached out directly to the Part C coordinator.

**ITCA and Part C website data merger—**The ITCA and Part C website data were then compared and combined. Identified disagreements in lists were discussed and researched by the team until a consensus was reached as to whether the condition should be included or not. The lists created from these data sources were combined into a single file.

**Merged data cleaning—**Upon compilation of the list of combined conditions, conditions described by more than one name (e.g., arthritis, juvenile, and juvenile arthritis) and those with multiple synonymous names (e.g., glycogenosis and glycogen storage disease) were combined. This process of combining conditions was overseen by B.B., R.W., a Centers for Disease Control and Prevention (CDC) epidemiologist with expertise in *International Classification of Diseases* (*ICD*) codes, and CDC administrator (CDC personnel from the National Center on Birth Defects and Developmental Disabilities). Each diagnosed condition was linked to an *ICD* code and then the entire data set was sorted in order to group potentially similar conditions. Conditions with the same *ICD* code were then color coded for easy identification, and the team met to discuss whether conditions were synonymous or not. Final determination was reached by group consensus; clearly synonymous conditions were ultimately combined (e.g., hearing loss, auditory impairment, and deafness were combined). The authors chose to not combine broad groups of conditions or connect them to subgroups, as there is limited information as to how these classifications might be implemented by Part C programs in determining eligibility. Thus, for example, a state may list vision impairment, hearing impairment, and sensory impairments; in this case, the specific impairments are listed separately from the broad classification of sensory impairments. Finally, when conditions were combined, they were counted as present if the condition was on either list. Cleaning the full list of combined conditions resulted in a compilation of 620 diagnosed conditions across 49 states, the District of Columbia, and four territories. One state and one territory were nonresponsive to data requests and did not have a list available online. The term “states” used in the following represents states, District of Columbia, and territories.

## Prevalence estimation

To determine the relative proportion of the U.S. population with each condition, the authors searched prevalence data available from the following sources: CDC, National Institutes of Health, National Organization for Rare Diseases, and Orphanet. When data were not available from these sources, the authors searched prevalence information from academic journals and online medical resources. All prevalence data were first compiled by B.B. and then independently reviewed and verified by a research assistant. Discrepant prevalence estimates were then reviewed and final determination was made by B.B. A table with condition names and reference sources is available as Supplemental Digital Content materials (available at: http://links.lww.com/IYC/A13). Prevalence ranges were condensed into categories:

- Very rare: <1/10,000 cases
- Rare: 1/9,999 to 1/1,000 cases
- Common: 1/999 to 1/100 cases
- Very common: ≥1/99 cases

For conditions reporting a range of multiple reported prevalence, the higher prevalence was selected, as surveillance estimates tend to be biased toward underascertainment (Wheeler et al., 1999). The prevalence analysis is limited to the subset of the top 66 conditions listed across states.

## RESULTS

Across 54 states, a final list of 620 unique conditions was identified. Hearing impairment ($n$ = 38) was the condition listed by the most states, followed by FAS ($n$ =34), Down syndrome ($n$ =32), vision impairment ($n$ = 29), cerebral palsy ($n$ =27), and autism spectrum disorder ($n$ =25). Of the 620 conditions, 554 (89.3%) were listed across fewer than 10 states and 168 of these were listed by single states. On average, a single condition was listed across four states ($SD$ =5.22; median = 2; min=0; max 38) (Table 1, first row), and states listed on average 48 conditions ($SD$ = 45.64; median = 33; min=0; max = 167) (Table 1, second row). Three states did not list any diagnosed conditions.

Of the 620 conditions on the full list, 66 were listed by 10 or more states. Of these most common conditions, each condition was found on average on 17 state lists ($SD$ = 6.00; median = 16; min=10; max 38) (Table 2, first row) and on average states listed 20 of these conditions ($SD$ = 17.73; median 19;min = 0; max 53) (Table 2, second row). Of these commonly listed 66 conditions, 47 (71.2%) were listed by fewer than 20 states. Most of the top conditions ($n$= 48; 72.7%) had a prevalence of “very rare or rare,” eight (12.1%) were “common,” six (9.1%) were “very common,” and four (6.1%) were “unknown” (Table 3). Table 4 shows the top 66 conditions by the number of states that include each condition in descending frequency and with estimated prevalence.

## DISCUSSION

To our knowledge, this is the first compilation of official state, District of Columbia, and territory lists of diagnosed conditions included in eligibility criteria for IDEA Part C EI services. Before undertaking this descriptive study, we anticipated that we would identify a handful of diagnosed conditions recognized by the vast majority of states as conferring automatic EI eligibility. Surprisingly, this was not the case. Instead, state lists were unexpectedly diverse, with 620 unique conditions included across 54 eligibility lists; state lists also ranged widely in the number of conditions listed, ranging from none to 167. This wide heterogeneity in the number and type of diagnostic conditions listed across states should be further investigated, as it may represent imbalances in the ability of children with diagnosed conditions to receive Part C EI services across states. Fetal alcohol syndrome, which is the second most commonly listed condition across states, is coincidentally the only specific condition included in IDEA regulations as an example of an established condition (34 C.F.R. § 303.21(a)(2)(ii)). This may have resulted from states efforts to comply with federal regulations, in addition to an increasing body of evidence related to FAS and developmental delay.

The conditions found on these state lists vary widely in type as well as number. For example, some states list a broad category such as neural tube defect, inborn errors of metabolism, or

anomalies of the brain whereas other states list only individual conditions under those terms such as spina bifida, galactosemia, or encephalocele. States that list broad terms can potentially provide eligibility based on diagnosed condition more readily and to more children with related conditions than those that list single conditions in the same category. However, considering that underfunding issues, personnel shortages, and other challenges can lead to more conservative decisions around acceptance to Part C (McManus, Magnusson, & Rosenberg, 2014; Rosenberg et al., 2008), broad, rather than more specific, diagnosed condition lists could result in lower service receipt, as there may be greater room for interpretation. Furthermore, although the conversation has focused on variability across states, there may be as much or more variability within states across local programs in terms of interpreting broad categories of conditions indicating Part C access, depending on local budgets and workloads. Notably, we are working on an assumption that increased clarity and visibility of state lists will lead to improved EI service receipt for children with diagnosed conditions; however, this hypothesis is currently untested and will require careful consideration and input from the broad EI community.

If well-constructed, state lists have the potential to help facilitate the entrance of children with diagnosed conditions via obviating the need for an initial evaluation, so as to hasten the initiation of the 45-day multidisciplinary assessment and individualized family service plan (IFSP) development (§ 303.321 (a) (3)(i)) and perhaps defray some costs related to eligibility determination. Because children can be eligible based on developmental delay in cognitive, physical, communication, social/emotional, or adaptive functioning (IDEA, 2004), children with a diagnosed condition have an alternate route to services if their diagnosed condition is not recognized. However, testing for developmental delay is resource-intensive (Snow & Hemel, 2008). Furthermore, additional delays in services may be incurred if a child's developmental delay due to a diagnosed condition is not immediately recognized by providers or parents, thereby delaying a referral to EI. Finally, states have the option of using an interim IFSP to initiate needed services before eligibility is determined (34 C.F.R. § 303.345), though this path still requires a full assessment and IFSP developed within 45 days, and it is unknown how frequently this option is implemented (Dragoo, 2018).

Each state is required to circulate for public comment under 34 C.F.R. § 303.208 its IDEA Part C policies and procedures, including its eligibility criteria for both its definition of developmental delay and its diagnosed conditions. Furthermore, states are required to include in their federal grant applications definitions of "developmental delay" that serve as their eligibility criteria (34 C.F.R. § 303.203(c)). However, there is no parallel requirement for a state to submit to the federal government its list of diagnosed conditions. It seems reasonable that families and primary referral sources such as physicians, EI service providers, and other early childhood service providers have readily available information to determine whether a child's diagnosed condition would automatically qualify him or her for an EI service assessment. Providing ready access to lists of diagnosed conditions is a simple step that has the potential to help states and Part C programs facilitate EI service access. Posting the list of diagnosed conditions in several easy-to-find web locations for both parents and health care providers; printing, distributing, and posting lists in clinics and hospitals; and including a link to the list on a state's standard referral form could all potentially help streamline the eligibility process. In addition, a compilation of diagnosed

conditions by state and territory could be posted on publicly available national websites such as the Early Childhood Technical Assistance Center (http://ectacenter.org) and the American Academy of Pediatrics (www.aap.org). Public access to diagnosed conditions lists could be helpful to caretakers and health care workers invested in early identification. It should be noted, however, that public access to a list may benefit children with certain conditions and not others. For example, children with many diagnosed conditions (e.g., Down syndrome) are commonly served across the majority of states on the basis of developmental delay and independent of their presence on an available state list. Well-known conditions such as these are unlikely to be affected by policy changes; however, children with lesser known conditions (e.g., Turner syndrome) may be more likely to benefit. Thus, beneficial impacts across states in services received by children with diagnosed conditions identified from public postings will likely vary depending on whether particular conditions are well known. In all situations, easing the caregiver and provide burden to hunt down this information is essential.

Greater transparency in understanding which conditions are served by different states represents an important first step in understanding the variability across states in the prevalence of conditions served. Estimates indicate that one in five children served by Part C has a diagnosed condition (Scarborough et al., 2006). As such, it is currently unknown what the burdens across states and territories include due to which conditions are elected to serve. Although it is certainly true that much of the state variability in services provided lies in the differential criteria states accept as evidence for the presence of a developmental delay (McManus et al., 2014; Rosenberg et al., 2008), the fact that some states have no conditions listed and others up to 167 indicates that differences between particular states could be quite substantial. This, however, will require more research to verify. Although states are well within their regulatory rights to include as few or as many diagnosed conditions as possible, decisions made by families and by Part C administrators would likely be facilitated by the transparent reporting of diagnosed conditions. Ultimately, however, the effects, positive or negative, are unknown. This article, and suggested public posting of diagnosed conditions lists, is merely the initiation of a broader discussion on the most appropriate way to increase awareness and understanding of the diagnosed conditions route to EI that balances transparency, early identification, and the appropriate routing of children with diagnosed conditions who have a high probability of developmental delays to EI services.

## LIMITATIONS AND FUTURE DIRECTIONS

This study is potentially limited by the difficulty obtaining information about diagnosed conditions for every state. Although every effort was made to collect official information based on state policy, the lack of publicly available lists in many states made this task difficult. The compiled list of diagnosed conditions required the work of several trained professionals and staff familiar with Part C state systems. Nevertheless, collecting the information was a difficult and time-consuming effort. Many state websites did not post lists of diagnosed conditions, and obtaining them through telephone calls and e-mail inquiries was unsuccessful in two cases. These limitations may have led to incomplete or outdated data for some states. Furthermore, although we attempted to identify the most recent prevalence data, many conditions were rare and obscure with a fairly small literature on

which to base estimates. Thus, prevalence estimates for many rare or very rare conditions are tentative. However, this limitation does not obviate that the value of these data lies in facilitating conversations around leveraging known networks for epidemiologists and Part C to aid in bettering estimates, on identifying sources of care for disability advocacy organizations, and for Part C administrators to use for strategic planning when considering conditions for state diagnosed conditions lists. Furthermore, the literature on diagnosed conditions is scant and we have interpreted findings as indicating that diagnosed conditions are commonly served (Scarborough et al., 2006); however, just because approximately 20% of children in EI have a diagnosed condition does not necessarily indicate that they were identified because of that condition and, instead, may have been identified because of associated delays (e.g., low birth weight; Division for Early Childhood, 2018). In addition, recent public health concerns about opioid use and potentially related cases of neonatal abstinence syndrome (NAS) may have led to discussions about Part C eligibility for babies with NAS in some states since data were collected for this study. Finally, we should underscore the likely tenuous relationship between state lists and children served. For example, the authors and reviewers of this article realize that the majority of states serve children with Down syndrome, even though this condition is not technically listed in all state lists. And, unless clearly communicated to the health and early childhood community, other conditions may not be actively identified and served via diagnosed conditions despite their existence on state lists.

Despite challenges related to diagnosed conditions, currently states have an OSEP approved policy regarding their eligibility criteria and are in full compliance with the law, with no requirement for state lists to be based on scientific evidence or otherwise empirically justified. Ultimately, any changes to diagnosed conditions will require more specific language in a reauthorization of IDEA. The compilation of the current brief top 10% list serves as a starting point of a much needed broader conversation about how states might better identify children with diagnosed conditions. Presumably, each of these conditions has some statistical relationship resulting in developmental delays warranting intervention. While the relationship in cases, such as Down syndrome, is widely known and accepted, the relationship to developmental delays in other conditions is unknown and even tenuous and impacted by numerous social, medical, and environmental factors. For example, the incidence of developmental delay in attachment disorders considered to be modest, though it is infrequently studied (Zeanah & Gleason, 2015), but 20 states found the evidence compelling enough to include on their list. Ultimately, the relationship between condition and delays warranting EI is likely complex for many conditions and will require much more continuing empirical work on a condition-by-condition basis. Currently, there is no formal empirical process for determining why particular diagnosed conditions should warrant placement on a list and others should not. Ideally, the process would be scientifically grounded with well-operationalized terms, perhaps via systematic reviews and meta-analyses of the literature on a condition-by-condition basis guided by input from the broader EI community including researchers, policy makers, and Part C coordinators. Ultimately, no state list is likely to be exhaustive, but with some effort, every list could be fielded with empirically validated conditions for which there is adequate evidence for probable developmental delays requiring intervention.

This is the first study to explicitly consider prevalence with diagnosed conditions within a Part C context, reflecting the diverse interests of public health, disability, EI, and public education fields. Within and across fields, there is a growing interest in maximizing the use of existing data systems to facilitate optimal service provision and unique federal mandates. Public health epidemiologists are interested in understanding the children Part C serves, particularly in relationship to diagnosed conditions, as partnerships could potentially aid in identification of rare or very rare cases of conditions. Furthermore, collaborative efforts between public health and the EI community are beginning to expand understanding of early identification beyond psychometric screener development and epidemiological counts to include studying the effects of community-based early identification systems and networks, such as Child Find on identified cases (Barger, Rice, & Roach, 2018; Barger, Rice, Simmons, et al., 2018; Bricker et al., 2013). Insights from the intervention community help public health grapple with the complexity of early identification; perspectives and methods from public health, such as prevalence estimates, could be useful to aid Part C coordinators and state legislators when refining diagnosed conditions lists. For example, prevalence estimates could be used to “shortlist” priority investigations into the relationship between particular conditions and developmental delays; very common conditions could be first considered as they are statistically more likely to be encountered by the system and might be considered higher priority, then common, and so on, until each condition has been vetted. Despite the ultimate approaches selected, the ultimate goal of these efforts is to maximize resources so that children in need of services might be optimally identified and served.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

From 2014 to 2015, Dr Barger was partially supported by a Policy Research Fellowship sponsored by the University of South Carolina: Disability Research and Dissemination Center in collaboration with the Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities, “Learn the Signs. Act Early” program; from 2015 to 2017, Dr Barger was partially supported by a grant for the Center for Leadership in Disability at Georgia State University as a University Center for Excellence in Developmental Disabilities (90DD0662), Administration on Intellectual and Developmental Disabilities. In addition, partial support was provided by RTOI Agreement 2010-05-007 Sub Contract Agreement No. 449, between the Association of University Centers on Disabilities and the Centers for Disease Control and Prevention.

The authors thank Drs Joe Sniezek (CDC-NCBDDD, retired) and Jennifer Williams (CDC-NCBDDD) for their work using ICD codes to identify redundant conditions for this project, and Ms Miyah Sundermeyer for her help in fact checking of the prevalence rate data.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the United States Department of Education, or any of its subcomponents.

## REFERENCES

Barger B, Rice C, & Roach A (2018). Response to Foreman’s commentary on socio-emotional surveillance in preschoolers. Child and Adolescent Mental Health, 23(3), 217–219.

Barger B, Rice C, Simmons CA, & Wolf R (2018). *A systematic review of Part C* early identification studies. Topics in Early Childhood Special Education, 38(1), 4–16. [PubMed: 28479651]

Beauchaine TP, & Klein DN (2017). Classifying psychopathology: The DSM, empirically-based taxonomies, and the Research Domain Criteria In Beauchaine TP, & Hinshaw SP (Eds.), Child and adolescent psychopathology (3rd ed., pp. 33–36). Hoboken, NJ: Wiley.

Bernier A, Dégeilh F, Leblanc É, Daneault V, Bailey HN, & Beauchamp MH (2019). Mother–infant interaction and child brain morphology: A multidimensional approach to maternal sensitivity. Infancy, 24(2), 120–138.

Bricker DD, Macy M, Squires J, & Marks K (2013). Developmental screening in your community: An integrated approach for connecting children with services. Baltimore, MD: Paul H. Brookes.

Danaher J, Shackelford J, & Harbin G (2004). Revisiting a comparison of eligibility policies for infant/toddler programs and preschool special education programs. Topics in Early Childhood Special Education, 24(2), 59–67.

Division for Early Childhood. (2018). New-position-statement: DEC position statement on low birth weight prematurity early intervention. Retrieved from http://www.dec-sped.org/single-post/2018/10/15/New-Position-Statement-DEC-Position-Statement-on-Low-Birth-Weight-Prematurity-Early-Intervention

Doebler P, Holling H, & Böhning D (2012). A mixed model approach to meta-analysis of diagnostic studies with binary test outcome. Psychological Methods, 17(3), 418. [PubMed: 22582866]

Dragoo KE (2018). The Individuals with Disabilities Education Act (IDEA), Part C: Early intervention for infants and toddlers with disabilities. CRS report R43631, Version 10. Updated. Washington, DC: Congressional Research Service Retrieved from https://files.eric.ed.gov/fulltext/ED593625.pdf

Fox SE, Levitt P, & Nelson CA III (2010). How the timing and quality of early experiences influence the development of brain architecture. Child development, 81(1), 28–40. [PubMed: 20331653]

Gluckman PD, Hanson MA, Cooper C, & Thornburg KL (2008). Effect of in utero and early-life conditions on adult health and disease. The New England Journal of Medicine, 359(1), 61–73. [PubMed: 18596274]

Guralnick MJ (2019). Effective early intervention: The developmental systems approach. Baltimore, MD: Paul H. Brookes.

Hebbeler K, Levin J, Perez M, Lam I, & Chambers JG (2009). Expenditures for early intervention services. Infants & Young Children, 22(2), 76–86.

Hirai AH, Kogan MD, Kandasamy V, Reuland C, & Bethell C (2018). Prevalence and variation of developmental screening and surveillance in early childhood. JAMA Pediatrics, 172(9), 857–866. [PubMed: 29987317]

Individuals with Disabilities Education Improvement Act. (2004). 20 U.S.C. 1400 et seq. and implementing regulations: Early intervention program for infants and toddlers with disabilities, 76 Federal Register 60140 (September 28, 2011). Retrieved from http://idea.ed.gov/download/statute.html and https://www.gpo.gov/fdsys/pkg/FR-2011-09-28/pdf/2011-22783.pdf

Litt JS, Glymour MM, Hauser-Cram P, Hehir T,& McCormick MC (2018). Early intervention services improve school-age functional outcome among neonatal intensive care unit graduates. Academic Pediatrics, 18(4), 468–474. [PubMed: 28780329]

Macy M, Marks K, & Towle A (2014). Missed, misused, or mismanaged improving early detection systems to optimize child outcomes. Topics in Early Childhood Special Education, 34(2), 94–105.

McManus B, McCormick MC, Acevedo-Garcia D, Ganz M, & Hauser-Cram P (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. Pediatrics, 124(Suppl. 4), S368–S374. [PubMed: 19948601]

McManus BM, Magnusson D, & Rosenberg S (2014).Restricting state Part C eligibility policy is associated with lower early intervention utilization. Maternal and Child Health Journal, 18(4), 1031–1037. [PubMed: 23929559]

Meaney MJ (2010). Epigenetics and the biological definition of gene × environment interactions. Child Development, 81(1), 41–79. [PubMed: 20331654]

Mott DW, & Dunst CJ (2006). Use of presumptive eligibility for enrolling children in Part C early intervention. Journal of Early Intervention, 29(1), 22–31.

Rosenberg SA, Zhang D, & Robinson CC (2008). Prevalence of developmental delays and participation in early intervention services for young children. Pediatrics, 121(6), e1503–e1509. [PubMed: 18504295]

Scarborough AA, Hebbeler KM, & Spiker D (2006). Eligibility characteristics of infants and toddlers entering early intervention services in the United States. Journal of Policy and Practice in Intellectual Disabilities, 3(1), 57–64.

Scarborough AA, Hebbeler KM, Spiker D, & Simeonsson RJ (2007). Dimensions of behavior of toddlers entering early intervention: Child and family correlates. Infant Behavior & Development, 30(3), 466–478. [PubMed: 17683755]

Schneider WJ, Smith S, Walters D, & Cooper JL (2010). Promoting young children's health and development: Taking stock of state policies. Retrieved from http://stage.nccp.org/publications/pdf/text941.pdf

Silverstein M, Sand N, Glascoe FP, Gupta VB, Tonniges TP, & O'Connor KG (2006). Pediatrician practices regarding referral to early intervention services: Is an established diagnosis important? Ambulatory Pediatrics, 6(2), 105–109. [PubMed: 16530148]

Snow C, & Hemel S (2008). Early childhood assessment: Why, what, and how (Vol. 1). Washington, DC: National Academies Press.

Squires J (2012). Benchmark measures for early identification/early intervention systems, final report, Association of University Centers on Disability/Centers for Disease Control and Prevention (RTOI Agreement 2010-05-007 Sub Contract Agreement No. 449), Eugene, OR: CDC.

Squires J, Bricker DD, & Twombly E (2015). ASQ-SE-2 user's guide. Baltimore, MD: Paul Brookes.

Stahmer AC, & Mandell DS (2007). State infant/toddler program policies for eligibility and services provision for young children with autism. Administration and Policy in Mental Health and Mental Health Services Research, 34(1), 29–37. [PubMed: 16758329]

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. [PubMed: 28187953]

Wang Q, Zhang H, Wee CY, Lee A, Poh JS, Chong YS, … Rifkin-Graboi A (2019). Maternal sensitivity predicts anterior hippocampal functional networks in early childhood. Brain Structure and Function, 224(5), 1885–1895. [PubMed: 31055646]

Wheeler J, Sethi D, Cowden M, Wall P, Rodrigues L, Tompkins D, … Roderick P (1999). Study of infectious intestinal disease in England: Rates in the community, presenting to general practice, and reported to national surveillance. BMJ, 318(7190), 1046–1050. [PubMed: 10205103]

White SW, Oswald D, Ollendick T, & Scahill L (2009). Anxiety in children and adolescents with autism spectrum disorders. Clinical Psychology Review, 29(3), 216–229. [PubMed: 19223098]

Woodman AC, Demers L, Crossman MK, Warfield ME, & Hauser-Cram P (2018). Part C early intervention dosage and growth in adaptive skills from early childhood through adolescence. Early Childhood Research Quarterly, 43, 73–82.

Zeanah CH, & Gleason MM (2015). Annual research review: Attachment disorders in early childhood—Clinical presentation, causes, correlates, and treatment. Journal of Child Psychology and Psychiatry, 56(3), 207–222. [PubMed: 25359236]

**Table 1.**

Descriptive Statistics of All Diagnosed Conditions Listed Across and Within U.S. 49 States, District of Columbia, and Four Territories

| | *n* | Mean (Rounded) | *SD* | Median (Rounded) | Min | Max | Range |
|---|---|---|---|---|---|---|---|
| Number of all diagnosed conditions listed across states | 620 conditions | 4 | 5.22 | 2 | 1 | 38 | 37 |
| States listing only one of the 620 diagnosed conditions | 49 states, District of Columbia, five territories | 48 | 45.64 | 33 | 0 | 167 | 167 |

**Table 2.**

Descriptive Statistics of the Top 66 Diagnosed Conditions Listed Across and Within U.S. 49 States, District of Columbia, and Four Territories

| | *n* | Mean (Rounded) | *SD* | Median (Rounded) | Min | Max | Range |
|---|---|---|---|---|---|---|---|
| Number of top 66 diagnosed conditions listed across states | 66 conditions | 17 | 6.00 | 16 | 10 | 38 | 28 |
| States listing only one of the top 66 diagnosed conditions | 49 states, District of Columbia, five territories | 20 | 17.73 | 19 | 0 | 53 | 53 |

**Table 3.**

Prevalence Categories of Top 66 Diagnosed Conditions

| Prevalence Labels | No. Conditions | % Conditions |
|---|---|---|
| Very rare | 30 | 45.5 |
| Rare | 18 | 27.3 |
| Common | 8 | 12.1 |
| Very common | 6 | 9.1 |
| Unknown | 4 | 6.1 |
| Grand total | 66 | 100 |

*Note*. Very rare ≤ 1/10,000 cases; rare = 1/9,999 to = 1/1,000 cases; common = 1/999 to 1/100 cases; very common ≥ 1/99 cases.

**Table 4.**

Estimated Relative Prevalence Categories of and Number of States Listing Diagnosed Conditions Identified on 10 or More State, District of Columbia, and Territory Lists for Eligibility for IDEA Part C Early Intervention Services

| Condition | Estimated Relative Prevalence Category | No. States |
|---|---|---|
| Hearing impairment | Common | 38 |
| Fetal alcohol syndrome | Common | 34 |
| Down syndrome (trisomy 21) | Common | 32 |
| Vision impairment | Common | 29 |
| Cerebral palsy | Common | 27 |
| Fragile X syndrome | Rare | 26 |
| Autism spectrum disorder | Very common | 25 |
| Waardenburg syndrome, Types I and II | Very rare | 24 |
| Intraventricular hemorrhage | Unknown | 22 |
| Cleft palate with or without cleft lip | Rare | 22 |
| Tuberous sclerosis complex | Rare | 22 |
| Trisomy 18 (Edwards syndrome) | Rare | 22 |
| Hydrocephalus | Rare | 21 |
| Prematurity | Very common | 21 |
| Holoprosencephaly | Very rare | 21 |
| Attachment disorders | Very common | 20 |
| Spinal cord injuries | Very rare | 20 |
| Meningocele | Rare | 20 |
| Arthrogryposis | Rare | 20 |
| Encephalopathy, congenital | Unknown | 19 |
| Peroxisomal disorders | Very rare | 19 |
| Low birth weight | Very common | 19 |
| Cytomegalovirus infection | Common | 19 |
| Rubinstein-Taybi syndrome | Very rare | 19 |
| Angelman syndrome | Very rare | 19 |
| Cri-du-chat syndrome | Very rare | 18 |
| Herpes simplex | Very rare | 17 |

| Condition | Estimated Relative Prevalence Category | No. States |
|---|---|---|
| Inborn errors of metabolism | Very common | 17 |
| Failure to thrive | Very common | 17 |
| Anomalies of the brain | Unknown | 17 |
| de Lange syndrome | Very rare | 17 |
| Hypothyroidism | Rare | 16 |
| Galactosemia | Very rare | 16 |
| Miller-Dieker syndrome | Very rare | 16 |
| Microdactyly | Very rare | 16 |
| CHARGE syndrome/association | Very rare | 16 |
| Lead poisoning | Very rare | 16 |
| Tracheostomy | Rare | 16 |
| AIDS | Very rare | 15 |
| Wilson disease | Very rare | 15 |
| Treacher Collins syndrome | Very rare | 15 |
| VACTERL syndrome | Very rare | 15 |
| Myasthenia | Very rare | 14 |
| Muscular dystrophy | Rare | 14 |
| Microcephaly | Very rare | 14 |
| Williams syndrome | Rare | 14 |
| Ventilator dependent | Very rare | 14 |
| DiGeorge syndrome | Rare | 13 |
| Leukodystrophy | Very rare | 13 |
| Myotubular myopathy | Very rare | 13 |
| Neural tube defect | Rare | 13 |
| Tetralogy of Fallot | Rare | 13 |
| Phocomelia | Very rare | 13 |
| Marfan syndrome | Rare | 12 |
| Turner syndrome | Very rare | 12 |
| Klinefelter syndrome | Common | 11 |
| Propionic acidemia | Very rare | 10 |
| Hurler-Sheie syndrome | Very rare | 10 |

| Condition | Estimated Relative Prevalence Category | No. States |
|---|---|---|
| Cystic fibrosis | Rare | 10 |
| Infantile spasms | Rare | 10 |
| Toxoplasmosis, congenital | Very rare | 10 |
| Encephalopathy, hypoxic | Common | 10 |
| Encephalocele | Very rare | 10 |
| Spina bifida | Rare | 10 |
| Persistent hyperplastic primary vitreous | Unknown | 10 |
| Russell-Silver syndrome | Very rare | 10 |

*Note*. Very rare ≤ 1/10,000 cases; rare = 1/9,999 to 1/1,000 cases; common = 1/999 to 1/100 cases; very common ≥ 1/99 cases. For estimate source, see Supplement Digital Content (available at: http://links.lww.com/IYC/A13).