

INFLUENTIAL ORGANIZATIONS IN FEDERAL EARLY INTERVENTION
POLICYMAKING: IDENTIFICATION, ROLES, AND IMPACT

by

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(Under the Direction of Cynthia O. Vail)

ABSTRACT

Policymaking at the federal level is a complex process that occurs across the three branches of government. There are many potential sources that policymakers can reach out to in order to inform their decision-making, but one not yet explored in early intervention (EI) federal policymaking is organizations. EI includes services for infants and toddlers with disabilities and their families and is legislatively authorized by Part C of the Individuals with Disabilities Education Act. What makes EI unique is that it is served across multiple state agencies and involves many fields, such as child welfare, behavioral health, public health, education, and more.

This two-study dissertation addresses the potential impact that organizations have on federal policymaking in EI. The first study used descriptive analysis to make an initial identification of potential organizations at the federal level who have the capacity to influence policy and practice and then explore what intermediary roles these organizations can fill. The second study identified what organizations policymakers utilize, through a case study of three EI-related policy documents. Overall, both studies explored how organizations bridge the gap in translating research to policy.

INDEX WORDS: Early Intervention, Individuals with Disabilities Education Act,
Knowledge Mobilization, Intermediary Organizations, Federal
Policymaking

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DEDICATION

This dissertation is dedicated to all those living with chronic illness. The community of support, laughter, and memes made by those with Ehlers-Danlos Syndrome, POTS, Fibromyalgia, Depression, Anxiety, and ADHD made me feel seen and heard during these past few years. Even as someone trained to navigate the medical and health systems, it can be extremely lonely having to fight with every doctor to convince them to acknowledge your symptoms. Knowing there are others out there counting spoons, having a friend body double, and generally just living with invisible disabilities, makes daily life seem a little bit more doable.

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it as such or not. Our work is never done, because disability crosses all cultures, countries, races, social classes, communities, and families. “Nothing about us without us!”

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CHAPTER 1

INTRODUCTION & LITERATURE REVIEW

Research use in policymaking is a complex process, with the government often funding and directing research and reaching out to experts for their knowledge, experts pushing into policymakers to nudge policymakers in a specific direction of ideology, and researchers hoping their research will get picked up by policymakers (Einfeld, 2019; Ion et al., 2019). For federal policymakers to use the most up-to-date data, communication from the field with researchers and organizations is vital to the policymaking process. Organizations compile, translate, and distribute research to policymakers in various ways; however, policymakers do not always pick up this knowledge (Jakobsen et al., 2019; Proctor et al., 2019). The complex process of gathering and using information can be more confounding when a policy issue area is made up of many systems.

The field of early intervention (EI) is one example of a policy area that is made up of multiple systems. EI encompasses services for infants and toddlers with disabilities and/or delays and their families and involves a variety of fields, including but not limited to disability, medical, child welfare, public health, and special education. Because of the system's complexity, the gaps in policymakers' use of knowledge and evidence are highlighted even more. EI is governed by Part C of the Individuals with Disabilities Education Improvement Act of 2004, which reauthorized the Individuals with Disabilities Education Act (IDEA). IDEA (34 C.F.R. § 303.1) provides a federal right to a free and appropriate education for children and specialized services to support children with disabilities. For ages 3 through 21, these services are provided through

school systems; however, for ages birth through 2, these services are delivered through different agencies appointed by each state's governor (Vail et al., 2018). Many different agencies oversee EI programs, and services differ vastly across states. With the variety of agencies, programs, and service delivery models, it should come as no surprise that at the federal level, policymaking for EI is complex.

Decision-makers in federal policy development use different sources to gather information, and it is well documented that organizations play a vital role in moving knowledge to and from policymakers (Sin, 2008); however, there is little documentation on how policymakers utilize these organizations or other experts in the field of EI. Organizations that move knowledge to and from policymakers come in many forms, such as think tanks, membership organizations, technical assistance centers, professional development organizations, and more (Franks & Bory, 2017). In order for knowledge and evidence to be used effectively in policymaking, individuals and organizations must be aware of their current roles in the decision-making process (Ion et al., 2019). The purpose of this dissertation is to explore how organizations affect federal policy regarding EI.

Introduction

Many sources of information are available for policymakers and practitioners, yet policymakers do not tend to use research as a primary source in policy creation (Lavis et al., 2004; Loncarevic et al., 2021). Even though the federal government has its own research agencies, such as the Office of the Assistant Secretary for Planning and Evaluation within the U.S. Department of Health and Human Services and the Institute for Educational Sciences within the U.S. Department of Education, federal policymakers also use non-governmental organizations to inform their policy decisions (Lucas et al., 2019). These non-governmental

organizations that mediate change between the federal government and researchers can be referred to as intermediary organizations (IOs) because of their role in mobilizing knowledge to policymakers (Honig, 2004; West, 2023). Knowledge mobilization refers to how knowledge is transferred to and from decision-makers (Fenwick & Farrell, 2012; Malin & Brown, 2020). With more emphasis on improving the utilization of research by policymakers, knowledge mobilization has been explored in educational research and policymaking for many years (Lavis et al., 2004; National Research Council, 2012). This dissertation expands research on the intermediary roles of organizations in policymaking by applying the Advocacy Coalition Framework.

Theoretical Framework: The Advocacy Coalition Framework

The Advocacy Coalition Framework (ACF) is a useful theoretical framework for describing relevant elements within a policy subsystem (Weible et al., 2011) and in different parts of the world (Jenkins-Smith et al., 2017; Pierce et al., 2017; Weible et al., 2011). ACF is used to conceptualize problem areas embedded within sociocultural, socioeconomic, and political structures that coalitions are addressing over time. Core assumptions of the ACF are that coalitions work within policy subsystems and that policy subsystems exist for every problem area (Sabatier, 1988). Policy subsystems may overlap with or be nested in other subsystems, and a singular subsystem may include multiple coalitions and competing beliefs. Policy subsystems exist in various states of change, sometimes going through small or large changes or remaining in stasis. A policy subsystem includes all individuals, called “actors,” and organizations that are trying to influence policy, as well as the factors that influence the actors (Jenkins-Smith et al., 2017). Actors can be researchers, journalists, policy analysts, government officials, members of non-profit organizations, lobbyists, and more (Sabatier, 1988; Jenkins-Smith et al., 2017). Belief

systems and political resources join these actors together, and thus form coalitions. Coalitions compete with each other to affect policymakers. Coalitions are influenced by a mix of long- and short-term opportunities, constraints, and resources, which are impacted by both “relatively stable parameters” and external subsystem events (Pierce et al., 2017, p. S15).

Relatively Stable Parameters and External Subsystem Events

Relatively stable parameters include basic attributes of the problem area, socio-cultural values, and the basic structure of policy making. For EI, the relatively stable parameters include varied quality, accessibility, and delivery of services, and responsibility for these factors is not housed within a consistent lead agency across states. These challenging parameters are compounded by fundamental socio-cultural values, including the values of capitalism, individualism, ableism, and perceived gender roles in the workforce. Early intervention is situated within a fundamental social structure that prioritizes K-12 and often does not include children younger than kindergarten age within the purview of the public domain, except for children with disabilities ages 3 through 21. In other words, early care and intervention have traditionally not been valued as federal responsibilities to uphold for every child, such as K-12 education.

The structure of policymaking, in general, is also essential to consider. The basic constitutional and policy structure of the United States as a democratic and publicly elected top leadership that then can select their leadership teams further complicates the challenges with policymaking for this age group. Additionally, the separation of the three branches of government and what each branch is responsible for, such as Congress passing legislation and the executive branch creating regulations, are important contexts to consider when examining the

EI policymaking system. These relatively stable parameters affect external subsystem events and long-term coalition opportunity structures.

External subsystem events include changes in socioeconomic conditions, changes in public opinion, changes in systemic governing coalitions, and changes in other policy subsystems (Pierce et al., 2017). The development of coalitions can be examined through the external subsystem events that influenced them, including World War I, the Great Depression, and World War II, among others. Reflecting the socio-economic effects of World War I, the National Civilian Vocational Rehabilitation Act of 1920 extended provisions for individuals with physical disabilities, with the intent of the law to grow programs for disabled veterans (Neuhaus et al., 2014). The Social Security Act of 1935 marked the effects of the Great Depression, with an increased value on helping older adults as well as women and children in poverty (DeWitt, 2010). The next at-large conflict, World War II, established a need for women to enter the workforce and, thus, children to be cared for outside of the family (Stolzfus, 2000; Michel, 2011). The removal of primary caregivers from the home required that childcare programs, whether formal or informal, be created, and Congress passed amendments to the Lanham Act in 1941 to provide educational aid (Child Care Aware of America, n.d.; Porter, 1951). Post-World War II, poverty was declared a socio-economic crisis, and its impact on the well-being of children, families, and communities was the focus of President Johnson's presidency and the 1964 Economic Opportunity Act. These pieces of legislation set the foundational components of federal involvement in directing services for young children with disabilities and their families.

Long-Term Coalition Opportunity Structures

Another component of the ACF is long-term coalition opportunity structures that result from external subsystem events. These structures include the degree of consensus needed for

significant policy change, the political system's openness, and overlapping societal divisions (Sabatier, 1988). They impact the constraints and resources of a subsystem's actors and set up a cycle of subsystem coalitions that impact other subsystems and the more extensive political system (Sabatier, 1988).

Overlapping societal shifts that changed the opportunity structure within which EI policy would be developed include the civil rights movement, the disability rights movement, a growing societal concern for the protection and care of young children, and changes in public education. The civil rights movement occurred in response to widespread discrimination, segregation, and a severe racial divide in the United States and was marked by the Supreme Court of the United States (SCOTUS) 1954 decision in *Brown v. Board of Education* and the Civil Rights Act of 1964 (Institute on Disabilities, n.d.). The SCOTUS decision that deemed segregation unconstitutional in public schools and mandated the integration of programs based on race set the stage for the integration of children with disabilities in public education. The Civil Rights Act significantly impacted the integration of the public and prohibited discrimination based on race, color, sex, religion, and national origin. However, it did not prohibit discrimination based on disability, which sparked the disability rights movement that gained traction after the passage of the Civil Rights Act (Institute on Disabilities, n.d.; National Council on Independent Living, n.d.). The disability rights movement advocated for individuals with disabilities to have civil and human rights equal to those without disabilities.

In another socio-economic and socio-cultural moment around the same time, the Medicare and Medicaid Act of 1965 addressed issues with private health insurance that did not provide coverage for older adults and individuals with disabilities. It also addressed the high cost of health insurance for individuals living in poverty (Institute on Disabilities, n.d.; National

Archives, 2022). As a result, the care of people with significant disabilities was placed outside of the home and community and into hospitals and institutions (Meldon, 2017). The inhumane living conditions and treatment of individuals with disabilities at these hospitals and institutions were brought to national attention through a visit from Senator Robert Kennedy in 1965 and an exposé by ABC news correspondent Geraldo Rivera in 1972 (Disability Justice, n.d.). The care and treatment of individuals with disabilities caused outrage amongst the public, even though the placement of individuals with intellectual and/or developmental disabilities into institutions would not be deemed illegal until 1999 (Institute on Disabilities, n.d.).

Amid these exposures, the Architectural Barriers Act of 1968 mandated that buildings and facilities that are built using federal funds, used or leased by federal programs, or have activities that use federal funds, have physical access barriers removed (Institute on Disabilities, n.d.; U.S. Department of Justice, 2020). This policy was brought about through policy focusing on employment and was one of the first pieces of legislation to address the rights of people with disabilities specifically. Then, in 1973, the Rehabilitation Act was passed, stating that individuals with disabilities should not be discriminated against in federal programs or programs receiving federal funding. Two years later, in 1975, the recognition that people with disabilities have the right to live and work in their homes and communities and be educated with their peers was marked by the Developmental Disabilities Assistance and Bill of Rights Act (Institute on Disabilities, n.d.). Clearly, the public view of rights for individuals with disabilities was changing.

A hallmark of the cumulative and compounding efforts in the disability rights movement was brought to fruition in 1990 through the Americans with Disabilities Act (ADA). The ADA is considered as much a cultural movement as it was a piece of legislation, with the Wheels of

Justice March and Capitol Crawl protests bringing the daily barriers that individuals with disabilities face straight into the halls of Congress (Crowley, 2024). Echoing provisions and supporting previous legislation, the ADA prohibited discrimination and addressed barriers that individuals with disabilities faced in their everyday lives across employment, government services, programs, or activities, and public accommodations in businesses and non-profits (Graber, 2022). The ADA defined disability to include not only physical disabilities but invisible disabilities as well.

However, in the United States, it is required that federal agencies implement legislation as a relatively stable parameter of constitutional governance, and that these federal agencies must create rules and regulations. The rules and regulations development process is long and often takes many years to finalize a set of regulations (Balla & Wright, 2003). Therefore, the disability rights movement did not stop at the passage of these pieces of legislation, especially regarding the settings in which individuals with intellectual and developmental disabilities were placed and served. The 1999 SCOTUS case, *Olmstead v. L.C.*, found that institutionalization of individuals with intellectual and developmental disabilities was still occurring in states and that states needed to provide services in the most integrated settings (Institute on Disabilities, n.d.). The ruling reiterated the rights set forth by the Developmental Disabilities Assistance and Bill of Rights Act.

Other federal policies affecting children that were passed in the 1960s, 1970s, and 1980s include a) Elementary and Secondary Education Act of 1965 (Skinner, 2024), providing supplemental federal funds to schools in poverty through Title 1 of the bill; b) the Child Abuse Prevention and Treatment Act of 1974, in response to the expanding body of state legislation concerning child abuse (Congressional Research Service, 2009); c) the Indian Child Welfare Act

of 1978, in response to the decades-long practice of removing America's indigenous population's children from their families (National Indian Child Welfare Association, 2018); and d) the McKinney-Vento Homeless Assistance Act, which was first passed as a subsection of the 1987 Stewart B. McKinney Homeless Assistance Act (National Coalition for the Homeless, 2006). The McKinney-Vento Act provided funds for states to support enrollment and sustained education for children experiencing homelessness through the Education of the Homeless Children and Youth program. In the 1994 reauthorization, amendments were made to the program that specified rights for preschool-aged children to a free and public preschool education and allowed their parents to have input on the child's school placement. While these pieces of legislation are not within the scope of this dissertation, they assisted in the mindset shift that the federal government be involved in the care of children.

Born out of business interests and civil rights to close the gaps between impoverished and minority students and those who had more advantages, No Child Left Behind (NCLB) was passed in 2001 (Klein, 2015). The passage of NCLB put pressure on K-12 education systems to be held accountable, implemented standardized testing, and provided funding for research-based approaches to teaching (Coriella, 2006; George W. Bush Presidential Library, n.d.). The impacts of NCLB included the identification of low-achieving schools and the need for technical assistance to serve students with higher needs, such as those with disabilities (Le Floch et al., 2007). Additionally, there was a larger focus on academics being presented in preschool to help students meet the testing requirements in third grade (Stipek, 2006). There were similar educational adjustments with the passage of Race to the Top (RTT) in 2016. RTT was born from a socio-economic event, the Great Recession, and included stimulus funds from the American Recovery and Reinvestment Act (Howell, 2015; Sanchez & Turner, 2017). RTT moved away

from school accountability towards college readiness and included a specific focus on early childhood learning. RTT charged states with providing high-quality and more accessible preschool programs and early care programs for children under 3 (The White House: President Barack Obama, n.d.). The moments in time when socio-cultural and economic changes allowed for advocates to break through to policymakers is a hallmark of the ACF. Coalitions organize, strategize, and act so that in moments of breakthrough, their beliefs and values are the ones at the top of policymakers' decision-making.

The Historical Influence of Research on Early Intervention Policy in the United States

There is a documented history of the influence of research on EI policy in the United States, beginning in the 1960s that coincided with some of the first longitudinal studies with young children. President Lyndon B. Johnson declared a “War on Poverty” in 1964 and established the Office of Economic Opportunity, which began the country’s first coordinated effort to mitigate poverty’s effects on child development by creating the Head Start Project (Office of Head Start, 2022). The original Head Start Project was an intervention program that ran for eight weeks and encompassed strategies that targeted communities to meet the needs of young children in disadvantaged conditions (Office of Head Start, 2022; Zigler & Valentine, 1979). Designed by a planning committee consisting of leading experts on child development from pediatrics and psychology, including pediatrician Robert Cooke, psychologist Edward Zigler, and psychologist Urie Bronfenbrenner, the project aimed to be “comprehensive” in its services for children, recognizing that children grow up in the context of families and communities (Zigler et al., 1993). This idea was revolutionary in child development theory as well as policy. In his many publications on the Head Start program, Zigler noted the influence of Bronfenbrenner’s ecological theory on the wrap-around services that Head Start provides for

children and families (Zigler et al., 1993; Zigler & Styfco, 2010; Zigler & Valentine, 1997), as well as all of the experts' personal and professional experiences in the fields of intellectual disabilities and poverty (Bronfenbrenner, 1979; Snyder, 2014; Zigler & Hodmapp, 1986; Zigler & Styfco, 2010). The systems thinking approach, that a child develops in the context of their family and community, had an impact on social services, and later, education (Bronfenbrenner, 1983).

In addition to the Head Start Project, studies were conducted during the 1960s and 1970s that focused on young children living in poverty and the effects of high-quality early intervention through center-based care (Bricker et al., 2020; Haskins, 2019). The Early Training Project, led by Susan Gray and Rupert Klaus in rural Tennessee, and the Perry Preschool Project, led by David Weikart in Michigan, focused on how classrooms and home visiting could have an impact on child development (Haskins, 2019). Project Re-ED, the Project on the Re-Education of Emotionally Disturbed Children, funded by the National Institute on Mental Health, used social learning theory to train teachers in both educational practices and psychology to address the needs of young children with emotional disabilities (Hobbs, 1983). A randomized controlled trial that provided intensive preschool intervention for young children and their families from low socioeconomic backgrounds was conducted in North Carolina by the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill, called The Carolina Abecedarian Project (Ramey, 2018). The Carolina Abecedarian Project is one of the only longitudinal studies that followed up with the children studied and was able to show the influence of high-quality early learning environments in the short and long-term (Barnett & Masse, 2007). These projects highlighted the importance of supporting children and families in a child's early years and demonstrated that intervention during a child's earliest years is essential

in mitigating the influence of developmental disabilities (Haskins, 2019). With the success of federally funded projects, legislation was created that established the need for multi-faceted approaches to supporting children in poverty and children with disabilities including the Economic Opportunity Act of 1964, which established the Head Start Program and the Education for All Handicapped Children (EHA) of 1975 (later reauthorized as the Individuals with Disabilities Education Act).

Part C of the Individuals with Disabilities Education Act

In 1975, special education services were federally established through EHA, formalizing the right to access to public education for all children, regardless of disability status. However, EI was not included, and the needs of the youngest children with disabilities were not addressed at that time. EI was later added as Part H in the 1986 EHA reauthorization (U.S. Department of Education, 2024) and significantly impacted the landscape of services for young children with disabilities. Part H stipulated that a) governors could opt in or out of the provision, b) governors who participated in EI had to designate a lead agency to administer the program and c) there was to be a formation of Interagency Coordinating Councils (both at the federal and state level). In addition, Part H established the Individualized Family Service Plan that included family outcomes, which differed from school-aged special education services (U.S. Department of Education, 2024; Bricker et al., 2020). The focus on the family as the unit for service provision with young children was a major shift for special education, rather than the focus being solely on the accessibility of academic environments and learning. Focusing both on the child and family reinforced what was learned in the research projects of the 1960s and 1970s.

In 1990, EHA was reauthorized as IDEA and continued the provision for EI programs. EI was again reauthorized in 1997 to be restructured as Part C of IDEA, reinforcing the provision

that services should be provided in the natural environment (homes and community settings rather than in clinics). The most recent reauthorization of IDEA in 2004 kept EI under Part C of the law and addressed significant additions for infants and toddlers. At the time of the 2004 IDEA reauthorization, Congress (Sec 1431(a)) found that

there was an urgent and substantial need a) to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first three years of life; b) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age; c) to maximize the potential for individuals with disabilities to live independently in society to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and d) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.

Overall, IDEA (2004) Part C (34 C.F.R. § 303.1) re-established and specified that one of the purposes of EI is to develop and implement a statewide, comprehensive, coordinated, multidisciplinary interagency system that provides early intervention services for infants and toddlers with disabilities and their families, with the caveat that it is still optional for states.

IDEA (2004) also re-established State Interagency Coordinating Councils and that their composition (Subpart G) must include various state agencies, the state legislature, and personnel preparation. They further mandated that at least 20 percent must be parents of young children with disabilities and another 20 percent must be public or private EI providers (§ 303.601). The

numerous agencies represented on the coordinating councils include, but are not limited to, Head Start, Medicaid and Children's Health Insurance Plans, the State Educational Agency and the agencies regulating childcare, private insurance, and foster care. Interventions and supports for families and children are delivered by multiple service fields, including social welfare, health, education, disability, and economics, among others. In addition, lead agencies that implement EI differ from state to state (Wiegand et al., 2022). While the U.S. Department of Education directs federal funds to states and monitors EI programs, the variation of lead agencies across states means there is room for inconsistency of practice, policy, and research being implemented and used.

The Federal Early Intervention Policy Subsystem

The advocacy coalitions for EI include actors who are considered experts in their field and may connect their knowledge and views to policymakers directly or through an organization (West, 2023). Organizations and groups have a long history of political influence in the United States, including in Congress, the SCOTUS, and federal agencies (Hamm, 1983; Hojnacki et al., 2012; Smith, 1995; Webb Yackee, 2006). The establishment of organizations with policy influence predates the federal government's involvement in early childhood development, care, and education. Some of these earliest groups that still exist currently include the American Association on Intellectual and Developmental Disabilities, created in 1876, the National Association for the Education of Young Children, first established in 1926 as the National Association for Nursery Education, and United Cerebral Palsy, created in 1949 (Bricker et al., 2020; Shonkoff & Meisels, 1990). Groups and organizations have led a collective charge for policy change and have served as a hub for information sharing and community-building.

Actors can assert their influence through drafting legislation that is easily adopted by policymakers, forming coalitions, lobbying for specific issues, and responding to federal agency rulemaking (Garrett & Jansa, 2015; Heaney, 2006; Webb Yankee, 2006). The direct contact between actors and policymakers is bidirectional, requiring an interest in both parties to be informed by one another (Lavis et al., 2003). Legislators have the ability to determine the effect that actors have on their policymaking; it is a mutually beneficial and influential relationship (Ainsworth, 1997). Actors must communicate with the legislators to influence policy, but it is not the actual congresspeople that they meet with, it is the staffers.

The Role of Staffers

Congress is vital to establishing statutes that authorize federal agencies and programs; federal agencies are significant in enacting these statutes through regulations, creation of programs, dissemination of information, and determination of grant funding to states and organizations. Through their staffers, Congresspersons speak with other staff, constituents, and experts in the field to create memos, reports, and legislation that makes it to committees and the Senate and House floors (West, 2023). These staffers and their conversations with others are vital to the movement of federal policies. Congresspeople must navigate representing their constituents, the demands of their caucuses, and the back-and-forth pull of power between the White House and the processes within and across the Senate and House of Representatives. Because of the complexity of their position, staffers are the ones who often meet with actors and consume and interpret research and beliefs from organizations for Congress.

The structure of policymaking in general is also important to consider. The basic constitutional and policy structure of the United States as a democratic and publicly elected top leadership that then can select their own leadership teams further complicates the challenges with

policymaking for this age group. Additionally, the separation of the three branches of government and what each branch is responsible for, such as Congress passing legislation and the executive branch creating regulations, are important contexts to consider when examining the EI policymaking system.

The federal agencies tasked with carrying out the provisions of the law and the people within them play various roles. Political appointees serve at the President's direction to lead the agencies. Additionally, and more important to the daily operations of the agencies, there are monitoring, evaluation, and technical assistance staff, congressional liaisons, researchers, and investigative and civil rights staff. These individuals help create the regulations from the authorized legislation and monitor and enforce programs. Congress and the executive branch, which includes a variety of federal agencies, are a part of the larger federal government system and are comprised of systems themselves, with people and agencies transferring information, enacting programs, and performing research. The curtain is rarely pulled back on the inner workings of these institutions, and it has been identified that people are essential in the movement of knowledge in the policy realm (West, 2023).

Research, Policy, Practice: Knowledge Mobilization

The components of research, policy and practices in early intervention and early childhood special education (EI/ECSE) need to be disentangled (Dunst, 2000). Gaps in translating early childhood research to policy, policy to practice, and practice to research have been identified for many years, yet they persist (World Health Organization, 2020). With the implementation of IDEA Part C delegated to the states, and due to the voluntary nature of how states adopted EI programs, the practices and policies in EI/ECSE vary (Friedman-Krauss & Barnett, 2023).

Creating and implementing policies and programs using a strong evidence base continues to be a struggle for policymakers across the field of education (Ungerleider, 2012). Newman et al. (2016) shared from their study on policymakers' use of research that while most policymakers had access to academic journals and resources, they only occasionally used academic research to improve policy. Focusing on the use of social research in policy, Weiss (1977) described that the misalignment between researchers and policymakers can be due to a deviation of values between the two entities. However, the use of government funding for the “what works” model in educational research demonstrates that policymakers are aware of the importance of research use, but possibly just at the practitioner level and not for themselves (Institute of Education Sciences, n.d.; National Research Council, 2012; Newman et al., 2016). Studying how research results and recommendations are moved across individuals with power to make change, both in practice and in policy, is necessary to ensure that policymakers are using accurate and peer-reviewed data to inform their decision-making. In educational research, there is a clear need for knowledge to be transferable and understandable by policymakers (Farley-Ripple et al., 2023; Lubinski et al., 2011).

The study of how research results and information are shared among groups, with a particular focus on how information gets to decision-makers, is termed knowledge mobilization (Fenwick & Farrell, 2012; Malin & Brown, 2020). A key component of knowledge mobilization is the relationships that occur between organizations and individuals (Farley-Ripple et al., 2023). Knowledge mobilization is a social process, as what is considered knowledge and what information is influential is determined by individuals (Farley-Ripple et al., 2023; Levin, 2008; Levin & Cooper, 2012). Levin and Cooper (2012) made a distinction that mobilization is more than dissemination of research findings – it is what occurs after knowledge has been initially

shared. Organizations and individuals take research findings and reframe it to an audience, often practitioners or policymakers, then make concerted efforts to move the information to decision-makers (Levin & Cooper, 2012).

Intermediary Organizations

There are clearly gaps and variations across research, policy, and practice, and organizations serve as brokers of knowledge to bridge the gap (Franks & Bory, 2017; Proctor et al., 2019). An organization that liaises between two other organizations or individuals with the purpose to “mediate or manage change” (p. 67) in the two is termed an *intermediary organization* (IO) (Honig, 2004). While an IO may serve in differing primary roles, such as a professional development organization or research center, there must be value added by the IO performing the duties between two organizations or individuals. Honig (2004) identified “technical assistance providers, vendors, collaboratives, capacity builders, community development coaches, resource and referral organizations, external support providers, professional development organizations, reform support organizations, design teams, regional reform organizations, and corporate law firms” (p. 67), in addition to policy and advocacy centers, as potential IOs. Philanthropies also have begun to be identified as potential IOs (Scott et al., 2015; DeBray et al., 2020). Philanthropies assist in funding other IOs and drive the direction of knowledge produced, as they have an agenda they are putting forward through their funding (Lubienski et al., 2014; DeBray et al., 2020).

Organizations can serve many different functions, such as providing professional development, technical assistance, or bringing about new resources (Honig, 2004). IOs can perform many functions and being classified as an IO does not disregard the primary functions of an organization. The addition of mediating or managing change is a distinction that Honig (2004)

makes for organizations to be classified as IOs. In the realm of educational policymaking, IOs play roles in “gathering, interpreting, and packaging particular research for policymakers” (Lubienski et al., 2011). The ability to translate evidence and research from a variety of disciplines is beneficial for IOs in education, as policymakers are unlikely to branch out of the field of education for educational issues (Lubienski et al., 2011). In the space of EI, this is beneficial due to the systems and multiple disciplines involved as lead agencies, funding and insurance claims, and service delivery.

Guiding Questions and Positionality

Research, policy, and practice gaps have persisted since the inception of EI. Understanding how these gaps are filled currently, at 20 years since the most recent reauthorization of IDEA, can bolster and support the field of EI. Knowing the “who is doing what” landscape can help blend and braid efforts across sectors.

This dissertation is a compilation of studies, guided by the following questions:

1. What organizations address early intervention at the federal/national level?
2. What intermediary roles do organizations play in knowledge mobilization?

Emerging Conceptual Framework and Positionality

To contextualize this paper and to be explicit about my bias as a researcher, it is useful to review how I as a researcher came to the field of EI policy. My career in EI began during my undergraduate and graduate education. Initially, I focused on early childhood special education as a teacher preparation student, then transitioned to studying the influence of systems during my graduate social work program. I realized that attempting to understand how teachers, social workers, families, or children can effect change without considering systems is pointless. Practitioners in education and social work recognize the importance of the communities in which

individuals reside, including themselves. As I deepened my understanding of intervening in individuals' lives, I heavily relied on Ecological Systems Theory (Bronfenbrenner, 1976, 1977). This theory enabled me to visualize how programs, communities, culture, time, and families fit into a comprehensive model.

As I moved through my professional career as a practitioner in EI/ECSE and child welfare, I entered my doctoral program. Parallel to learning about the historical context of EI and the laws that govern it, I gained firsthand experience in its implementation. My role as an EI supervisor and trainer began shortly before the onset of the COVID-19 pandemic. I embarked on navigating a system where I could not have foreseen a physical removal of all practitioners from homes and schools, nor the financial constraints imposed by a global pandemic on governmental systems.

Throughout my education and professional career, I have been a part of national and state organizations, recognizing the important role that organizations serve for their members. Two examples come to mind of my experiences of organizations translating policy to practice: 1) Wendy Clifton, Esq., who does a beautiful “what does this mean” regarding social work-related legislation each year for Georgia’s Association of Social Workers Day at the state capital; and 2) participating in a federal disability policy fellowship with the U.S. Senate Health, Education, Labor, and Pensions Committee and the National Association of Councils on Developmental Disabilities.

As I contributed to the professionalism of EI providers through leading trainings, I sought guidance on where to find best practices. Using the technical assistance centers that are government funded, the national organizations I was a part of, and the information gathered through various networks across states, I began to develop my go-to list on where to look for

evidence-based practice. As a researcher, I noticed the gap between research, policy, and practice at the state and federal levels. Research was not aligning with the policy I saw trickle down from the federal to state to local levels. There were instances where the law did not have components needed for decision-making or where the law had the intent, but individuals ignored it outright. I sought to understand the nature of these decision-making gaps and their underlying causes. Thus began the conceptual framework for this dissertation.

Another concept in the framing of this dissertation is systems theory. Systems theory is a conceptual framework that is based on the understanding that parts of a system should not be understood in isolation but are best understood when examining the relationships between the parts and other systems (Wilkinson, 2011). Systems theory spans the fields of biology, ecology, sociology, psychology, mechanical disciplines, business, and technology (Adams et al., 2013; Wilkinson, 2011). The terms general systems theory and systems theory in the field of psychology and sociology are interchangeable and based upon the works of Ludwig von Bertalanffy (American Psychological Association, n.d.; Adams et al., 2013; Wilkinson, 2011). Von Bertalanffy (1972) stated that “a system may be defined as a set of elements standing in interrelation among themselves and with the environment” (p. 417) and that “in order to understand an organized whole we must know both the parts and the relations between them” (p. 411). The exploration of the elements in EI systems and seeking to identify and understand these interactions are key components of this dissertation.

Format of Dissertation

This dissertation focuses on the policy subsystem of EI at the federal policy. The second chapter is written as a journal manuscript that is a qualitative descriptive study conducted using content analysis of national organizations’ websites that have a focus on early intervention. The

third chapter is written as a journal manuscript that is a qualitative case study using document analysis on three EI-related federal policy documents published in 2023. The final chapter brings together conclusions across both studies with next steps for research, action, and advocacy.

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CHAPTER 2

EARLY INTERVENTION RESEARCH, POLICY, AND PRACTICE: A GLANCE AT EI NATIONAL INTERMEDIARY ORGANIZATIONS

In the United States, early intervention (EI) serves as the primary source of services and support for infants and young children with developmental delays and disabilities, as well as their families (Centers for Disease Control and Prevention, 2023). In the 1986 reauthorization of the Education for All Handicapped Children Act (EHA), the right to EI was established as Part H (U. S. Department of Education, 2023). Prior to 1986, comprehensive services for young children ages birth through 5 years with disabilities were not in a defined program within federal legislation. However, there were components of EI being provided through other legislation, such as home visiting programs and medical services within Title V of the Social Security Act of 1935 (U.S. Department of Social Security Administration, n.d.); there were also other agencies supporting services for infants and toddlers that funded and supported demonstration projects (Gray, 1975). Currently, EI services fall under Part C of the Individuals with Disabilities Education Act (IDEA), which was reauthorized in 2004.¹

Introduction

It is essential to acknowledge that within the field, and in the very purpose of EI, a systems approach is necessary to explore the impact of research, policy, and practice. Children ages birth to 3 rely on the support of their families and communities and the many systems of

¹ For clarity in this paper, the acronym “IDEA” is used to reference the most recent reauthorization of the Individuals with Disabilities Education Act, titled the “Individuals with Disabilities Education Improvements Act of 2004.”

which they are a part (Bronfenbrenner, 1986; Dunst, 2000; Guralnick, 2005). When targeting healthy development and appropriate interventions, policies cannot focus only on a singular component of a child's life (McWilliam, 2016). The understanding that multiple systems affect young children is echoed within the legislation of EI, offering financial support to states to establish and implement “a statewide, comprehensive, coordinated, multidisciplinary, interagency system” for delivering early intervention services to infants and toddlers with disabilities and their families (IDEA, 2004). The goals of this interagency system are to strengthen state capacity to provide high-quality early intervention services and enhance existing services for infants and toddlers with disabilities (Dragoo, 2024). Some of these systems include, but are not limited to, social welfare, child development, education, special education, and family functioning. These systems cannot be ignored or discounted when investigating the programs and organizations that engage with young children with disabilities and/or delays, along with their families.

In IDEA's reauthorization of 2004, Congress found that there was “an urgent and substantial need”

- (1) to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first three years of life;
- (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
- (3) to maximize the potential for individuals with disabilities to live independently in society

- (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
- (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care

However, even with the “urgent and substantial need” of specialized services for children ages birth to 3 with disabilities and/or delays and their families, providing these services is not mandatory for states. IDEA Part C services are enforced through an optional grant program, and when Congress reauthorized IDEA in 2004, EI continued as a voluntary program that states could opt into. If states do not pursue or accept IDEA Part C grant monies, then the state does not have to provide IDEA Part C services.

In addition to EI being optional for each state every year, the federal government has not required EI to be housed within a consistent lead agency across each state. IDEA Part B services, which provide special education for children ages 3-21, are housed within states’ Departments of Education; however, with Part C, governors were directed to choose the agency that would be a best fit to implement EI. States initially faced, and continue to deal with, “legislative and budgetary constraints” as well as challenges in coordinating with state, local, and various public and private funding sources, which complicates the delivery of early intervention services. (Adams et al., 2013, p. e1074). The culmination and continuation of EI being placed in various agencies across states has created and perpetuated barriers to high-quality and collaborative services for young children with disabilities and their families (Friedman-Krauss & Barnett, 2023). Additionally, differing criteria of eligibility for EI services and lack of appropriate data collection across states has made services inequitable across states (GAO, 2023b).

The inconsistencies within EI are exacerbated by an established need for research to be translated into policy and practice and for policy and practice to inform research (Burns & Schuller, 2007; Fixsen et al., 2007; Lavis et al., 2004). Implementation science has historically addressed the fidelity of specific research-based practices and how to increase the use of these practices, but it does not traditionally address the way research and evidence makes its way to decision-makers (Burns & Schuller, 2007). Understanding how research is adopted, utilized by, and impacts decision-makers in policy is vital for those who create policies intending to enhance outcomes for young children with disabilities (Lavis et al., 2003; Nutley, 2007).

Within the broader field of education, there is a recognized need to address the gap in the use of research for policy and practice, as well as to understand how information grounded in research is disseminated and translated into actionable policies (Cooper, 2010; Levin & Cooper, 2012; Sa et al., 2011). It is important to examine how knowledge reaches decision-makers, particularly through “intermediary organizations” that connect researchers and decision-makers (Honig, 2004; Lavis et al., 2003). This study used the advocacy coalition framework to explore which organizations are involved in early intervention and their roles in bridging the gaps between research, policy, and practice.

Theoretical Framework

The advocacy coalition framework (ACF) is a theoretical framework designed to better understand the policymaking process (Pierce et al., 2017; Sabatier, 1988). The core assumption of the framework is that policymaking consists of subsystems comprising policy areas, which are influenced by coalitions of organizations and individuals, known as actors. Actors form coalitions based on shared beliefs and values, and coalitions use strategies to affect

policymaking. Such strategies may include passing knowledge to policymakers and working in tandem to create evidence that informs policy decisions.

Literature Review

Early Intervention: Programs and Systems

The Office of Special Education Programs is housed within the U.S. Department of Education, who provides non-regulatory guidance and manages the Annual Performance Reports of states' Part C programs. Despite this, there is a lack of consistency across lead agencies at the state level (Wiegand et al., 2022). This inconsistency of lead agencies leads to variability in services, policies, and practices (Bailey et al., 2004; Harbin et al., 2004; Prenatal-to-3 Policy Impact Center, 2020; Twardzik et al., 2017), with identified inequities occurring at greater rates for children of color and those living in low-income areas (Friedman-Krauss & Barnett, 2023; Gillispie, 2021). These inequities are highlighted across states, territories, and the District of Columbia through differing parts of programming that states can “opt in” to. Five states (Iowa, Maryland, Michigan, Minnesota, and Nebraska) are considered “birth mandate” states, where services for children with disabilities are free and family fees are not allowed (Prenatal-to-3 Policy Impact Center, 2023). Six states (Colorado, Connecticut, District of Columbia, Maryland, Missouri, and Tennessee) chose to adopt the Part C extension option (34 CFR § 303.211), covering ages three through five within their EI system (Early Childhood Technical Assistance Center, n.d.). Eight states have chosen to serve children “at risk” for a delay or disability (GAO, 2023b). Within EI, children “at-risk” is defined as those who are under age 3 who may develop a delay if they are not provided services (34 C.F.R. § 303.21). The IDEA Infant Toddler Coordinators Association (2024) shared that all states are participating in EI, there would be an assumption that similar services are occurring across all states; however, as demonstrated with

birth mandate states and the states who opt-in for serving children in the at-risk category, that is not the case.

As long as 25 years ago, a workshop organized by the Committee on Integrating the Science of Early Childhood Development of the Board on Children, Youth, and Families identified the need to address the inconsistencies in policies and programs providing EI services (National Research Council & Institute on Medicine, 2000). The workshop convened individuals across service areas - health care, early care and education, programs for children experiencing homelessness, substance abuse programs, interventions for children with or at risk of developmental disabilities, and children's mental health services. They identified that there is a need for a more cohesive integrated early intervention infrastructure, but that the limitation of "politics of human service delivery" (National Research Council & Institute on Medicine, 2000, p. 32) makes an integrated infrastructure too difficult.

Even with the need for EI programs being established by Congress in 1986 through the EHA (Hanft, 1988), there continues to be a targeted effort to determine what service delivery models are best practice, how services should be funded, and what is considered high-quality and of importance for prioritization at multiple levels - national, state, and local (Wiegand et al., 2022). The voluntary nature of EI at the beginning of its implementation has led to variability across the nation's landscape on service delivery, funding and insurance practices, best practice implementation, and more (Dunst, 2000; Friedman-Krauss & Barnett, 2023; Garwood, 1987; Vail et al., 2018).

In the field of EI, the research gap is even more expansive than in special education or education broadly (Boyd et al., 2016; Vivianti et al., 2017). In their most recent annual Tipping Points Surveys, the IDEA Infant and Toddler Coordinators Association (2021, 2022, 2024)

reported significant variability in how EI programs collaborate with other states and with other state agencies on services for young children. Some states' EI programs actively engage in activities with other state agencies while others do not take advantage of state partners or multiple partnership opportunities. The inconsistent program and systems integration contradicts what is documented as best practice in supporting healthy child and family development from a research and practice perspective (Bronfenbrenner, 1986; Dunst, 2000). While IDEA Part C (2011) identified that there should be a state interagency coordinating council with representation from various state agencies and programs affecting young children with disabilities (34 CFR § 303.125), the requirement does not ensure these agencies and programs collaborate effectively.

The Research, Policy, and Practice Gap

The influence of many systems, combined with the variability in service delivery models, creates barriers that hinder evidence-based information entering the policy and practice arenas (Dunst, 2000). The lack of opportunities for collaboration between practitioners and researchers to share information has been identified as one of the reasons for the research to practice gap (Greenwood & Abbott, 2001). Another reason for the gap in research getting to practitioners and policymakers is the nature of research on disabilities and EI specifically. Due to the variety of intervention options and the primary delivery of services occurring within the community, small environment-controlled studies lose the contextual components needed to account for the application and generalization of research findings (Romano and Schnurr, 2020). Indeed, most research on EI is qualitative due to the variety of issues addressed. In a more recent report from the National Academies of Sciences, Engineering, and Medicine (NASEM: 2022) on the Institute for Educational Sciences, there was an explicit call for value to be placed on studies that deviate from empirical, highly controlled studies. This differs from what legislation calls evidence

(Foundations for Evidence-Based Policymaking Act, 2019), which calls for statistical activities conducted for statistical purposes.

Research itself and dissemination of research findings take time (Greenwood and Abbott, 2001). There is a delay in research-produced evidence dissemination and uptake by programs and policymakers, and this delay can cause a backlog of the most recent research moving into federal, state, and local policy decisions. Policymakers focus on current issues, and often research does not quickly produce results that can be considered helpful in policy decision-making (Plank, 2014). Additionally, the value of evidence for researchers and policymakers differs; researchers value the theoretical and global applications while policymakers value what is helpful to their constituents. Even the U.S. Government Accountability Office (GAO), the research arm of the United States Congress, has made recommendations to policymakers on how to use research for evidence-based policymaking (GAO, 2023a). In their report, GAO highlighted the role of “various organizations, programs, and activities – both within and external to the [federal] agency” (p. 20) in contributing to evidence-based policymaking, suggesting that policy decision-makers can use outside organizations to create, collect, analyze, and evaluate data.

The Roles of Intermediary Organizations

Coalitions and their actors can serve as brokers between policymakers, practitioners, and researchers, serving an important role in shaping the influence of evidence (Cooper, 2010). Organizations that liaise between other organizations, groups, and individuals with the purpose of making or mediating change are termed intermediary organizations (IOs) (Honig, 2004). While an IO may serve multiple functions, such as a professional development organization or a research entity, there must be value added by the IO liaising between groups to be considered an

IO. While organizations may have a targeted audience or purpose, if they serve as an interface between two entities and have a purpose to impact one or both, then they are an IO.

Honig (2004) identified potential IOs, including “technical assistance providers, vendors, collaboratives, capacity builders, community development coaches, resource and referral organizations, external support providers, professional development organizations, reform support organizations, design teams, regional reform organizations, and corporate law firms” (p. 67), in addition to policy and advocacy centers. There is also evolving research that suggests philanthropies should be included in IO research due to their roles beyond funding, such as conveners, organizers, and advocates (DeBray et al., 2020; Scott et al., 2009). IOs bring a diverse set of constituents together, not only assisting providers in providing high quality services and using data effectively, but also connecting public and private resources and educating policymakers (Blank et al., 2003). IOs play an important role in mediating knowledge movement to decision-makers at the various levels of government (local, state, and federal), especially when decisions are made in a top-down approach (Corcoran et al., 2015). IOs act in network with other organizations to bring about change, produce novel ideas and strategies, and create trusted relationships between entities (Caloffi et al., 2015).

While IOs may serve some of the same functions, they differ in key ways, including which levels of government they operate in; the composition of the IO (such as staff and/or membership); the organization’s physical location and if their work is primarily within that geographical area or outside of their geographical area; their scope of work, if across a singular, smaller jurisdiction or multiple, larger jurisdictions; and the IO’s funding source, if private, public, or a mix of both (Honig, 2004). One of the first steps to understanding the nature of IOs in a field is to identify them (Caloffi et al., 2015).

Defined Intermediary Roles

Franks and Bory's (2015) study of intermediary organizations in implementation science can serve as a starting point for identifying various roles that can describe intermediary organizations within early intervention coalitions. Through an international conference on implementation science, the authors sent out a survey to organizations, and in the responses, the organizations self-identified the mission of the organization (intermediary and/or purveyor), its funding sources, and activities and functions of the organization, in addition to other characteristics. Through their analysis of the activities and functions, the authors were able to further develop and define the roles of IOs as: consultation and technical assistance activities; best practice model development; purveyor of evidence-based practice; quality assurance and continuous quality improvement; outcome evaluation; training, public awareness, and education; and policy and systems development. The seven core intermediary roles and corresponding competencies identified (Franks & Bory, 2017, p. 32) were:

1. **Consultation and technical assistance activities** with competencies in knowledge of best practices; analytical skills; engagement skills; content knowledge; experience working with systems; collaboration and conflict resolution skills; and problem solving.
2. **Best practice model development** with competencies in knowledge of best practices; observation and assessment skills; ability to synthesize complexity, understanding outcome research and evaluation, benchmarking; understanding of fidelity and fidelity monitoring; ability to operationalize and create practice models; and understanding of implementation science.
3. **Purveyor of evidence-based practice** with competencies in knowledge of best practices; knowledge and skill implementation science and dissemination; ability to translate

research into practice; understanding of fidelity and fidelity monitoring, data collection and synthesis; training experience; engagement skills; and experience working with organizations complex systems.

4. **Quality assurance and continuous quality improvement** with competencies in knowledge and skill in developing and implementing quality assurance and continuous quality-improvement models; knowledge of quality assistance/quality improvement tools and procedures; skills in data analysis, management, synthesis, and reporting; and engagement and consultative skills.
5. **Outcome evaluation** with competencies in knowledge of research design, development, data collection, and management; statistical knowledge and ability to synthesize data and monitor outcomes; and experience with benchmarking and linking outcomes to programmatic and funding goals.
6. **Training, public awareness, and education** with competencies in experience in training, teaching, and community engagement; and context knowledge and mastery of subject matters; communication and public awareness skills
7. **Policy and systems development** with competencies in ability to work with complex systems and political environment; ability to translate research and complex material into brief policy statements and recommendations; engagement and collaborative skills; and ability to align priorities with political will and available resources.

Franks and Bory (2017) acknowledged that these core roles may not fit all networks and systems but there have been no adjustments or additions to these roles in the literature.

Current Research on IOs

Research on IOs has yet to reach EI specifically, but has occurred in related fields, such as child welfare, K-12 public education, specific disabilities, and mental and behavioral health, as well as across multiple governmental levels (Almquist et al., 2023; Corcoran et al., 2015; Davis et al., 2022; DeBray et al., 2014; Lopez et al., 2005; Mosely & Ros, 2011; Parsons, 2018). In these fields, there has been research specific to how IOs assist in implementing evidence-based interventions with practitioners (Almquist et al., 2023; Crane et al., 2023; Proctor et al., 2019; Scott et al., 2014). According to Blank and colleagues (2003), IOs in the social services field address multiple policy areas, such as early care and education, school-community partnerships, and workforce development. Additionally, IOs can serve as capacity builders for families, with the organizations stepping in to ensure that families' needs are a priority in settings that their children are in on a continual basis, such as schools (Lopez et al., 2005; Westra et al., 2010).

In the broader education arena, with more research on IOs being performed in recent years than in any other related field, IO research has focused on the influence of organizations on the production and dissemination of data, the evolving creation of policy networks, the politics of advocacy organizations, the influence of business and market practices on education through organizations, knowledge brokering and transfer, and the emergence of philanthropies as IOs (Aydarova, 2024; DeBray et al., 2020; Lubienski, 2019; Yamashiro et al., 2023). Even the Congressional Research Service (Gallo, 2020) and GAO (2020), both congressional research entities, have put out information on the roles of organizations and centers in education and research development.

Research Questions

To understand the current landscape of national organizations and their roles in mediating change in the field of EI, it is useful to identify the IOs associated with EI policymaking. Additionally, with the understanding that there is limited documentation on knowledge mobilization in and research on early intervention policymaking, this study will address the following research questions:

1. Who are the organizations at the national level working in the field of early intervention?
2. What are the identified organizations' functions, funding sources, and potential intermediary roles?

Methods

Study Design

This study is descriptive in nature, following documented features of qualitative descriptive research (Kim et al., 2017). Descriptive research is appropriate for gaining insights, seeking additional information, and exploring data in its natural state. This study utilizes organizations' websites as the primary data source and content analysis of the websites to explore the organizations' roles.

Data Collection

With the understanding that organizations create networks amongst themselves to achieve policy change (Blank et al., 2003; Pierce et al., 2017), the researcher used a network-based approach in determining where to look for organizations (Blank et al., 2003; Nutley et al, 2007; Pierce et al., 2017). The researcher used a data collection method called “trawling” to identify potential organizations. Trawling is the process of choosing sources of digital data and exploring

through internet search engines to gather broad material, then refining the identification based on specific issues (Whiting & Pritchard, 2021).

The first search for which organizations serve in EI research, policy, and practice started with national, federally funded technical assistance and data centers. By examining funding streams for these organizations and their partnerships, the second search expanded to include organizations, centers, and associations, including professional membership organizations. Through these searches, organizations that solely contributed to state or local levels were eliminated from the sample. The sampling strategy used was “saturation sampling,” in which the process of trawling was no longer generating new information (Whiting & Pritchard, 2021), in this case, new organizations. The final list included all organizations that could be considered potential IOs in EI policymaking.

Analysis

Each organization’s website was examined to determine its essential function, funding source(s), and relevant focus area, which aligns with Honig’s (2004) five dimensions of IOs. The researcher then used the Franks and Bory (2017) set of IO roles with activities as codes and corresponding competencies as a code book to determine potential intermediary roles. Activities used as defining features of each code (role) are listed in Table 2.1, located in Appendix B. Through a content analysis of each organization’s website, including reviewing mission statements, projects, publications, and partnerships, the researcher assigned a code to organizations that reflected one or more of their potential intermediary roles. Secondary coding for reliability purposes was completed for 20% of organizations by a second researcher.

Results

Function, Funding, and Focus Areas

Function, funding sources, and relevant focus area(s) or sub-focus area(s) of organizations are identified in Table 2.2, located in Appendix B. An initial identification of potential IOs produced 65 organizations across various organizational structures and core functions, such as advocacy centers; coalitions; communities of practice; data centers; demonstration, research, and training centers; news organizations; philanthropies; policy and advocacy organizations; policy centers; professional development centers and organizations; professional-membership organizations; research and training centers and organizations; research centers; resource centers; technical assistance centers; and think tanks. Organizations were primarily focused on the federal level with some working at the state level or performing roles that were not confined to a governmental level; for example, a professional development center may have resources that are applicable across governmental levels. Organizations that targeted both federal and state government levels or that primarily functioned in a practitioner space with resources and projects that spanned across geographic areas included

Alliance for Early Success

- Center for Parent Information and Resources
- Early Childhood Collective
- Early Education Leaders Institute
- Family Guided Routines Based Intervention
- Institute for Early Childhood Policy
- The Communication and Early Childhood Research and Practice Center
- The Early Childhood Policy Network

- The Family, Infant and Preschool Program (FIPP)
- The Heising Simons Foundation
- The Henry and Marilyn Taub Foundation

Organizations such as the Family, Infant and Preschool Program function at the state level but have application in research and practice across other states. The Family, Infant, and Preschool Program provides other states and localities training in a service-delivery model and teaming model, Primary Service Provider Model and transdisciplinary teaming, with connections to multiple states, even though they primarily serve as a center and training organization for the state of North Carolina.

Organizations were funded variously through private donations, philanthropies, public and government sources, and memberships. Notably, some organizations were funded primarily through federal grants but were housed within a larger center that was financed by multiple sources, such as the Early Childhood Technical Assistance Center (ECTA) housed at the Frank Porter Graham Child Development Institute at the University of North Carolina Chapel Hill. There were also some organizations for which researchers were not able to identify funding sources (Haring Center, Early EdU Alliance, Family Guided Routines Based Intervention [FGRBI], SRI Education, and the Infant and Toddler Policy Research Center) at the time of data collection due to the organizations not publishing that information publicly on their websites. The various funding sources of these organizations demonstrates that early intervention is a multi-faceted system with interests that include government, philanthropies, practitioners, and others.

Included in Table 2.3, located in Appendix B, are the organizations' potential intermediary roles that they may fill in the early intervention research, policy, and practice

process. Listed in Table 2.4 are the number of organizations that were coded that could perform the seven intermediary roles. The table includes number of organizations in each intermediary role as well as the percentage of organizations in each role ($n=65$). For reference, activities of these intermediary roles are included in Table 2.1, located in Appendix B.

Case Examples: Networks and Coalitions

While analyzing the websites of organizations, it was found that organizations work with each other through funding, projects, research, and training collaborations. IOs are part of different networks, and applying the ACF, they also work together as part of known or unknown coalitions affecting policy. Described in Case 1 is a formalized coalition, as recognized through an organization's activities, specifically the First Five Years Fund, whose partners and supporters and described in Case 2 as an informal coalition, identified by connections through a main actor, the Early Childhood Technical Assistance Center, that were explored as part of collecting data on organizations in this study.

Case 1: First Five Years Fund Partners and Supporters

In Figure 2.1, a picture of the First Five Years Fund's partners and supporters are listed. These are the organizations that the researcher identifies as a formalized coalition of actors in collaboration with First Five Years Fund's early childhood policy subsystem. These actors include the Buffett Early Childhood Fund, Bill & Melinda Gates Foundation, Irving Harris Foundation, George Kaiser Family Foundation, W.K. Kellogg Foundation, the David & Lucile Packard Foundation, Heising-Simons Foundation, Saul Zaentz Charitable Foundation, Ballmer Group, Pivotal Ventures, and Valhalla Foundation. Notable for the organizations that are in collaboration with First Five Years Fund is that each organization outside of the main actor is a philanthropy. The working partners for this organization reiterate the integration of

philanthropies as active members of coalitions and as IOs. The publications from this network through the First Five Years Fund have the capability to be used by national, state, and local policy, practice, and research decision-makers.

Table 2.4

Number and Percentages of Potential Intermediary Roles of Identified Organizations

Intermediary Role	<i>n</i>	%
Consultation and technical assistance activities	21	32
Best practice model development	29	45
Purveyor of evidence-based practices	33	51
Quality improvement and continuous quality improvement	12	15
Outcome evaluation	15	23
Training, public awareness and education	39	60
Policy and systems development	33	51

Note. All organizations were coded for potential intermediary roles (*n*=65)

Figure 2.1

Formalized Coalition Example, with Organizations and Funders



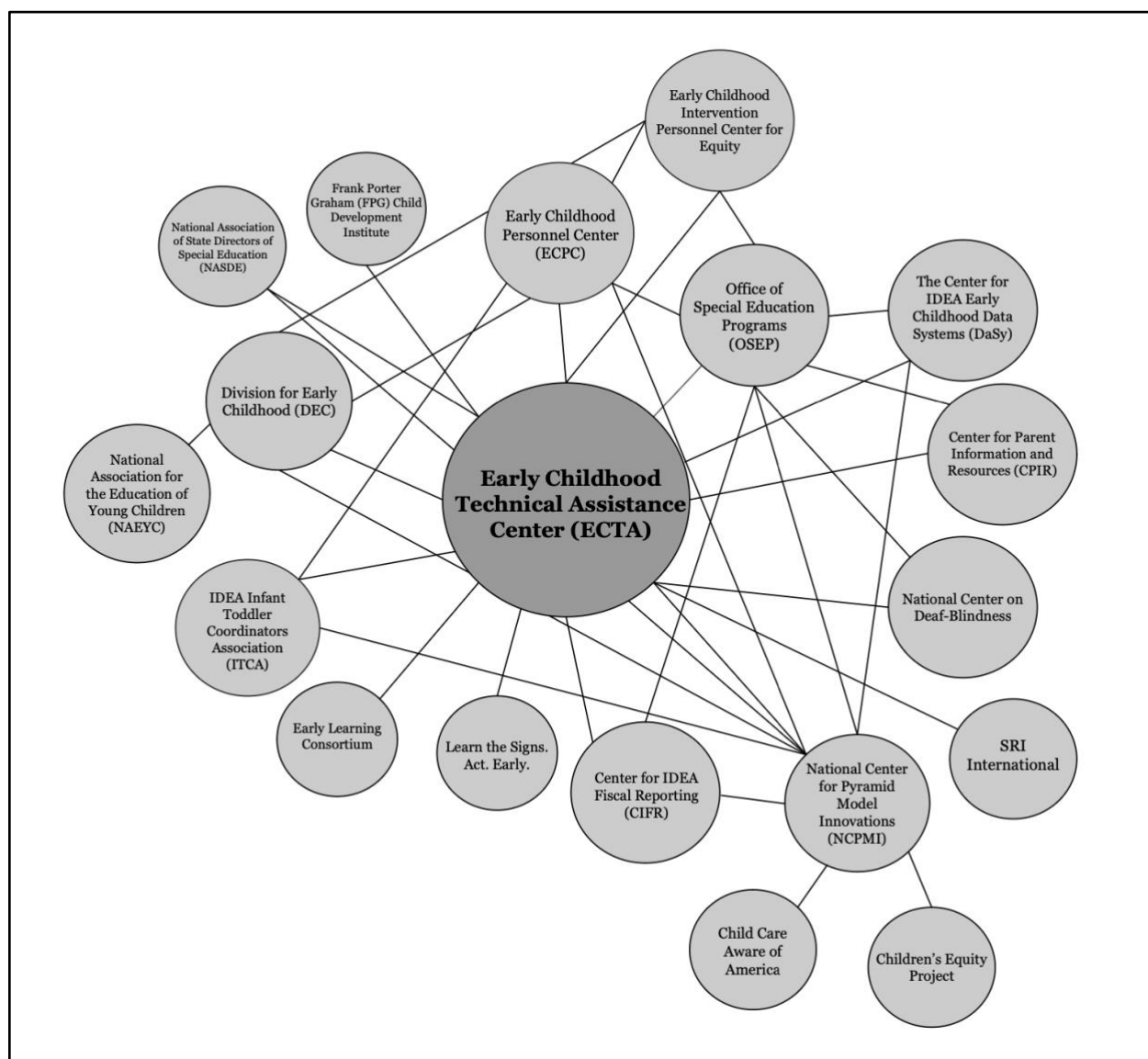
Note. Captured on September 1, 2024, at <https://www.ffyf.org/about-us/>

Case 2: Early Childhood Technical Assistance Center Informal Network

In Figure 2.2, the Early Childhood Technical Assistance Center, a federally funded center focused on EI and preschool special education practice, is centralized as the main actor with connections to other organizations. Cross analyzing actors from each organization, connections were identified that de-centralized ECTA. For example, the Early Childhood Intervention Personnel Center for Equity and the Division for Early Childhood have formalized connections that were identified outside of ECTA. Additionally, through the early stage of this network, individuals can see coalitions with actors that may not have formalized relationships, even though they are working within the same policy subsystem, such as early intervention and early childhood special education. Examples include the Children's Equity Project being connected to the National Association of State Directors of Special Education by way of the National Center for Pyramid Model Innovations and then through ECTA. While Children's Equity Project does not have a formalized connection or partnership with the National Association of State Directors of Special Education, they are connected through their focus on early intervention and early childhood years as well as the organizations with which they partner

Figure 2.2

Informal Coalition Example, Network View of a Singular Organization as the Main Actor with Selected Connected Actors



Note. Information for figure collected on September 1, 2024, through a network and flows approach (Davies & Nutley, 2008) on the ECTA website, starting at:

<https://ectacenter.org/about.asp>

Discussion

Identifying organizations is the first step in understanding the mechanisms of organizational influence at the national policymaking level (Caloffi et al., 2015). The variability and multiple systems interacting in the field of EI make for complex research, policy, and practice. This inquiry shows that a range of IOs perform different roles, serve in other functions, and are funded by many sources, echoing previous research on differences between IOs (Honig, 2004). The role with the largest number of organizations as potentials is training, public awareness, and education, which indicates that reaching the public and providing education to others may be a primary goal of organizations in EI coalitions. All philanthropies demonstrated activities related to training, public awareness, and education, showing that even through funded grants and projects to other organizations, they share information with the public related to their issue areas. The finding that philanthropies were categorized as serving an intermediary role aligns with previous research establishing philanthropies as IOs (Lubienski, 2019). Acknowledging that philanthropies are both funding sources and IOs demonstrates the extended reach that philanthropies have in the policymaking process; not only do they move forward their beliefs and values through financial means, but they also contribute as mediators of change through training, awareness, and education.

The roles that had the second largest potential organizations included purveyors of evidence-based practices and policy and systems development. As identified by Cooper (2010), research does not always translate to policy and practice. Pulling together innovative and best-practice models as well as targeting policy demonstrates that IOs are a part of filling the research, policy, and practice gap, identified through results of the top potential roles being training, public awareness, and education; purveyors of evidence-based practices; and policy and

systems development. These findings highlight the importance of knowledge mobilization as an essential component of national IOs. The coalitions that are built, formalized or not, in the EI policy subsystem represent a variety of functions with numerous policy outputs, demonstrating what Sabatier (1988) and Pierce and colleagues (2017) indicated is part of the policy subsystem coalition process. Many of the identified organizations are tangential to EI, yet their efforts contribute to the movement of the field of EI. As Blank and colleagues (2023) shared in their research, social services address many fields and multiple policy areas in addition to the organizations' identified focal areas. The results from this study also add to broader education IO research in that it considers national organizations, whereas previous research has focused at state and local levels, as performed by Aydaroya (2024), DeBray and colleagues (2020), Lubieniski (2019), and Yamashiro and colleagues (2023).

Sabatier (1988) highlighted that coalitions work together, whether they are aware that they are coalitions or not. There may not be direct connections to actors in a policy subsystem, but actors may be in alignment, even if their values and beliefs do not always align (Pierce et al., 2017; Sabatier, 1988). As seen in Figure 2.1, philanthropies play a vital role in some organizations' efforts, thus making them a part of an advocacy coalition as well. If a philanthropy's primary objective is to fund a project through selective means, they are setting the priority for the efforts of organizations. The primary funding of the Early Childhood Technical Assistance Center, shown as the central actor in Figure 2.2, comes from a federal grant, demonstrating federal policymakers' need for an organization to contribute to their decision-making capacities. The coordination of policymakers in moving forward certain values and beliefs and then utilizing organizations, programs, and activities to seek out evidence is a recommended path from GAO (2023a). Known coalitions are exemplified by Figure 2.2, in that

all organizations listed were identified through the main actor's website as funders, partners, or collaborators. Selected organizations outside of the main connections show that organizations may be working in coalition without a formalized agreement, creating informal coalitions. While the National Research Council and Institute of Medicine (now known as the National Academy of Medicine) called for a more integrated EI system in 2000, which the scope of this research did not fully address, promising results of this investigation are a) the knowledge that there are many IOs in the EI field and b) that these organizations are working in coalition together to move forward EI policy, research, and practice. There is a clear need to continue collaboration across systems with the abundance of organizations working across many focus areas.

Limitations and Next Steps

Although the present study was rigorous in its search of organizations, future studies can build on the foundation of this study to create a fully comprehensive list of the IOs and explore the coalitions that exist. Further studies exploring the impact of IOs on EI would be beneficial to investigate the specific knowledge that is translated into practice and policy by these organizations. Additionally, the analysis process of identifying roles was done by a researcher rather than the IOs self-identifying their roles. A next step in this line of research can include an adaptation of the Franks and Bory (2015) survey, which would allow organizations to self-identify their primary function and intermediary roles, would reach more potential IOs through sharing networks, and would allow for more exploration of advocacy strategies. Future directions can include network mapping to identify how these organizations interact, an analysis of products and information being produced, and exploring how policymakers at the federal level are interacting with these organizations and the value they place on organizations.

Conclusion

Identifying the organizations that work in coalitions with others as well as identifying their roles is the first step in understanding the systems that disseminate and influence research, policy, and practice. With an initial recognition of IOs that use more than one input and output, individuals in EI at all levels can pull resources together to inform their research, policy, practice, and advocacy. As with the finding of this study that training, public awareness, and education are important roles for EI coalitions in policymaking, training, public awareness, and education about how and what information is moved to and from policymakers will strengthen the field of EI and the empower the coalitions to make strong policy change.

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CHAPTER 3

ORGANIZATIONS AS KNOWLEDGE BROKERS IN POLICYMAKING: A CASE STUDY OF EARLY INTERVENTION-RELATED FEDERAL POLICY DOCUMENTS

Researchers continue to grapple with how to best move knowledge to policymakers and emphasize the need to explore how policymakers access and use evidence (National Research Council, 2012; Oliver et al., 2014; Tseng, 2012). Determining the exact method by which policymakers access information can be difficult, as there are many barriers to accessing information from “behind the veil” of policymaking. Some of these barriers include access to and interactions with staff, congressional libraries, and ethically sound insiders (West, 2023). One way to think about these interactions is to identify what information is being referenced by policymakers. Examining the information that policymakers are putting forward through requests, hearings, reports, and statements is an effective way to probe into which knowledge is utilized.

Introduction

In 2023, it was the first year of the 118th Congress and the third year of the Biden-Harris administration. Congress was split. The House of Representatives had Republicans in the majority, and the Senate had Democrats in the majority. As a result, legislation and appropriations came to a halt. Meanwhile, within the executive branch, the federal Office of Special Education and Rehabilitative Services finally received its permanent appointment of Assistant Secretary in the Biden-Harris White House (Council for Exceptional Children; 2023) after having an interim Assistant Secretary for the previous two years. The leadership across the

legislative and executive branches became strained, with Congressional agreements taking extraordinary amounts of time. Examples of these lengthy agreements include the 15 rounds of voting for the first Speaker of the House, two weeks of delay and four rounds of voting for the second Speaker of the House, an extended session in the summer for negotiation on the federal debt limit to avoid a default, and the multiple continuing resolutions and non-passages of appropriations bills for fiscal year 2024 and 2025 (Congressional Research Service, 2024; DeSilver, 2023; McDaniel, 2023; Peter G. Peterson Foundation, 2023; Statista, 2023; Solender, 2023).

In addition to appropriations issues, Congress also faced rising social pressure surrounding the discontinuation of the American Rescue Plan Act (ARPA), with its stabilization funds that bolstered the economy during the coronavirus-19 pandemic. In relation to young children with disabilities and their families, the stabilization funds supported early care and education, early intervention programs, infant and early childhood mental health services, special education, and other areas (American Rescue Plan, 2021; Caler, 2023; Gibbs & Falgout, 2022; Zero to Three, 2023a). The discontinuation of the ARPA funds highlighted the inadequacy of access to early care and education for young children with disabilities in the absence of federal funding (Gibbs & Falgout, 2022). Historically, there has been inequitable access to early care and education programs for young children with disabilities, and in recent years, this has been no different (Booth-LaForce & Kelly, 2004; Friedman-Krauss & Barnett, 2023; Kelly, 2022; Novoa, 2020).

Because federal policymaking occurs across all branches of government, when legislation comes to a standstill, there can be emphasized attention on what other forms of policy come out of Congress and the executive branch. Federal agencies release policy statements, guidance,

rules, and regulations. Congress holds hearings and roundtables, and releases reports and requests for information, in addition to proposing and passing legislation. The Congressional Research Service and the U.S. Government Accountability Office (GAO), both research entities that serve Congress, perform research, release reports, hold briefings, and participate in hearings, moving information to both the public and to each of the branches of government (Library of Congress, 2024; GAO, n.d.). Even without legislation being passed by Congress, families, groups, organizations, and policymakers turned 2023 into a year of focus for federal infant and toddler policy (Zero to Three, 2023b).

Early Intervention Policy

Services for infants and toddlers with disabilities and their families fall under Part C of the Individuals with Disabilities Education Act (IDEA) and are termed early intervention (EI). IDEA Part C authorizes states to develop EI programs for children with disabilities ages birth through 2 and their families and provides supplemental funding for states to support these programs through a grants process (IDEA, 2004). Across and within states, EI services vary greatly due to the complexity of the EI systems, leading to a fragmented implementation system (Friedman-Krauss et al., 2023; Wiegand et al., 2022).

The most recent regulatory policy that has occurred for EI was in 2011, when the federal rules and regulations were set for Part C of IDEA by the U.S. Department of Education (Early Intervention Program for Infants and Toddlers with Disabilities, 2011). It took seven years from the reauthorization of IDEA in 2004 for these regulations to be finalized and then implemented, lagging behind the two years it took for Part B of IDEA which covers ages 3-21 (Assistance to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities, 2006). Now at 20 years post reauthorization and 13 years post regulations, there

have been advances in medical and social research that inform the field of EI but have not been encapsulated by current legislation or regulatory policy. There has been a call for IDEA to be reauthorized due to the current version continuing past the 5-year reauthorization requirement and not funding special education at a higher level (Council of Administrators of Special Education, 2017; Kolbe, et al., 2022; Yarrell, 2024). The federal government is not upholding the educational rights of children with disabilities as the policy said it would.

The Advocacy Coalition Framework

One lens through which to explore the policymaking process is to use the Advocacy Coalition Framework (ACF). ACF is a tool for viewing policy subsystems that are bounded by an issue (Pierce et al., 2020); for this paper, the focus is the EI policy subsystem. Per the ACF, policy subsystems are formed by actors, who then work in coalitions based on beliefs and resources (Pierce et al., 2017; Sabatier, 1988). Actors who form coalitions can include individuals from various levels of government, social groups, interest groups, research, media outlets, and others (Fenger & Klok, 2001). These coalitions are affected by relatively stable parameters, external subsystem events, short-term constraints and resources, and long-term opportunity structures (Pierce et al., 2017). Within the policy subsystem, coalitions of actors work through strategies that are then picked up by government leaders, with the aim that these government officials will make decisions that change rules, create policy outputs, and then ultimately have an impact on policy (Pierce et al., 2017). Coalitions may be structured and formalized, such as the Consortium for Constituents with Disabilities or the Leadership Conference on Human and Civil Rights, or actors may unknowingly work in tandem with each other. In 2023, there were external events and short-term resources that opened up opportunities for coalitions to mobilize and implement strategies: the ending of ARPA funds and the

publication of two original research documents, GAO's study on Part C eligibility inconsistencies (2023b) and the National Institute of Early Education Research's report on national and state EI trends (Friedman-Krauss & Barnett, 2023). These documents provided an evaluation of the impact of not reauthorizing IDEA and a starting point for the next reauthorization based on research and practice. By examining these documents, insight can be gained about the roles of organizations and government entities in policy subsystems and how each influences policymaking.

Literature Review

Policymakers become educated on topics from various sources, and their staffers play a critical role in navigating evidence to use (West, 2023). What is valued as evidence can differ across types of federal policymakers and depends on which branch of government - executive or legislative - is putting forth the policy. Challenges to their own understanding also influence policymakers and can be slow to have their beliefs changed by evidence (Weiss, 1977). The relationships that policymakers have with researchers, experts, and organizations play a vital role in how policymakers determine what is and is not useful knowledge or evidence and from where they collect that information (West, 2023). It is often considered a hope of researchers and aim of policymakers that practitioners and policymakers will pick up research results and conclusions, but there are many barriers to policymakers and their staff accessing and using evidence (Cairney & Oliver, 2017; Weiss, 1977). The process of translating research into policy is complicated by differing views on what constitutes valid knowledge.

Types of Knowledge

There are multiple perspectives on what counts as knowledge. The two main factors considered in policymaking are authority-based knowledge and science-based evidence

(Gambrill, 1999). In a recent report to federal policymakers on using evidence-based policymaking, GAO (2023a) highlighted and used multiple definitions of evidence, including “information produced as a results of statistical activities conducted for a statistical purpose” from the Foundations for Evidence-Based Policymaking Act of 2018 and “the available body of facts or information indicating whether a belief or proposition is true or valid” from the White House’s Office of Management and Budget (GAO, 2023a, p. 7). The Office of Management and Budget uses the Foundations for Evidence-Based Policymaking Act of 2018 definition of evidence and states that evidence can be used more broadly for organization and agency performance. The broader definition of evidence by the Office of Management and Budget encompasses “quantitative or qualitative information” that “may be derived from a variety of sources” and the “sources included foundational fact-finding (e.g., aggregate indicators, exploratory studies, descriptive statistics, and other research, performance measurement, policy analysis, and program evaluation” (GAO, 2023a, p. 7). These definitions reflect the diverse sources and methodologies used to inform policymaking.

In this chapter, the term “authority-based knowledge” encompasses knowledge produced by experts that cannot be contested by others, and the term “science-based evidence” encompasses material that falls under research results, which have historically been limited to quantitative, randomized control trial-based studies (Archibald, 2015; Biesta, 2010). Authority-based knowledge is knowledge that is held to a social standing but is not able to be disproven (Daviter, 2015; Gambrill, 1999). The use of authority-based knowledge has been documented in policymaking by prioritizing ideology and customs to move forward arguments and wording of policy rather than incontestable information (Daviter, 2015). There is value in knowledge that comes from personal and professional experience, but relying solely on interactions does not

move forward effective policy and practice (Gambrill, 1999). There is a persistent and vocal call for science-based knowledge to be used, specifically in educational policymaking (Lubienski et al., 2014).

Science-based evidence is primarily derived from research. The key components of research include an attempt to discover facts, investigate or describe topics and events, identify differences in variables, and do so in an observable or experimental manner (American Psychological Association, 2018). There is a call within the field of educational policy to ensure that research does not only reflect the ideals of policymakers but rather that “research and evaluation must be objectively executed and accurately reported, even if the results challenge policies of the administration in office at the time” (Vinovskis, 2009, p. 229). In the field of education, science-based research use is a priority for policy, particularly within federal legislation such as the Education Sciences Reform Act (2002) and the Individuals with Disabilities Education Act (2004). Research used in educational policymaking comes from many types of actors, such as national councils, professional associations and membership organizations, and researchers housed within institutes of higher education or organizations, among others (Tseng & Nutley, 2014). When results cannot be critiqued and held as an accepted truth or fact because they have been held to the standard of peer review, there becomes a disconnect from what is happening in the field and what is not (Gambrill, 1999). Additionally, it should be noted and considered that the knowledge and evidence that makes its way to and is used by policymakers often perpetuates inequities and privileged voices (Hollar, 2020; Rubin & Schneider, 2021). When exploring the information that is used in politics, there is always bias, even in research.

Policymaking is complex and is significantly shaped by values, opinions, and actions that steer decisions in specific directions (Almeida & Báscolo, 2006). Both authority-based knowledge produced by experts and science-based knowledge produced by researchers are factors in the policymaking process (Christensen & Brown, 2021). Applying the ACF, both researchers and experts are considered actors and come together in coalition with each other to influence policy based on their beliefs and values (Sabatier, 1988).

Research Use in the Policymaking Process

Policy influences include public opinion, media, economic climate, legislative/policy infrastructure, political ideology and priorities, stakeholder interests, expert advice, resources, and research (Loncarevic et al., 2021; Redman et al., 2015). Research evidence can be used in many aspects of policymaking, including the co-production of knowledge between policymakers and researchers, where policymakers, researchers, and stakeholders bring about new information together (Cairney & Oliver, 2017). There are many factors that affect a policymaker's decision to use research in their policymaking process (Redman et al., 2015). The external context, including deadlines, political influences, and availability of research, often has an effect on whether the research is viewed as relevant or acceptable. Other factors include the policymakers' own value placed on research, engagement with researchers, and their staff's ability to understand and apply research within the policymaking process (Redman et al., 2015). Additionally, there are factors within the institution of policy itself. These factors include internal policies that encourage or require the use of research, leadership who encourage or model the use of research in their policymaking processes, systems within the institution to gather and disseminate research, resources for access, and relationships with researchers (Redman et al., 2015).

Barriers to Accessing Research in Policymaking

Policymakers, or more specifically, their staff, face many barriers to accessing and utilizing evidence in their decision-making (Innvær et al., 2002; Oliver et al., 2014). In a systematic review of literature, Oliver and colleagues (2014) identified the top barriers to policymakers' use of evidence in their decision-making as "lack of availability of research, lack of relevant research, having no time or opportunity to use research evidence, policymakers' and other users not being skilled in research methods, and costs" (p. 4). Another barrier highlighted from the researcher perspective was that researchers had different priorities than policymakers when communicating their research, often needing to prioritize publishing in peer-reviewed research journals, which often exist behind paywalls. There is a growing focus on bridging the research to policy and practice gaps, which focuses on how to effectively move knowledge and evidence from researchers to decision-makers (Cooper et al., 2009).

Knowledge Mobilization

Knowledge mobilization, or the process by which research results are shared among educators, policymakers, and the public, is an area of focus that attempts to detangle the complexity of information sharing across social processes and various influences (Fenwick & Farrell, 2012). Both individuals and organizations are considered knowledge mobilizers but what is being shared by researchers does not always meet the needs of practitioners and policymakers, thus contributing to the research-policy-practice gap (Malin & Brown, 2020). It is important to note that knowledge mobilization and the use of knowledge are not solely a movement in a singular direction from organizations to policymakers but are part of a dual process where policymakers also are active participants in deciding what knowledge is used (Wesselink & Hoppe, 2020). Social and political interactions mediate how knowledge is moved in research,

policy, and practice (Levin, 2008). Researchers themselves cannot deem what information is politically relevant or what is acceptable by policymakers; organizations have important roles to fill in moving knowledge. Policy created and implemented across organizations and local, state, and federal governments impact practice and research, with research and practice, in turn, impacting policy (Emmons & Chambers, 2021). There is little tracking of knowledge mobilization at the local, state, or national level, either in development, adoption, or implementation (Emmons & Chambers, 2021). If it were tracked, it would be informative for all entities involved.

Organizations as Knowledge Brokers in Policy and Education

Federal and national level organizations, such as think tanks, interest groups, research and policy centers, and others, can include aims and functions of connecting to policymakers, and policymakers use organizations to influence their policy and the policy of their peers (Ainsworth, 1997; Garrett & Jansa, 2015; Lucas et al., 2019; Stone, 2000; West, 2023). Research has shown the need to understand how knowledge moves past an academic setting and into the hands of decision-makers in policy and education (Cooper, 2015; Cooper et al., 2009; Malik, 2020). Understanding how organizations participate in policy informs the policymaking process (Caloffi et al., 2015). Identifying which organizations are being used by policymakers and the networks in which they are connected allows for better collaboration for innovative policy implications. Additionally, the importance of organizations in brokering knowledge and conveying to policymakers the legitimacy and credibility of such knowledge is useful in ensuring that policymakers are aware of and using current evidence to support their decision-making (Doberstein, 2017; Lubienski et al., 2011). Organizations, more specifically, the individuals who

make up organizations, play a critical role in building relationships with policymakers and can be a reliable source of information and positions in policy creation (West, 2023).

Organizations that mediate change between entities are termed “intermediary organizations” (IOs) and add value between the entities (Honig, 2004). IOs have many roles and serve various essential functions, such as think tanks, research centers, and non-profits (Franks & Bory, 2017; Honig, 2004). One role of IOs is policy and systems development, which includes organizations that have

[the] ability to work with complex systems and political environments; [the] ability to translate research and complex material into brief policy statements and recommendations; engagement and collaborative skills; [and the] ability to align priorities with political will and available resources. (Franks & Bory, 2017, p. 32)

IOs can hold the primary role of knowledge brokers in the political world (Lubienski et al., 2011) and echo the roles of knowledge brokers such as information managers, linking agents, capacity builders, facilitators, and evaluators (Hollar, 2020). Research evidence has long been a challenge for federal policymakers to access and synthesize, and there continues to be a gap between the creation and utilization of research evidence in policymaking (National Research Council, 2012). Identifying which organizations policymakers gather knowledge from and how policymakers use said knowledge can support organizations and individuals in ensuring evidence is used by policymakers (Cooper & Shewchuk, 2015; Tachino, 2012).

Research Questions

The federal government moves policy forward in a variety of ways, and some of these can be more influential in practice than legislation or regulations alone. This manuscript will

examine documents that represent non-legislative actions and show which knowledge and organizations federal policymakers use. The research questions addressed include:

1. In federal policy documents released by federal policymakers in the EI policy subsystem from 2023, which sources, and more specifically organizations, were referenced?
2. What information is being moved within the identified documents and by whom?

Methods

Study Design

The study design is a case study, which can be described as an investigation into a bounded system (Merriam, 1998). Investigating a case is the study of a phenomenon within a context from which it cannot be separated (Merriam, 1998). The bounds of this case study include federal policy documents and hearings related to infants and toddlers with disabilities in the first year of the 118th U.S. Congress and the third year of the Biden-Harris Administration. The focus on the knowledge and intermediary organizations (IOs) being utilized by federal policymakers allows insight into the social process of knowledge mobilization.

Document Selection

In 2023, there was important federal policy developing to support infants and toddlers with disabilities. While no documents were published from the Supreme Court of the United States (2023; 2024), there were documents created by the executive and legislative branches. From EI-related federal agencies, rules, proposed rules, and notices were published by the Administration for Children and Families, housed within HHS, including 165 documents and the Department of Education (ED) published 508 documents, with 11 documents focused on early intervention and 36 documents focused on children overall (Federal Register, 2023). While the

documents produced by the agencies are numerous, they demonstrate activities performed by the agencies, not policy documents with the intent to persuade a change in policy or practice.

In a search of documents produced by Congress in the congressional record (Library of Congress, n.d.) for 2023 (search term “child”), 1,291 results were produced, with 663 attributed to the U.S. House of Representatives and 560 to the U.S. Senate (search date November 4, 2024). In searching for documents about early intervention (search term: “early intervention”), 24 results were produced. The results included movements to suspend or support legislation, remarks on topics, individuals, or legislation, resolutions, and appointments of individuals to boards and federal agencies, amongst others. Both searches for child- and early intervention-related results included duplicates, such as a statement or resolution being recorded in the U.S. House of Representatives and the U.S. Senate records. While the results appear as a significant number, especially regarding searching for “child,” most results did not fall within the scope of the EI policy subsystem (such as focusing on international wars and the impact on children or legislation and topics outside of the scope of this study); thus a deeper search was required to determine documents to be reviewed as part of this study. Press releases from the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP Committee) (2023a) on a report with a related committee hearing, a GAO (2023c) report focused on EI, and the federal agencies of U.S. Department of Education (ED) and the U.S. Department of Health and Human Services (HHS) joint policy statement (ED, 2023) highlighted the documents as priorities coming out of federal policymakers. The included documents are:

- [Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs](#) (ED/HHS Joint Policy Statement) (ED/HHS, 2023)
- [Supporting Working Families: The Need for Ongoing Support for the Nation’s Child Care Sector](#) (HELP Committee Report) (HELP Committee, 2023b)
- [Special Education: Additional Data Could Help Early Intervention Programs Reach More Eligible Infants and Toddlers](#) (GAO Report) (GAO, 2023b)

Description of Documents

The ED/HHS Joint Policy Statement (2023) expanded on a previous HHS/ED joint early childhood policy statement published in 2015 (HHS/ED, 2015). ED and HHS also shared that the joint policy statement “states that all young children with disabilities should have access to high-quality inclusive early childhood programs that provide individualized and appropriate support so that they can fully participate alongside their peers without disabilities, meet high expectations, and achieve their full potential” (ED, 2023). Per ED and HHS, the responsibility for high-quality inclusion should be “shared by federal, State, and local governments, early childhood systems, early childhood programs and providers, local educational agencies (LEAs), and schools” (ED, 2023). The ED/HHS Joint Policy Statement (2023) covers foundations of inclusion in early childhood, opportunities for early childhood programs to improve inclusions, a plan to create a culture of inclusion across the nation, recommendations for state and local agencies to elevate high-quality inclusion for young children with disabilities, and resources for entities to support inclusion.

The HELP Committee Report (2023b) addressed support for child care. It was produced ahead of a full committee hearing titled “Solving the Child Care Crisis: Meeting the Needs of Working Families and Child Care Workers” (HELP Committee, 2023a) and a later bill

introduction to provide continued stabilization funds for the child care sector (HELP Committee, 2023c). The HELP Committee Report (2023b) covers the current state of the child care workforce, why stabilization funds were needed due to the impact of COVID-19, and what states did with stabilization funds. The positive impacts covered child care stabilization grants, Child Care and Development Block Grant Supplemental Funds, access and affordability for families, supports for the early childhood workforce, and the growth in the capacity of providers. Additionally, the report highlighted how temporary funds demonstrated the need for a permanent investment from the federal government.

Report (2023b) was created in response to an inquest from HELP Committee members Senator Patty Murry (former HELP Committee Chair), Senator Bernie Sanders (HELP Committee Chair at the time of report release), and Senator Tim Kaine. GAO was asked to “review barriers to states effectively carrying out Part C requirements under IDEA, and any inequities in access to early intervention services for families” (GAO, 2023b, p. 2). In response, GAO conducted an original research study where staff reviewed Part C eligibility information in states and territories and analyzed data from a national survey that reported child health metrics from 2016 to 2021. Additionally, GAO reviewed data from ED from 2016 to 2021 on Part C child counts and settings and interviewed ED agency staff and ED-funded technical assistance center staff. GAO also disseminated a survey via the internet that collected original data on challenges states face on implementation of Part C; number, race, and ethnicity of children referred, evaluated, found eligible, and served in Part C; and individuals and entities that were primary referral sources. The survey data was collected across 2021 and 2022. In the report, GAO provided an overview of Part C EI legislation and implementation, differing definitions of Part C eligibility across states, workforce shortages in Part C, and referral and enrollment rates in

Part C programs. GAO shared implications of what they found in their data analysis, including areas of opportunity that ED is not currently supporting. GAO also reviewed the use of ED-funded technical assistance centers and concluded its report with considerations for Congress and recommendations for federal executive agencies, such as ED, to improve Part C implementation.

Analysis

Document analysis of the three policy documents was completed using content analysis. Document analysis uses artifacts, primarily documents with text and images, to be interpreted by an individual (Bowen, 2009). Content analysis uses objective means to make inferences, provide new knowledge and insights, and describe a phenomenon (Downe-Wambolt, 1992; Elo & Kyngäs, 2007; Krippendorff, 2019). Classifying observations and interpretations enables researchers to communicate phenomena and supports the validity of qualitative research (Kyngäs, 2020; Newman, 2000) systematically and objectively. Utilizing secondary coders supports the trustworthiness, rigor, and reliability of the analysis and results (Azungah, 2018).

The lead researcher (Coder A) and two additional coders (Coders B and C) reviewed the three documents. Coder A was a special education doctoral candidate who was knowledgeable in early intervention and federal disability policy. Coder B was a social work doctoral candidate with a graduate certificate in interdisciplinary qualitative studies. Coder C was a methods expert in analysis interpretation and held a PhD. The ability to use a team-based approach with software that allows for comparing codes and building a codebook helped increase reliability (Cascio et al., 2019). The three documents were organized and managed using the qualitative document software MAXQDA. MAXQDA was selected for its highlighted focus on content analysis and the ability to organize coding schemes with rules. MAXQDA also allowed for team coding,

keeping coded documents separate with the option to merge, export, and import documents with the same and different codes.

The analysis consisted of two phases. The first phase included the identification of types of references in the policy documents; Coder A and Coder B separately reviewed the reference lists for all three policy documents and inductively categorized reference authors. Upon discussion, all references were categorized and agreed upon. For the second phase, an inductive approach was used to analyze the content and themes of the information sourced from organizations. Coder B was directed to apply a critical lens, pose questions, check coding schemes, and search for additional options to process and interpret the data. In the second phase, Coder A and Coder B independently developed codes for 10% of the data to establish reliability and validity. Once consensus was reached on the code list, 10% more were coded independently, and there was a near-perfect agreement of codes. Where there were differences, a consensus was reached through discussion, creating more refined codes. Next, both coders coded the remaining data and met to discuss every coded unit to reach a consensus in the first coding pass. The process was iterative, with several passes through the data and seven meetings to clarify and refine codes as well as to create subcodes. For example, one pass involved identifying the type of organization, and the second pass included further detail needed after coding the first pass and discussion.

After Coder A and Coder B finished coding, Coder C coded all non-governmental references for the type of research the sources included. Coding for the type of research within each reference allowed for a distinction between an organization doing its own tasks and one that was mediating between entities, such as other organizations and policymakers, thus enabling the identification of intermediary organizations. Additionally, Coder C coded for access to the

references - whether the source was behind a paywall or not. After all coding was completed, Coder A used the subcode statistics function within MAXQDA to produce numerical and percentage data.

Results

Organizations and Knowledge Utilized

The following publishers of sources were identified using websites and links within the references: governmental sources such as federal executive branch agencies and the GAO, state governments, federal legislation, and federal rules and regulations; news sources; and organizations. Types of sources included federal data, federal legislation, federal regulations or standards, federal reports, federal websites, journal manuscripts (peer-reviewed journal articles), new stories, notes, original research data, organizational data, organizational reports, and state government reports or press releases. The number and percentages of types of sources within and across the three policy documents are located in Figure 3.1. Repeated citations, such as the same source being referenced more than once, were removed from total count due to the focus being on the type of source being utilized, not the absolute number of references.

Table 3.1*Number and Percentages of Source Type in Coded Policy Documents*

Source Type	GAO Study (n=41)		ED/HHS Statement (n=83)		HELP Committee Report (n=42)		Total Across All Documents (n=166)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Federal Data	1	2	4	5	3	7	8	5
Federal Legislation	14	34	0	0	0	0	14	8
Federal Regulations or Standards	0	0	4	5	0	0	4	2
Federal Report	6	15	6	7	11	26	23	14
Federal Website	0	0	0	0	1	2	1	1
Journal Manuscript	1	2	46	55	0	0	47	28
News Story	0	0	0	0	3	7	3	2
Notes	17	41	0	0	1	2	18	11
Original Research Data	1	2	0	0	0	0	1	1
Organizational Data	1	2	0	0	1	2	2	1
Organizational Report	0	0	23	28	11	26	34	20
State Government Report or Press Release	0	0	0	0	11	26	11	7

Note. Repeated citations were removed from each GAO Study (n=12, 23%) changing the total from n=51 to n=41; ED/HHS Joint

Policy Statement (n=23, 22%) changing the total from n=106 to n=83; and the HELP Committee Report (n=18, 30%) changing the total from n=60 to n=42.

Many organizations were identified, and the structure of these organizations fell into the categories of philanthropies/non-governmental organizations, professional/membership organizations, policy centers or think tanks, research centers or organizations, and technical assistance centers. Table 3.2 shows the identified organizations, grouped by structure.

Table 3.2

Identified Organizations by Structure

Structure	Organizations
Philanthropy/Non-Governmental Organization	Advocates for Children of New York Citizens' Committee for Children of New York
Professional/Membership Organization	Child Care Aware of America Division for Early Childhood IDEA Infant and Toddler Coordinators Association National Association for the Education of Young Children Zero to Three
Policy Center or Think Tank	Center for American Progress Center for the Study of Social Policy Child Health and Development Institute Children's Equity Project Children's Equity Project & Bipartisan Policy Center Cutler Institute for Child and Family Policy Hunt Institute The Education Trust Urban Institute
Research Center or Organization	Child Trends National Institute for Early Education Research SRI International Start Early
Technical Assistance Center	Center for the Study of Child Care Employment Early Childhood Learning and Knowledge Center National Center for Pyramid Model Innovations Tribal Early Research Center

Two organizations were referenced across the HELP Committee Report and the ED/HHS Joint Policy Statement. One organization was the Center for American Progress (CAP), a think tank; the other was the Center for the Study of Child Care Employment (CSCCE), a technical assistance center. From CAP, cited publications included child care reports regarding use of public funds related to ARPA stabilization grants (Jessen-Howard & Workman, 2020), inequities for families of children with disabilities (Novoa, 2020), and workforce numbers (Coffey & Khattar, 2022). From CSCCE, cited publications included information on child care workforce compensation (Montoya et al., 2022), employment (CSCCE, 2023), and use of public funds related to ARPA stabilization grants (CSCCE, 2021).

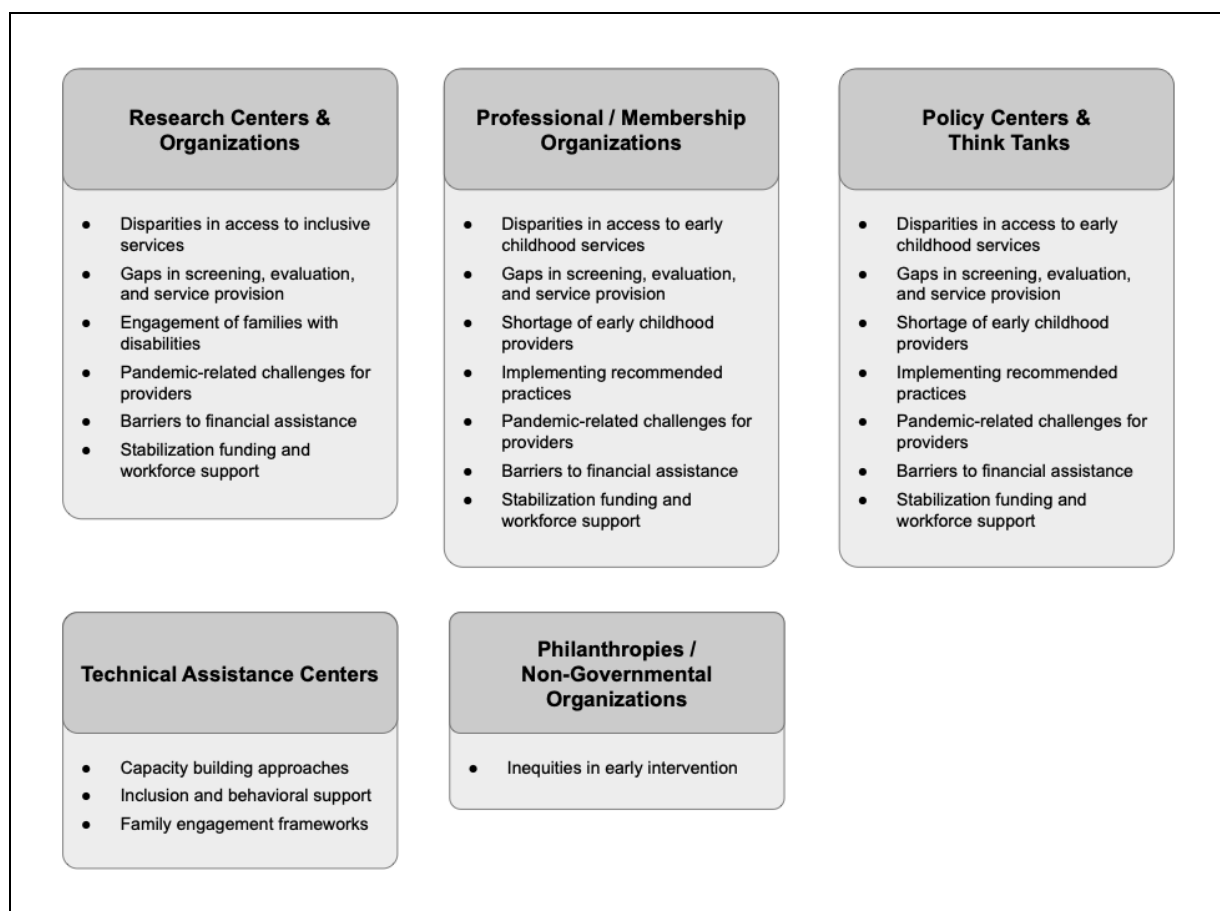
Information published from research centers and organizations, professional/membership organizations, policy centers, and think tanks provided content in similar issue areas, such as disparities in access to inclusive or early childhood services, gaps in screening, evaluation, and service provision, shortage of providers and pandemic-related challenges for providers, as well as stabilization fund distribution for workforce support and barriers to financial assistance. These findings are unsurprising, as these organizational structures are well known for translating research into policy action items. For technical assistance centers, primary content sourced included capacity-building approaches, inclusion and behavior support, as well as family engagement frameworks. These roles align with the IO roles of federally funded technical assistance centers, which typically lean toward capacity building for practice and program improvement. Information shared by type of organization can be found in Figure 3.1.

Additionally, the format of the information produced by organizations was varied. Organizational information sourced came in many formats, such as reports, policy briefs, press releases, and news stories. A sample of examples is included in Table 3.2. Across both the

ED/HHS Joint Policy Statement and the HELP Committee Report, there was information pulled from original research studies, secondary analyses of research, recommendations for practice and policy, listings of resources, and organizational statements.

Figure 3.1

Information Shared by Organizations, Grouped by Organization Structure



Additionally, the format of the information produced by organizations was varied. Organizational information sourced came in many formats, such as reports, policy briefs, press releases, and news stories. A sample of examples is included in Table 3.2. Across both the ED/HHS Joint Policy Statement and the HELP Committee Report, there was information pulled from original research studies, secondary analyses of research, recommendations for practice and policy, listings of resources, and organizational statements.

Table 3.3*Sample of Formats and Examples of Organizational Sources*

Format of Organizational Source	Example
Reports	Children’s Equity Project & Bipartisan Policy Center. (2020). <i>Start with equity: From the early years to the early grades</i>. https://childandfamilysuccess.asu.edu/sites/default/files/2020-10/CEP-report-101320-FINAL_0.pdf * Whitesell, N. R., Asdigian, N. L., Trucksess Howley, C., Sarche, M., Clifford, C., & Tribale Early Childhood Research Center PEDS Community of Learning. (2021). <i>Pilot exploration of developmental screening in tribal communities</i>. Tribal Early Childhood Research Center. https://coloradosph.cuanschutz.edu/docs/librariesprovider205/trc/2-trc-tribal-peds-final-report.pdf * Li, F., Heyman, M., Akobirshoev, I., Williams, Z., & Mitra, M. (2022). <i>How many parents with disabilities are in the United States?</i> National Research Center for Parents with Disabilities, Brandeis University. https://heller.brandeis.edu/parents-with-disabilities/pdfs/prevalence-of-parents-with-disabilities-in-us-pl-x.pdf *
Policy Brief or Whitepaper	Rausch, A., & Strain, P. <i>Why focus on quality inclusion as part of statewide pyramid model implementation?</i> National Center for Pyramid Model Innovations https://challengingbehavior.org/docs/Why-quality-inclusion_whitepaper.pdf * The Hunt Institute. (2021, February 12). <i>What’s next for child care? What states are learning in the COVID-19 crisis</i>. https://hunt-institute.org/resources/2021/02/whats-next-for-child-care-what-states-are-learning-in-the-covid-19-crisis/ **
Article	Ahlers, T., Cheatham, D., Cohen, J., & Andujar, P. (2021). <i>Recommendations on developmental screening follow-up practices and policy for federal, state, and community level stakeholders</i>. ZERO TO THREE Policy Center. https://www.zerotothree.org/wp-content/uploads/2022/11/Recommendations-on-Developmental-Screening-Follow-up-Practices-and-Policies-for-Federal-State-and-Community-Level-Stakeholders.pdf *

Format of Organizational Source	Example
Policy Recommendations	Jessen-Howard, S., & Workman, S. (2020, April 24). <i>Coronavirus pandemic could lead to permanent loss of nearly 4.5 million child care slots</i>. Center for American Progress. https://www.americanprogress.org/article/coronavirus-pandemic-lead-permanent-loss-nearly-4-5-million-child-care-slots/ ** National Association for the Education of Young Children. (2020, July 13). <i>Holding on until help comes: A survey reveals child care's fight to survive</i>. https://www.naeyc.org/sites/default/files/globally-shared/downloads/PDFs/our-work/public-policy-advocacy/holding_on_until_help_comes.survey_analysis_july_2020.pdf **
Press Release	Child Care Aware of America. (2022, October 13). <i>New report finds that increases in the price of child care continue to exceed the rate of inflation</i> [press release]. https://info.childcareaware.org/media/price-of-care **

*Referenced in the ED/HHS Joint Policy Statement

**Referenced in the HELP Committee

Coalitions – Case Examples

In relation to coalitions, an identified reference came from the Office of Planning, Research, and Evaluation within the Administration for Children and Families of the U.S. Department of Health and Human Services that supports the tenet of ACF that coalitions include a variety of actors. Through a funded project, the Child Care and Early Education Policy and Research Analysis, a grant managed by Child Trends, a publication was produced by multiple authors across organizations (Burwick et al., 2020). Individuals from Child Trends (a research organization), Mathematica, the University of Minnesota, and Rand Corporation were brought together to co-author a special topics paper/report called *Promoting Sustainability of Child Care Programs during the COVID-19 Pandemic: Considerations for States in Allocating Financial Resources* (Burwick et al., 2020). Simply in viewing the authorship and funding source of this singular reference, it is evident that a coalition has formed around the policy subsystem of child care, crossing government, think tanks, research organizations, and an institute of higher education. The diversity of membership through a publication that the HELP Committee utilized in their policy document demonstrates what information can be put forward by coalitions. Additionally, two publications were co-authored by two organizations. The Advocates for Children of New York and the Citizens' Committee for Children of New York (2019) publication specifically highlighted disparities in access to EI programming within New York City, with data from a local government and obtained by a research journalist in the health field.

The next publication that was identified as having two organizational authors, *Start with Equity: From the Early Years to the Early Grades* was authored by Children's Equity Project and the Bipartisan Policy Center (2020), but upon further investigation turned out to have many contributing individual co-authors, similar to the above-mentioned publication from Child Care

and Early Education Policy and Research Analysis (Burwick et al., 2020), with institutes of higher education, think tanks, and research centers identified as project partners. Organizational partners included the Center for Racial Equity and Excellence, The Century Foundation, New America, and institutes of higher education including Arizona State University (home of the Children's Equity Project), University of Oregon, Bank Street College, Trinity University, Vanderbilt University, Yale University, and Florida International University. In addition to the authors' home organizations, other entities were recognized through funding, such as The Heising Simons Foundation and the T. Denny Sanford School of Social and Family Dynamics at Arizona State University. Research assistance, document review, and logistics were supported by individuals at The Children's Equity Project, University of Oregon, Vanderbilt University, University of Miami, Southwest Human Development Center, American University, Center for American Progress, Early Childhood Funders Collaborative, University of North Carolina – Chapel Hill, The Education Trust, National Association of State Directors of Special Education, Affinity Group, Georgetown University, Berkeley University, and the Bipartisan Policy Center. Looking at the output, or arguably an advocacy coalition strategy, there are a total of 23 organizations represented working in tandem together through their various actors. What might be even more surprising is the recognition of experts from a large variety of organizations who attended two separate convenings, shown in Figure 3.2.

Figure 3.2

Page 3 of the Children's Equity Project and Bipartisan Policy Center's Report, Showing Individuals and Attached Organizations

**THIS REPORT WAS INFORMED BY EXPERTS WHO ATTENDED
TWO CONVENINGS IN 2019, INCLUDING:**

Shantel Meek, PhD, Arizona State University, Children's Equity Project Founder and Director	Barbara Chow, PT, Heising-Simons Foundation
Linda Smith, Bipartisan Policy Center	Dean Tagawa, EdD, Los Angeles Unified School District
Arabella Pluto-Ehlers, Bipartisan Policy Center	Kristen Harper, MD, Child Trends
Arlyn Moreno Luna, MPP, Berkeley University	Phyllis Glink, MPP, Irving Harris Foundation
Oscar Jimenez-Castellanos, PhD, Trinity University, Children's Equity Project partner	Shannon Rudisil, MSW, Early Childhood Funders Collaborative
Eva Marie Shivers, JD, PhD, Indigo Cultural Center, Children's Equity Project partner	Carol Martin, PhD, Arizona State University, Children's Equity Project
Roberto J. Rodriguez, EdM, Teach Plus	Sharon Yandian, MEd, U.S. Department of Health and Human Services Office of Head Start
Rafael Lopez, Independent Consultant	Candida Hunter, First Things First
Eugene Garcia, PhD, Arizona State University	Amaya Garcia, MA, New America Foundation
Ermina Garcia, MEd, Higley Unified School District	Laura Bornfreund, MA, New America Foundation
Dina Castro, PhD, University of North Texas	Catherine White, MA, National Women's Law Center
Ruby Takanishi, PhD, New America Foundation Fellow	Bonnie Mackintosh, EdD, Office of the State Superintendent of Education, Washington, D.C.
Conor Williams, PhD, The Century Foundation, Children's Equity Project partner	Nicola Edge, PhD, University of Arkansas for Medical Sciences
Walter Gilliam, PhD, Yale University, Children's Equity Project partner	Torrie Dunlap, CFP, Kids Included Together
Mary Louise Hemmeter, PhD, Vanderbilt University, Children's Equity Project partner	Lauren Hogan, MA, The National Association for the Education of Young Children
Rosemarie Allen, PhD, Center for Equity and Excellence, Children's Equity Project partner	Gladys Montes, United Way Center for Excellence in Early Education
Dawn Yazzie, MA, Center of Excellence for Infant and Early Childhood Mental Health Consultation, Children's Equity Project partner	Ryan Pontier, PhD, Florida International University, Children's Equity Project partner
Christine P. Sims, PhD, University of New Mexico	Amy Stephens, PhD, The National Academies of Sciences, Engineering, and Medicine
Kelly Capatosta, MPA, The Ohio State University, Children's Equity Project partner	Nino Perez, MA, MomsRising
Evandra Catherine, PhD, Arizona State University, Children's Equity Project	Mousumi Belangady, MSW, MPP, U.S. Department of Health and Human Services
Dianna Carrizales-Engelmann, PhD, University of Oregon, Children's Equity Project partner	Carrie Gillispie, EdD, The Education Trust
Hakim Rashid, PhD, Howard University, Children's Equity Project partner	Ellen Roche, MEd, Trust for Learning
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Jennifer Tschantz, PhD, U.S. Department of Education	Jennifer Oppenheim, PsyD, Substance Abuse and Mental Health Services Administration
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Discussion

Within the ED/HHS joint policy statement, peer-reviewed research articles represented 55% of source material, and organizational reports accounted for 28%. In the GAO report, notes on information produced within the report (41%), such as definitions and explanations on specific data points, and federal legislation (34%) were the majority of sources utilized. In the HELP Committee report on supporting the workforce and the need for child care, federal reports (26%), organizational reports (26%), and state government reports or press releases (26%) were the primary sources cited, with no peer-reviewed research articles being used. The HELP Committee report used state governments and news sources, whereas neither the GAO nor ED and HHS reports did, reinforcing the notion that science-based evidence, specifically that which is peer-reviewed and produced by researchers is difficult to access (Innvær et al., 2002; Oliver et al., 2014). Only the GAO and the ED and HHS documents used sources of research published in peer-reviewed journals. Of note is the lack of public access to the peer-reviewed journal articles that were referenced, with 28 being behind a paywall and 18 being open-access to download. Organizations may play a stronger role in congressional policymaking than academics, specifically related to congressional offices, as organizational reports were largely cited by the federal agencies and the congressional committee. Being able to translate, package, and deliver recommendations based out of evidence to policymakers in a form they understand removes some of the barriers that policy staffers face in accessing science-based evidence. Organizations demonstrated the capacity and ability to move information out of EI-related content fields to policy decision-makers.

Organizations' Role in Knowledge Mobilization

Information published from research centers and organizations, professional/membership organizations, policy centers, and think tanks provided similar content about issue areas, such as disparities in access to inclusive or early childhood services, gaps in screening, evaluation, and service provision, shortage of providers and pandemic-related challenges for providers, as well as stabilization fund distribution for workforce support and barriers to financial assistance. These findings are unsurprising, as these organizational structures often include the component of connecting to policymakers as one of their aims (Ainsworth, 1997; Garrett & Jansa, 2015; Lucas et al., 2019; Stone, 2000). For technical assistance centers, primary content sourced included capacity-building approaches, inclusion and behavior support, and family engagement frameworks. These roles align with the IO roles of federally funded technical assistance centers, which typically lean toward capacity building for practice and program improvement (Franks & Bory, 2015; Franks & Bory, 2017).

The knowledge mobilized by organizations supported the position of the policymakers in their documents, which is in line with the use of social research by policymakers (Weiss, 1977). Organizations also demonstrated the production of research, whether their own original research or secondary analyses, and often included policy recommendations alongside their results. Rather than detailing out in an academic format like peer-reviewed research journal articles, organizational authors wove data with stories and recommendations, creating a quick snapshot that a policymaker could pull information to use without needing to understand methodology. Organizations fill the intermediary role of policy and systems development when they translate research into policymakers' language (Franks & Bory, 2015; Franks & Bory, 2017). The large

number of organizations being utilized by policymakers reinforces their role as knowledge brokers, mediating change in both practice and policy.

Authority-Based Knowledge and Science-Based Evidence

The standout document of the three documents reviewed with significant differences in both content and sources is the GAO report on eligibility in Part C. The GAO report centered their own research study, supported primarily with notes on content, federal legislative definitions, and one peer-reviewed journal article. An organization that is considered the “watchdog” of the United States would be expected to use science-based evidence in their process. However, a critical component of science-based evidence is that methodology and results meet high research quality (Weiss, 1977). GAO does not have an external process in their publications, making their research fall under the category of authority-based knowledge, even if the research produced is in line with GAO’s definition of evidence (2023a). While GAO has content and research experts, the finding that there is no external review might make those who utilize federal data think twice about how the data is produced and its validity. Transparency in research methodology should apply to government-produced research (Erkilä, 2020). The federal government uses their own resources to contribute to the policymaking process, as evidenced by the use of federal data, reports, and rules and standards. Federal government entities, including GAO, are actors in policy subsystems. These government actors can be strong influencers, as evidenced across all documents.

Within the sourced material for organizations, the same consideration of whether information is truly science-based evidence should be questioned. When exploring the referenced material from organizations, often the sourced information included research from the organizations. However, the research from organizations did not go through a peer-review

process, similar to the GAO produced research. The lack of peer review may move information produced by organizational and federal entities from science-based evidence to authority-based knowledge because the information has not been through a review using standards of rigorous research, even though the information was produced by researchers (Daviter, 2015; Gambrill, 1999).

The peer-review process, a hallmark of academia, moves information from solely authority-based knowledge to science-based evidence. The shift from only authority-based knowledge to science-based evidence has strong implications for researchers in organizations and government in the policymaking process. Transparency and external review of methodology can support the reliability and validity of federally produced research. It also supports the questioning of the influence of beliefs and values on research. Bias cannot be fully removed from any form of research, and research requested and produced by the government is always influenced by the current administration, make-up of Congress, and rulings from the judicial branch. However, information produced by any source should be contestable in order to move into the category of evidence. The move from solely authority-based knowledge to science-based evidence would support evidence-based policymaking.

Implications for the Current Political Climate

The context that marked the 118th Congress and the last two years of Biden's presidency demonstrated the complex climate that policy subsystems can be a part of. The permanent appointment of an Assistant Secretary in the Office of Special Education and Rehabilitative Services halfway through the third year of the administration and the lack of appropriations being approved in the split Congress demonstrate the difficulties and limitations of policymaking. In 2024, there will be an election that determines the next presidency and

administration, with Biden continuing as a candidate not being an option, there will be a true shift in beliefs and values, regardless of who is elected. The Assistant Secretary could only end up serving for a year and a half if the new administration's leadership does not share the beliefs and values that brought about her appointment. Additionally, the majority and minority statuses of Congress have the potential to be different for the 119th Congress. There will be a different Congress due to elections. Democrats may hold leadership across both the House of Representatives and the Senate, or it may be republicans in the majority. Congress could also be split again, with the current state of republications being in majority in the House of Representatives and democrats holding majority in the Senate or the opposite could happen. The influence of elections cannot be understated because who holds leadership directs the research and policies coming out of Congress and executive branch agencies. Different organizations may be chosen as trusted sources due to their alignment in beliefs and values, and the research produced by both organizations and the federal government must be held to the same standards and peer-reviewed rigor, regardless of the belief systems driving the research.

Limitations and Next Steps

It is important to remember that knowledge mobilization cannot be considered linear, that the themes and examples here are a snapshot of the relationship between policymakers and actors in the given context at the moment in time each document was published. This study highlighted a small number of documents to explore the landscape of policy outputs related to early intervention. Further studies should consider addressing the relationships that are created and maintained from these organizations and policymakers, the decision-making process for choosing sources, deeper dives into how organizations choose what to research and focus on, and if that process includes discussing with policymakers on usefulness of research results.

Conclusion

Organizations are valuable to policymakers across branches of government and types of policy being created. Congressional staffers primarily utilized open-access material, which suggests that barriers to accessing research remain, while the federal agencies used a mix of peer-reviewed research from journals and the Government Accountability Office completed its own original research. Actors are shown to work in coalition together to create, translate, and move knowledge to policymakers. In EI, this is done through organizations that may not identify as having a focus on infants and toddlers with disabilities, but their work is applicable.

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CHAPTER 4

GENERAL DISCUSSION

Organizations and Their Influence

Knowledge mobilization and the roles that intermediaries play in bridging the gap between research, policy, and practice were highlighted across these studies and contribute to the larger research base on knowledge mobilization and intermediary organizations (IOs).

Organizations are a part of a larger political system and demonstrate the importance of working in coalition to address a policy subsystem, such as one focusing on early intervention (EI).

Organizations are connected through funding sources, uptake of others' research, formalized coalitions, collaborative projects, and more. Information on the use of research in policymaking, the knowledge mobilization process, and roles of intermediary organizations primarily have been documented for K-12 education in general or the social service fields rather than the more specific special education or early intervention (Aydarova, 2024; Blank et al., 2003; Davis et al., 2022; DeBray et al., 2020; Lopez et al., 2005; Lubienski, 2019; Yamashiro et al., 2023).

Compared to the literature on educational policymaking, knowledge mobilization, and intermediary organizations, the findings in this dissertation indicate that multi-organizational coalitions can impact federal EI policymaking. Identification of organizations is the first step in analyzing how organizations move knowledge to and from decision-makers in policy and practice.

Identification of Organizations

Think tanks, policy centers, research centers and organizations, technical assistance centers, data centers, and philanthropies are all organizations that can impact policymaking. In the first study, potential organizations were identified using a networks approach, using the theoretical concept that organizations work together in a coalition. With this initial probe into organizations that focus on the federal level, over 60 organizations were identified as having the potential to influence federal policy. These organizations were comprised of multiple funding streams, from private and philanthropic funds to government funds. Within this group of organizations, some focus areas included early childhood education, child care, early intervention, and children and families. The complexity of early intervention and its related fields was reiterated through the identified organizations, their structures and essential functions, and their focus areas.

The second study echoed the identification of a variety of organizations. Results from policy document analysis yielded multiple sources that policymakers utilize in their sourcing of information. In the second case example, over 23 organizations were identified as having direct input into a singular report, with more organizations acknowledged in the recognition of experts. The abundance of organizations across many focus areas holds an implication for the EI policy subsystem: coalitions are made up of many actors that may not share primary functions or focal points but have some aligned beliefs and values. Organizations identified in the first study have the potential to impact policymakers, but not every organization does. Organizations were utilized in the second study, but did these organizations match those identified in the first study? The organizations identified in the first study and used by federal policymakers in the second study include:

- Bipartisan Policy Center
- Center for American Progress
- Child Trends
- Children's Equity Project
- Division for Early Childhood
- IDEA Infant and Toddler Coordinators Association
- National Association for the Education of Young Children
- National Institute for Early Education Research (NIEER)
- SRI International
- Zero to Three

Of the above-listed organizations, all except SRI International were identified as having a potential intermediary role in policy and systems development. The use of these organizations by policymakers reinforces the idea that policy and systems development was an appropriately identified intermediary role within the first study's results. These organizations were able to mobilize knowledge to policymakers, and policymakers were able to pick up and use the information from the organizations. In their original study, Franks and Bory (2015; 2017) did not include philanthropies as IOs. However, this dissertation's results add to the literature showing that philanthropies can be intermediary organizations (DeBray et al., 2020; Lubienski et al., 2019).

Roles and Knowledge Mobilization

Organizations have the potential to serve in many roles when it comes to mediating change with decision-makers. Some organizations may only serve one role - what they have

identified as their purpose - and others, such as NIEER and ECTA, may serve a larger number of roles due to funding streams, connections to other organizations, and the actors within their organizations. In the first study, organizations' potential intermediary roles were explored, and the findings demonstrate that an organization can mediate change with evidence-based knowledge creation, policy and system development, technical assistance and consultation efforts, and more. Organizations can serve different levels of government, such as federal and state, with the potential to directly impact multiple levels. The First Five Years Fund, the Prenatal-to-Three Policy Impact Center, and the National Institute for Early Education Research are examples of such organizations that produce data for federal and state policymakers.

Organizations were shown to work within networks and in coalition with others to produce policy change. As demonstrated across both studies, organizations worked with others through formal coalitions and networks and through informal structures, such as being connected through another organization to each other. The connections to other organizations were documented in Figures 2.1 and 3.2, demonstrating that funders and convenors affect what organizations produce. In Chapter 3, information was shared regarding the intersection of multiple organizations across various issue areas, such as civil and human rights, in formal coalitions.

Influence of Research

In the second study, an analysis of publications referenced by policymakers showed that information was provided by various organizations and in various forms. Federal policymakers used information from philanthropies, technical assistance centers, research centers and organizations, policy centers and think tanks, professional/membership organizations, federal agencies and policy, and peer-reviewed research journals. Policymakers also utilize multiple

types of documents to access information, such as research reports, policy briefs and whitepapers, legislation and federal rules and regulations, research articles, press releases, and more. In acknowledging the barriers that policymakers face in accessing research, it was unsurprising that the congressional committee report primarily used open-access, organizational-based knowledge and evidence. In contrast, the federal agencies' policy statement and the Government Accountability Office research study used more original and academic-based research. Future studies should further explore the limited nature of source material used by congressional committees.

As shared in the introductory chapter, federal government involvement in research has significantly impacted federal policy related to young children (Bricker et al., 2020; Haskins, 2019). Historically, EI policy was heavily influenced by the Head Start program, which was created out of the Office of Economic Opportunity (Office of Head Start, 2022). When research on young children in the context of their environment began to emerge, it laid the foundation for EI as a part of IDEA (Zigler et al., 1993; Zigler & Styfco, 2010; Zigler & Valentine, 1997). Mapping the same concept of the influence onto current EI policy shows a stark difference than in the mid to late 1900s, especially regarding legislation and regulatory policies. IDEA has not been reauthorized in 20 years, while research has continued to be produced and organizations have continued sharing that change needs to happen, as highlighted by the IDEA Infant Toddler Coordinators Association's annual tipping points surveys (2021, 2022, 2024) and the NIEER's 2023 report on the state of EI and early childhood special education (Friedman-Krauss, 2023). As demonstrated in the second study, federal policy continues to be produced by government entities. However, it does not have the authority to hold states and programs accountable, as legislation and federal regulations do.

Implications and Recommendations

Understanding that organizations play a vital role in policymaking, influence each other and policymakers, and are knowledge producers and mobilizers allows researchers and others to access current knowledge movement streams. Barriers to policymakers have been identified using evidence. If researchers cannot effectively communicate and build relationships with policymakers, whether directly or through organizations, then their research may never have an impact at the federal level. Federal policymakers put out policy in numerous ways, and it is the responsibility of individuals – including those with disabilities, their families, their community members, researchers and academics, and other policymakers – to ensure that policies are effective for the population they serve.

In EI, the complexity of potential actors, coalitions, and networks is heightened, but it is not unattainable to influence policymaking with research. Researchers must consider how to communicate their results to policymakers effectively. Policymakers across both the legislative and executive branches use research to inform their decisions. However, the current study shows that legislators may use open-access information from organizations and the federal government rather than information from peer-reviewed research journals. Identifying that organizations play a large role in communicating knowledge and evidence in the field of EI is valuable information for academic researchers and organizations alike. While publishing in a peer-reviewed journal may be a researcher's end goal, it cannot be the only goal. Researchers must ensure that their evidence is translated for policymakers. One strategy is for researchers to partner with organizations to publish research in an open-access manner, utilizing a peer-review process and language familiar to policymakers. As knowledge brokers, organizations are vital in policymaking, allowing policymakers to overcome barriers to creating evidence-based policy. In

order to navigate the gaps that exist in research, policy, and practice, researchers, policymakers, and practitioners should look to a variety of sources to inform their decision-making.

Additionally, research, whether produced by academic researchers, federal agencies, the GAO, or organizations, must be held to high rigor, reliability, and validity standards. The reliance of congressional committees on organizational input and information leans towards primarily valuing authority-based knowledge, which cannot be contested in the same high-quality fashion as peer-reviewed research. Moving into a new election year with the potential to shift values and beliefs of the federal government, from leadership to implementation, science-based evidence is even more valuable, as that information withstands scrutiny in ways that authority-based knowledge cannot. If EI-specific or related legislation or rules and regulations creation occurs at the federal or state level, organizations are actors that will have influence. Within the lens of the ACF, the policymaking process includes actors who form coalitions based on beliefs and values, and organizations, government leaders, and policymakers can all work in coalition to move specific issues forward (Sabatier, 1988). If IDEA were to get reauthorized or if the Head Start Act were to be reauthorized and with an amendment of Part C of IDEA, there would be opportunities for coalitions to move forward science-based research to policymakers and for policymakers to pick up and implement the recommendations of the coalitions. Depending on the federal leadership elected, these coalitions may or may not align with policymakers' beliefs and values and would need to consider how they will mobilize their knowledge. Based on the information and results presented in this dissertation, organizations are in a prime position to influence policymakers, and researchers need to translate their research into a format that will be transferrable to policymakers. The policymaking process cannot exist without actors moving their values and beliefs forward in useable formats, and the use of data is

critical for policymaking. Research results should move solely out of authority-based knowledge and into science-based evidence to withstand the critiques and negotiations in policymaking.

Lingering Questions

While this dissertation has involved the identification of organizations and intermediary roles and the use of organizations and types of knowledge by federal policymakers in the EI subsystem, the researcher is left with questions for consideration and next steps. This dissertation is an initial exploration into the world of federal organizations and their influence, specifically in the field of EI. The EI system is made up of many sectors and these sectors have influence and bearing on what occurs in EI policymaking. There are many more organizations performing intermediary roles within the EI policy subsystem, and these organizations have an impact that should be explored even further. Questions have risen about what organizations are doing work in federal EI policymaking that may not have a primary focus in early childhood years and what this work looks like. Additionally, while the first study identifies some organizations and assigns potential intermediary roles, what do these and other organizations in EI believe their roles to be?

Looking at policy documents is a singular way to view the interactions between the EI policy subsystem's actors. The following steps could include gaining multiple perspectives of evidence-based decision-making in policy from organizational actors, government actors, and researchers, specifically related to EI, as this has previously been explored in education and not yet in EI. Final questions include: Who are these organizations influencing EI policy? Where do they see themselves in the EI policy subsystem? What are the partnerships or potential collaborations that form coalitions, and what strategies are coalitions using to influence policymakers related to EI?

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Appendix A

Terms

1. Early Intervention (EI): Services defined through the Individuals with Disabilities

Education Improvement Act (IDEA) of 2004, 20. U. S. C. § 1432:

The term “early intervention services” means developmental services that –

- (A) are provided under public supervision;
- (B) are provided at no cost except where Federal or State law provides for a system of payments by families, including a schedule of sliding fees;
- (C) are designed to meet the developmental needs of an infant or toddler with a disability, as identified by the individualized family service plan team, in any 1 or more of the following areas:
 - (i) physical development;
 - (ii) cognitive development;
 - (iii) communication development;
 - (iv) social or emotional development; or
 - (v) adaptive development;
- (D) meet the standards of the State in which the services are provided, including the requirements of this subchapter;
- (E) include—
 - (i) family training, counseling, and home visits;
 - (ii) special instruction;

- (iii) speech-language pathology and audiology services, and sign language and cued language services;
- (iv) occupational therapy;
- (v) physical therapy;
- (vi) psychological services;
- (vii) service coordination services;
- (viii) medical services only for diagnostic or evaluation purposes;
- (ix) early identification, screening, and assessment services;
- (x) health services necessary to enable the infant or toddler to benefit from the other early intervention services;
- (xi) social work services;
- (xii) vision services;
- (xiii) assistive technology devices and assistive technology services; and
- (xiv) transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to receive another service described in this paragraph;

(F) are provided by qualified personnel, including—

- (i) special educators;
- (ii) speech-language pathologists and audiologists;
- (iii) occupational therapists;
- (iv) physical therapists;
- (v) psychologists;
- (vi) social workers;

- (vii) nurses;
- (viii) registered dietitians;
- (ix) family therapists;
- (x) vision specialists, including ophthalmologists and optometrists;
- (xi) orientation and mobility specialists; and
- (xii) pediatricians and other physicians;

(G) to the maximum extent appropriate, are provided in natural environments, including the home, and community settings in which children without disabilities participate; and

(H) are provided in conformity with an individualized family service plan adopted in accordance with section 1436 of this title.

2. Federal Agencies: departments within the executive branch of the U.S. government; to primarily include, but not limited to, the
 - a. U.S. Department of Education (ED)
 - i. Institute for Educational Sciences (IES)
 - ii. Office of Special Education and Rehabilitative Services (OSERS)
 1. Office of Special Education Programs (OSEP)
 - iii. Office of Legislation and Congressional Affairs (OLCA)
 - iv. Office for Civil Rights (OCR)
 - v. Office of Elementary and Secondary Education (OESE)
 1. Office of Discretionary Grants & Support Services
 - vi. Office of Inspector General (OIG)
 - b. U.S. Department of Health and Human Services (HHS)
 - i. Administration for Children and Families (ACF)

- ii. Administration for Community Living (ACL)
 - iii. Agency for Healthcare Research and Quality (AHRQ)
 - iv. Assistant Secretary for Planning and Evaluation (ASPE)
 - v. Centers for Disease Control and Prevention (CDC)
 - vi. National Institutes of Health (NIH)
 - vii. Office for Civil Rights (OCR)
 - viii. Office of Inspector General (OIG)
- c. Department of Justice (DOJ)
 - i. Civil Rights Division
 - ii. Office of Legislative Affairs (OLA)
 - iii. Office of the Inspector General (OIG)
- 3. Legislators: elected federal officials that serve in Congress; to include House Representatives and Senators; primarily including, but not limited to, the
 - a. House Committee on Education and Workforce (Ed & Workforce)/Education and Labor (Ed & Labor)
 - b. Senate Committee on Health, Education, Labor & Pensions (HELP)
- 4. Policymakers: Decisionmakers at the federal level, to include legislators and leadership in federal agencies

Appendix B

Tables for Chapter 2

Table 2.1

Intermediary Roles Codebook

Intermediary Role (code)	Inclusion Criteria
Best Practice Model Development	Work with a researcher or model developer to further operationalize or establish a best practice model Work with a researcher or model developer to implement and/or disseminate a best practice model
Consultation and/or Technical Assistance Activities	Provide services to provider organizations, state agencies and/or state governmental organizations, consumers, private (for profit) organizations, or other
Outcome Evaluation and Research	Provide evaluation or research for an established evidence-based practice Participate in an institutional review board process Conduct outcome evaluation or research for an emerging or innovative model
Purveyor of Evidence-Based Practices	Act as a purveyor for an established evidence-based practice Seek and receive appropriate credentials to be a “licensed” or “sanctioned” purveyor of an evidence-based practice Act as a purveyor organization for two or more evidence-based practices Create or establish a purveyor role for a new or recently established evidence-based practice

Intermediary Role (code)	Inclusion Criteria
Policy and Systems Development	Make policy recommendations to stakeholders and policymakers Successfully facilitate policy changes Develop policy briefs on identified issues Make specific recommendations on systems building or development to support the delivery of best practices Work with other stakeholders to develop new systems or build the capacity of an existing system Work with governmental agencies to develop new systems or build the capacity of an existing system
Quality Assurance and/or Quality Improvement	Provide quality assurance or quality improvement for an established based practice, a best practice model, and/or for an emerging or innovative model Share results in regular and/or summary reports with the provider organizations Present results at national or international conferences Share results in regular and/or summary reports with funders
Training, Public Awareness, and Education	Develop web content for the internet Create marketing or educational materials Develop a website or webpage Audiences include providers, state or federal agency staff or providers, and nonprofit agencies

Table 2.2*Early Intervention-Related National Organizations, Ordered by Essential Function (n=65)*

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
First Five Years Fund	Advocacy Center	Philanthropies, Private	Early Childhood
SPAN Parent Advisory Network	Advocacy Center	Government, Private, Public	Families of Individuals with Disabilities
Alliance for Early Success	Coalition	Philanthropies	Early Childhood Advocacy
Early Childhood Collective	Coalition	Public	Inclusive Early Care and Education
The Early Childhood Policy in Institutions of Higher Education (ECPIHE)	Coalition	Philanthropies, Private	Early Childhood Policy
Early Childhood Data Collaborative	Data Center	Philanthropies, Private	Early Childhood
Georgetown University Center for Child and Human Development (GUCCHD)	Demonstration, Research, and Training Center	Government, Philanthropies, Private, Public	Early Childhood sub-focus
Haring Center	Demonstration, Research, and Training Center	Unknown	Early Childhood Education sub-focus
The Family, Infant and Preschool Program (FIPP)	Demonstration, Research, and Training Center	Public, Private	Early Intervention

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
The Hechinger Report	News Organization	Philanthropies, Private	Early Education sub-focus
Bezos Family Foundation	Philanthropy	Private	Early Learning sub-focus
Buffett Early Childhood Fund	Philanthropy	Private	Early Childhood
Heising-Simons Foundation	Philanthropy	Private	Early Childhood Education
Pritzker's Children Initiative	Philanthropy	Private	Infant, Toddlers, and Families
The David and Lucille Packard Foundation	Philanthropy	Private	Children, Families, and Communities
The Henry and Marilyn Taub Foundation	Philanthropy	Private	Early Childhood sub-focus
Vroom	Philanthropy	Private	Family Practice
W. K. Kellogg Foundation	Philanthropy	Private	Children, Families, and Communities
Bill and Melinda Gates Foundation	Philanthropy	Private	Maternal, Newborn, and Child Health sub-focus; Early Learning sub-focus
The Hunt Institute	Policy and Advocacy Organization	Philanthropies, Private	Early Childhood sub-focus

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
Prenatal to 3 Policy Impact Center	Policy Center	Philanthropies	Prenatal through Toddler Policy
Early EdU Alliance	Professional Development Center	Unknown	Early Childhood Educators
IRIS Center	Professional Development Center	Government	Special Education
The Communication and Early Childhood Research and Practice Center (CEC-RAP)	Professional Development Center	Public	Early Intervention
Evidence-Based International Early Intervention Office (EIEIO)	Professional Development Organization	Public	Early Intervention
Family Guided Routines Based Intervention (FGRBI)	Professional Development Organization	Unknown	Early Intervention
Division for Early Childhood (DEC)	Professional Organization	Membership	Early Childhood
IDEA Infant and Toddler Coordinators Association (ITCA)	Professional Organization	Membership	Part C of IDEA
National Association for the Education of Young Children (NAEYC)	Professional Organization	Membership	Early Care and Education
National Conference for State Legislatures	Professional Organization	Membership	Early Care and Education sub-focus
Society for Research in Child Development	Professional Organization	Membership	Child Development

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
Zero to Three	Professional Organization	Membership	Early Intervention Ages
Early Childhood Policy Centers Collaborative	Research and Training Center	Research and Training Center	Early Childhood Policy
Institute of Early Childhood Policy	Research and Training Center	Philanthropies	Early Childhood Policy
Early Education Leaders Institute	Research and Training Center	Government, Philanthropies, Private, Public	Early Care and Education
National Center for Children and Families	Research and Training Center	Government, Philanthropies, Private, Public	Early Care and Education sub-focus
National Center for Pyramid Model Innovations	Research and Training Center	Government	Early Intervention and Early Education
Project LAUNCH	Research and Training Organization	Government	Child, Families, and Communities
SRI Education	Research and Training Organization	Unknown	Early Childhood sub-focus
Frank Porter Graham (FPG) Child Development Institute	Research Center	Government, Philanthropies, Private, Public	Early Intervention & Special Education sub-focus
Infant and Toddler Policy Research Center	Research Center	Unknown	Infants and Toddlers Policy
National Center for Research on Early Childhood Education (NCRECE)	Research Center	Government	Early Childhood Education

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
National Center on Special Education Research (NCSER)	Research Center	Government	Special Education
National Institute for Early Education Research (NIEER)	Research Center	Philanthropies, Private, Public	Early Education
The Children's Equity Project (CEP)	Research Center	Philanthropies	Early Years and Early Grades
American Institutes for Research (AIR)	Research Organization	Government, Philanthropies, Private	Early Childhood and Child Development sub-focus
Center on the Developing Child	Research Organization	Philanthropies, Private	Child Development
Child Trends	Research Organization	Government, Philanthropies, Private	Early Childhood
EI Northwestern	Research Organization	Government	Early Intervention
EI Clearinghouse	Resource Center	Government	Early Intervention
Help Me Grow National Center	Resource Center	Government, Private	Early Childhood
Bright Futures National Center	Technical Assistance Center	Government, Private	Child and Adolescent Medical Care
Center for Parent Information and Resources (CPIR)	Technical Assistance Center	Government	Families of Children with Disabilities

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
Center for the Integration of IDEA Data (CIID)	Technical Assistance Center	Government	Part C of IDEA sub-focus
Early Childhood Personnel Center (ECPC)	Technical Assistance Center	Government	Early Childhood
Early Childhood Technical Assistance Center (ECTA)	Technical Assistance Center	Government	Early Childhood
National Technical Assistance Center for Preschool Development Grants Birth Through Five (PDG B-5 TA)	Technical Assistance Center	Government	Early Childhood
STEM Innovation for Inclusion in Early Education (STEMI2E2) Center	Technical Assistance Center	Government	Inclusive Early Childhood Education
T.E.A.C.H. Early Childhood® National Center	Technical Assistance Center	Government, Philanthropies, Private, Public	Early Childhood Care
The Center for IDEA Early Childhood Data Systems (DaSy)	Technical Assistance Center	Government	Early Childhood
The Center of Excellence for Infant and Early Childhood Mental Health	Technical Assistance Center	Government	Infant and Early Childhood Mental Health
The National Center for Healthy Safe Children	Technical Assistance Center	Government, Private	Child and Family sub-focus
The National Training and Technical Assistance Center for Child, Youth, and Family Mental Health (NTTAC)	Technical Assistance Center	Government	Infant and Early Childhood sub-focus
Bipartisan Policy Center	Think Tank	Philanthropies, Private	Education, Early Childhood

Name of Organization	Essential Function	Funding	Relevant Focus Area (or sub-focus)
Center for American Progress	Think Tank	Philanthropies, Private	Early Childhood Policy
Learning Policy Institute	Think Tank	Philanthropies, Private	Education Policy and Practice

Note. Under Funding, Government = Federal government grants and Public = Other state or local funding

Table 2.3*Potential Intermediary Roles of Early Intervention-Related National Organizations*

Name of Organization	Intermediary Role						
	C-TAA	BPMD	PEBP	QA-CQI	OE	T-PA-E	P-SD
Alliance for Early Success	X						X
American Institutes for Research (AIR)	X	X			X		
Bezos Family Foundation		X				X	
Bill and Melinda Gates Foundation		X	X			X	
Bipartisan Policy Center							X
Bright Futures National Center	X		X	X			
Buffett Early Childhood Fund		X				X	
Center for American Progress							X
Center for the Integration of IDEA Data (CIID)	X		X				
Center for Parent Information and Resources (CPIR)	X					X	
Center on the Developing Child		X			X	X	X
Child Trends	X	X	X	X	X		X
Division for Early Childhood (DEC)			X			X	X
Early Childhood Collective		X	X			X	
Early Childhood Data Collaborative	X		X	X	X		X
Early Childhood Personnel Center (ECPC)	X		X	X	X	X	X

Name of Organization	Intermediary Role						
	C-TAA	BPMD	PEBP	QA-CQI	OE	T-PA-E	P-SD
Early Childhood Policy Centers Collaborative		X	X			X	
The Early Childhood Policy in Institutions of Higher Education (ECPHIE)		X	X			X	X
Early Childhood Technical Assistance Center (ECTA)	X		X	X	X	X	X
Early EdU Alliance						X	
Early Education Leaders Institute	X	X	X			X	X
EI Clearinghouse			X				
EI Northwestern		X	X				
Evidence-Based International Early Intervention Office (EIEIO)					X	X	
Family Guided Routines Based Intervention (FGRBI)		X				X	
First Five Years Fund							X
Frank Porter Graham (FPG) Child Development Institute		X	X			X	
Georgetown University Center for Child and Human Development (GUCCHD)	X	X			X	X	X
Haring Center		X	X	X	X	X	
Heising-Simons Foundation			X			X	X
Help Me Grow National Center			X	X		X	X
IDEA Infant and Toddler Coordinators Association (ITCA)					X		X
Infant and Toddler Policy Research Center	X	X					X
Institute of Early Childhood Policy		X	X		X	X	

Name of Organization	Intermediary Role						
	C-TAA	BPMD	PEBP	QA-CQI	OE	T-PA-E	P-SD
IRIS Center			X			X	
Learning Policy Institute							X
National Association for the Education of Young Children (NAEYC)			X			X	X
National Center for Children and Families	X	X		X		X	X
National Center for Pyramid Model Innovations		X	X		X		
National Center for Research on Early Childhood Education (NCRECE)		X	X			X	
National Center on Special Education Research (NCSER)		X	X	X	X	X	
National Conference for State Legislatures							X
National Institute for Early Education Research (NIEER)	X	X	X	X	X	X	X
National Technical Assistance Center for Preschool Development Grants Birth Through Five (PDG B-5 TA)	X						X
Prenatal to 3 Policy Impact Center							X
Pritzker's Children Initiative		X				X	X
Project LAUNCH		X	X				
Society for Research in Child Development	X	X	X				X
SPAN Parent Advisory Network						X	
SRI Education		X	X	X			
STEM Innovation for Inclusion in Early Education (STEMI2E2) Center	X	X	X		X	X	X
T.E.A.C.H. Early Childhood® National Center	X		X				X

Name of Organization	Intermediary Role						
	C-TAA	BPMD	PEBP	QA-CQI	OE	T-PA-E	P-SD
The Center for IDEA Early Childhood Data Systems (DaSy)			X			X	
The Center of Excellence for Infant and Early Childhood Mental Health	X					X	
The Children's Equity Project (CEP)							X
The Communication and Early Childhood Research and Practice Center (CEC-RAP)		X				X	
The David and Lucille Packard Foundation						X	X
The Family, Infant and Preschool Program (FIPP)		X				X	
The Henry and Marilyn Taub Foundation						X	
The Hunt Institute							X
The National Training and Technical Assistance Center for Child, Youth, and Family Mental Health (NTTAC)	X						
The National Center for Healthy Safe Children	X		X	X			X
Vroom						X	
W. K. Kellogg Foundation						X	
Zero to Three			X			X	X
	C-TAA	BPMD	PEBP	QA-CQI	OE	T-PA-E	P-SD
Total of IOs in Roles	21	29	33	12	15	39	33

Note. C-TAA = Consultation and technical assistance activities; BPMD = Best practice model development; PEBP = Purveyor of evidence -based practice; QA-CQI = Quality assurance and continuous quality improvement; OE = Outcome evaluation; T-PA-E = Training, public awareness, and education; P-SD = Policy and systems development