

CORE CONSTRUCTS IN FEDERAL STATUTES FOR YOUNG CHILDREN WITH OR AT RISK FOR DISABILITIES AND THEIR FAMILIES: IMPLICATIONS FOR COMPREHENSIVE EARLY CHILDHOOD POLICIES AND SYSTEMS

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Publicly funded services and supports for children from birth to age 5, with or at risk for disabilities, and their families have been guided by a complex web of federal and related state statutes, as well as their associated implementing regulations or policy statements. These statutes and implementing regulations generally are identified with one of four primary early childhood program sectors: (1) health, mental health, and nutrition; (2) early education and learning, including special needs/early intervention; and (3) family support.¹

The Individuals with Disabilities Education Act (“IDEA”), reauthorized in 2004, and most recently amended in 2015 through the passage of Public-Law 114-95, the Every Student Succeeds Act, is the primary federal statute that governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million infants, toddlers, children, and youth with disabilities.² In 2016–2017, almost 725,000 infants and toddlers, birth through age 2 with or at risk for disabilities and their families received early intervention services under IDEA and 760,000 children 3 through 5 years of age received individualized preschool and related services.³

Early childhood programs funded under IDEA are considered one program “sector” under a broader array of publicly funded programs that provide services and supports for young children with or at risk for disabilities and their families. Each of these programs initially was authorized for different purposes under different federal and state statutes with separate implementing regulations. In addition, the programs have been administratively housed in different federal or state agencies or offices within these agencies. Among the programs and associated statutes are Early Head Start and Head Start authorized under Public Law 110-134, the Improving Head Start for School Readiness Act of 2007;⁴ early education and care programs authorized under the Child Care and Development Block Grant Act of 2014 (Public Law 113-186);⁵ Title V

1. See Rachel Schumacher, *Updating the “Ovals”: A Guide to Our Rationale* (2011), http://www.buildinitiative.org/Portals/0/Uploads/Documents/Updating_the_Ovals_Guide_to_Rationale.pdf.

2. See Individuals with Disabilities Education Act of 2004, 20 U.S.C. § 1400 et. seq. (2012).

3. *Id.* § 1401(9)(c)–(d).

4. See 42 U.S.C. § 9831 et. seq. (2012).

5. Child Care and Development Block Grant Act of 1990, 42 U.S.C. § 9857 et. seq. (2012).

of the Social Security Act, the Maternal and Child Health Services Block Grant Program, which supports maternal, infant, and early childhood home visiting programs under section 701 and services for children with special health care needs as specified in section 701(a)(1)(D);⁶ and the Child Abuse and Prevention Treatment Act (CAPTA, amended as Public Law 111-320 in 2010).⁷

Historically, these programs generally operated independently and under separate authority. This resulted in services and supports that were often fragmented and unevenly accessible or available to infants, toddlers, and preschool children with or at risk for disabilities and their families. Moreover, services and supports often were only available or were only provided in segregated settings (i.e., settings in which only young children with disabilities or with identified risk factors were served).

After many years of advocacy and informed by theory and research that confirms the interrelated nature of health, early learning, and family support for promoting optimal child development and long-term health and well-being,⁸ each of the contemporary federal statutes described above and their associated implementing regulations explicitly reference or require the coordination of services and supports for young children with or at risk for disabilities. For example, under 1302.14(b)(1) of the Head Start Program Performance Standards, a Head Start program must ensure at least 10% of its total funded enrollment is children eligible for services under IDEA.⁹ Since 2003, CAPTA has required states to have provisions and procedures in place for referral to early intervention for a child under the age of 3 who is involved in a substantiated case of abuse or neglect.¹⁰ Funds distributed to states through the Child Care Development and Block grant to provide child care assistance to families of low income are to be prioritized for an array of services for children who have experienced poverty, disability, or homelessness. These alignment and coordination efforts have been important advancements in early childhood disability policy. Nevertheless, in contemporary early childhood systems building efforts occurring nationally and within states and communities much remains to be done with respect to early childhood policy, in general, and the integration of core concepts from early childhood disability policy in early childhood policy, specifically.

6. Maternal and Child Health Services Block Grant, 42 U.S.C. § 711 (2012).

7. CAPTA Reauthorization Act of 2010, 42 U.S.C. § 5101 et. seq. (2012).

8. INSTITUTE OF MEDICINE AND NATIONAL RESEARCH COUNCIL, FROM NEURONS TO NEIGHBORHOODS: AN UPDATE: WORKSHOP SUMMARY 2 (2012) [hereinafter FROM NEURONS TO NEIGHBORHOODS].

9. 45 C.F.R. § 1302.14(b)(1) (2017).

10. 40 U.S.C. § 5106a(xxi) (2012).

CORE CONCEPTS FROM EARLY CHILDHOOD DISABILITY POLICY TO INFORM CONTEMPORARY EARLY CHILDHOOD POLICY

Over the past 15 to 20 years, concerted efforts have been underway at federal, state, and community levels to coordinate and integrate programs designed to support the health, growth, and learning of *all* young children in the context of their families and communities.¹¹ These efforts are known as early childhood systems building or early childhood comprehensive systems.¹² Systems building requires integrating and aligning services and supports provided to all young children and their families across program sectors (i.e., health, mental health, nutrition; early education and learning, including special needs; and family support. It also necessitates ensuring core concepts such as inclusion, equity, family engagement, cultural responsiveness, and accountability undergird these efforts so young children with or at risk for disabilities or those with other vulnerabilities are not marginalized or further marginalized.¹³ From a policy perspective, it means examining, aligning, and perhaps reaching consensus on how to define or redefine core concepts that appear in federal and state early childhood statutes and associated implementing regulations and policy statements, given the important roles these policies play in structuring the provision of comprehensive services and supports for *all* young children.

In the remainder of this paper, we identify and discuss core concepts from early childhood disability policy. We assert including these core concepts in the next generation of early childhood policy would support and enhance further the development, implementation, and evaluation of comprehensive and integrated early childhood systems for all young children and their families.

Inclusion. Inclusion, rather than segregation and exclusion, has been identified as a primary goal for services and supports provided to infants, toddlers, and preschoolers with or at risk for disabilities and their families.¹⁴ Yet, 2016–2017 data from the Office of Special Education Programs in the United States Department of Education show only 39.9% of preschool children with disabilities spend 10 hours or more a week in early childhood programs with their peers without disabilities and receive the majority of their IDEA services in that location. These data indicate

11. See Patricia A. Snyder et al., *Frameworks for Guiding Program Focus and Practices in Early Intervention*, in HANDBOOK OF SPECIAL EDUCATION 865, 866 (James M. Kauffman et al. eds., 2017).

12. Cf. Schumacher, *supra* note 1.

13. See Snyder et al., *supra* note 11, at 866.

14. U.S. DEP'T OF HEALTH & HUMAN SERVS. & U.S. DEP'T OF EDUC., POLICY STATEMENT ON INCLUSION OF CHILDREN WITH DISABILITIES IN EARLY CHILDHOOD PROGRAMS 1 (Sept. 14, 2015).

that more than 25 years after the passage of the American with Disabilities Act, more than 40 years after the passage of IDEA, and more than 50 years after the passage of Head Start, the majority of young children with disabilities have yet to experience inclusive early learning opportunities. This is particularly problematic given the recognized importance of the first 1825 days of a child's life and the early experiences that shape brain architecture.¹⁵ As a core concept, inclusion should be further defined and refined in the context of early childhood systems building and in early childhood policy to ensure access to and participation in inclusive early learning opportunities for all children and particularly for those children with vulnerabilities.

Equality and equity. Equality and equity are two interrelated core concepts that have been implicit in early childhood disability policy and disability policy more broadly.¹⁶ These two concepts have also received significant attention in discussions about contemporary education policy and practice. By equality, we adopt the definition of Cramer, Little, and McHatton meaning “all students [children] receiving the same.”¹⁷ In contrast, equity means considering opportunities and challenges that have shaped an individual's experiences, which might necessitate accommodations or individualized services and supports to create conditions that facilitate full inclusion or participation.

The concept of equity is receiving significant attention in early childhood. The National Association for the Education of Young Children has drafted a position statement on “Advancing Equity and Diversity in Early Childhood Education.”¹⁸ One important reason for this position statement is that data overwhelmingly show significant barriers to quality early care and education and early health and mental health services and supports, particularly for children and families of color, families and children who have limited English proficiency, immigrant children and families, and children with or at risk for disabilities and their families.¹⁹ Despite the ubiquitous discussions occurring about equity in early childhood, few federal statutes or implementing regulations to date explicitly include this core concept.

15. FROM NEURONS TO NEIGHBORHOODS, *supra* note 8, at 19.

16. See Elizabeth Cramer et al., *Equity, Equality, and Standardization: Expanding the Conversations*, 50 *Educ. & Urban Soc'y* 483, 485 (2017).

17. *Id.* at 484.

18. *DRAFT NAEYC Position Statement: Advancing Equity and Diversity in Early Childhood Education*, NAEYC, <https://www.naeyc.org/resources/position-statements/equity-draft>.

19. Christine Johnson-Staub, *Equity Starts Early: Addressing Racial Inequality in Child Care and Early Education Policy*, CLASP (Dec. 20, 2017), <https://www.clasp.org/publications/report/brief/equity-starts-early-addressing-racial-inequities-child-care-and-early>.

Family engagement and trusting family-professional partnerships. Since the late 1980s, family-centered has been a core concept that guides services and supports for young children with or at risk for disabilities. Under IDEA Part C (the early intervention program for infants and toddlers with disabilities), the individualized program of services and supports is known as the individualized family services (or support) plan.²⁰ The law explicitly acknowledges the central role that families play in the development and learning of infants and toddlers. Moreover, the Children and Youth with Special Health Care Needs (“CYSHCN”) program provides family-centered and community-based coordinated care.²¹ Though the key principles of family-centered or family-centered care have evolved somewhat over time, generally accepted core principles are (a) families are treated with dignity and respect, (b) providers communicate and share information with families that is affirming and useful, (c) individuals and families build on their strengths by participating in experiences that enhance feelings of control and independence, and (d) collaboration among children, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.²²

Within early childhood policy, the core concept of *family engagement* has emerged. “Family engagement refers to the systematic inclusion of families in activities and programs that promote children’s development, learning, and wellness, including in the planning, development, and evaluation of such activities, programs, and systems.”²³ Strong family engagement is recognized as central, not supplemental to promoting children’s development and learning, supporting their preparation for school, and supporting success in elementary school and beyond. There is a reciprocal and transactional relationship between family engagement in early childhood systems and programs and the providers, programs, and systems that support children and families.

Although family engagement is a core concept in early childhood policy and practice, Ann Turnbull has recently advocated for moving beyond the concept of family engagement to the concept of *trusting family-professional partnerships* to support positive outcomes for all

20. See 20 U.S.C. § 1401(15) (2012).

21. See *Children & Youth With Special Health Care Needs*, AMCHP, www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx.

22. Dana Hughes, *A Review of the Literature Pertaining to Family-Centered Care for Children with Special Healthcare Needs* 3–4 (Oct. 2014), https://www.lpfch.org/sites/default/files/field/publications/review_of_the_literature_pertaining_to_family-centered_care_for_cshcn.pdf.

23. U.S. DEP’T OF HEALTH & HUMAN SERVS. & U.S. DEP’T OF EDUC., POLICY STATEMENT ON FAMILY ENGAGEMENT FROM THE EARLY YEARS TO THE EARLY GRADES 1 (May 5, 2016).

children and families.²⁴ She asserts that building relationships or partnerships with families to support family well-being, strong relationships between parents and their children, and ongoing learning and development for both parents and children is an explicit part of family engagement frameworks emanating from the Head Start Performance Standards, the HHS/DOE position statement on family engagement,²⁵ and the Division for Early Childhood Recommended Practices in Early Intervention/Early Childhood Special Education.²⁶ Trusting family-professional partnerships are predicated on communication, competence, respect, commitment, equality, and advocacy.²⁷

Consensus has not yet been reached with respect to whether core concepts in early childhood policy should focus on family-centered care, family capacity building, family engagement, or trusting family-partnerships. Turnbull's conceptualization would suggest that trusting family-partnerships is an overarching core concept that likely subsumes family-centered care, family capacity building, and family engagement.²⁸

Family capacity building. An explicitly stated premise for the early intervention program of IDEA is to enhance the capacity of families to meet the needs of their infants and toddlers with disabilities.²⁹ In addition, the law requires a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant and toddler.³⁰ The Division for Early Childhood Recommended Practices explicitly describe practices that have been demonstrated through research to be those most likely to enhance family capacity.³¹ As integrated early childhood policies are developed, implemented, and evaluated for all children and families, the core concept of family capacity building reflected in IDEA and the DEC recommended practices will be useful resources.

Cultural competence and responsiveness. Children with or at risk

24. See Ann Turnbull, *Beyond Family Engagement to Trusting Family-Professional Partnerships: Positive Outcomes for All* (Jan. 26, 2018), <https://ceecs.education.ufl.edu/disability-policy-advocacy/> (presentation at the Anita Zucker Center for Excellence in Early Childhood Studies Starting Ahead, Staying Ahead Colloquium Series 2018 at the University of Florida).

25. See U.S. DEP'T OF HEALTH & HUMAN SERVS. & U.S. DEP'T OF EDUC., POLICY STATEMENT ON FAMILY ENGAGEMENT FROM THE EARLY YEARS TO THE EARLY GRADES 1 (May 5, 2016).

26. *DEC Recommended Practices*, DIVISION FOR EARLY CHILDHOOD, <http://dec-sped.org/recommendedpractices>.

27. Turnbull, *supra* note 24.

28. See *id.*

29. 20 U.S.C. § 1431(a)(1) (2012).

30. 20 U.S.C. § 1436(a) (2012).

31. *DEC Recommended Practices*, DIVISION FOR EARLY CHILDHOOD, <http://dec-sped.org/recommendedpractices>.

for disabilities and from culturally and linguistically diverse backgrounds have historically experienced negative consequences in schools, including disproportionality in suspension or expulsion rates and inaccurate referrals for special education. Specific to early childhood, preschool suspension and expulsion has reached alarming rates and racial and gender disparities exist.³² Practitioners working with culturally, linguistically, and ability diverse children and their families need to demonstrate cultural competence and responsiveness in their interactions with each other and with the children and families they serve. Cultural competence refers to the ability to recognize one's culture and to interact effectively with individuals from different cultures. Culturally responsive refers to learning environments as well as interactional and teaching practices that consider children's cultural, linguistic, and ability diversity. Although cultural competence and cultural responsiveness are important core concepts in practice, they often do not appear explicitly in early childhood statutes or policies.

Accountability. Rud Turnbull and Matthew Stowe define accountability as methods of ensuring the designated outcomes of policy and services.³³ This includes legal (e.g., procedural safeguards, rights or action, remedies), fiscal/financial, professional (e.g., certifications, accreditation), administrative (e.g., ombudsman, inspectors general, human rights committees, service linkages and coordination), and electoral accountability. Accountability provisions appear in most federal and state statutes and implementing regulations.³⁴ Cramer and colleagues caution that accountability has been identified as a way to address inequities.³⁵ Nevertheless, they assert it is important to be cautious about standardizing instruction, assessment, and behavioral expectations with the assumption that all students will ultimately learn the same things, at the same time, in the same way.³⁶ These authors suggest a need to reframe the accountability concept to assure equity of opportunity and differentiation, individualization, and integrated or wrap-around services to meet the needs of the whole child and family. We assert these conversations are particularly important in the context of early childhood policy that supports the development, implementation, and evaluation of

32. U.S. DEP'T OF HEALTH & HUMAN SERVS. & U.S. DEP'T OF EDUC., POLICY STATEMENT ON EXPULSION AND SUSPENSION POLICIES IN EARLY CHILDHOOD SETTINGS 1.

33. See Rud Turnbull, *The Core Concepts of Disability Policy, Organizing Principles, and the Principle of Dignity* (Jan. 26, 2018), <https://ceecs.education.ufl.edu/disability-policy-advocacy/> (presentation at the Anita Zucker Center for Excellence in Early Childhood Studies Starting Ahead, Staying Ahead Colloquium Series 2018 at the University of Florida); Rud Turnbull & Matthew J. Stowe, *A Model for Analyzing Disability Policy*, 55 INTELL. & DEV. DISABILITIES 223, 224–25 (2017).

34. *Id.*

35. Elizabeth Cramer et al., *supra* note 16, at 485.

36. *Id.*

comprehensive early childhood systems.

Dignity. Turnbull and Stowe have also identified dignity as an overarching core concept important for inclusion in disability policy and early childhood disability policy.³⁷ In the preamble to the United Nations Convention on the Rights of Persons with Disabilities the state parties (countries) to the present convention, including the United States, recognized “the inherent **dignity** and worth and the equal and inalienable rights of all members of the human family and the foundation of freedom, justice and peace in the world.”³⁸ The general principles of the Convention that operationalize core concepts related to dignity are (a) respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; (b) non-discrimination; (c) full and effective participation and inclusion in society; (d) respect for difference and acceptance of persons with disabilities’ human diversity and humanity; (e) equality of opportunity; (f) accessibility; (g) equality between men and women; and (h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. The Convention goes on to identify general obligations of states parties “to adopt all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the Convention; to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs, and practices that constitute discrimination against persons with disabilities; and to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs.”³⁹ Specific to young children with disabilities, the Convention acknowledges that states parties “shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”⁴⁰ We assert that the core concept of dignity is important not only for young children with disabilities but for all children. As Nelson Mandela astutely noted, “There can be no keener revelation of a society’s soul than the way it treats its children.”⁴¹

37. Turnbull, *supra* note 33.

38. United Nations Convention on the Rights of Persons with Disabilities, pmbl., May 3, 2008, 2515 U.N.T.S. 3 (emphasis added).

39. *Id.* art 4.

40. *Id.* art. 7.

41. *Nelson Mandela quotes about children*, NELSON MANDELA CHILDREN’S FUND (Dec. 8, 2015), <http://www.nelsonmandelachildrensfund.com/news/nelson-mandela-quotes-about-children>.

REACHING CONSENSUS ABOUT CORE CONCEPTS

Reaching consensus about the core concept(s) that will be used in contemporary early childhood statutes and policies will be important for moving concepts and related principles into actionable behaviors of families, providers, policymakers, and scholars and the systems in which they interact. This will help ensure that core concepts associated with “policies on the books” are defined, translated, and enacted through evidence-informed practice “on the streets”⁴² for the benefit of children, families, the interdisciplinary early childhood workforce, and ultimately, the future of our society.

42. Turnbull & Stowe, *supra* note 33, at 223.