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# Paralleled Support Models for Young Adults with Intellectual and Developmental Disabilities

Lucy Ellen Klym  
*Walden University*

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# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,  
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2017

Abstract

Paralleled Support Models for Young Adults with  
Intellectual and Developmental Disabilities

by

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MA, Lewis University, 2012

MA, University of North Dakota, 2009

BA, University of North Dakota, 2007

Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Philosophy  
Public Management and Leadership

Walden University

May 2017

## Abstract

In the State of Indiana, for students over the age of 14 who have been diagnosed with intellectual or developmental disabilities, the transition from special education to Medicaid waiver oversight should occur seamlessly, but gaps in integrated and aligned goal development strategies remain. As a consequence, students who need adult-based support may not be receiving the full scope of services to which they are entitled. Using common-pool resource theory as a foundation, the purpose of this explanatory case study of transitional services to Indiana Medicaid was to understand, from the perspective of disability support service staff, the barriers to effective quality of life outcomes and collaboration among government agencies involved in the transition process. In-depth interview data were collected from a total of 6 vocational rehabilitation specialists, directors, and transition coordinators. These interview data were inductively coded and thematically analyzed according to identified common pool action areas. Key research findings included: (a) the need for implementation of student self-determination principles, (b) a strengthening of sustainable goal development directed toward student employment, and (c) an overall enhanced collaboration between key disability service support staff roles to create sustainable structures. Positive social change opportunities include recommendations to the Indiana Division of Disability and Rehabilitation Services to improve the overarching student-to-adult transition process, reduce redundant funding streams, and streamline goal development to create a sustainable, collaborative experience for students over their lifespan of support.

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## Dedication

I dedicate this study to people of all ages with intellectual and developmental disabilities. I will never know the personal path many will take or have been part of, but I hope policy decisions surrounding their respective care continue to move forward. For many people with intellectual and developmental disabilities, their respective path was chosen for them, and these decisions resulted in institutionalization, diminished rights, and lack of educational opportunities. This study demonstrates the value and impact of self-determination. While history cannot be undone, avenues for change lie ahead, and people with intellectual and developmental disabilities should have the collaborative tools to drive their preferred supports.

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I would first like to acknowledge my family. They have been incredibly supportive as I pursued this degree. As a life-long student, my parents, David and Ellen Klym, and siblings have championed my educational pursuits. My husband, Shaine Lund, has been incredibly understanding and motivating when educational priorities arise, and he has rooted for my success. To my family, I say thank you.

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## Chapter 1: Introduction to the Study

People with intellectual and developmental disabilities in the United States receive services guided through federal and state policy. Current policy measures reflect inclusive standards generated by preferences of the person receiving support fostering self-determination to lead an independent life (Braddock & Parish, 2001). Self-determination requires that people with intellectual and developmental disabilities frame their goals, thus support models. These same support models impact the cost and supports of long-term supports and services when they are established early on in an educational setting (Lane, Carter, & Sisco, 2012). Special education represents an initial service point and guidepost across the lifespan of care for people with moderate to severe intellectual and developmental disabilities. Special education provides an introduction to goal development and paired service delivery in state-driven plans. In this study, I examined measures to generate effective strategies for establishing long-term supports and services for students in the State of Indiana with intellectual and developmental disabilities in order to prepare them for adulthood. This would be accomplished through transition planning delivered in a special education framework initiated at the age of 14, which would provide the first opportunity to bridge supports with adult-based services offered under the Medicaid Home and Community-Based Services (HCBS) waiver (Family Social Services Administration, 2015; Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2013; Indiana Department of Education [DOE], 2015; Zakrajsek, Hammel, & Scazzero, 2014). Self-determination creates increased involvement of persons with identified disabilities in their own treatment and care, which has been shown to increase

effectiveness of outcomes and supports overall under the Medicaid waiver model (van Loon et al., 2013).

As financial and service driven sustainability factors are addressed through a variety of state Medicaid options, including managed care, methods for fostering effective transition planning that could lead to the establishment of critical service guidelines in the client's plan for care warranted further study (Long & Campbell, 2013). Support platforms for this population in the State of Indiana rest on two key documents: the Individualized Education Program (IEP), developed through the State of Indiana Department of Education (DOE), and the Individualized Support Plan (ISP), implemented through the Medicaid HCBS waiver operated and managed by Indiana's Family and Social Services Administration (FSSA; DOE, 2015; FSSA, 2015). These documents exist without any cohesive expectations and limit a document review in the span of care for someone with an intellectual or developmental disability. In this study, I researched barriers to cohesive strategies in goal development. The limitation of collaboration between DOE and FSSA exists due to the current state criterion that each funding source and service model operate independently of the other. However, for effective transition planning to occur, increased involvement of stakeholders for the person with an intellectual or developmental disability may generate momentum toward ideal supports. Carter, Austin, and Trainor (2012) identified factors of sustainability such as employment, inclusion, and utilization of care strategies beyond paid supports in transition planning.



Social change implications of this study are that it may contribute to people with intellectual and developmental disabilities having the same preparatory standards as students without disabilities for adulthood that are part of graduating from adolescence to the next phase of life, such as further education or employment. The inclusive model of care has the potential to lessen the social distinction of people with intellectual and developmental disabilities and promote a society of integration and natural support among the overall community.

### **Background of the Study**

For people with intellectual and developmental disabilities, care bridging educational and adult-based supports was isolated to the institution for people with intellectual and developmental disabilities from the late 19<sup>th</sup> century to the mid-1970s (Braddock, 2007). Institutional placements, the purpose of which was treatment and cure, represented best practices in care, which were rooted in the medical model. The ineffectiveness and lack of quality of life outcomes negated the idealized goals of institutions, and the resulting policy at state levels guided institutional closures (Braddock, Hemp, & Rizzolo, 2004). Harpur (2011) framed the historical perception of people with disabilities and the transformation that has promoted a social model of support grounded in inclusivity. This transition in perception drove policy rooted in quality of life measures that were focused on satisfaction of supports, continuity of care, and individualized goal development (Chowdhury & Benson, 2011).

One key quality of life measure is gauged through effective transition planning for people with intellectual and developmental disabilities, which demonstrates continuity of

care (Carter, Harvey, Taylor, & Gotham, 2013). As students transition to adulthood, the finalization of an educational benchmark becomes a turning point for the future. People with intellectual and developmental disabilities participate in similar benchmarks in an educational setting, but the social model of care lacks the communication standards necessary to ensure that isolating environments generated in institutional settings for decades are not replicated in individual homes after a student graduates from high school, especially in regard to employment prospects and social integration opportunities (Carter, Austin, & Trainor, 2012).

A transition-based policy, anchored by special education guideposts, can be lacking with adult-based services (Carter, Brock, & Trainor, 2014). Foley, Dyke, Girdler, Bourke, & Leonard (2012) found significant gaps in coordinated transition planning, especially for students with moderate to severe disabilities. Their study found that decreased access to collaborative adult services limited quality of life outcomes for transitioning students.

Effective transition planning occurs when persons with the intellectual or developmental disability can exercise self-determination and guide their supports based on personal preferences (Field & Hoffman, 2012; Laragy, 2004). Practices learned early in accord with self-determination guideposts have the capacity to shift transition-based supports, but they can also generate the framework for ongoing goal development rooted in adult-based services. Rowe, Mazzotti, and Sinclair (2015) studied GO 4 IT, a teaching strategy targeting goal setting, persistence, self-awareness, motivation, and personal progress monitoring as a tool of self-determination that enhances individual strengths.

This tool was applied in a special education classroom and supported people with a wide range of intellectual and developmental disabilities. It features a core framework that can be adapted to individual strengths, with the “G” representing goal setting, “O” representing four selected objectives, and “IT” indicating an identified timeline (Rowe, Mazzotti, & Sinclair, 2015, p. 135). Wehmeyer (2015) called for the increased use of self-determination teachings for all students, not specifically those identified with an intellectual or developmental disability, because not only can inclusive services be expected with special education policy, they can also be a natural pathway to collaboration thus leading to inclusive service delivery for adult-based supports (p. 21).

Brown, Hatton, and Emerson (2013) presented opportunities for improving the quality of life indicators by fostering self-determination and highlighting the capabilities and strengths a person can exhibit through self-directed planning. Self-determination in transition planning can lead to effective approaches that can be extended throughout adulthood. Recognizing and owning individual strengths in a collaborative setting represents a platform for eliminating restrictive supports for people with intellectual and developmental disabilities.

Federal and state governments have supported people with intellectual and developmental disabilities since the generation of state-operated institutions in the late 19<sup>th</sup> century (Braddock, 2007). The 1999 *Olmstead v. L.C.* Supreme Court decision ensured that supports for people with intellectual and developmental disabilities must initiate in an inclusive setting. It is now time to ensure the inclusivity of not only the setting but also the planning efforts initiated by the person with the identified disability.

In this study, I looked at the policy-making process in the State of Indiana in regard to self-determination as a collaborative effort for people with moderate to severe disabilities, viewing it through the lens of educational and adult-based support standards that promote goal development and sustainable continuity of care.

### **Problem Statement**

There is a problem in the method of collaboration toward transitioning supports for people with intellectual and developmental disabilities in the State of Indiana from special education services to Medicaid waiver supports (Carter, Brock, & Trainor, 2014; Test, Smith, & Carter, 2014). Despite the expectation of transition planning with IEPs initiated at the age of 14 for people with a diagnosed intellectual or developmental disability in the State of Indiana, limited parallel goal development occurs among collaborating entities from special education and Medicaid waiver oversight (FSSA, 2015; Gross et al., 2013). This problem has negatively impacted people with intellectual and developmental disabilities because inclusive opportunities are overlooked for long-term supports services in the HCBS Medicaid waiver guidelines (FSSA, 2015). Test et al. (2014) found that rigor, relevance, and relationships should be emphasized as critical guideposts in supporting transition planning. Rigor signifies the need for dedication among stakeholders to the transition process, relevance ensures that the process is person-directed, and relationships occur beyond a paid service model. A dual planning process led by the student presents a prime opportunity to establish a foundation for self-directed services early in the support services structure (Field & Hoffman, 2012). A qualitative case study that investigated the barriers to collaboration between DOE and FSSA as well

as perspectives on the opportunities to use self-determination practices could help guide transition planning toward a path of inclusive long-term supports and services.

### **Purpose of the Study**

The purpose of this case study was to discover the transition-based policy-making process for care standards for people with moderate to severe disabilities from the perspectives of the DOE and the FSSA in the State of Indiana. In this study, I described perceived best practices toward collaborative expectations from each department in regard to transition plan development and implementation for people with intellectual and developmental disabilities. A transition-based policy was generally defined as standards supporting continuity of care and goal development in an educational support setting funded through special education onward through adult-based services offered under the Medicaid HCBS waiver.

### **Research Questions**

RQ1: Relative to transition planning, what do stakeholders perceive as barriers to quality of life outcomes for students with moderate to severe intellectual and developmental disabilities in the State of Indiana?

SQ1: How do policy makers from the DOE foster self-determination practices within transition planning?

SQ2: How do policy makers from the FSSA foster self-determination practices within transition planning?

RQ2: Relative to transition planning, what do stakeholders perceive as barriers to collaborative policy-making from the DOE and the FSSA in the State of Indiana?

## **Conceptual Framework**

In this study, I applied the institutional analysis and development (IAD) framework and the common-pool resource theory in regard to social service resources across state-funded budgets in the State of Indiana, using the “action situation” as the specific schema. The “action area” is a designation of actors, processes, and tools, while the theory applies necessary assumptions. Ostrom (2011) defined an “action situation” as an opportunity to explain the dynamics that occur among institutions (p. 11). The institutional processes reviewed in this study were the “action area” where transition planning occurs through the “action situation” among the DOE and FSSA for transition based supports.

Ostrom (2011) initiated understanding of the IAD framework by defining the separate nature of frameworks and theories. Frameworks provide the general analysis between institutions, while theory narrows in on the elements for particular components of the “action area,” such as the rule-making strategies. Blomquist and deLeon (2011) recognized the IAD framework for its capacity to clarify questions and anchor the researcher in the collaborative relationship through organized inquiry (p. 1). Institutional arrangements are critical to understanding the mission of each component in shaping process and behavior in developing policy. As groups become larger, which has occurred for students with intellectual and developmental disabilities and their respective stakeholders, the need to designate the framework first is essential to understanding and developing formal policy structures within the “action situation” of the IAD framework (McGinnis & Ostrom, 2014).

### **Theoretical Foundation**

In fostering understanding of the next layer from framework to theory, Ostrom's definition stated, "Theories make assumptions that are necessary for an analyst to diagnose a specific phenomenon, explain its processes, and predict outcomes" (2011, p. 8). Common-pool resource theory is largely utilized as an ecological theory focused on interactions that promote sustainability (Gallaher, Heikkila, Patterson, Frank, & Weible, 2013). Sustainability represents a key concept in the interactional focus for transition-based policy, especially concerning the common pool of funding from the Indiana State budget.

Tang, Callahan, and Pisano (2014) applied common-pool resource theory to local government sustainability initiatives, recognizing that the generation of a revenue pool from diverse funds parallels similar ecological qualities in the collective action that comes from the depletion of resources and criteria for sustainability.

Common-pool resource theory operates under eight design principles (Ostrom, 2006). First, clearly defined boundaries must exist, which is demonstrated through DOE and FSSA process focus areas, policy expectations, and internal budgets. Second, there must be proportional equivalence between benefits and costs. This exists through the state requirement of a balanced budget. Collective choice arrangements, monitoring, graduated sanctions, conflict resolution, organization, and nested enterprises return to the overarching IAD framework demonstrating the components within the interaction taking place. The common pool signifies the common resources available, which then can be

utilized according to the priorities and capacity for sustainability displayed (Tang et al., 2014).

Frischmann (2013) demonstrated how common-pool resource theory can represent an interdisciplinary approach to collaboration toward the improvement of overall systems through a social science lens. For the purpose of this study, there was a common pool of people supported, common initiatives from separate departments, and a common pool of revenue. The key for this study was to understand the interaction within the “action area” and common pool that were driven by the shared service aims of both bureaucratic entities. Therefore, the IAD conceptual framework guided the common-pool resource theory throughout this study.

### **Nature of the Study**

This research centered on the interaction among the DOE and FSSA in the State of Indiana. I used an explanatory case study approach (Yin, 2013). An explanatory case study allowed for the inductive learning process to take place among both institutions in a bounded time and focus model emphasizing transition-based policy collaboration efforts for people aged 14 to 18 with intellectual and developmental disabilities. Yin (2013) described the value of a case study as the research design model where “the more that your questions seek to explain some present circumstance, the more that case study research will become relevant” (p. 4). Understanding institutional analysis and development through the lens of networking and policy formation is critical for people with intellectual and developmental disabilities in a lifelong support model. The



explanatory case study design provided information on the causal links among the two institutions from policy development to policy implementation outcomes.

Data were collected from interviews with policy personnel and stakeholders advancing policy initiatives for the DOE and FSSA relative to supporting people with intellectual and developmental disabilities from each funded sector. Interviews came directly from the policy makers, both personnel responsible for quality and budgetary oversight and personnel charged specifically with transition-based measures. Additional data sources came from shared institutional documents, including memos of understanding, IEPs, and ISPs. These individualized documents shed light on the implementation effectiveness of projected policy goals. Interviews and documentation sources were coded toward the analysis of themes emerging from the research questions.

### **Definitions**

*Intellectual disability:* Throughout this study, the definition of this term was critical for establishing the current terminology and the historic path of reference for supports for people with disabilities. The American Association on Intellectual and Developmental Disabilities defines intellectual disability as “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (Schalock & Luckasson, 2013, p. 88). The cutoff in age for diagnosis, 18, was the benchmark in this study in regard to adulthood and the defined disability that was present. Luckasson and Schalock (2013) spoke to the organizational application for health diagnosis as well as eligibility for programs in an educational and waiver-based

setting. *Intellectual disability* represents a term previously assigned to mental retardation, imbecility, idiocy, and the likeliness to become a public charge (Pfeiffer, 1993).

*Developmental disability*: This term was used as an added clarification for people with a certain disability structure. In many instances, intellectual disability and developmental disability are used interchangeably, but in the State of Indiana's waiver manual (FSSA, 2012), the definition of intellectual disability stands alone. Therefore, intellectual disability and developmental disability are both used throughout this study. The State of Indiana defines developmental disability as attributed to intellectual disability, cerebral palsy, autism, or a condition requiring similar treatment and services to those with an intellectual disability. Indiana folds intellectual disability under developmental disability terminology, while current literature sets it apart (Luckasson and Schalock, 2013). Developmental disability by State definition stands as occurring before the age of 22 and being likely to continue indefinitely. The disability definition clarifies substantial functional limitation in three areas: self-care, use of language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (FSSA, 2012, p. 3). Use of the State of Indiana's definition was necessary for this study's qualitative sources, but the age frame for this study was capped at 18 for similar adulthood reference.

*Special education*: The State of Indiana, through the DOE, defines special education as "specially designed instruction provided to students who have been determined eligible through an educational evaluation" (DOE, 2007, p. 8). This evaluation establishes support criteria through an IEP and adheres to free and appropriate

public education (FAPE) requirements in the least restrictive setting. People identified with an intellectual or developmental disability before age 21 meet criteria status, and individual educational pathways are structured according to the services necessary to meet educational guideposts.

*Individual Education Program (IEP):* This term was utilized throughout this study as the anchoring document for designated program assignments and funding to ensure necessary guidelines are in place through an educational setting for people with intellectual and developmental disabilities. The IEP must uphold federal standards that supports are provided in the least restrictive setting and are supported on an individualized level. According to Indiana Code 511-IAC-7-32-48 (2014), the definition includes how the student will participate in the general education curriculum and the needed support to accomplish the overall inclusive goal of special education services.

*Inclusion:* In this study, inclusion meant supports for people with intellectual and developmental disabilities to minimize barriers to participating in community opportunities. Simplican, Leader, Kosciulek, and Leahy (2015) defined social inclusion as the interaction between two major life domains: interpersonal relationships and community participation (p.22). This integrative philosophy was employed as an expectation of care in educational and adult-based services.

*Employment:* As a broad term for service goals for people with intellectual and developmental disabilities, employment referred to paid work opportunities for people with disabilities that included the standard of payment at or above minimum wage. In a state analysis, Burgess and Cimera (2014) demonstrated that people with intellectual and

developmental disabilities have decreased hours, receive lower wages, and participate less in ongoing career-based skill development. For employment to represent effective transition-based outcomes, the standards for employment must be the coexist and operate on the same federal standards of minimum wage for all citizens.

*Transition:* For the purpose of this study, a transition was bounded for children aged 14 to 18. Indiana Code (2014) defines transition in Article 7 511-IAC-7-32-100 as a “coordinated set of activities that facilitate movement from school to post-school activities, including (a) postsecondary education, (b) vocational education, (c) integrated employment, (d) continuing and adult education, (e) adult services, (f) independent living, or (g) community participation (p. 21).” Of particular importance to this study was the expectation, through the IEP, to develop employment or other post-school adult living objectives.

*Long-term services and supports (LTSS):* As a concept, LTSS establishes the paradigm that people with an intellectual or developmental disability require support across the span of their life and by definition needing care before the age of 18. *LTSS* is a term employed under a policy lens through Medicaid funding, and for the purpose of this study, it was utilized to highlight cost of care as it related to sustainability through the Medicaid HCBS waiver (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013).

*Medicaid Home and Community-Based Services (HCBS) waiver:* Medicaid funding is a large funding source that comes from the federal and state levels to support people with a variety of health and well-being services. The HCBS waiver was the waiver type utilized in this study to narrow in on funding for people with intellectual and

developmental disabilities. Medicaid uses waiver specifications to isolate funding toward desired causes. The HCBS waiver assists people in the State of Indiana by directing funds to residential and community-based supports (Rizzolo et al., 2013).

In 2012, Indiana began sectioning the HCBS waiver toward the Family Supports Waiver and the Community Integration and Habilitation Waiver. The Family Supports Waiver allows families to support children in their homes, and waiver funding has begun to occur shortly after diagnosis, helping to ensure that there is no longer a waiting list for care (FSSA, 2015). This has allowed children to be dually and simultaneously supported through special education and the HCBS waiver.

*Individual Support Plan (ISP):* As a counterpart to the IEP, the ISP identifies service definitions and program requirements for HCBS waiver services. In the State of Indiana, the ISP defines team members, desired outcomes, and required supports to ensure health and safety (FSSA, 2012). As a representative document for the FSSA, the ISP was analyzed throughout this study as a channel to collaborative supports.

*Supports:* Within the scope of this study, supports were demonstrated by the direct link between care from an educational or waiver representative that impacts the life of a person with an intellectual or developmental disability. Wehman, Chan, Ditchman, & Kang (2014) demonstrated the positive support component necessary to promote forward-thinking goal development.

*Natural supports:* Zakrajsek et al. (2014) defined natural supports as resources for people beyond paid support. As the level of waiver funding decreases toward sustainability, efforts to enhance unpaid resources fulfill two objectives. First, natural

supports demonstrate preferences made by the persons served regarding assistance in achieving their desired outcomes. Second, natural supports emphasize community integration and inclusive measures. Natural supports can provide an avenue to facilitate community partnerships when paid supports are not in place to generate social inclusion pathways (Petner-Arrey, Howell-Moneta, & Lysaght, 2015).

*Sustainability:* Sustainability is a desired outcome for Medicaid funding, LTSS, and utilization of inclusive services of enhancing the quality of life for people with intellectual and developmental disabilities throughout their lifespans. For the purpose of this study, sustainability through the common pool of transition planning represented the avenue to collaborative change.

### **Assumptions**

This study operated on the assumptions from perspectives of supports for people with intellectual and developmental disabilities, goal development measures, and collaboration efforts desired to improve service delivery. The overall goal of expanding the knowledge base through this study was to enhance the transition model already in place in the State of Indiana through increased understanding of the values that brought actors to the “action area” and the knowledge structure each actor used as operational tools (Ostrom, 2011). For the purpose of this study, the assumed actors as policy makers came from the DOE and FSSA.

A foundational assumption in this study rested on the postulation that people with intellectual and developmental disabilities have the desire and expectation for integrated

supports. The motivation is furthered by opportunities to develop employment, friendships, and natural supports that are currently lacking in one's support structure.

For this study, it was also assumed that planning for integrated supports began when a child was supported in an educational setting and that priorities set forth by FAPE policy were introduced when a student enters a special education program (DOE, 2015). It was presumed that the supports one receives in an educational setting are held to goal development and fading standards set forth within a transition program. It was also presupposed that transition planning occurs when a student is 14 years old in the State of Indiana, despite capacity of faculty in training and numbers of teachers available (West & Hardman, 2012).

By assuming that transition planning occurs, it was necessary to presume that some form of communication occurs among the two bureaucratic entities and the stakeholders of support providers while a student is receiving supports toward goal development and fading in an IEP and through Medicaid HCBS waiver supports in the ISP. The purpose of these assumptions strengthened the scope of the study in measuring effectiveness of these supports and communication strategies toward the ideal system of natural supports and integrative service settings.

### **Scope and Delimitations**

The aim of this study was to have a better understanding of the collaborative process from the DOE and FSSA for transition-based policy, funding, and implementation of quality measures. A missing component surrounding transition planning was collaborative efforts that ensured a transfer of information, goal

development strategies, and integrative networks already in existence through education-based supports. Carter, Austin, & Trainor. (2012) recognized these efforts as lacking and founded limited search opportunities for expansion on inclusive services already in place, especially for employment efforts.

Through the selection of an identified population, the perspectives of policy makers and stakeholders respective to transition-based strategies in an effort to describe the effectiveness of collaborative processes was examined. A key perspective from people supported was not included in this study as the ages within this study fell below 18, and permission for services in educational, community-based, and residential services occurred through guardian consent. This missing perspective limited full understanding of the quality measures.

The IAD framework and common-pool resource theory was applied for their discovery of collaboration strategies (Ostrom, 2011). The values and structure of each entity were already in place; therefore, the advocacy coalition framework was not utilized (Weible et al., 2011). The self-determination theory was an explored theory prospect for the bridging capacity of service delivery led by the student and waiver participant, but due to the population selection and use of the collaborative policy lens, this theory did not apply (Deci & Ryan, 1985).

### **Limitations**

Qualitative research has the capacity for subjective tendencies when conducting interviews, reviewing documentation, and analyzing projected data through coded processes (Patton, 2015). Controlling biases was critical to ensuring subjective tendencies



were eliminated and data was utilized in a standalone fashion when the flexibility of the data-gathering process may be criticized for the saturation of information (Yin, 2013).

Data gathered must be objective, despite the level of subjectivity when qualitative data was generated. Therefore, bias was disclosed up front in the research process. As I am an employee operating under the Medicaid HCBS waiver and an employee of an accrediting body for organizations supporting people with intellectual and developmental disabilities, my perceptions of future goals or collaborative efforts were to be held in check. An additional bias came from my role as a guardian for an adult with a developmental disability and my witnessing of policy in action on a personal level.

A criticism of qualitative data rests on generalizability (Patton, 2015; Yin, 2013). Using a case study approach bounded the research to bureaucratic entities, but one can operate on the platform that state policy for each department chosen has federal oversight. Consequently, capacity for future comparable research on state and federal levels exists.

Policy measures supporting people with intellectual and developmental disabilities have undergone numerous changes at the federal and state levels of government (Braddock, Hemp, & Rizzolo, 2004). Anchoring the IAD framework and common-pool resource theory outside of a largely environmental focus is under-researched and may present limitations in its application through this study (Tang et al., 2014).

### **Significance of the Study**

Supporting people with intellectual and developmental disabilities has been grounded in policy development, direction, and implementation since the distinction of disability was made. The distinction generated a policy framework for supports and services that are separated, yet the goal of inclusivity remains. This study filled a gap that exists in the literature where efforts to bridge supports and services from an educational to a Medicaid waiver–funded model promote goal development and fading strategies across the scope of care, recognizing the overarching requirement through state-funded services for a balanced budget and emphasis on sustainability (Bouck & Joshi, 2014). Sustainability has been demonstrated when people with intellectual and developmental disabilities take the lead on their supports. People supported in an empowerment capacity have the tools to shape change when the policy provides the mechanism for its promotion.

### **Significance to Practice**

Finding avenues to enhance the lives of people with intellectual and developmental disabilities through practices rooted in policy was the mechanism to guide *positive social change*. Recognizing the scope of care by sharing information in an IEP and ISP to generate one cohesive document demonstrated not only cohesive measures but also collaborative and forward-thinking teams working with and for the person supported.

Coordinated services are a necessity in guiding *positive social change*. Working with people requires awareness to preferences, dislikes, program needs, funding strategies, and efforts at sustainability. Innovative coordinated supports, such as a team-

focused model implemented in Colorado where supported people drive the efforts of their service team, broadens the scope of care and people available to advocate, network, and provide proactive service delivery (Block, Wheeland, & Rosenberg, 2014).

Services and supports coordinated effectively demonstrate collaborative paradigms across educational and Medicaid waiver settings. Collaboration represents a critical component to ensure the sharing of information and that planning resources are grounded, effective, and cover a broad scope of service options (Carter et al., 2014).

### **Significance to Theory**

Ostrom's (2011) conceptual IAD framework and common-pool resource theory typically operate under an ecological lens. Tang et al. (2014) applied common-pool resource theory toward government sustainability and efforts to increase quality. This study strove to add breadth to the case study approach using the IAD framework and to add application to the common-pool resource theory using a social service platform. This study promoted recognition of transition supports acting as a common-pool resource where both special education and adult Medicaid waiver services are funding disability supports for the same people, yet demonstrate ineffective outcomes (Carter et al., 2011).

Ostrom (2010) argued that for sustainability to occur in a common-pool resource, trust, collaboration, and a framework for rule-making will enhance efforts to overcome similar dilemmas and appropriation issues. Sustainability qualifies as a fiscal goal, while collaboration offers not only the mechanism to improving supports but also common language, common goal development strategies, and common quality measures.

### **Significance to Social Change**

The implications of *positive social change* through the completion of this study rested on the overall recognition that people with intellectual and developmental disabilities have the capacity to drive their supports forward. Learning this skill at an early age opens up the world to increased integrative opportunities and varied resources for people with intellectual and developmental disabilities to utilize toward their overall objectives.

Self-determination as a transition planning mechanism offers the person methods to bridge educational and waiver supports. Self-determination ensures not only that goals, programs, and services are defined but also that the common message trickles through both service documents (the IEP and the ISP). Most of all, self-determination ensures that strengths are shared and that transition planning is led by the person (Powers et al., 2012).

Today, people with disabilities suffer hardships of social opportunities and employment, limiting overall confidence in a developing person (Wehman, Chan et al., 2014). Early empowerment situations will begin to remove barriers that were once generated by perception alone.

### **Summary and Transition**

Services and supports for people with intellectual and developmental disabilities require clarification on the history, pathway, and objectives for future care. Recognizing the lifespan of care and the opportunities for people supported to direct their care supports an expectation through integrative requirements defined in *Olmstead v. L.C.*

This expectation furthers the next step to create a platform that promotes successful integrative measures.

Self-determination represents a natural and forward-thinking paradigm to bring stakeholders from special education and Medicaid waiver services toward a common ground through transition planning. For this study, the scope of transition planning was emphasized, because it represented a bridge toward adult-based services and a crucial opportunity to foster change. Self-determination utilized in transition planning also served as an avenue to change historical themes of separation and labeling people based on funding priorities. Individualized measures have the capacity to review a common pool of resources, dually being employed through special education and Medicaid waiver funding, as an approach solution and example of collaboration for all people utilizing state entitlement services.

## Chapter 2: Literature Review

### **Introduction**

Support for people with intellectual and developmental disabilities has undergone numerous transitions in care relative to policy, culture, and access to integrated service models (Mirenda, 2014). This chapter establishes a foundational understanding of how people with intellectual and developmental disabilities have been treated through a historical lens focused on United States policy transformations. As policy changes have shifted with respect to resources, transformational policy outcomes have come through stakeholder groups fostering key policy decisions that brought about measures supporting sustainability.

From settling and learning among the melting pot of society, the methods to care for all people have adapted as definitions of citizenship have changed. (Lowi, 1964; Wolbring, 2012). This chapter emphasizes the historical context of serving people with intellectual and developmental disabilities from 1971 to the present, in which integrative standards have been drafted and enforced through policy changes specific to people with intellectual and developmental disabilities. The policy aspects under review in this study centered on long-term supports and services of residential and educational institutions (Braddock, 2007, Carnaby, Roberts, Lang, & Nielsen, 2011; Pfeiffer, 1993). Long-term supports and services can become sustainable through quality transition planning for persons between the ages of 14 and 18, which represents the final theme of the literature review. Improved collaboration techniques offered on a multisystem and multipersonnel

process guided by the student's interests lead to the most effective transition outcomes (Noonan, Morningstar, and Erickson, 2008).

### **Literature Search Strategy**

Completion of the literature review relied on three databases: Political Science Complete: A Full Sage Text Collection, PsycINFO, and Education Research Complete. Google Scholar provided additional articles once specific themes and topic areas were identified. Databases were accessed through the Walden University Library.

The literature review began with a history of disability supports and policy demonstrating themes of separation from families and general public and public assistance. For topics relative to disability history, searches included the following terms: *disability supports, asylums, development of institutions, public charge, supports for idiots, imbeciles, morons, IQ, policy, deinstitutionalization, feebleminded, support models, and ICF/MR*. In the literature review, the initial topic reviewed was challenging due in part to the terminology utilized to describe people with intellectual and developmental disabilities. Therefore, searches included terminology during the initial generation of institutions in colonial America through the deinstitutionalization movement.

For topics relative to the HCBS waiver, the searches included the following terms: *Medicaid, federalism, policy, generation, individualized planning, sustainability, collaboration, qualitative, support models, funding, role of the states, and Indiana*. Throughout the literature review, when the State of Indiana was not specifically identified as the key subject of a case study, I noted that a large amount of research

participation had come from the state. Outside of information on the generation of the HCBS waiver policy, the most articles were published in the last five years.

Transition policy represented the most current and abundant literature. The literature was narrowed to the last five years, and topic searches included the following terms: *participation, individualized planning, sustainability, collaboration, advocacy, education, self-determination, inclusion, and IEP*. The parallel themes of individualized planning, sustainability, and collaboration were researched in both the HCBS waiver–specified areas and through special education transition policy. The most current literature referenced self-determination as a contributing evidenced-based practice to improve support delivery for people with intellectual and developmental disabilities in all settings.

### **Conceptual Framework**

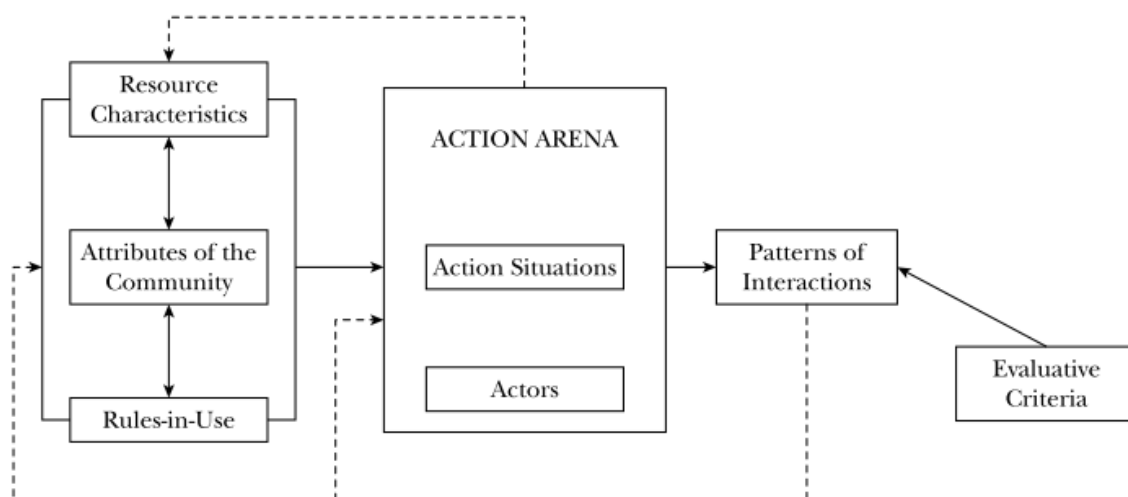
The IAD framework offered a lens to view institutional dynamics, which was of importance to this study of two bureaucratic entities. Ostrom (2011) presented the early work surrounding change efforts in 1982 and has added to the body of the research through increased detail regarding the “action area.” The “action area” is where transition planning strategies were applied.

The conceptual framework further narrowed with the use of common-pool resource theory in this study. Ostrom (2011) designated frameworks from theories to ensure the focus and operating foundation remained accurate and bounded in ideals, recognizing the variety of theories that can be applied through the IAD framework.



Ostrom also defined frameworks based on the general awareness necessary for policy researchers to foster reform and policy transition.

Within the conceptual framework, most effort guiding change occurred in the “action arena.” Assumptions in the “action arena” involve resources, values, knowledge acquisition, and directional focus. According to Ostrom (2011), “The term ‘action situation’ is used to refer to an analytic concept that enables an analyst to isolate the immediate structure affecting a process of interest to the analysis for the purpose of explaining regularities in human action and results, and potentially to reform them” (p. 10). Finding the framing structure is important to fostering sustainability because the “action area” must be able to adapt to changing environments and utilize actors who support the change. Figure 1 demonstrates the effect of the “action area.”



*Figure 1.* Institutional analysis and development framework. Reprinted from “Background on the Institutional analysis and development Framework” by E. Ostrom, 2011, *Policy Studies Journal*, 39(1), p. 15. Used with permission from The Ostrom Workshop at Indiana University, [ostromworkshop.indiana.edu](http://ostromworkshop.indiana.edu) (Appendix D).

McGinnis (2011) defined the varied choice structures where policy decisions occur in the “action area.” Operational choice is led by practical implementation strategies. Collective choice demonstrates collaboration and also serves as a platform for collective rule-making to guide change. Constitutional and metalevel analysis choices are rules and cultural norms that enhance institutional efforts and change over time. The analysis of choice decisions within the “action area” of transition planning served as a guide to the qualitative research questions for this study.

Feiock et al. (2014) applied the IAD framework to city charters in a manner that parallels institutional documents supported through the DOE with the IEP and the FSSA with the ISP. The authors found through their analysis of institutional statements that institutional rule-making measures create a level of consistency across institutions using common goals. The authors called for additional research regarding rule-making development pathways when common language was not already in place.

Consistency in rule-making strategies is often applied in the IAD framework using an ecological focus. Two studies offered application to human service avenues. First, Mincey et al. (2013) recognized the value in institutional partnerships to enhance efforts toward sustainability. Sustainability of long-term supports and services requires collective efforts (LaPlante, 2013). Watkins, Massey, Brooks, Ross, and Zellner (2013) found the desired outcomes using a qualitative approach and that the IAD framework helped to identify the institutional setup that fostered the sharing of information, guiding collaboration toward the overarching goal of improvement in the use of resources.

Oakerson and Parks (2011) extended the framework to the public economy. The budgetary constraints of sustainability exist beyond natural resources, and allocation and collaboration efforts are necessary for specialized services and entitlement programs to continue supporting people well beyond current budgetary guidelines and quality measurement perspectives.

### **Theoretical Foundation**

Common-pool resource theory represents a specific paradigm in the “action arena” where common pools are identified as a public good with common criteria (McGinnis, 2011). Ostrom (2011) designated frameworks from theories by stating how theories take elements from the framework and apply the key principles through the functioning mechanism of necessary assumptions. For the purpose of this study, the common pool of resources was structured for the dual funding that occurs from DOE and FSSA to support students through goal development and fading strategies using two varying criteria service documents, the IEP and the ISP. The principles of common-pool resource theory were utilized for this study in an effort to discover collaborative processes in place for the common service provided in special education and Medicaid waiver services.

Common-pool resource theory, like the IAD framework, was developed by Ostrom, who designated eight principles for the management of common-pool resources in 1990. Ostrom (2011) postulated that the greater the number of principles in place, the greater the opportunity for sustainable practice measures. Since Ostrom’s passing in 2012, her work has transpired through the foundation dedicated to the work of her and

her husband, Vincent Ostrom, at Indiana University. The Ostrom Workshop is an ongoing force in the field of collaboration hosting seminars and studies on ongoing and developing efforts toward the particular cause adhering to the core principles.

The first principle rests on the criterion that boundaries are clearly defined (Ostrom, 2011). Recognizing key stakeholders as operators of the resources ensures that participants who have institutional awareness contribute to rule-making and management strategies. For the purpose of this study, the two departments of DOE and FSSA exist through separate funding, oversight, and reporting measures.

The second principle recognizes congruence between provision and appropriation rules. This speaks to sustainability efforts that were presented in this study. Tang et al. (2014) found that local level decisions of overall governance can encourage stakeholders to go beyond institutional boundaries through collaborative measures and recognition of the common good.

The third principle of collective choice processes supports the transition-based support structure where current parallel efforts are underway for students and waiver participants aged 14 to 18. Basurto (2013) found that institutional differences bring ongoing emergence and endurance measures to the common pool due to the variety of perspectives and driving forces, which exists from DOE and FSSA.

Ostrom's remaining principles are focused on oversight when managing a common pool from specified monitoring to graduated sanctions furthered by dispute resolution mechanism (McGinnis, 2011). Minimal recognition and nested enterprises protect the collaborative efforts from going beyond the common pool of resources.

Tang et al. (2014) presented opportunities for government-financed decisions to be managed and operated using common-pool resource theory principles. Establishing an environment through a common pool of resources that fosters competence, autonomy, and relatedness is strengthened through collaboration (Shogren, Luckasson, & Schalock, 2014).

Kinzig et al. (2013) researched the emergence of social norms when the need, or lack thereof when government policy fails to sustain the public good. The public good for the purpose of this study was the dual funding mechanisms supporting children aged 14 to 18 under special education and Medicaid waiver funding. Common-pool resource theory can provide the development components toward the formation of policy when social norms fail to deliver the public good. Kinzig et al. (2013) found that cooperative behaviors begin to emerge when repeated interactions occur in smaller networks that use punishment and communication to promote the needs of the community.

McGinnis and Ostrom (2014) researched the need for common understanding to support a long-term resource. The researchers found that as groups become larger and harder to sustain, formal laws and institutions become essential. Key measures of inclusive supports, education, and providing awareness for the student are necessary during all phases of the transition planning conversation. Increased understanding through formal mechanisms has the opportunity to develop under one cohesive management structure and become solidified for common understanding to strengthen the resource as a public good.

### **Separation and Public Assistance**

A review of the literature presented two themes that permeate the policy models and treatment for people with disabilities throughout history. The first theme, separation of people from their natural supports, established a culture recognizing that people with intellectual and developmental disabilities could not be treated by their natural supports under the medical model and therefore needed to be removed from the family or environment in the local community (Pfeiffer, 1993). The second theme, definition of care to legitimize public assistance, has transitioned from derogatory terminology forming exclusive frameworks in segregated settings toward a current inclusive approach through Medicaid gateposts (Braddock, 2004). Recognition of the cyclical return to what was once a natural model of growth and direction of opportunity was the focus of this paper through an educational lens.

Gallagher, Connor, and Ferri (2014) emphasized the separation of mechanisms and paradigms as tools to legitimize forward-thinking decisions with respect to treatment of people with intellectual and developmental disabilities. However, establishing criteria to justify separation platforms deteriorated a sense of citizenship and belonging for centuries in United States policy on treatment and avenues of opportunity toward the “American Dream” (McCartney, 2011, p. 342).

The United States has undergone a dichotomy of care where up to the early colonial period of American history, people with intellectual and developmental disabilities were integrated into the family and community network (Meekosha, 2011). The formation of the first public hospital for people with mental illness, the Pennsylvania

Hospital, and criteria of becoming a public charge generated the policy paradigm that care was to be offered, then directed, as a component of public service (Wickham, 2006).

The parallel themes of separation and guidance implemented through public assistance existed in historical frameworks for people with intellectual and developmental disabilities in educational settings. The right for people with intellectual and developmental disabilities to be educated was not formally put in place until 1975 with the Education for All Handicapped Children Act, Public Law 94-142 (Agranoff, 2013). The evolution of educational supports began in institutional settings, through state schools, which will be later referenced specific to the State of Indiana, and in the initial and current stages of integrative methods for learning (Gallagher et al., 2014).

The quest for unity among people with intellectual and developmental disabilities existed when differences were not distinguished based on the person's inabilities but harmony was offered to the entire community (Connors & Donnellan, 1993; Kapp, 2011; Loja, Costa, Hughes, & Menezes, 2013). When one's capacity to work demonstrated ability to provide support to the community, the lack of ability created isolation and diminished opportunity. Housing people who could not work, nor care for themselves independently, led to the establishment of socially isolating institutions and the viewpoint of policy and society that people with disabilities must become segregated from peers (Pfeiffer, 1993). Establishing a foundation of past support standards was critical to understanding future policy platforms and pathways to serve people with intellectual and developmental disabilities in a truly integrated manner. It was not until the 1970s that the United States returned to this paradigm of care.

### **Initial Separation From Society**

The theme of separation of people with intellectual and developmental disabilities began when Native Americans suffered cruelties of colonization, disrupting the harmony of the established tribe (Senier, 2013). Treatment for people with intellectual and developmental disabilities within American federal and state policy began by recognizing the equal respect given to people with disabilities as peers in the Native American tribe prior to the colonization of American shores and limitation of segregated expectations without public assistance. This represented a key concept from the initial construction of integration toward the goal of returning to inclusive methods of recognition and support as citizens to the larger community (Kapp, 2011).

The recognition surrounding citizenship for people with intellectual and developmental disabilities includes the concept of ableism and contribution to one's society (Schweik, 2011). The rise of ableism established constructs for people to fit in a certain capacity, especially relevant to education and aptitude toward employment that could be applied to current policy measures (Meekosha, 2010; Wolbring, 2012). Measures regarding capacity to work formed initial separation strategies that permeated across the developing nation.

When European immigrants came to the United States, the impact of religious freedom guided behavior toward people with intellectual and developmental disabilities. Under the lens of a religious paradigm, people with mental illness or physical disabilities were considered idiots and thought to be evil for their perceived sins that needed to be cleansed (Bengtsson, 2014). Cleansing was conducted with the hopes of restoring



normality because normal was seen as tied to the Creator. Those who were not normal were not to be part of the progressive state (Baynton, 2013).

Separation in colonial society took place in almshouses among the felons, outcasts, and orphans under harsh standards of living and care. As religious platforms served as the driving component to caring for people, this philosophy spread throughout the respective colonies, thus disrupting initial integrated models throughout tribal society and supporting the removal of people with intellectual and developmental disabilities from natural care centers, including localized villages and communities (Baynton, 2013).

Prior to the development of locales of separation, people with intellectual and developmental disabilities were living in their family home (Dain, 1976). As subjects of embarrassment in the initial stages of progress, the numbers of people supported in homes, almshouses, prisons, and later institutions remain skewed. Initial U.S. Census figures in 1840 reflected the compilation of mental illness. Initial diagnosis information would not become legitimized until the generation of state-specific rosters, institutions, and coined schools for the feeble-minded, deaf, and dumb (Baumeister, Hawkins, Lee Pow, & Cohen, 2012; Carlson, 1976).

After people with intellectual and developmental disabilities were removed from their natural environment, it spurred the medical model reflecting that treating people with disabilities could be cured and required treatment that neither the family nor the immediate community could provide (Dorn, Fuchs, & Fuchs, 1996). Colonial Virginia represented a colony at the forefront of housing people with intellectual and developmental disabilities following recognition that some people could not be treated

through medical models of care using methods of lobotomies and bleeding out, thus returning to the restorative philosophy rooted in religious perspectives of ridding of sin (Bengtsson, 2014; Wickham, 2006). Due to the religious freedom formation held in the colonies, the Bible became a beacon of reason in treatment for people with intellectual and developmental disabilities.

The religious and medical models were blended as one, and this paradigm led to the creation of the first hospital for people who were considered idiots, incapable of completing work tasks or tasks to advance the community as a whole. The Pennsylvania Hospital was the first to offer this service as concepts of public charges for people supported were being introduced in American society (Dain, 1976).

**Limitation of rights.** The limitation of rights for slaves, women, and immigrants represented one of the key separatist philosophies and policy distinctions that existed among the evolution of American progressivism exclusions. Slavery and disability joined the separatist paradigm in that disability was used as a justification for limitations in understanding, physical weakness, and distinction in religious or political philosophy.

As work became a benchmark for the growth of America, people with intellectual and developmental disabilities were removed from society and represented as a weakness. At the same time, the treatment of people overall tested society's moral compass with the use of slaves as an opinioned lesser status (Baynton, 2013). Slaves working for White Americans developed a philosophical standing. This way of thinking was enhanced through public forums, traveling freak shows, and scientific presentations

on how Blacks were biologically and physiologically incapable of being as smart as White Americans (Baynton, 2013).

The limitation of rights justified through policy was extended to women. With disability as an avenue for further justification, women were seen as weak and unable to work in the growing economy. Women's suffrage and a path toward equality began by overcoming the separatist disabled culture that women were inferior and could not accomplish skills beyond their means (Baynton, 2013; Carlson, 2001). The accomplishments of overcoming diversity still exist in today's political framework, and the return toward complete harmony remains.

Harmony inside and outside American borders was especially significant during the Industrial Revolution. Dolmage (2011) presented the obstacles and processes that occurred at Ellis Island for immigrants. The challenges were especially significant if someone was deemed likely to become a public charge, which meant a cost, rather than a contributor to economic progress. "Likely to become a public charge" represented a theme that was further defined in the literature as the link between public assistance and responsibility by the American taxpayer that was rooted in separation and extended beyond immigrant entry points. From 1882 to 1891, the first federal immigration law prevented any idiot or person liable to become a public charge from entering American shores (Baynton, 2013).

In 1907, public charge paradigms were centered on economic projects beyond idiots and extended toward definitions of feeble-mindedness and physical disabilities as restrictive approaches to segregate people from coming to the United States (Farreras,

2014). Ellis Island is often written about as the entry point of discretion to separate, then remove, the economic risk of caring for another from the realm of possibility. Baynton (2013) wrote how disability culture began as a center point of overcoming hardships.

Diversity and separation are based in definition. *Feeble-mindedness* is a separatist term utilized as a criterion of diminished skill set during the 19<sup>th</sup> and 20<sup>th</sup> centuries. Farreras (2014) presented that the term *feeble-minded* was classified into three groups. The first group represented people coined *idiots* who could not guard themselves from danger and had an IQ below 25. The second group was classified as *imbeciles* and represented people who were unable to earn a living and had an IQ range of 25 to 50. The third group was labeled *incapable* or *morons* and represented people who could not complete essential tasks but had the capacity to contribute to society with an IQ above 50 (Cooper, 2014; Schalock & Luckasson, 2013).

The classification of each level of contribution depended on results from the IQ tests, using Goddard's Binet-Simon scale (Cooper, 2014; Farreras, 2014; King, 2003). This same scale then served as a method to prevent people from reaching criteria of failing to contribute to society and remain institutionalized under forced standards rooted in specific state policy. Questioning surrounding the legitimacy of the tests and their implementation generated a growth of practicing psychologists in institutional settings. Cooper (2014) demonstrated the impact that terminology and IQ criteria had on historical service delivery with an economic need for people to be served in or outside institutional settings using specific ranges of identified mild intellectual disabilities compared throughout history.

**Establishment of institutions.** A review of disability policy deserved significant attention to institutional developments, requirements, and service platforms. Mansell and Beadle-Brown (2010) reviewed the literature for specific characteristics of an institutional versus community setting. First, institutions were large establishments serving multiple people. Second, they were physically and socially segregated. Third, guideposts for leaving an institutional setting were unclear. Lastly, the rigidity and depersonalization of the institutions limited opportunity for initial or continued identity formation. The origins of institutions provided essential information toward the paradigm shift in care. No longer were people seen as people. People who were different became part of a segregated society that was isolated from view and relationships and faced diminished opportunities for integrated services. These highlighted the shift from natural settings toward forced care (Anastasiou & Kauffman, 2011).

In the State of Indiana, institutional generations, presences, and decisions in caring for people with intellectual and developmental disabilities paralleled the development across the United States with regard to capacity and formation of multiple institutional settings to meet demand. While Indiana statistically stands out for separatist philosophy for sterilization, the enhanced separatist opportunities began in the early 19<sup>th</sup> century with the development of large institutions; however, the focus of this literature review is on the state developmental centers serving people with intellectual and developmental disabilities, termed at the time *idiots*, *epileptics*, or *paralytics*, according to 1887 state laws initiating the first specified institutional setting (Coons, Bowman, & Bowman, 2010; Tilley, Walmsley, Earle, & Atkinson, 2012).

The Fort Wayne Developmental Center began serving patients in 1890. These patients were divided into two specific classes: industrial and custodial. People who fit into the industrial class had opportunities for learning a trade. Custodial care reflected the housing model of colonial philosophy, where people lived but did not thrive (Coons et al., 2010). The Fort Wayne Developmental Center remained open until 2007. Throughout its history, its expansion mirrored the perspectives and policies that guided service change under the separation umbrella of supports on institutional land, sterilization, and limitations of community activity, thus representing reduced choice options.

Dorn et al. (1996) wrote about the themes of transitions throughout institutional development, describing preferred treatment in cottages versus large-scale environments. Supports in cottages offered lower staff to person supported ratios and more personalized care. This concept was not always well received when the employee pool was small (Dain, 1976; Pfeiffer, 1993).

Dain (1976) wrote about the historical evolution and devolution of the impact that religion played in the treatment of people with intellectual and developmental disabilities. As it relates to sterilization, the public believed that the reproduction opportunities for citizens with a defined disability must be ceased. The Fort Wayne Developmental Center was a large contributor to the sterilization movement (Coons et al., 2010).

Indiana was the first state to implement forced sterilization in 1907 as part of the institutionalization effort legitimized through intelligence testing and standard of justification for suppressing individual rights. Farreras (2014) described how

*feeble-minded*, as a term signifying difference in a variety of physical or mental capacities, provided justification for institutionalization and sterilization.

Sterilization occurred in Indiana institutions up to the point of the post–World War II era, when criticism of Nazi behavior shed light on actions of forced separation and permanent removal of any integrative opportunities (Tilley et al., 2012). The questions regarding capacity to care for reproductive needs and parenting were justified through IQ testing and admittance to an institution (Farreras, 2014; Grossberg, 2011). Despite the elimination of the actions in institutional settings, it did not eliminate the philosophy and removal of rights when increased integration into community settings began to occur in the 1970s.

To this day, a landmark U.S. federal court case, *Buck v. Bell* (1927), remains to be overturned. The case represented a Supreme Court decision justifying the sterilization of a rape victim deemed “feeble-minded” as a protection to the public and for society. Grossberg (2011) described the philosophy of stopping the heredity of imbeciles and a review of the impact of family, state, and institutional decision-making over respect of the person toward individual rights and lack of present-day due process. *Skinner v. Oklahoma* (1942) left the decision to the state to implement civil rights and individual consent for the person with a disability. The open nature of *Buck v. Bell* represents a justified separation still in existence despite individual state efforts. Curry (2010) called for increase in public awareness and a review of individual history to recognize this shameful trend in human rights for people with disabilities.

The criticism of the deinstitutionalization movement for people with intellectual and developmental disabilities reflected the fear of diminished health and safety when provided in a natural setting (Anastasiou & Kauffman, 2011). Chowdhury and Benson (2011) completed a literature review of studies conducted surrounding the quality of life indicators for people after leaving the institution, reaching 1,238 participants reflecting greater choice, activities of interest, interaction, and dignity. In an institutional setting, people participated in activities of trade, institutional upkeep, and leisure, but one missing theme was choice. Choice in activities was a key factor in the development of waiver policy and service models during the deinstitutionalization push. All of these transitional changes were contributed by public awareness and knowledge of a segregated society that was attractive by design. The Fort Wayne Developmental Center reached as many as 2,599 people in the 1960s, on the cusp of the deinstitutionalization movement (Coons et al., 2010).

The Muscatatuck State Developmental Center originated as a colony serving only men, but in 1941, it began serving women as well (Coons et al., 2010). Over the course of 30 years, the population at Muscatatuck tripled in size to a maximum of 2,048 people. While construction reflected the population growth, the amount of people served with a limited employee base contributed to deteriorating services in institutional settings, leading to a change in public perception and corresponding policy. It is to be noted in the context of the literature review that the perspective of Coons et al. (2010) is heavily documented within their book about the positive impact of institutionalization and the service offered to the public and a gratified waiting list. Considering the recent



publication date, the positive impact of integration has not become the agreed-upon paradigm of service in all human service industries. A review of literature specific to current service models was reviewed within this chapter.

Change during the deinstitutionalization movement was brought about by public awareness (Grossberg, 2011; Pollack, 2011). Parents, families, and advocates began taking charge of their network to adopt change and move beyond separation toward a culture of integration. Social policy began to change in the 1950s and 1960s, and the service model of support began to blend through supports implemented by means of public assistance.

### **Public Assistance**

Since the earliest days of government, policy and funding were interrelated directional concepts as drivers for change. One of the most scrutinized public concepts that taxpayers disputed inside and outside of political parameters were social service policy. The roots of social service policy were presented within this section of the literature as a parallel historical platform recognizing that once people with intellectual and developmental disabilities were removed from the public, the questions of payment and level of support began to guide treatment decisions across the medical and social models. The independent living model was discussed as a platform for the Medicaid waiver as support for transitioning out of institutions began to flourish in the 1970s.

**Colonial model.** When people came to America to found a nation built on freedoms, some philosophies of European culture trickled into treatment for people with intellectual and developmental disabilities. Mirroring colonial initiation of American

policy, a review of the funding mechanisms for almshouses and the deemed poor were warranted. Quigley (1996) analyzed the colonial resources that generated services for the infirmed. Much of the service model was built from county taxpayers on an individual basis, but as the capacity to work as established criteria shifted when jobs became scarce and tax dollars decreased, the changing financial capabilities led to more cost-effective large-scale housing options (Quigley, 1996; Wickham, 2006). For counties or towns unable to cover the cost, sales of people unable to care for themselves went to the lowest bidder for care or such people were dropped off in neighboring counties to absorb the cost (Braddock & Parrish, 2001).

Almshouses represented one mechanism for removal to be justified through payment by the taxpayer, charity, or individual family (Wickham, 2006). The Elizabethan Poor Laws justified the philosophy that the county would be responsible for its independent almshouse or housing facility (Dain, 1976; Wickham, 2006). The spread of support outside the family home or natural support network was justified through payment, where people would utilize other towns and counties as avenues to drop their fellow citizens with or without disabilities, because all idiots were represented under a common heading and opportunity to live in an almshouse away from the public could be absorbed by an alternate funding source.

**Indiana poor laws.** In the State of Indiana, poor laws mirrored those of colonial society with a level of responsibility in both the physical and financial paradigms of care (Marshall, 1997). Financial support shifted from the county to the state as state policy initiated the purchasing of land for service institutions for people with intellectual and

developmental disabilities (Coons et al., 2010). As structures developed through state law in the late 1800s, social service stipends and responsibilities fell on superintendents of the institutions, which was a highly political assignment due to the financial opportunities it could offer. This position was not free from conflict and exploitation toward the Indiana county taxpayer (Marshall, 1997). Decisions were often justified based on profit, rather than impact to the person. The medical and social models guided superintendent decision-making (Coons et al., 2010).

**Public charge.** Baynton (2013) presented the impact that a person would have a public charge when coming to American shores in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries. The concept of a public charge represented a clear demonstration of two themes melded together: the initial separation and the cost tied to the separation. Ellis Island portrayed the conflict between exclusion and inclusion in a multitude of ways as people emigrated, but the one tie to disability history rests in the exclusion based on cost and the likely return to their native county (Carlson, 1976).

**State cost for institutions.** The federal and individual state systems of support began to exist with the development of state-operated institutions, with the first one created at the Pennsylvania State Hospital (Dain, 1976). Coons et al. (2010) demonstrated how state-operated facilities in Indiana began out of state law providing funding and authorization to begin taking admissions. Specific architecture philosophies guided the authorization of funds to the respective buildings across Indiana from a campus model, where people would transition among the purchased land in different specified buildings, to a hospital format, where the medical model of support dominated care (Pfeiffer, 1993).

The hospital format and structure were much more cost-effective because more people could live in one setting with fewer people providing care.

The initial annual report to the governor of Indiana for the Muscatatuck Colony for Feeble-minded (1920) established the approved cost for the purchase of land and an operating budget of \$250,000 overseen by a board of trustees and superintendent (Annual Report for the Muscatatuck Colony for the Feeble-minded, 1920). Twenty males represented the initial population of inmates at the colony, but the operating budget accounted for construction, settling the land, food, and physician supplies. The physician supplies included the cost for recommended sterilization upon admission (Annual Report for the Muscatatuck Colony for the Feeble-minded, 1920).

The level of admission acceptance correlated to the dollars spent, and as populations rose, the level of support required to sustain the institution often remained the same, thus expenses were proportioned individually. Coons et al. (2010) demonstrated that the early institutions often relied on the help of the people living there to maintain the upkeep, and with deinstitutionalization policy paralleling fair labor laws, states were required to pay for people supporting preservation of the institution (Coons et al., 2010; Cooper, 2014; Pfeiffer, 1993). The Fair Labor Standards Act Amendments of 1966 represented an equality measure to ensure that people supported receive fair wages for the work that contributed to the benefit of the upkeep of the institution (Pfeiffer, 1993). Coons et al. (2010) presented the impact of historical events on depleting costs to institutions and learning to work in the constraints of a budget when a nation was headed

toward conflict during World War I and World War II. Labor pools were reduced, and resources were scarce (Carnaby et al,2011).

**Deinstitutionalization.** When resources were threatened, policy, funding, and changing ideologies fostered the deinstitutionalization movement. Deinstitutionalization represented a step toward integration and inclusion in a community setting. Resources shifted toward that goal as a representation of cost savings versus living in an institution placement through the individual state mandate and generation of Medicaid (Chowdhury & Benson, 2011).

Relative to funding driving deinstitutionalization, Braddock (2007) researched the rise of federalism as it related specifically to funding the deinstitutionalization movement. Braddock (2007), as a key policy analyst for individual state planning, cited four factors as the driving forces to counter the development of over 200 institutions operated under budgets between 1848 and 1970.

The first demonstration toward a shift in federal policy was the Fogarty congressional hearings in 1955. The media called attention to the care that people with intellectual and developmental disabilities were receiving, which sparked a federal outcry by the U.S. Congress. This occurred in relation to the established appropriation for the 1950 federal mandate for aid to the permanently disabled (Braddock, 2007).

The second call for change at the federal level came from the initiation of Medicaid during the President Lyndon Johnson era of the Great Society from 1964 to 1968 (Braddock, 2007). Care for people with disabilities took a turn as federal appropriations guided policy but did not change the expectations of the 10<sup>th</sup> Amendment

to leave state responsibility in policy development and implementation. Lowi (1964) stated, “Distributive issues individualize conflict and provide the basis for highly stable coalitions that are virtually irrelevant to large policy outcomes” (p. 18). Chowdhury and Benson (2011) demonstrated through a review of deinstitutionalization-specific literature that states most often utilize non-governmental organizations (NGOs) in both private and public sectors as the key stakeholders in carrying out the policies at the state level. The relationships with the stakeholders represent a key piece to the policy triangle and will be reviewed relative to literature on transition planning.

The third aspect of change was specified under Medicaid funding toward state-operated facilities in smaller community-based settings, often referred to as group homes in the literature. The facilities were operated with state oversight and funded through Medicaid and the line item of Intermediate Care Facility (ICF). State line items existed under the umbrella of Medicaid funding but were not tied to defined Medicaid waiver services. The ICF program was initiated in 1971 to begin transitioning people out of institutions in manners feasible to ensure health, safety, and transitions to an integrated community life (Mansell & Beadle-Brown, 2010). For this reason, 1971 represented the initial piece to policy-driven expectations surrounding integration and public assistance geared toward the philosophical support shift. Care in ICF facilities held many institutional attributes, but as integration became fiscally possible, the federal government’s Medicaid appropriations drove the initial step forward (Braddock, 2007).

Braddock (2007) demonstrated the policy transition from ICF waiver funding to HCBS waiver funding a decade later with the use of a cost-comparison budget (FSSA,

2015). A cost-comparison budget is utilized today in the State of Indiana to compare the cost of a HCBS waiver with that of services provided in an ICF setting. The initiation of the HCBS waiver illustrated the fourth federal driver of change. As the federal government executes oversight over the entire Medicaid program, the favored allocation of funds and professional resources are demonstrated by offering increased support to the least restrictive setting. Chowdhury and Benson (2011) illustrated that the decreased cost offered under a HCBS waiver also led to improved quality of life for people with intellectual and developmental disabilities. Kim, Larson, and Lakin (2001) analyzed behavioral outcomes of people leaving an institutional setting and found that the behavioral outcomes were statistically significant when transitioning to a community setting.

For people with intellectual and developmental disabilities, the transitions in policy were guided by ideals of separatism toward paradigms of funding appropriately to drive change in the direction of integration under the Medicaid program. The addition of Medicaid spending was an essential guidepost to manage care from a distance and ensure that if a state wanted access to the funding sources, the respective state had to demonstrate the capacity to do so under each respective waiver guideline.

### **Medicaid 1915(c): Home and Community-Based Services Waiver**

The Medicaid support system was initiated through the Social Security Act amendments in 1965 reflecting concern for ongoing resources dedicated to the elderly, the poor, and people with disabilities (Agranoff, 2013; Huberfeld, 2011). The amendment to the Social Security Act represented a bridge to ensure healthcare for the poor and

disadvantaged. Following initiation of the Medicaid service delivery system, the federalist dynamic was created relative to state responsibility versus federal guidance.

From 1965 to 1981, the method of funding services for people with disabilities through Medicaid resources was channeled toward institutional care (Grabowski et al., 2010). The Developmental Disabilities Services and Facilities Construction Amendments of 1970 established state councils for supporting people with intellectual and developmental disabilities in a more localized manner, and a developing trend of states managing supports gained momentum.

In 1981, the policy shift was demonstrated through the initiation of the HCBS waiver under the Medicaid system, authorizing states to develop methods of supporting people with intellectual and developmental disabilities in a more integrated setting outside the structure of the law (Agranoff, 2013). The HCBS waiver was initiated through the Omnibus Budget Reconciliation Act with the Social Security Amendments to move toward cost-effective service models for each state (Burkhauser, Daly, & Houtenville, 2001). The waiver program under the Medicaid system reflected the model that certain service options under Medicaid funding can be waived for a specific purpose through demonstration of a more cost-effective option versus institutional care (Kane, 2012). Focus on integrative service options represented a key guidepost toward the new HCBS waiver. Advocates of service models paralleling the deinstitutionalization movement generated resources toward the philosophical service shift through information on successes of the process, emphasis on due process and human rights, and value in integration for fostering natural supports (Agranoff, 2013; Kane, 2012).



The HCBS waiver provides a model of success relative to federalism and states managing cost-neutral service options in a partnered federalist model. Huberfeld (2011) demonstrated that the role of the state toward Medicaid has taken on two roles, ensuring the Medicaid mechanism both meets financial benchmarks and becomes an avenue to test philosophical change before implementing it on a larger federal scale. Each individual state is charged with building an individualized plan to implement services under Medicaid funding including the HCBS waiver.

### **Indiana HCBS Waiver Implementation**

In a report generated by Burkhauser, Daly, & Houtenville (2001) in correlation with the University of Minnesota at the request of the Health Care Financing Administration, now known as the Centers for Medicare & Medicaid Services (CMS), the group was charged with evaluating implementation of the HCBS waiver in the state of Indiana using a qualitative approach through conducted interviews with stakeholders. Indiana began utilizing waiver supports in 1990 with a specific focus on serving people with autism, then implemented the specific HCBS waiver in 1992 under headings of the Developmental Disabilities Waiver and Support Services Waiver (FSSA, 2015; Burkhauser, Daly, & Houtenville, 2001). In reflecting on the nine years of missed opportunity to utilize community-based supports, Indiana represented a state entering into the philosophical support model late in the service delivery process on the national scale, which made its respective implementation unique to this particular study.

Indiana implements the HCBS waiver through the FSSA. The FSSA oversees the Bureau of Developmental Disability Services and the Bureau of Quality Improvement

Services, both of which monitor service delivery from community providers (FSSA, 2015). The FSSA also administers the individual and comprehensive allocated budget options through the Office of Medicaid Policy and Planning (FSSA, 2014; Bowen, 2014). These resources were utilized within the study conducted by Burkhauser, Daly, and Houtenville (2001) and remain as key departments of oversight today.

Burkhauser, Daly, and Houtenville (2001) found that there were dominating issues hindering effective implementation of waiver supports. The first challenge existed in building and sustaining a well-trained workforce. The second challenge focused on collaboration and dissemination of information to people supported and those on a waiting list for care on how services ought to be provided. The third theme as a hindrance to effective implementation was focused on forward-thinking service delivery rooted in quality assurance furthered by necessary emphasis on enhancement for all contributing stakeholders.

Burkhauser, Daly, and Houtenville (2001) emphasized a need for the State of Indiana to monitor its waiting list and communicate information effectively. These themes remained at the forefront for the State of Indiana over the following years. According to statistics from the Division of Disability and Rehabilitative Services for the State of Indiana, the number of people on a waiting list for support has transitioned from its peak in 2010 of 21,217, with 11,988 receiving waiver services, to 13,441 in 2012, with 13,168 receiving waiver services. According to the FSSA (2015), 1,595 people began receiving supports in 2013, and 3,507 people began receiving supports in 2014. Up to

1,072 people are targeted to begin services in 2015, demonstrating a drastic reduction in the waiting list.

There are two reasons for the large shift over a short time period: new waiver philosophies initiated in 2012, and reorganization of the waiting list, which refocused service needs (FSSA, 2015). First, on September 1, 2012, the State of Indiana combined the Developmental Disabilities Waiver and Autism Waiver into one comprehensive needs-based waiver called the Community Integration and Habilitation Waiver (FSSA, 2015). This waiver, as a needs-based waiver, must be demonstrated as a necessary service model for sustainable care following exclusive criteria due to its extensive cost range. The Supports Services Waiver, now referred to as the Family Supports Waiver, represented a fixed waiver model with a set rate on a smaller scale, allowing more people to enter into services.

The entry point for services was reorganized so that the initial service opportunity began with the Family Supports Waiver. The goal was for more people to utilize natural support models and focus on community integration opportunities for people to utilize external sources as a service outlet versus staying on the waiting list. In 2012, people who were on respective waiting lists for each waiver were combined into one, thus eliminating any name duplications, which had resulted in artificially higher numbers on the respective lists. The waiting list was also thinned out as a result of people moving to another state, no longer meeting the definitions of support, or utilizing natural support models (FSSA, 2015).

**Woodwork effect.** The use of waiver supports has grown in Indiana. Grabowski et al. (2010) completed a survey review of stakeholders associated with long-term supports and services specific to Indiana and found that people associated with development and implementation supported rebalancing services toward more HCBS waiver service options versus institutional funding sources, which represented the preferred method in driving change corresponding to the focus areas of the HCBS waiver models. This concept has been extended over the two decades of HCBS waiver supports in Indiana and generated the preferred service model leading to a woodwork effect, where the more attractive model of service prompted people to “come out of the woodwork” and enter services at the preferred time.

The woodwork effect played a significant role in the waiting list problem for the State of Indiana. The woodwork effect reflects the movement of people into services beyond the previous pathway of transition from the institutional setting or nursing support when the HCBS waiver became available (Chattopadhyay, Fin, & Chattopadhyay, 2013). Some people avoided care altogether until an integrative model of care for alternative funding sources came into existence (Kane, 2012; LaPlante, 2013). LaPlante (2013) found that during the growth of Medicaid spending, the woodwork effect presented itself for the supports encompassing services for people with intellectual and developmental disabilities, because as HCBS 1915(c) waivers increased, Medicaid spending increased by 8% overall.

Harrington, Ng, and Kitchener (2011) presented the positive impact of the woodwork effect in that people who previously were eligible for supports in an

institutional setting did not choose that option out of avoidance of the restrictive setting. Prior to the HCBS waiver, many people were receiving support from their families and/or natural supports. (Braddock, 2004). When people began service initiation outside the scope of their respective service model, it did not create cost neutrality with new people coming into Medicaid waiver funding supports versus living in an institution in the prior years, because it established an additional cost outside of the established Medicaid budget. Beginning in 2012, the preferred method of initiating supports was through the family/natural support model, not institutional care (FSSA, 2015).

Medicaid LTSS offered under the HCBS waiver presented a more cost-effective approach to assist people under the Medicaid support structure over time. LaPlante (2013) recognized the initial spur in costs when the HCBS 1915(c) waiver became available, especially when states were paralleling supports in and out of institutional settings. But today, they have the capacity to offer improved services emphasizing integrated outcomes. Chattopadhyay et al. (2013) found that overall efficiency improved as HCBS waiver utilization increased across states. With respect to the State of Indiana, the authors placed Indiana in the low-efficiency range, with improvements demonstrated between 1999 and 2007. High-efficiency states have effectively offered services outside of institutional settings and explored the wide range of services offered under Medicaid beyond the waiver to improve health services, delivery, and utilization overall (Chattopadhyay et al., 2013). Indiana implements two service waivers for people with intellectual and developmental disabilities, with limited opportunities to adjust toward preferred services, thus limiting efficiency. Harrington et al. (2011) found that the State

of Indiana ranked 42<sup>nd</sup> among comparable states in terms of cost savings from institutional to community-based supports under the HCBS waiver at a \$184 million cost differential (p. 209).

**Participant direction.** Variability in the type of services offered under specific waivers across the United States is cause for analysis and efficiency improvements in the overall Medicaid structure at the initial federal level passed down to individualized states. Rizzolo et al. (2013) completed a comprehensive review of individual states in reference to overall spending and services offered under the HCBS 1915(c) waiver. Rizzolo et al. (2013) found that Indiana offered a variety of service options regarding residential habilitation, day habilitation, and family support (p. 14). Specific therapies, health supports, and opportunities to expand service variability were cause for concern, which in effect created individualized state waiting lists for care, and corresponding analysis of quality services and outcomes based on individualized service needs warrant further review. The call for focus on individualized care and planning is paralleled as a discussion of the development of special education for people with intellectual and developmental disabilities as it relates to sustainability of LTSS from an early age (Gross, Blue-Banning, Turnbull, & Francis, 2014).

Efforts to establish sustainability and support HCBS waiver paradigms were anchored by key policy decisions. The Americans with Disabilities Act (1990) sparked a philosophical change in the goals of services for people with disabilities. Having foundations established within federal and state policy, expectations of improved service were solidified for future policy standards and research towards effectiveness at each

governmental level. Integration across domains of public assistance, accommodations, employment, housing, and technology set the tone for improvements in constructive efforts toward integration (Agranoff, 2013). In 2010, President Barak Obama enacted Rosa's Law, which federal law mandated that the term *intellectual disability* replace the term *mental retardation* (Agranoff, 2013, p. S127). *Intellectual disability* is the term referenced in the most current literature and represents the progressive tone to keep supports moving from institutional parameters and focus.

In an effort to uphold the Americans with Disabilities Act, the Supreme Court in *Olmstead v. L.C.* established the court ruling that individuals with disabilities have the civil right to live, learn, and socialize in the community of their choice (Agranoff, 2013). The *Olmstead v. L.C.* decision solidified the philosophy of integration through the HCBS waiver by ensuring that despite financial expectations and service delivery options under Medicaid, people with intellectual and developmental disabilities were afforded the same level of supports offered to all utilizing a similar service (Grabowski et al., 2010). There are approximately 10 cases heard each year at the federal level with the expectation of upholding the *Olmstead v. L.C.* criteria of care (Ng, Wong, & Harrington, 2014). More cases are being heard toward the length of time people are waiting for services and expansions in care, which has been demonstrated through the changing waiting list and waiver models in Indiana since 2012.

Christensen and Byrne (2013) completed a review of *Olmstead v. L.C.* plans at each state level calling for more specific policy criteria rooted in key numbers of people supported, implementation expectations, and evaluations of effectiveness. Indiana's

specific plan lists housing as the largest issue promoting integration. Christensen and Byrne (2014) countered that priority, because from their analysis, housing can be found and integrative methods to counter the social model of differences must be built. The authors called for collaboration beyond disability support networks as an outcome of their state-by-state analysis. Add current HCBS Waiver guidelines

In a quarter of a century, policy criteria and implementation strategies have transitioned from a focus on institutional living and direction to a waiver model rooted in choice. Participant direction represents the method of putting choice into action (Moseley, Kleinert, Sheppard-Jones, & Hall, 2013). Utilizing individualized supports, service provider management, and individualized budgets, people supported and their families are able to guide services in the direction of preferred outcomes (Gross et al., 2013). In a review of National Core Indicators, Moseley et al. (2013) paralleled the results recognizing the need for people to direct their own service delivery. This study demonstrated how expansion of effective service models is necessary within the breadth of the government investment toward individualized and sustainable LTSS, recognizing emphasis beyond paid support, but more importantly, community integration opportunities led by the person supported.

To support the government investment in a sustainable structure, Agranoff (2013) called for networks and collaboration. These networks ought to have specific policy focus areas and cross a variety of support models to create an inclusive and integrated approach toward improved service. Money Follows the Person represents a current federal initiative for states and service providers to promote innovative services. By identifying



people's needs and sampling innovative supports, improved service delivery is possible when funding options are widened beyond current boundaries. Denny-Brown, Hagen, Bradnan, and Williams (2015) found that involvement among stakeholders is stronger and more collaborative when integrative supports are deemed possible.

Managed care is a model of support that exists in states around the country, and it is beginning to trickle into Indiana through the Medicaid waivers specifically tied to aging and blind-specified services (Agranoff, 2013, p. S128). The Affordable Care Act has the potential to move LTSS forward. Reinhard, Kassner, and Houser (2011) presented the use of a score card to promote quality, collaboration, and integration at the state level as a parallel in cost management and effective services at the federal level.

**Indiana next steps.** In January 2014, CMS announced a requirement for individual states to review services offered in HCBS waiver settings. Indiana, per federal responsibilities to the Medicaid funding system, was charged with submitting an individualized state plan by the end of the calendar year for both the Community Integration and Habilitation Waiver and Family Supports Waiver (FSSA, 2015) Themes of individualized service, sustainability, and collaboration are key pillars to the state of Indiana transition plan and represent efforts toward building a LTSS model that Medicaid can continue to uphold.

Per CMS, all states are required to implement key aspects of their philosophical shift to the next stage of integrative supports. According to CMS 224-F/2296-F of the 1915(c) Home and Community-Based Services Waivers Final Rule (2014), emphasis on

individualized outcome models of preferred integrative service options and strategies are a priority.

Indiana has implemented this focus into its respective state plan by clearly defining the expectation that person-centered planning will be guided by the person supported in waiver services to generate individualized plans and support the expectation of participant direction. Moseley et al. (2013) recognized positive change in the State of Tennessee toward policy implementation when service priorities were clearly conveyed in all forms of written and verbal communication.

Taylor and Taylor (2013) defined the origins of person-centered planning in the advocacy movement of the 1980s and 1990s to ensure that people with intellectual and developmental disabilities were not spoken about without their presence and input. Person-centered planning reflects the paradigm of goal definition rooted in dreams, decisions, choices, opportunity, and collaborative measures (Schwartz, Jacobson, & Holburn, 2000, p. 38). Indiana has adopted this platform to uphold a level of individualized service in support measures generated through the ISP (FSSA, 2015). For Indiana service providers to be effective in implementing this platform, accountability from all stakeholders is necessary, including the person supported and his or her natural support network.

Zakrajsek et al. (2014) completed a mixed method study of staff intervention for fostering community participation for people with intellectual and developmental disabilities. The authors found choice-making to increase when staff became more aware of the impact it made for the person. Within the qualitative method of the overall study,

the authors found that exploring community connection opportunities beyond visiting toward connecting and participating fostered a long-term sustainable impact (Zakrajsek et al., 2014, p. 159). Educational opportunities for service providers on emphasizing participation can generate natural supports and transition from unsustainable long-term paid supports.

Sustainability is reflected in the Indiana State plan by ensuring that full access to integrative settings is employed. Grabowski et al. (2010) demonstrated the cost-effective nature of HCBS waiver measures through transitioning services to integrated settings. Harrington et al. (2011) presented sustainability in moving costs from institutional to community-based settings. Schalock and Verdugo (2013) called for improved data analysis, specifically for service providers to recognize the impact of transition support outcomes through emphasis points on quality of life and continuous quality improvement. Cost-effectiveness, inclusive service delivery, and implementation monitoring are all reflected as priority service measures in the HCBS waiver update for the federal and state levels, including in the Indiana State plan.

The HCBS waiver update for the State of Indiana reflected a level of assumed vulnerability in its transition plan relative to collaborative measures toward enriching individualized supports and sustainability through community-based care (FSSA, 2014, p. 33). Through an empirical analysis of Medicaid waiver administrators who responded to a service change survey, specific service measures demonstrated gaps in transition strategies from an educational service system (Merryman, Miller, Shockley, Eskow, & Chasson, 2015). Identified gap analysis through a qualitative case study between waiver

services and educational perspectives offered an opportunity to view collaboration as a bridge to enhancing LTSS from an early age.

## **Special Education**

### **Educational History**

Education is a staple of American policy rooted in an individual's strive to establish a foundation of skills toward his or her future. For people with intellectual and developmental disabilities, opportunities for equal education did not become policy and was not required on a state level until the passage of Public Law 42-142, the Education for All Handicapped Children Act of 1975. Key pieces of the initial act remain in place today with the reauthorization of the act under the new title of the Individuals with Disabilities Education Act (IDEA) in 1997 and key federal amendments passed to improve supports up to 2006 (Department of Education, 2006). The defined tenets in the initial and current special education laws required state implementation of FAPE, due process safeguards, least restrictive environments (LREs), individualized planning, and nondiscriminatory testing and evaluation (Scruggs & Mastropieri, 2013).

The platform of FAPE defines the relationship between the federal government and the state in a manner that parallels Medicaid HCBS waiver relationships with each respective state (Beatty, 2013). In exchange for federal funding offered to the states for special education, the individualized state is responsible for funding education in a manner similar to all public education requirements from the respective taxpayer and defining its individualized policy (Department of Education, 2006).

Indiana's special education rules are written in Indiana Administrative Code 511, commonly known as "Article 7" (Indiana Department of Education, 2009, p. 2). With an update completed in December 2014, Indiana's implementation strategies adhere to all required measures per federal IDEA policy with specific administrative rules mirroring the benchmarks of FAPE and LRE.

Rule 43 under Article 7 is of significance to this literature review within an established foundation to LTSS in that 511 IAC 7-43-4 is specific to a transition individualized education plan, which will be in effect when the student enters grade 9 or turns 14, whichever occurs first (Indiana Department of Education, 2014, p. 101).

The aspect unique to special education is individualized planning through an IEP, which serves as a method of service planning, goal development, and transition planning. In Indiana, requirements of an IEP must include current levels of functional and achievement performance; appropriate measurable post-secondary goals relative to training, education, employment, and independent living skills; and corresponding transition adult services. Adult services in 511 IAC 7-43-4 are defined as a vocational rehabilitation services program, the Indiana Department of Workforce Development, the Social Security Administration, the Indiana Bureau of Developmental Disabilities Services, a community mental health center, a community rehab program, or an area agency (Indiana Department of Education, 2014, p. 102).

Indiana has recognized collaborative bodies in the transition process and post-secondary educational goals, but participation and collaboration are lacking from transition criteria. The student (if over 18) or guardian can provide an invite to adult

services through the transition IEP, but adult services are not defined as a required participant in the planning process. Gross et al. (2014) found in a review of participant direction techniques for adults that efforts need to move beyond choice in services and toward the implementation of effective goals that are guided by the person but anchored in a solid policy structure.

**Inclusive measures.** As a service, special education policy implements key procedural safeguards to ensure the student and family are aware of the expectations of the educational model, including integrative and inclusive supports based on the learning environment (Mandic, Rudd, Hehir, & Acevedo-Garcia, 2012). LRE represents an initial method to ensure children were educated outside of an institutional setting, then through policy revisions began to call for integration and inclusive supports in a traditional classroom. Carter, Swedeen, Walter, and Moss (2012) found that parent-led inclusive efforts toward community outreach represented an effective step toward creating community partners and improving awareness to inclusive service opportunities as a foundation for long-term supports and services. The purview of inclusive supports parallels the Community Integration and Habilitation Waiver and Family Supports Waiver expectations by generating sustainable and natural supports overall (Zakrajsek et al., 2014). Carter et al. (2013) recognized a need for increased relationship training and development for children with autism during the high school years. The authors called for intervention strategies rooted in social and communication skills to facilitate employment and the criteria of relationships beyond paid supports.

To help establish relationship skills before high school, IDEA amendments in 2004 and 2006 defined how educational services should begin in a regular classroom setting, then be transitioned to specialized service based on need, rather than moving in the opposite direction. Hyatt and Filler (2011) presented how individualized planning enhanced through IDEA amendments and updates has provided mechanisms to implement LRE effectively, rather than based on classroom availability. Obiakor, Harris, Mutua, Rotatori, and Algozzine (2012) furthered this argument by calling on school personnel from all sources to create expectations that students within special education service settings are contributing and valued members of the school community.

O'Rourke (2014) studied the role that technology plays in moving inclusive supports forward and found that teachers struggle with the development of an inclusive setting at its origin to limit the effective measures technology could serve. Erten and Savage (2012) extended the implementation argument by moving beyond literature support of LRE as necessary and emphasizing the next phase of asking how it can build effectively.

**Learning needs.** Policy relative to supporting the field of special education has become more focused on education as an establishment for the future by ensuring that the person has skills to be engaged in his or her respective local community and access needed resources to obtain some form of employment (Carter et al., 2013). The focus on parallel and developed supports for children as they enter adult services and establish a platform of LTSS is rooted in transition planning. A key piece of Public Law 105-17 of the IDEA Amendments in 1997 recognized the need for transition planning after children

had been receiving special education services and moved into adult life and demonstrated limited effectiveness of outcomes (Blackorby & Wagner, 1996; Bouck & Joshi, 2014).

Indiana has implemented transition criteria within Public Law 105-17 Article 7.

### **Transition Planning**

The 2004 amendments to IDEA furthered the philosophy of adult and transition planning by establishing the expectation that children prepare for further education, employment, and independent living through effective special education services for children between the ages of 14 and 21 (Carter et al., 2013). Transition policy and planning were implemented through their contributors and efforts built on outcomes. Bouck and Joshi (2014) utilized data from the National Longitudinal Transition Study-2 (NLTS2) and found that transition planning took place through an IEP but that transition services were limited, indicating a lack of implementation. The authors also found that transition planning needed to extend beyond an educational setting, creating misalignment between goal definition and outcomes.

Of relevance to collaboration measures for sustainable LTSS established at an early age, Carter, Brock, and Trainor (2014) completed a review of transition assessment perspectives for people in a phase of transition to adulthood, and they found that more collaborative components could have enhanced the assessment and planning process. Bouck and Joshi (2014) reported similar findings, and the authors cited the lack of invitation to the IEP transition planning meeting as a contributing factor to the minimization of participation of adult services, similar to those offered through the HCBS waiver in Indiana. With a recent Indiana special education policy update, the lack



of recommendation and requirement for adult services participation demonstrates an opportunity for continued policy enhancement in transition measures.

Grigal, Hart, and Migliore (2011) recommended through their analysis of NLTS2 that when more adult services participants focus on inclusive and employment-based outcomes, it creates an added expectation toward a more integrated network. Fraker et al. (2014) found through an analysis of one-year impacts post-transition that effective strategies were built on employment-promoting measures where work experience was valued in an educational setting. For a student utilizing Social Security as primary or secondary income, education on benefit impacts is necessary for sustainability. Fraker et al. (2014) found that the longer students went without paid employment, the less likely they were to find employment opportunities, thus highlighting the necessary collaborative efforts from an educational and adult-based model. This employment priority recognition generates the early opportunity for forward-thinking supports at an early age.

Doren, Flannery, Lombardi, and Kato (2013) completed a mixed-method study of IEP goal development for transition planning and levels of improved post-educational measures following the completion of professional development in this area. The authors found that goal writing was improved, and teachers commented on appreciation for the learning opportunity. As a consideration for future practice and research, continued professional development for post-educational-focused goals is an opportunity area toward improved practice.

In the State of Indiana, application sources are available to meet the training deficit (Bowen, 2014). The Indiana Secondary Transition Resource Center is a training-

focused entity centered on improved transition planning with the goal of improving transition IEPs. The center recognizes the need for interagency collaboration, but it is of note that the facility's respective collaboration-specific resources have not been updated since 1996, 10 years before the IDEA updates of 2006.

### **Specific IEP Development for Students With Diagnosed Severe Disabilities**

The range of support within special education services is encompassing to accommodate multiple needs. Severe disabilities in the literature relative to transition support planning is specific to students with intellectual disabilities, autism, and/or multiple disabilities having extensive support needs (Carter, Austin, & Trainor, 2011, p. 60). Dr. Erik W. Carter has written on this demographic delineation in special education literature to narrow the focus within the scope of opportunities available and place emphasis within special education services toward this specific population.

Carter et al. (2011) found that employment-focused educational opportunities remain limited as the search for integrated community-based opportunities remains small. Carter et al. (2011) called for practice completed in natural settings and increased understanding of paid employment as a foundation toward adulthood. Carter, Austin, and Trainor (2012) continued this research by finding that the efforts of parents to appreciate and facilitate employment-based outcomes from an early age led to improved results. Carter et al. (2011) and Carter, Austin, and Trainor (2012) focused this research on establishing the expectation for integrative and inclusive goal development as the strongest pathway to ensure that IDEA and its emphasis on planning for the future are upheld. In addition, Swedeen, Carter, and Molfenter (2010) found opportunity mapping

as an effective avenue of expanding inclusive services in an educational setting, because it provided an initial pathway to understand and develop avenues for social inclusion and unpaid supports.

Parker Harris, Renko, and Caldwell (2014) completed a qualitative study with people who utilized social entrepreneurship to create a network of employment opportunities through the recognition in small business opportunities. The independent nature of individualized employment-based goals can be initiated, nurtured, and enhanced throughout one's education, then bridged into adult services when conducted and communicated effectively. Internship opportunities provide a vehicle to personal development and integrative services as a transition mechanism. Moore and Schelling (2015) found that significant positive employment outcomes occur for people with intellectual and developmental disabilities who utilize post-secondary education opportunities as a bridge. The challenge remains in startup costs, but social learning through natural supports and creativity in goal development can provide an avenue for future planning by emphasizing employment strategies for people with intellectual and developmental disabilities.

Ross, Marcell, Williams, and Carlson (2013) found that employment and independent living outcomes for people with intellectual and developmental disabilities exceeded the population of fellow peers with similar diagnosis and support needs when supports were offered in a natural and inclusive setting. In a study of 125 students participating in college classes through a college campus with peers, effective transition outcomes were demonstrated. The authors called for similar support standards to be

offered in transition planning discussions and recognized as an adult-based support model of opportunity within natural settings.

Providers for people with intellectual and developmental disabilities have supported planning under the Medicaid HCBS waiver. Sheppard-Jones, Kleinert, Druckemiller, and Ray (2015) found through a survey of Midwestern states that providers value higher education and would like to be part of the conversation to create these service opportunities early on for people served. Efforts completed through collaborated transition planning help to bridge the service models.

Wehman, Chan, Ditchman, and Kang (2014) researched the impact of supported employment on the vocational rehabilitation process and outcomes for 23,298 students who participated in the program in an educational setting. Supported employment represents a fading and goal development strategy to guide the student or adult with the necessary support when working in a paid job. The authors found that employment reduced the overall cost of adult care and that students utilizing transition supports with an employment focus were 12.49% more likely to be employed in the long term.

Upholding key aspects of future planning must be supported when the child is not in school. Wagner, Newman, Cameto, Javitz, and Valdes (2012) found that parents were more likely to participate in transition planning meetings toward the generation of an IEP when their son or daughter was at a younger age than when he or she was in high school. Using data from NLTS2, the authors also found that children with diagnosed severe disabilities had decreased attendance by parents due in large part to the expectation that their respective son or daughter may not meet established post-secondary goals. Wagner

et al. (2012) called for additional research in this particular area as an educational opportunity for increased parent involvement and carryover into goal development areas at home. Obiakor et al. (2012) recommended parent liaisons so that parents are also more greatly included in informational opportunities.

Martinez, Conroy, and Cerreto (2012) found similar results using data from NLTS2 in terms of parent participation, but the authors utilized qualitative responses from parents to address areas of limited awareness, decreased involvement, and aspirations of post-school educational opportunities for children with significant support needs. From this demographic of parents, 60% did not know the desired purpose of transition planning, and many reported a lack of understanding of its collaborative intentions, especially when their son or daughter may not have had similar opportunities to their peers based on independent capabilities. For this demographic, Martinez et al. (2012) recommended additional research into lifelong learning opportunities, which can be offered under the HCBS waiver as a possible adult service and transition in care.

The method to transition services occurred through the summary of performance (Carter, Austin, and Trainor, 2012; Prince, Katsiyannis, & Farmer, 2013). The summary of performance is a required document, but the Council for Exceptional Children (2012) has suggested that it contain specific parts. Part 1 is centered on student demographics and formal and informal assessments completed during the transitional IEPs. Part 2 describes the post-secondary goals. Part 3 evaluates academic, cognitive, and functional levels of performance. Part 4 provides recommendations, and Part 5 is where the student

is encouraged to offer input to establish a foundation toward self-determination and advocacy toward individual quality of life goals.

### **Self-Determination for Children With Diagnosed Severe Disabilities**

Self-determination provides the ideal method to ensure that individualized planning, sustainability, and collaboration create a foundational support model where the person directs his or her supports and services from an early age. The preferred method of individualized planning, through evidenced-based practice, occurs when the person takes the opportunity to lead. Wehmeyer (1996) defined self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regard one’s quality of life free from undue external influence or interference” (p. 22).

In a survey of 223 paraprofessionals, Lane et al. (2012) found that they attributed high levels of importance to self-determination platforms for students with moderate to severe disabilities. The paraprofessionals generated necessary adaptive tools and provided empirical evidence to adapted supports in service planning.

Powers et al. (2012) evaluated the practice of self-determination and its impact on children in special education and foster care when guardianship fades away as the student turns 18. The program that students participated in was part of a study called *Taking Charge*, which pairs people in local communities to students in special education in a coaching/mentoring role (Powers et al., 2012, p. 2181). The effectiveness of the program was measured using the Arc Self-Determination Scale before and after the coaching/mentoring occurred. The authors found that the coaching efforts enhanced self-determination and improved transition outcomes. The authors called for continued efforts

to capitalize on the effectiveness of coaching to foster relationships among liaisons in the local area as a staple person coaching the transitional practice from education to adult life.

Seong, Wehmeyer, Palmer, and Little (2014) completed a study of the effect of self-directed education programs for people with intellectual disabilities and found the Self-Directed IEP to be a contributing factor in improved outcomes. The lessons of choice, decision-making, and leadership fostered increased advocacy in one's planning meeting and involvement in the transition process. Similar to the study completed by Powers et al. (2012), Seong et al. (2014) utilized the Arc's self-determination scale. The authors called for increased implementation of self-directed practices to create a more interactive support model for all disability support services, which elevates the capacity to generate a sustainable system of LTSS from an early age.

Sustainability and self-determination rest on individual awareness to find methods to foster growth in the educational system and creating opportune measures that allow for Medicaid funding source extensions for generations to come. Systems advocacy, as part of the independent living model, is a method to ensure that children and adults are aware of issues at the local, state, and federal levels. Systems advocacy also demonstrates how people with intellectual and developmental disabilities can contribute as any fellow citizen to ensure that their individualized interests are upheld after years of having to ensure that the protection of basic human rights in the United States constitutional framework and civil rights advancements have come to existence (White, Simpson, Gonda, Ravesloot, & Coble, 2010). Self-determination as it relates to sustainability

recognizes the contribution that each person can make to ensure that services continue to advance, become more inclusive, and be supported naturally in the person's identified social network. Warfield, Chiri, Leutz, and Timberlake (2014) found that providers who worked together decreased family stress and improved outcomes for self-direction.

Self-determination relative to collaboration rests in assurance that the student is educated and presented all opportunities to invite applicable adult services to his or her respective IEP transition meeting (Seong et al., 2014). Obiakor et al. (2012) recognized collaboration as a key component for the student to expand his or her support network and thus champion goals toward further education, employment, and independence.

### **Collaboration in Transition Planning**

Oertle, Trach, and Plotner (2013) have called for collaboration education, stating, "Little research has focused on collaboration; therefore, research based evidence is needed to develop strategies to enhance collaboration among professionals, families, and transitioning youth" (p. 33). Providing the mechanism to support collaboration represents the next step in building an effective transition framework. Trach (2012) called for a vehicle to enhance collaboration and avoid the potential for service redundancy among educational and Medicaid waiver support providers.

Noonan et al. (2008) described effective strategies for interagency collaboration based on a conducted study of 29 high-performing school districts that have led stronger transitional outcomes. The authors concluded that personnel specific to the transition process were essential. Flexible scheduling and staffing models promoted stronger communication and collaboration based upon a proven understanding of necessary



timeframes. Thus, networking among transition stakeholders was a key strategy promoted as an outcome of the study and will be reflected in this study.

Baer, Daviso III, Queen, and Flexer (2011) found poor alignment in post-school goals within the transition from middle school to high school. In a survey of 4,500 students and respective IEPs and post-school outcomes, efforts for collaboration were lacking among educational settings. Therefore, if they are lacking an internal system, then efforts among two bureaucratic entities must be analyzed as well.

Employment-minded service delivery represents the largest component of empirical evidence bridging collaboration strategies between an educational and Medicaid waiver support model emphasizing sustainability. When students move into an adult support model with continuous paid employment, efforts to stay employed are greater and the impact on entitlement programs decreases, specifically among Medicaid waivers and Social Security (Fraker et al., 2014; Wehman, Chan, et al. (2014). A key component of the transition process resides with vocational rehabilitation as a bridging entity and potential collaborating body in the State of Indiana (FSSA, 2015).

Oertle et al. (2013) surveyed vocational rehabilitation service providers on their perspective of the collaboration process within transition planning. The results showed that vocational rehabilitation service providers would like more communication among stakeholders of the transition meeting and would expect more communication than they have currently. Follow-up on the transition process ensured the communication loop was closed and represents another collaboration strategy for analysis in this study as an effective measure or current barrier to success (Noonan et al., 2008).

## Summary and Conclusions

A review of the literature surrounding the history and development of policy for people with intellectual and developmental disabilities has presented separation tied to public assistance as the primary source of the rebuilding necessary today. Throughout the generation of HCBS waiver policy and improvements in special education services, the cyclical call through federalist expectations is a return to a model of inclusiveness and harmony (Kapp, 2011).

An in-depth review of the literature was warranted to demonstrate how a short time period of integrative policy has fostered a rebuilding of centuries of limited opportunity. The woodwork effect brought people to services, and the calls for change expanded with increased stakeholder involvement and critiques of public spending through Medicaid and educational funding mechanisms.

Public spending tied to policy in the State of Indiana has offered improvements for individualized planning, sustainability, and collaboration. A review of the literature has shown that collaboration is necessary but lacking (Carter et al., 2011). It is known that this is an area needing improvement, especially since Indiana guidance in this particular area has not received proper updates in training materials since 1996 (Bowen, 2014).

A missing component within the literature review is how to foster collaboration between HCBS waiver providers in adult services and special education transition stakeholders for children aged 14 to 18 with severe intellectual and developmental disabilities. The focus of the research study asked how collaboration can occur to bridge

this particular gap in the literature and gap in service toward sustainable service outcomes. Self-determination theory and models of individualized planning have paved a way to bridge both areas and were worthy of continued research within this particular study.

### Chapter 3: Research Method

Transition-based policy for students with intellectual and developmental disabilities takes place under a special education framework of oversight and research (Carter et al., 2013). However, in the State of Indiana, more students have entered into a dual model of adult-based care under the Medicaid HCBS waiver, and while opportunities for collaboration exist, they have been ineffective or underutilized (Carter et al., 2011; Moore & Schelling, 2015). Therefore, the purpose of this explanatory case study was to gain a better understanding of current collaborative efforts and possible barriers to effective outcomes surrounding inclusive supports, adherence to employment priorities, and long-term goals initiated by the person through a self-determined method (Parker Harris et al., 2014).

This explanatory case study relied on IEPs and ISPs as documented evidence of collaborative goal development through the key guideposts of service provisions and funding under each bureaucratic agency from the Indiana DOE and FSSA. Additional data sources came from interviews conducted with stakeholders from both bureaucratic perspectives.

As a stakeholder and an employee under the HCBS waiver model in the State of Indiana, I believe that transparency and removal of bias will be critical in the disclosure of procedures, data analysis, and communication with stakeholders. The American Political Science Association's Committee on Professional Ethics, Rights, and Freedom (2012) defined production and analytic transparency as an understood standard of research behavior. Because this particular study includes human perspectives and the

research focuses on a vulnerable research population, interviews with people with intellectual and developmental disabilities did not occur. Those data were obtained through the document review of IEPs and ISPs as representations of collaborative goal development and fading strategies in an integrative and reflective capacity of each bureaucracy's service priorities.

### **Research Questions**

RQ1: Relative to transition planning, what do stakeholders perceive as barriers to quality of life outcomes for students with moderate to severe intellectual or developmental disabilities in the State of Indiana?

SQ1: How do policy makers from the DOE foster self-determination practices within transition planning?

SQ2: How do policy makers from the FSSA foster self-determination practices within transition planning?

RQ2: Relative to transition planning, what do stakeholders perceive as barriers to collaborative policy-making from the DOE and the FSSA in the State of Indiana?

### **Study Design and Rationale**

For the purpose of this study, a qualitative design was chosen as the preferred method to understand how systematic functions at two governmental departments interacted to impact the framework of service for people with intellectual and developmental disabilities during an educational phase of transition (Patton, 2015). Patton (2015) described qualitative research as a core strategy that yields thick description regarding personal perspectives through inductive review (p. 46). Trach

(2012) called for a qualitative analysis of collaboration themes and patterns that promote improved methods in a transition framework. Information on transition support outcomes has been largely quantitative, resulting from the NLTS2 demonstration of gaps in specific measures, not perspectives during the process (Bouck & Joshi, 2014). Francis, Blue-Banning, and Turnbull (2014) recognized an underuse of qualitative methods relative to quality of life outcomes for people with intellectual and developmental disabilities.

To gauge comparable perspectives from stakeholders toward transition-based policy for people with intellectual and developmental disabilities, a case study represented the ideal research tradition. Yin (2014) cited decisions and processes as focal points in case studies; therefore, a qualitative case study was applicable to the research questions and accepted multiple sources of evidence. The perspectives shared by stakeholders measured the components of collaboration efforts and bound the cases regarding process successes or defeats surrounding transition policy for people with intellectual and developmental disabilities (Patton, 2015). A similar case study was conducted regarding perspectives from parents and participation in transition procedures for students with intellectual and developmental disabilities (Gross et al., 2013).

this research design, qualitative data came from policy-driven documentation in the IEP and ISP and from interviews with stakeholders relative to policy development and implementation. Documentation was requested through The Arc of Indiana, a large advocacy network for people with intellectual and developmental disabilities and their families. Interviews with policy stakeholders from the FSSA and the DOE provided data toward inquiries of effectiveness in transition systems and procedures for children

leaving a special education setting. The purpose in utilizing both qualitative sources of information was that it added depth to the research and assisted in triangulating the information for increased confirmability with the results (Patton, 2015).

Previous to the case study selection, a phenomenological study was explored for its application to a select group of people over a period of time. As policy-driven efforts shift service delivery on a regular basis, such as the changes in Medicaid waiver guidelines in 2012 and revisions to special education guidelines in 2014, efforts to ensure complete historical awareness and shifts in service would be challenging, especially for children aged 14 to 18 who have only recently begun having access to both service options through the DOE and the Medicaid HCBS waiver (DOE, 2014; FSSA, 2015). For this study, the purpose was to understand what barriers exist in policy to limit opportunities that enhance the continuum of care as a student enters an LTSS model and demonstrate ongoing efforts toward inclusive care.

### **Role of the Researcher**

The role of the researcher in this study was one of an observer-participant. I was the person collecting data from both qualitative sources through documentation review and conducted interviews. By participating in the interviews with stakeholders for policy development, my professional role in an Indiana provider agency for children and adults with intellectual and developmental disabilities was disclosed. In my professional role, I have the capacity to shape internal organizational policy, but I do not impact policy relative to comprehensive service delivery in the State of Indiana. Patton (2015) described the need for neutrality by ensuring the researcher is true to emerging

perspectives and not influenced by previous beliefs, nor participation in processes toward the study.

To eliminate bias, no form of qualitative data originated from my professional organization. Interviews took place in locations of each stakeholder's preference, but not within my organization. An additional area of disclosure came in my role as a guardian and advocate for two people with diagnosed developmental disabilities. While their service model may be offered in another state, efforts toward inclusive care exist in all programs with federal oversight. Patton (2015) describes empathetic neutrality grounded in mindfulness by recognizing the quest to bring experience into action and ensuring complete focus and individual attention to all qualitative reviews (p. 58). I employed mindfulness as well as truthful note taking and analysis to ensure empathy did not develop into bias.

## **Methodology**

### **Participant Selection Logic**

Yin (2014) suggested as a principle toward qualitative data collection that multiple sources of data be utilized. There are two population sources in this qualitative study. Each was described based on sampling strategy and saturation toward the procedure within the research design. The first population was reflected in the documents submitted for review. Essential comparisons of IEPs to ISPs for students/children aged 14 to 18 during the 2015-2016 school year provided additional qualitative data to support process analyses and comparison examples to authenticate or counter the conducted interviews. The sample was purposeful in that only children with both IEPs and ISPs



could have their documents submitted for review. The essential nature of both documents provided the written process with State of Indiana guideposts for collaboration during the transition process. Up to 20 combinations of IEPs and ISPs were collected toward the generation of themes as they each required similar policy guideposts of effective and measurable goal development. The specific sampling strategy represented was quota sampling, where a predetermined number of cases were preselected to fit the criterion of having both IEPs and ISPs from a larger pool of people utilizing LTSS (Patton, 2015). This sample was determined from the number of parents who volunteer to submit their child's IEP and ISP until the quota of 20 is reached.

The population of stakeholders for the conducted interview process came from the criterion that participants in the interview must have a direct link toward policy development or in the writing of the state-guided implementation procedures for writing the IEP or ISP. In the State of Indiana, there are stakeholders who draft policy for waiver and educational supports and those who implement the defined expectations within their respective service domain. Since the bounded case represents collaboration policy, a sample of 10 stakeholders was selected under the key informants, key knowledgeable, and reputational sampling strategy from both the IEP and ISP development and implementation perspective (Patton, 2015). This sampling strategy was designed to go to the stakeholders directly impacting or impacted by the policy that shapes the service delivery in educational and waiver settings. Patton (2015) defines the key informant sampling strategy as a method widely used to identify trends and future directions; however, this method of qualitative inquiry must be mindful of the scope of the sample,

and for that reason, stakeholders who develop and implement policy relative to transition-based supports were interviewed within this study (p. 284).

## **Instrumentation**

### **Interview protocol**

A developed interview protocol (Appendix A) was utilized in this study as a guidepost to the qualitative data collection process. This represented one of two instruments used as tools within this study. The basis of the interview protocol (Appendix A) came from current literature assessing awareness, planning, and perceived effectiveness of transition policy. Key themes with respect to present effective measures and benchmarks toward integration, employment, and self-determination strategies were utilized in the interview protocol (Appendix A). The interview protocol (Appendix A) ensured common themes were captured to demonstrate if the bridge between supports in an educational and natural supports waiver setting is clearly captured both in the IEP and the ISP, based upon perceived information sharing procedures and implementation.

The interview protocol (Appendix A) included the expectation that Level 1 questions were asked of the stakeholder. Yin (2014) describes Level 1 questions as bounded and required questions that leave limited interpretation to sway from the interview protocol (Appendix A) and add validity to the study (p. 110). The interview protocol (Appendix A) defined the questions that were asked of each stakeholder despite his or her educational or Medicaid waiver affiliation. However, the interview closed with one Level 5 question, which was an open-ended question as a recommendation toward policy improvement as it relates to transition-based supports from both bureaucratic

perspectives as a way to gauge forward-thinking viewpoints on policy measures.

Interview responses were captured on an iPad using the Interview Recorder application, which allowed for the generation of an interview template and the recording of individual questions upon receiving permission. The application promoted consistency upon completion of the template to ensure one question followed the next. After the responses were gathered, they will be analyzed for themes using NVivo.

### **Documentation Rubric**

The second instrument was a review protocol (Appendix B) generated in a rubric (Appendix B) for measuring effectiveness in goal development grounded in the IEP and ISP. While the IEP and ISP may represent qualitative data, a common comparison rubric (Appendix B) was necessary to add credibility to the research process. Quality information sharing should be demonstrated in common goals and objectives through the IEP and ISP to create a solid grounded practice for service delivery in both settings as a platform to LTSS. The IEP and ISP are policy-driven documents recommended in guidelines from each bureaucratic entity. They are the strongest source of policy measures, because the templates for both the IEP and ISP are grounded in desired outcomes of each service provided. Therefore, a tool to analyze the common themes in both documentation sources was measured through a goal development rubric (Appendix B) for the person supported. If 80% or more goals were similar in the IEP and ISP for students/waiver participants aged 14 to 18, the rubric would score a 4—60% to 79% would score a 3, 59% to 40% would score a 2, 39% to 20% would score a 1, and less than 20% would score a zero. Themes of employment, inclusive service objectives, and self-

determination objectives will be collected by the type and frequency of goals in each document and coded by the researcher toward the overall qualitative data review within NVivo. The rubric will serve as a component of secondary comparison evidence in the triangulation of qualitative data.

The researcher in this research design generated both data collection instruments. The instruments addressed the overall research questions by demonstrating perceived barriers to transition outcomes, implementation of self-determination processes, and measured barriers to bridged service delivery. To promote content validity, questions will include current literature guideposts of quality of life outcomes, but they will not ask if implementation is specifically in place to ensure questions are not guided in the interview. I built the interview protocol (Appendix A) and rubric to ensure they are standardized and narrowly tailored to the topic of inquiry.

### **Pilot Study**

For the purpose of the qualitative case study, a pilot study was conducted with waiver case managers in the State of Indiana supporting children in transition aged 14 to 18. Case management companies in the State of Indiana were presented with the interview opportunity to pass forward to their employees on a voluntary basis of participation. An e-mail was sent to the CEOs of the five Medicaid waiver case management companies asking for the ability to pass forward this volunteer opportunity. Ten waiver case managers were utilized for the pilot study based on who volunteers first. Since Medicaid waiver case managers have experience with the IEP and ISP, and they also support transitions for people with intellectual and developmental disabilities and

respective natural support networks, the Medicaid waiver case managers set the time to meet in the professional office location of their choosing. Recognizing that Medicaid waiver case managers operate independently as contractors, utilizing my professional environment may be necessary for the pilot study but not preferred. Secure private meeting rooms at local libraries were the preferred meeting location as services and perspectives across the State of Indiana were assessed. The insight of waiver case managers was valuable to gauge effectiveness and impact of likely interview questions developed toward the interview protocol (Appendix A) and case study protocol (Appendix C) as it relates to the parallel nature of current literature surrounding the topic of supporting people with intellectual and developmental disabilities during a transition (Yin, 2014). Waiver case managers received a \$10 Starbucks gift card for their time following the completion of the interview.

Data from the pilot study interviews were collected from responses and conveyed as themes in the compilation of the study, but they were specifically transcribed as they were the main study. The researcher captured the responses to the interview questions in notes, reviewed the responses for themes, and analyzed them for possible necessary improvements prior to the main study. Recognizing that the collected information was not utilized in the formal research design and analysis, the value of the testing questions added legitimacy to the overall research design and qualitative data collection process. Yin (2014) presented that the importance of the pilot study report reflects toward the lessons learned within the research design and procedures, which may also include recruitment strategies in gathering interview participants. The generated pilot study was

included in the results as a standalone process meant to test the interview protocol (Appendix A) toward the main study and was submitted with the institutional review board (IRB) application as a component of the research process.

While the document review utilized in the main study was not included within the pilot study, its contribution toward effective procedures grounded in policy expectations of service transition was assessed during both the pilot study and the main study using the interview protocol (Appendix A). Following the completion of the proposed interview questions, the waiver case managers were given a copy of the template and asked for strengths and weaknesses of the assessment tool. The questions remained open-ended and be analyzed for themes.

The rubric (Appendix B) was presented to participating waiver case managers to gauge their feedback on the use of the generated instrument. The instrument was subject to feedback prior to implementation within the main study. As waiver case managers review both documents guided by state policy, the pilot study ensured both instruments were assessed and improved upon prior to the main study following approval from the Walden IRB.

### **Procedures for Recruitment, Participation, and Data Collection**

An important consideration within the main study for participants in the interview protocol (Appendix A) and document review was that the standards of questions and policy review be the same for both perspective sources. But for data analysis, the initial distinction of DOE or FSSA was necessary, DOE stakeholders spoke toward the generation of the IEP, and FSSA stakeholders spoke toward the development of the ISP

and its implementation through Medicaid HCBS waiver funding. Transition coordinators were also interviewed as empirical evidence recognizes their role as essential to effective communication and collaboration (Noonan et al., 2008). Both bureaucratic sources of information answered the overall research questions and sub-questions.

### **Interviews**

The overall research question surrounding the perception of barriers to quality of life outcomes for students with moderate to severe intellectual disabilities were asked in the interview protocol (Appendix A), but questions also went toward the perception of quality of life outcomes overall. Additionally, the interview protocol (Appendix A) asked about self-determination practices and collaboration experiences. I was the person collecting information from the stakeholders and interviewed as many policy-relevant stakeholders as needed until saturation occurred. The current sampling strategy is set for 10 participants for each bureaucratic perspective.

Interest for participation in the qualitative study began with the DOE and FSSA relative to policy developers and financial planners for supports toward people with intellectual and developmental disabilities. An e-mail explaining the purpose of the study and requesting participation in the interview was sent out to each respective bureaucratic director with a follow-up phone call. The e-mail sought permission to forward the e-mail on and directly reach out to e-mail contacts that are publically available through each department's website in a manner of snowball sampling (Patton, 2015). Based on the returned response to participate, the necessity of seeking out additional stakeholders was assessed. Stakeholders directly tied to the DOE and FSSA were preferred as a

demonstration of collaboration-based policy. However, implementation perspectives from educational and Medicaid waiver providers added insight into the collaboration opportunities specific to transition planning based on day-to-day experience. Should additional stakeholders be necessary, then e-mails were sent out to statewide principals and Medicaid waiver providers that support students/children aged 14 to 18 with intellectual and developmental disabilities.

Due to the nature of the questions referencing effective policy measures for educational supports, interviews were conducted during times when a school session is not initially underway, such as in the months of August and September for transition-age students. In addition, interviews were avoided during the months of January and February, recognizing that policy developers will be connected to a current legislative session. All other months were available to conduct interviews. Interviews were completed in the professional location of the participant's choosing, and time preferences for conducting the interview throughout the day were determined by the participant. The researcher was planning to block out one day a week to ensure open availability to conduct interviews at the time and preference of the participant.

Each interview was anticipated to last less than one hour and was recorded electronically recorded using the iPad application Interview Recorder, which allowed for manual note taking and recording of responses. If someone participating in the study chooses not to be electronically recorded, an understanding that notes will be taken during the interview was be conveyed to the participant. One interview from each bureaucratic entity represented the goal per week during the data collection phase to



ensure that one bureaucratic entity does not dominate as a data source and that participation in the interviews is neutral. Data was collected for up to 20 participants or until saturation occurred. However, if there are too few participants or saturation of themes did not occur, an additional advertising strategy or incentive to participate would have been explored.

Upon completion of the interview, a \$10 Starbucks gift card was sent to each participant and a link with the completed study will be dispersed previous to the data entry process. A transcribed or written summary of the interview will also be sent to the participants to ensure agreement in their responses as a form of member checking (Patton, 2015). Only in the event that extensive outlier information was presented would follow-up interviews be necessary. The provision of a summary and the possibility of the necessity for follow-up questions were clearly communicated to participants before the interview occurs.

### **Rubric**

The rubric (Appendix B), as a measure of collaboration and self-determination, was utilized as a document review source. This rubric (Appendix B) would not answer questions about perceptions, as those will come from the interview, but the review of the IEP and ISP was a necessary component of data within the qualitative design.

Data was collected from the submitted dual IEPs and ISPs by parents or natural supports of children supported in the State of Indiana. Data was collected and sorted by The Arc of Indiana, then passed forward to the researcher under full disclosure of participation that this process will occur. To utilize The Arc of Indiana's platform of

communication, an initial meeting with the director of organization was requested to provide education and ask permission to utilize the organization's weekly newsletter to communicate information about participation in the study. As an advocacy organization, The Arc of Indiana's support of children and students with intellectual and developmental disabilities, along with the families who are supporting them, served as an invaluable partnership within this study. To help explain the information sharing and data collection process, a flow chart was designed and reviewed with the key contact or contacts at The Arc of Indiana and forwarded to participants in the study.

Training on the essential process, confidentiality, and security measures occurred with The Arc of Indiana contacts, and a training verification form was signed. A preferred number of no more than two Arc of Indiana contacts ensured that the scope of handling documents remained small.

The flow chart explained that the weekly newsletter from The Arc of Indiana serves as the advertising component. Parents and guardians agreeing to share information will understand that they are sharing private information with The Arc of Indiana, and the contacts at The Arc of Indiana will receive necessary training to ensure that the received documents are kept private. It was not a breach of confidentiality if a parent volunteers to share the individualized goal development documents written in the IEP and ISP for his or her child. This researcher does need to know names, simply age, level of diagnosed intellectual or developmental disability, and established goals. This study was looking at information sharing between both state-guided documents.

After receiving the IEPs and ISPs with The Arc of Indiana, the flow chart explained that the documents were redacted for individual names and then kept in a locked filing cabinet or password-protected file on the computer of the key contact. This level of security and collection was disclosed in the initial communication with The Arc of Indiana. Once 20 paired documents were collected, the key contact at The Arc of Indiana contacted the researcher for either confirmed e-mail communication in the sharing of the password-protected file or through pickup. The documents, should they be hard copies, were kept in a fire-safe case and stored in the personal office of the researcher. The documents were then shredded after they have been reviewed, and a witness will verify through the signature of a document destruction form that the documents have been eliminated. Should a password-protected file be removed, verification of this process would occur and a signed witness agreement that this has taken place would follow. To close out the flow chart, the data analysis and completion of the study explained that participants will have access to review the completed study. Member checking did not occur during this portion of the qualitative interview to ensure confidentiality.

The Arc of Indiana knew who has shared documents through participation in this study. The organization asked people who agree to share their respective child's ISP and IEP to sign a form consenting to the review of their information. This consent was kept with The Arc of Indiana under the agreement that no IEP or ISP was passed forward without this consent. The consent ensured that nothing will be acted upon with the learned information from the IEP and ISP beyond information review. Both the risk to

the people interviewed and the risk of utilization of retrieved information are negligible in the data collection and analysis process for this study.

Parents who have developed partnerships with The Arc of Indiana have an established trust, which was demonstrated in their ongoing review of their weekly newsletter. Nonetheless, the key contacts at The Arc of Indiana need to ensure that names were redacted before passing information forward. After the documents had been passed forward or e-mailed electronically, they were shredded. Maintaining contact information with the parent participating was necessary to ensure that the child/student and parent received a \$20 gift card to Walmart and access to review the completed study. Contact beyond those occurrences was not necessary following participation in this study.

The documentation request occurred over four weeks in an Arc of Indiana weekly electronic newsletter. If more data was necessary, an additional advertising strategy or incentive measure for participation would have explored. No follow-up occurred with the documentation/policy reviews, but The Arc of Indiana received cards and the \$20 Walmart gift cards to pass forward as measures of gratitude. The results of the study will be shared with The Arc of Indiana and participants who submitted IEPs and ISPs.

### **Data Analysis Plan**

There will be two forms of data collected during the research phase. Data coming from document review, captured in a comparison rubric (Appendix B), and through conducted interviews. Each data source was necessary to ensure that both research questions were addressed within this study. The document review represented a demonstration of collaboration, and the interviews provided information on the

perspectives from policy stakeholders. Each data source was entered in NVivo for thematic analysis.

Utilizing NVivo was valuable due to the depth of information that could develop from the interview process. Part of the coded review in comparing the IEP and ISP occurred through the rubric (Appendix B), as recognition of educational and adult-based supports. As Patton (2015) presented, there was value in hand coding and working with the information beyond data entry in a computer program. For this reason, the rubric (Appendix B) became a tool linked to the coding process. I used the rubric (Appendix B) only as a comparison measure, but the developed data was included in the comprehensive NVivo program as a contribution or deflector of overall themes. Should there have been outliers in the data review process, the scale of impact was determined utilizing an inductive analysis approach (Patton, 2015).

As this study represented an explanatory case study, Yin (2014) presented the necessary step of ensuring that the data answer the initial sub-questions, then more encompassing research questions in a progressive phase. The projected analytic strategy rests on an inductive process of using theoretical propositions through the literature review to begin developing a matrix with corresponding categories following the data review (Yin, 2014). The data are meant to speak for themselves, and coded information depends on the results of the overall information. This coding technique was valuable with these two data sources to ensure that all information was captured and promoted data review development and consistency.

After reviewing these data, explanation building, as a form of pattern matching, was utilized as a parallel to the inductive review. Yin (2014) cited the causal links and respective policy process as key opportunity areas for future policy action using this data development and analysis process. The steps of the process included developing the initial proposition, comparing findings, and reviewing additional findings through the inductive process (p. 149). It was important to recognize that additional data reviews may have been necessary. Current coded topics from the literature review that have been added within the interview questions were focused on the transition meeting flow, leadership from the student with an intellectual or developmental disability, networking opportunities among stakeholders, and barriers to the transition process (Noonan et al., 2008). The responses from the interview questions led toward alternative review measures.

An additional key recognition to the explanation building data analysis process was to ensure that the inductive strategy does not lose focus on the key topic. It is important to consistently return to the research questions and key sub-questions as a measure of dependability in the analysis process. Yin (2014) described the challenge of inductive review in failing to link all the pieces together toward key themes. Patton (2015) recommended continuing to look for recurring regularities through pattern analysis on an ongoing basis. These themes were pinpointed in the interview protocol (Appendix A), rubric (Appendix B), and guided questions within this study.

## **Issues of Trustworthiness**

### **Credibility**

To ensure credibility within this study, two techniques were employed. Saturation was utilized in the interviews to ensure that information was gathered until repetition in the answers was displayed. Triangulation served as a method of data comparison and verification.

Patton (2015) defined saturation as information redundancy where there was a small sample size (p. 300). Patton (2015) cautioned researchers in using saturation to validate the information redundancy, because it tied to variation in the actual sample as well as the size. To ensure credibility, a variety of stakeholders shared perspectives during the qualitative interview collection process, and they had the opportunity to review the transcribed information through member checking (Houghton, Casey, Shaw, & Murphy, 2013). Patton (2015) recommended using ongoing analysis as a reflection process. As notes were taken in this study, in addition to recorded interviews, comparison opportunities within data collection were possible.

Yin (2014) recommended collecting information from multiple sources in a case study to promote confirmatory evidence. Triangulation of the evidence occurred in this study through the comparison of IEPs to ISPs to what was learned in the interview process. Strengthening credibility was a contributing factor in selecting both sources of evidence as well as in utilizing a pilot study. Lastly, findings from the study were shared with all participants. Houghton et al. (2013) promoted the use of member checking as a method to enhance qualitative rigor within the study.

## **Transferability**

The interactive policy model enhanced the opportunity for transferability where one state represents a larger federal system and the dynamics in which special education and Medicaid HCBS waivers are upheld to generate ongoing funding. Therefore, the elements guiding transferability were high, because what was learned through the research questions with respect to collaboration and self-determination practices can be applied to other states. However, while additional applications to other states did not occur within this qualitative case study, a review of similar descriptive data did take place. Lincoln and Guba (1985) established a descriptive data-driven comparison as a qualifier for transferability in a qualitative methodology. All states have an overarching policy network guiding disability supports, and all states utilize an ISP and IEP to shape service delivery (Rizzoli et al., 2013).

Operating in similar policy implementation guidelines, the description of this study can serve as a foundation for an additional case study model in another state or in a multi-state comparison analysis as a vehicle to guide federal policy change. Requests for participation in IEP and ISP comparison can be mirrored across state lines or additionally as the foundation for a longitudinal study to demonstrate effectiveness of inclusive and self-determination efforts through increased education for people supported, natural supports, and policy makers. Lastly, stakeholders will always have a role in shaping policy for people with intellectual and developmental disabilities. The opportunity to gather interviews can be transferred toward future studies.



**Dependability**

To promote dependability within this case study, triangulation using multiple sources represented a supporting method. However, the primary triangulation method came from participant review from the transcribed interview or notes, depending on participant preference, following the interview and before each individual's data was entered into NVivo. This validation ensured that the information collected was accurately conveyed in the findings. Due to the level of importance in policy development for people with intellectual and developmental disabilities supported by special education and Medicaid HCBS waiver services, accurate interpretation has the capacity to extend toward improved policy measures. Patton (2015) states, "Researchers and evaluators can learn a great deal about the accuracy, completeness, fairness, and perceived validity of their data analysis by having the people described in that analysis reach to what is described and concluded" (p. 668).

**Confirmability**

Patton (2015) defined reflexivity as efforts by the qualitative analyst to ensure authenticity and trustworthiness (p. 603). Working in the field supporting people with intellectual and developmental disabilities, I can anticipate a level of questions regarding what other interviewees or the data have to say early on in the collection process. As the researcher, I let the body of work speak for itself but also delve further into why questions may be asked.

Patton (2015) presented three questions toward reflexive inquiry. The first question asks how one knows what one does. Beyond the literature review, the researcher

must know what perspectives exist in order to ensure that the paradigms surrounding service delivery do not shape questions or behavior when conducting qualitative analysis. The second question focuses on the reflexivity of those interviewed by recognizing their perspective of the process and experience. The third question delves toward introspection from the audiences furthering interpretation from the interpretation (Patton, 2015, p. 604).

### **Ethical Procedures**

Supporting people with intellectual and developmental disabilities one must maintain a level of confidentiality and second assurance to guarantee names, diagnosis, and service model are respected to one's individual care. A parallel level of support occurred within this study.

Anticipated documents needed to ensure ethical procedures were upheld were submitted to the IRB through Walden University and submitted with my application. First, a permission form from The Arc of Indiana was necessary to gather IEPs and ISPs. The Arc of Indiana also had parents who are participating on behalf of their child aged 14 to 18 sign permission forms, including Health Insurance Portability and Accountability Act compliance and verification of the flow chart process, for their child's IEP and ISP to be reviewed. An understanding that The Arc of Indiana was the filter of information to ensure anonymity will be clearly conveyed. The review process occurred under full disclosure that the information and study were described and results shared. One ethical consideration from the gathering of data rested on the age of the population. To promote anonymity, names were redacted from each document gathered, then passed forward

from The Arc of Indiana. Recognizing that the parent makes a majority of service decisions until the child is 18, permission goes to the defined guardian. This was a voluntary gathering of documentation, and no documentation was reviewed unless submitted in this manner. No children will be directly involved.

Adult stakeholders needed to sign a permission form and have permission from their respective employer to participate. They must have also agreed to the recording of the interview or the taking of written notes throughout the interview. It was important that the interviews take place in a professional setting to ensure comfort and confidentiality. Should stakeholders choose not to participate in the interviews, it may have been necessary to acquire additional stakeholders should saturation not occur.

Data utilized within this study were-anonymous for the document review. The Arc of Indiana agreed to shred all information beyond the participant name and address, which was used to submit a token of appreciation. A third party gathering the information and redacting the information ensures that I did not select documents based on perspective and preference. After the data were-reviewed and coded, the documents were shredded with signed witness verification. Until that time, the documents were kept in a fire-safe box within the home office of the researcher. If the Arc of Indiana scanned redacted documents electronically, they were kept in a password-protected file on a password-protected laptop, then deleted following the completion of the study. A witness provided signed confirmation of the deletion.

Data from the qualitative interviews were collected in a confidential manner. Recordings from the interview were stored on a password-protected iPad. Upon

completion of the study, the information was deleted with a witness signature.

Information was kept only through the duration of this study.

As a personal laptop was used to review IEPs and ISPs, NVivo was used for data analysis, and an iPad was used for interview data collection, the security of information was critical to this study. First, securing my laptop occurred through an initial login and secured login for the password-protected folder. This folder was shared through Dropbox and can be manually accessed in the event that the laptop is stolen. My iPad was protected through Find My iPad settings, and the *wiping out all information* option would have been engaged should the iPad have disappeared. Information from my iPad can be accessed through Apple's iCloud. Added protection from the Lookout application served as a parallel function. Throughout the study, both my personal laptop and iPad were kept in a locked briefcase as an additional security measure in my professional role to ensure the research gathered remains out of professional property.

As I am a stakeholder in the field, efforts to remain neutral were also critical. Interviews were conducted in my professional environment, and no known documents came from people supported by my organization. This study was not one that serves in a professional capacity. The purpose of this study was to learn about collaboration efforts to improve supports for people with intellectual and developmental disabilities overall.

### **Summary**

Moore and Schelling (2015) called for an increase in qualitative and outcome-based research to parallel the growth in employment initiatives and educational opportunities as people with intellectual and development disabilities are leaving high

school. This explanatory case study served the purpose of understanding barriers and efforts underway to promote integrative models of care.

Using two forms of data—conducted interviews and documents in IEPs and ISPs this study addressed the research questions using two collection techniques. Data was analyzed using NVivo but also captured through a rubric (Appendix B) as a mechanism of initial document review. Participants and stakeholders were selected using strategic sampling methods, all procedures were disclosed, and efforts to maintain and ensure confidentiality occurred. As I am a stakeholder in the support industry for people with intellectual and developmental disabilities, efforts to ensure mindfulness throughout the process were maintained. Data toward documentation collection were gathered from an outside entity, and professional boundaries were disclosed but never utilized as a data source.

Improving supports for people with intellectual and developmental disabilities represents the goal of continuing the path of inclusive services throughout history as guided by policy initiatives. Completion of this study provided a demonstration of the ongoing efforts of collaboration between two bureaucratic entities toward this goal. This study served as a representation of the development of sustainable long-term services and supports guided by forward-thinking measures.

## Chapter 4: Results

Information sharing and mutual training are collaboration frameworks that establish a successful transition plan toward improved long-term objectives for students with intellectual and developmental disabilities (Noonan, McCall, Zheng, & Erickson, 2012). This study reviewed perspectives and processes of stakeholders that generate, implement, and evaluate policy surrounding transition-based supports for students with moderate to severe intellectual and developmental disabilities aged 14–18 in the State of Indiana using the following research questions:

RQ1: Relative to transition planning, what do stakeholders perceive as barriers to quality of life outcomes for students with moderate to severe intellectual or developmental disabilities in the State of Indiana?

SQ1: How do policy makers from the DOE foster self-determination practices within transition planning?

SQ2: How do policy makers from the FSSA foster self-determination practices within transition planning?

RQ2: Relative to transition planning, what do stakeholders perceive as barriers to collaborative policy-making from the DOE and the FSSA in the State of Indiana?

Through interviews and review of state-driven documents, I studied barriers to quality of life outcomes, self-determination practices, and opportunities for collaboration during the transition process. While there exists a formal advisory council for transition planning, the critical component for students with intellectual and developmental

disabilities rests on the personal experiences and individual application of current policy guideposts.

In this chapter, I will review the pilot study, overall study framework, and analyses of collected data. Before collecting data, changes to the scope of case management organizations participating in review and access to state-driven documents prompted a procedural change. The IEP and ISP are two critical documents that demonstrate transition planning. However, access to these documents from case managers, as even the case management organization assumed, was not available, and procedural changes occurred after the pilot study.

Following the pilot study, the lack of information and participation impelled procedural changes to the research process. The Walden IRB applications reflected necessary changes, and final approval was granted upon procedural changes and the receipt of Letters of Cooperation from FSSA (Appendix F) and the DOE (Appendix G). The Walden IRB approval number is 04-08-16-0365764.

Throughout the research process, lack of participation also prompted seeking additional resources for perspectives on transition-planning and qualifiers for success. Vocational rehabilitation became especially valuable as a resource when other viewpoints were lacking. Perspectives from Vocational Rehabilitation fall under FSSA, and the transcripts of their respective interviews were able to be utilized and reviewed.

Analyses of the data demonstrated that the information obtained through interviews and state-driven resources provided an ongoing opportunity for improved collaboration pathways. The platform for anchored systems that elevate the expectations

and opportunities available for students aged 14–18 with moderate to severe intellectual and developmental disabilities in the State of Indiana could enhance employment avenues and preferred social roles that are determined by the students, thus giving the students confidence to create their preferred goals and strategies of support.

### **Pilot Study**

A pilot study was utilized to help ensure the interview questions were conducive to stakeholders participating in transition based supports. Initially, the pilot study was structured to review the interview protocol (Appendix A) and documentation rubric (Appendix B) among five case management organizations in the State of Indiana. Due to the lack of response among the five case management agencies through e-mail and phone call communication, one case management organization agreed to participate. Indiana Professional Management Group agreed to have a field support supervisor review the interview protocol (Appendix A). The Walden IRB approved this change.

The interview protocol (Appendix A) was the only source of examination as a review of the documentation rubric (Appendix B) was no longer necessary. Through adjustments made within the Walden IRB application, a decision was made recognizing that the standalone documents would represent a perspective and would not prompt a change in the documents themselves.

The pilot study only reviewed the interview protocol (Appendix A). During the evaluation of the interview questions and their contents, it was by a representative from Indiana Professional Management Group recommended the insertion of a question surrounding Vocational Rehabilitation. The added question was a valuable contribution



to the interview as Vocational Rehabilitation in the State of Indiana falls under leadership from FSSA and the Division of Disability and Rehabilitative Services, which represents a critical bridge from DOE and Medicaid waiver supports. Utilizing a pilot study before implementation of the interview questions was essential to the study. Adding a question about Vocational Rehabilitation provided a necessary policy link to transitional expectations for service delivery. The interview protocol II (Appendix E) was updated before interviews took place.

### **Research Setting**

The participants to be interviewed to gather qualitative data came from the DOE and Division of Disability and Rehabilitative Services (DDRS) under FSSA. Initially, a source of qualitative data was established to come from an Indiana case management organization. However, due to ongoing turnover and unresponsive communication, I decided to move forward with available qualitative data through interviews.

Qualitative data were designed to come from interviews with DOE and DDRS. A majority of people interviewed chose to participate by phone due to their respective schedules, despite the offer to meet them in a preferred location. Throughout this study, key themes of time, turnover, and opportunity to facilitate change rose to the surface, thus impacting the participants available in this study.

Many requests for interviews reflected how busy participants were and resulted in a limited response. As a state agency, responsiveness to public requests is an expectation for each bureaucratic agency. Upon sharing that delay in response was a common theme, e-mail responses began to reference that expectations for response may exceed a week or

more. Often, e-mails were not returned, hindering opportunities for dual perspectives surrounding collaboration.

### **Demographics**

Participants in this study came from those directed by the DDRS. The director of DDRS was a key representative to FSSA and could speak most specifically on the research topics covered in this study. The director of DDRS provided a variety of potential participants to reach out for interviews to shed light on varying collaborative perspectives. Two key perspectives came from the Bureau of Developmental Disability Services (BDDS) and Vocational Rehabilitation. In the last year, Vocational Rehabilitation has joined DDRS and FSSA as a service to improve employment efforts and outcomes for children and adults with disabilities.

Vocational Rehabilitation was not an initially identified perspective, but it returned to the purview of FSSA and represented long-term supports and services. The input from these participants was valuable as a collaborative entity and bridge between the school setting and long-term supports and services. Ju, Osmanir, Koning, and Zhang (2015) found a positive correlation between transition outcomes, pay, and sustainable employment with a utilization of vocational rehabilitation services.

A missing perspective for this study was from the DOE. After two months of contacts through e-mail, phone calls, and a second review with the director, communication ceased. At two points, the interview protocol (Appendix E) was shared to demonstrate questions regarding goal development and collaborative strategies toward demonstration of impact. The perspectives from Vocational Rehabilitation included

insights from the educational setting, communication, and collaborative strategies for initial student transition success. However, the identified bureaucratic perspective from DOE remained out the study.

### **Data Collection**

The qualitative data for this study came from six interview participants using the amended Interview protocol (Appendix E), adjusted as a result of the pilot study. Interviews were prompted through DDRS, gaining perspectives from long-term disability supports offered under the Medicaid waiver. Also, Vocational Rehabilitation was able to speak toward collaborative principles and current system pathways for transition age children.

A demonstration of documented goal development through the IEP and ISP was not available as was intended during this study. Following the amended process, an agreement was made with a Medicaid waiver case management organization to gather a sample of redacted IEPs and ISPs. Case management organizations in the State of Indiana have access to this information. Over eight weeks of reassurance that the documents existed and following back up through e-mail, which was the preferred communication method, communication then fell away. During this same time, interviews were conducted using the Interview protocol (Appendix E), and enough qualitative data was available to answer the research questions. Therefore, the Document Rubric (Appendix B) did not contribute in gathering additional qualitative data as a defined tool.

The use of a waiver case management organization versus the Arc of Indiana was a noted change in the Walden IRB review. Utilizing a Medicaid waiver case management

organization yielded the same result for gathering redacted information, and it eliminated the need for training and requesting and managing the security of information from an additional party.

Requesting information and participation was the largest obstacle for data collection within my study. Through snowball sampling, contacts and requests for participation were always acted upon and followed up, but it often yielded limited response, especially from the DOE. Ideally, perspectives from DOE would be in the study. The pilot study prompted utilization of Vocational Rehabilitation, so some insight on the educational experience exist.

The six qualitative interviews took place over the month of August 2016. One interview was in person, and the other five interviews took place by phone. The offer was always made to meet in the preferred location and at the preferred time, yet a majority of participants, due to time management and distance, desired for the interview to be over the phone. Perspectives from DDRS, representing Medicaid waiver supports and FSSA, came from across the State of Indiana, including Bloomington, Richmond, Noblesville, and Indianapolis. One additional interview was set up; however, the person chose to have a more casual conversation versus using the Interview protocol (Appendix E) and did not want to be part of a recording, and the data honored his preferences.

A transcription recording and upload software called TranscribeMe<sup>®</sup> was utilized and provided accurate detail of the interviews. The interview was recorded then uploaded to the service, which then prompted a returned transcription for each interview. All participants were made aware of the recording and software in use. The saved recording

ensured a second review of the returned document was available. Due to the ease of the recording, transcription, and verification, more interviews would have added strength to the study.

### **Data Analysis**

Six transcripts from TranscribeMe® imported into NVivo™ to complete data analysis for my case study. As an explanatory case study surrounding perspectives of collaboration, self-determination, and quality of life outcomes for student with moderate to severe intellectual disabilities aged 14 to 18, a review of the transcripts was necessary to pull out and cross-reference coded phrases and identify as nodes within NVivo™. The process utilized was explanation building. Explanation building looks for patterns to explain how and why something occurs (Yin, 2014). Due to the narratives obtained from the transcriptions, access to causal links in the process represented the first step. First I identified similarities, extracted themes, then looked for relationships to create generalizations among the nodes toward categories, then toward themes to answer the research questions. Table 1 lists the initial codes.

The nodes utilized within this study began around initial perspective. Perspectives shared most often came from FSSA, and no perspectives came from the DOE. Since Vocational Rehabilitation was so prevalent within this study, a code was created looking at their contribution toward employment success. All interviews touched on this point.

Additional codes, therefore, identified nodes, were reviewed around opinions of self-determination. Some perspectives shared a lack of student involvement. Pairing self-determination perspectives then led to the coding of processes surrounding self-

determination. Participants shared sentiments on current application; then they shared the level of implementation or lack thereof. A majority of perspectives shared that students missed out in planning goals that were relevant to them and removed from the specific planning meeting. There was a coded theme surrounding improvement in adult based supports as a quarterly process paralleled to attendance.

Driving process review, self-determination perspectives led to codes of knowledge of fellow roles in the IEP/ISP as a way to improve system process. Also, ensuring the student is involved in planning, and a continued call among team members demonstrated opportunities for student involvement and collaborative opportunities, thus were added nodes in the data analysis process and are noted in Table 1.

Table 1

*Categories from Identified Codes*

Category: Self-determination	Category: Program success	Category: Quality of life outcomes
Codes: <ul style="list-style-type: none"> <li>• Personalized systems</li> <li>• Improved self-determination</li> <li>• Lack of self-determination</li> <li>• Student included in regular meetings</li> </ul>	Codes: <ul style="list-style-type: none"> <li>• BDDS perspective</li> <li>• Plan for overlap</li> <li>• VR inclusion</li> <li>• Transition advisory council</li> <li>• Transition focus</li> <li>• Knowing fellow roles of team members</li> <li>• Desired contact with schools</li> <li>• Up-to-date IEPs</li> <li>• Call for follow-up</li> </ul>	Codes: <ul style="list-style-type: none"> <li>• Employment success</li> <li>• Transportation</li> <li>• Workforce,</li> <li>• Use of community resources</li> <li>• Raising expectations</li> </ul>

When a strong team is involved, a code that came through transcript review was the relationship to the local level. Interview participant stated,

Transition planning's individualized, so that's the individual student. We have about 56,000 students between the ages of 14 and 21 that are impacted. So the state only does half the policy and compliance, and they try to set the stage for it to happen, but it all happens at the local level. The state doesn't really help that piece as much. They give out all the policy requirements that have to go on and procedures and guidance and then compliance issues, so that question's a little-- It's hard to answer that because the state doesn't write those transitions. IEP's local person does.

Recognizing this as a coded theme became more prevalent as Vocational Rehabilitation perspectives shared their knowledge or local school practices, connections, and applications.

Having solid collaborative practices represented a bridge to the quality of life outcomes focusing on the success and capabilities of the student. Codes of raising expectations and relevant goal development were necessary. A Vocational Rehabilitation participant shared,

Too often still we're not all teachers and parents and just the community in general, we're not necessarily having an expectation or not a higher expectation of for people with disabilities. And I think that's an important first step. If that expectation is not set, by the time Voc Rehab starts seeing those students, it's hard. It's hard if that expectation hadn't been set in that you just happen to instill in that person that you're going to be an adult, and adults work.

Shifting expectations for the student and among the team would be a paradigm shift from the current service and goal development structure. This paradigm shift is necessary to drive a transition planning process forward that is rooted in integrative and visionary pathways. Strengthening the skillset of capabilities versus returning to ineffective documents should keep the student and team engaged. Therefore, outdated IEPs and ensuring relevant goals were coded themes, and nodes tracked within NVivo™.

Additional coded points surrounding quality of life outcomes focused on areas of opportunity and need, presented in Table 1. The utilization and call for more personalized systems were a code. The call for increased community resources became a category,



capturing improved transportation, workforces, and improved overlap for students in an educational setting to working with a provider.

The codes were furthered into categories of self-determination, program success, and quality of life outcomes, using comparisons against original code and themes. Yin (2014) shared that comparison across narratives supports the building of themes. Program success became a bridge to ensuring self-determination practices, thus fostering quality of life outcomes for the transition age student.

### **Evidence of Trustworthiness**

#### **Credibility**

Throughout this explanatory case study, the lack of perspectives from the DOE and elimination of ISPs and IEPs as potential qualitative data sources removed opportunities for triangulation of information. Having more perspectives and anchoring sources within the study would have added to the possibility for triangulation to build a coherent justification for the established themes (Creswell, 2009). Ideally, more perspectives would have been gathered from interviews and supporting policy demonstration through documents reflecting the goal development and priority standards from DOE and FSSA.

Despite the offer for member checking to review transcripts, the explanation of the purpose of TranscribeMe<sup>®</sup> did allow for a review of the established transcripts through the saved interview. Interview participants were made aware of the software and instead chose to review a summary of the results, perhaps due to the increased familiarity

of talking to text software, understanding the review procedure, and accepting of transcription. The participants did not request transcription.

Even without the full scope of reviewed qualitative data, saturation of themes was available surrounding employment, integration, and raising the expectations for people with intellectual and developmental disabilities surrounding quality of life outcomes and self-determination concepts.

### **Transferability**

The Interview protocol (Appendix E) and Document Rubric (Appendix B) were unable to be utilized as supporting tools for gathering qualitative data. The purpose of the Document Rubric was to review IEPs and ISPs for students aged 14 to 18 with moderate to severe intellectual and developmental disabilities for goal development strategies and service guideposts. Due to the absence of information from the document sources, opportunities for triangulation and transferability of the procedure diminished within my study.

Through a review of the pilot study, information with the revised Interview protocol (Appendix E) demonstrated the ability to gather different perspectives surrounding quality of life outcomes and self-determination strategies. Because of similar bureaucratic entities across all states, monitored under federal oversight, the opportunity to utilize the Interview protocol (Appendix E) would be available and would add reliability to information and themes for improved support standards for transition age students with moderate to severe intellectual and developmental disabilities.

**Dependability**

Dependability in the qualitative data expanded through the use of TranscribeMe<sup>®</sup>. This transcription resource verified from a review of the transcript of the recording through the study. With reliable transcripts, the opportunity to analyze qualitative data supported opportunities for explanation building during the data analysis process (Yin, 2014).

Use of an audit trail technique to describe the review and pathway to the generation of themes enhances dependability of the qualitative study (Shaw, 2013). For this study, the use of Interview protocol (Appendix E) provided an initial starting point to finding codes, comparing across narratives, and leading to the generation of themes. Reviewed by a fellow doctoral student, the codes captured in NVivo<sup>™</sup> for similar generation of themes enhanced dependability.

**Confirmability**

As a researcher who has personal connections to the field of supporting people with intellectual and developmental disabilities, the opportunities for reflexivity in this study to ensure the body of work spoke for itself and were especially important due to the reduction in qualitative resources. Yin (2014) stated that good qualitative research includes mindfulness of reflection on personal background and perspective. Throughout this study, I found it especially valuable to conduct research surrounding transition age students with intellectual and developmental disabilities and establishing a platform for success versus the parameters I professionally work in serving adults under the Medicaid HCBS waiver. From this neutral perspective, the themes provided from the qualitative

analysis generated a platform for policy improvement recommendations and collaboration among bureaucratic entities.

## **Study Results**

### **Quality of Life Outcomes**

My study reviewed what barriers exist to the quality of life outcomes for transition age students with moderate to severe intellectual disabilities. Themes surrounding these barriers were rooted in integration, raising expectations, and ensuring equal opportunities are available for education, employment, and finding meaningful social roles. Coding frequencies and themes captured through NVivo™ exist within Table 2. Improving quality of life outcomes for students with intellectual and developmental disabilities represented the overall service delivery goal for both bureaucratic entities. However, Table 2 presents how various perspectives can attribute to varied quality of life outcomes and pathways to achieving those identified benchmarks

Table 2

*Coding Frequencies of Quality of Life Outcomes*

<u>Codes and subcodes</u>	<u>Frequency</u>
Number of Interviews	6
Perspectives from BDDS (FSSA)	2
Perspectives from VR	4
Perspectives from DOE	0
Goal development	6
Celebrating employment success	6
Raising expectations	4
Including VR in planning	4
Relevant goals for the student	3
Plan for overlap	3
Access to community	6
Finding available jobs	4
Using community resources	3
Access to transportation	2

The highest perspective interviewed throughout this study came from Vocational Rehabilitation services under FSSA. This perspective guided the highest level of the quality life outcomes in achieving employment success. As the highest level of agreement, all perspectives noted this critical benchmark for students to achieving quality of life outcomes. Carter, Austin, and Trainor (2012) found that established employment guideposts not only represented a celebrated social role, but it attributed to increased independence and social skills. Employment success, recognized as a critical component of improved quality of life for students with intellectual and developmental disabilities, may also stand for a catalyst to other contributing factors.

While Vocational Rehabilitation focused on inclusion and highlighting their need for participation in goal development, an additional theme through a review of the data was rooted in raising expectations for people with intellectual and developmental disabilities. Upon asking the question regarding barriers to effective collaboration, an FSSA interview participant answered:

One of the things is low expectations for the students. I think it's regardless of who has the low expectations. Sometimes it's the students themselves. I'm not sure what they can do. I'm not sure what's possible. Sometimes it's parents or guardians. Sometimes it might even be teachers or us, perhaps. I think that we run into, at times, low expectations and we need to be thinking about what the potential is and what the possibilities are. I think we're always trying to keep that in the back of our mind. Understanding the roles of other agencies and what everybody has to offer, what are the roles of all the various stakeholders and who can do what to assist and, maybe, sometimes even appropriate understanding of what isn't a role of a stakeholder. Those maybe the main things in terms of just transition planning.

Her response spoke to many attributes toward contributing collaboration success and improving the quality of life outcomes for students. Efforts to demonstrate collaboration were rooted in improving overall successful benchmarks for the student and all shared in the mutual goal.

## Self-Determination

Improving efforts to increase self-determination was a question asked in every interview; however, there were mixed perspectives regarding the level of involvement and impact among students according to different perspectives. Table 3 presents these perspectives. For example, someone who provides research and tools for educational success feels that there are efforts in place. While someone who works in the educational setting finds areas for improvement by ensuring relevant goals and that the students are involved and attending their goal development and planning meetings, which are both documented within the IEP and ISP.

Table 3

### *Coding Frequencies of Self-Determination*

<u>Codes and Subcodes</u>	<u>Frequency</u>
Number of Interviews	6
Perspectives from BDDS (FSSA)	2
Perspectives from VR	4
Perspectives from DOE	0
Self-Determination Appearance	6
Perspective practice in place	1
Lack of self-determination	2
Relevant goals for the student	3
Student involved in meetings	3

An Indiana Institute on Disability and Community interview participant stated that,

So a lot of the components of self-determination when they are problem-solving towards making decision making. However, it's promoted very strong in both the planning process as well as from VR perspective. And self-advocacy as

part of the DOE initiative with our transition resource center, we have been working doing a lot of training around self-determination. So this past year I think we had four regions that we went through training all our school to work projects. Teachers have been doing curriculum. The evidence they've practiced for probably three years now. We've had teachers - and some of this has been funded by DOE, so their funding initiative that a lot of professional development around self-determination and skill development. A lot of immersion of it was in the transition IEP goals. We see that quite a bit. People understanding their accommodations, and making choices, and communicating those kinds of things.

While a Vocational Rehabilitation interview participant when asked about appearance and impact of self-determination stated,

A lot of times the student isn't even involved in the meeting. It's just parents. The student was invited, but I think a lot of times it's so sensitive because I see that a lot in my meetings here. Parents will say, "Can I talk to you without them in the room?" "No." This is their meeting. It's about their future, their job goal. And I think parents, of course, have that same perspective when it comes to IEP meetings. They don't want their kid to know they have a disability. Sometimes in meetings I've had, I feel like it's the first time the student's even considering or has heard that they have a disability. So, the student may know the meeting is happening, but I feel like a lot of times the parents sort of spin it like, "We just have to meet and sign some papers." I don't see a lot of kids involved. The few that I've been to, the kids have had very little to say. They want to get back to



class. They're missing lunch. The significance of what we're doing there is not emphasized, so there's not a lot of value in it to them.

The varied perspectives parallel the data and coded themes in Table 3. While efforts may be underway, it is not encompassing as a successful goal development strategy toward implementation and self-determination impact for the student to guide their IEP and act as the identified bridge to the ISP to ensure collaboration and consistency. Self-determination, like employment success, represents contributing attributes to post-school outcomes. Shogren, Villareal, Lang, and Seo (2016) found that utilization of self-determination principles promoted autonomy, psychological empowerment, and self-realization.

### **Collaboration**

Collaboration among bureaucratic entities represented the systematic question within this study to improve service delivery, heighten the quality of life outcomes, and promote self-determination. The interviews favored toward Vocational Rehabilitation and Bureau of Developmental Disability Services. Both perspectives fall under the umbrella of FSSA. Perspectives throughout this study lacked from DOE; therefore, an overall determination of perspectives surrounding collaboration cannot exist as an encompassing systematic validation or critique.

Using available qualitative data produced themes highlighted previously of raising expectations for the student, including Vocational Rehabilitation in the process, and ensuring plans overlap. Table 4 presents these themes. A plan for overlap was a coded theme generated from responses to ensure the IEP and ISP reflect similar goal

development strategies and the student's team is operating as a cohesive unit for long-term success.

Table 4

*Coding Frequencies of Collaboration in Goal Development*

Codes and subcodes	Frequency
Number of Interviews	6
Perspectives from BDDS (FSSA)	2
Perspectives from VR	4
Perspectives from DOE	0
Goal development	6
Raising expectations	4
Including VR in planning	4
Relevant goals for the student	3
Plan for overlap	3
Collaboration practice	6
Lack of formal systems	5
Need for understanding team roles	3
Call for follow-up	3
Outdated IEPs	2
Call for student participation	1

### Summary

The research questions within my study asked about barriers that hinder the quality of life outcomes for students with moderate to severe intellectual or developmental disabilities aged 14-18, current application of self-determination principles, and perspectives surrounding barriers to collaboration. Collaboration among bureaucratic entities is essential to student success, and there is a lack of formal system, which could be valuable to improve the IEP and ISP goal development strategies. When

guided by employment focus, contributing quality of life, self-determination, and collaboration practices may coexist.

Missing viewpoints from DOE, conclusive answers to perspectives guiding the IEP and ISP development process cannot be determined. However, utilizing perspectives from Vocational Rehabilitation and BDDS, the interviews were able to answer that employment success and to raise expectations for students with intellectual and developmental disabilities are two key pieces of extending quality of life outcomes.

Also, self-determination, while not widely encompassing from varied perspectives, also cannot be determined as an expectation of goal development strategy due to missing perspectives from DOE. Nonetheless, calls for more formalized mechanisms to training, raising expectations for the student, stakeholders, and family, can all enhance self-determination and self-advocacy efforts for the student to lead the planning process.

When the students are well aware of their goals, and know members and resources on their team, and are encouraged to share their personal vision, opportunities for formalized collaboration may or may not be necessary. The IEP and ISP is a reflection of state guideposts and goal development strategies for the student, and as the student ages, empowering the student with higher expectations and more tools represent a bridge to change ideological paradigms, social dynamics, and sustainable educational and Medicaid waiver policy.

## Chapter 5: Discussion, Conclusions, and Recommendations

Improving transition supports for students with intellectual and developmental disabilities is crucial to establishing a platform for long-term supports and services. This study reviewed current factors that could foster improved processes in the State of Indiana, including collaboration among bureaucratic entities and utilizing self-determination principles with goal development, thus improving the quality of life outcomes for students. The IEP and ISP are goal driven documents that recognize strategies for students among two different bureaucratic entities. The IEP comes from the DOE, and the ISP comes from the FSSA. Both goal driven documents generate from formal team meetings that are expected to extend forward-thinking goals for the student.

Through interviews with participants from FSSA, including some from the DDRS and Vocational Rehabilitation, opportunities for improved collaboration were initiated with greater understanding of each team member's role. By including all necessary transition participants together, there are opportunities for goal-driven strategies to be shared, clearly communicated, and understood by the student. When students are aware of the opportunity to put forward goals, personal investment in their preferred strategies increases because they were involved in choice-making (Wehmeyer, 2015). Based on interview responses, self-determination strategies are not widely utilized in the education for the student. These strategies could also to serve as the specified bridge to facilitate goal development across the support team. According to the interview participants, forward-thinking goal development should be built on employment and raising the student's expectations.

### **Interpretation of Findings**

While the DOE was not part of the interview process and therefore did not contribute data, the findings paralleled current literature in the field of supporting people with intellectual and developmental disabilities. First conclusions regarding the quality of life outcomes focus on highlighting strengths, raising expectations, and emphasizing employment opportunities. Collaboration is essential among all parties including bureaucratic entities to help develop these outcome areas as goals. Including representatives from Vocational Rehabilitation in the study furthered the development of employment goals and fostered social inclusion. Knowing the goals that matter most may require new tools for the goal development team, but it is critical that the student has ownership of the process and understands the contents of the IEP and ISP, as it is a reflection of their future pathway in an educational and social setting.

### **Quality of Life Outcomes**

The purpose of supports driven by the IEP and ISP process is to ensure that goals promote independence and enhance the quality of life of people served. Schippers, Zuna, and Brown (2015) found that policy that focuses on improving the quality of life through organizational practice results in successful outcomes for long-term supports and services. For students supported in the State of Indiana, this occurs through the development of goals.

A theme from the data focused on raising expectations for the students served. For students with moderate to severe intellectual and developmental disabilities, raising expectations should begin by looking beyond a diagnosis of disability toward existing

strengths. Placing capabilities at the start of goal development and social opportunity planning creates personal investment for the student in the transition process because it is rooted in interests and emphasizes what the student is capable of or has accomplished (Szidon, Ruppard, & Smith, 2015). Highlighting strengths facilitates the raising of expectations for social and communication pathways and thus mitigates the fading of services and promotes the sustainability of a long-term support model.

One of the most important factors in improved quality of life outcomes for students with intellectual and developmental disabilities centers on employment. Increasing employment opportunities for students was the desired change shared by interview participants. This confirms current policy expectations in the Home and Community Based Service Waiver guidelines and extends current literature in regard to its value (Carter et al., 2012). According to a federal report generated from an Advisory Committee on Increasing Competitive Integrated Employment (Mank, 2016), recommendations from committee resources and current literature put forth as policy guideposts that early work experiences should be encouraged, and all parties in goal development should raise expectations. Employment success requires system integration. These recommendations are reiterated in the study results and emphasize the necessity of collaboration.

### **Collaboration**

Taylor, Morgan, and Callow-Heuser (2016) found through a survey that Vocational Rehabilitation counselors and school administrators held high regard for collaboration but low expectations for implementation effectiveness. For parties driving

goal development for students with intellectual and developmental disabilities, understanding roles and perspectives represents an integral starting point. This reveals the qualities and resources that each stakeholder can bring to enhance the service structure, promote fading, and drive self-determined practice (Carter et al., 2014). In the interviews, one of the most significant role perspectives came from Vocational Rehabilitation. All interviews shared the value the service provides to foster employment and promote sustainability for long-term supports and services.

A student diagnosed with an intellectual or developmental disability in the State of Indiana requires that the disability is lifelong. The service structure exists for long-term supports, yet the cost structure is unsustainable for all those in need. Collaboration is essential to knowing and including all perspectives in goal development (Mank, 2016). Perspectives from the interviews shared that this effort was an area of opportunity to enhance understanding and recognize the resources that each party can bring to the development of a student (Pennington, Courtrade, & Ault, 2016).

Vocational Rehabilitation in the State of Indiana falls under the DDRS. This partnership parallels the expectation for employment outlined in federal guideposts. Mank (2016) identified the term of “presumed employability” as an expectation that students with intellectual and developmental disabilities can become employed (p. 24). By understanding all roles and raising expectations, participation and leadership from Vocational Rehabilitation early in the process can foster opportunities for sustainability beyond a long-term funded service structure.

**Self-Determination**

Goal development begins with the student receiving supports from one or both service structures from DOE and FSSA. At some point, both services will happen under the long-term supports and services structure. The constant in the goal development process is the student and the family involvement. They represent guardians for ensuring collaboration among service entities and that the student's objectives are upheld, thus improving transitional outcomes (Wehmeyer et al., 2012). To accomplish this goal, education for long-term stakeholders is critical (Diliberto & Brewer, 2012).

Consistency in services requires understanding the specific bureaucratic process but also understanding the goals that matter most to the student. Knowing what matters most to the student begins by understanding interests and current relationships and emphasizing strengths. The student has ownership in all of these perspectives, and the team that is supporting the student has the opportunity to expand and help promote these factors going forward.

One perspective shared from the interviews was that there are self-advocacy efforts currently in place. Other shared viewpoints illustrated that there is no widespread self-advocacy effort across all goal development platforms. For self-advocacy efforts to become more prevalent, more tools are necessary. One tool that has been developed to improve teacher and stakeholder self-advocacy efforts is called the Self-Determination Learning Model of Instruction. The Self-Determination Learning Model of Instruction has been shown to increase awareness of goals that matter most to the student as shared by the teacher. It has had the impact of increasing the expectations teachers had for the



student in what they could accomplish (Shogren, Plotner, Palmer, Wehmeyer, & Paek, 2014). Application of tools such as the Self-Determination Learning Model of Instruction, therefore, can provide the student with opportunities to lead the meeting, establish their goals, and recognize progress, which drives supports forward. When students have opportunities to share their goals, they do not get lost from process to process, and the student becomes the bridge to long-term supports and services. The majority of perspectives from the interviews further additional education regarding self-determination capacity and implementation.

### **Limitations of the Study**

The largest limitation of this study was the lack of DOE perspectives given their lack of study participation. Without their perspective, processes guiding improved collaboration strategies were one-sided from the ISP process. It is essential to knowing what the DOE values for improved quality of life outcomes, collaboration, and self-determination concepts. A quantitative study may have garnered more responses and increased generalizability to address this limitation for future research (Yin, 2013). It is essential to better understand collaboration among bureaucratic entities by finding the best method to gather perspectives from DOE. The DOE establishes the initiation of long-term supports and services through the establishment of goal development strategies.

In addition to the lack of perspectives from DOE, there was a general lack of response from interview participants. There were four people who had agreed to interviews from DDRS, and then upon initial agreement communication fell away. It was

apparent from e-mail and phone communication that people in both bureaucratic entities were busy. While the time frame and expectations never exceeded the 20-30 minutes conveyed in the participation invitation, one may question if that length of time was too intimidating for possible participants; therefore, alterations in future research methods, such as quantitative approaches that are less personal and time-consuming, may be needed. The lack of qualitative responses can hinder generalizability to broader systematic collaboration strategies (Patton, 2015).

One last limitation may have rested on my perspective of someone who works in a similar support industry. Keeping the range of support at a smaller age range than one I typically serve, bias was not a factor in the collection and analysis of data. As a majority of interviews came from Vocational Rehabilitation, opportunities for influence diminished as it represents an unrecognized service in my current professional capacity.

### **Recommendations**

Implementing the guideposts from the institutional analysis and development (IAD) framework further narrowed by the common pool resource theory would serve as collaborative implementation and evaluation measures to improve goal development, paired sustainable service delivery, and review of forward-thinking philosophies to support students with moderate to severe intellectual and developmental disabilities. Ostrom (2011) described the *action area* where sustainable resource development and collaboration occurs. The action area generates collaboration parameters furthered into implementation through the collective choice model.

A collective choice model uses rule-making from a collective platform to guide change (McGinnis, 2011). As the interview participants shared the strategy for improved processes in understanding roles, there is also the opportunity to come together to initiate service parameters. The common pool resource theory centers this on the first principle of establishing boundaries and knowing what each stakeholder may bring to the “action area” (Ostrom, 2011). There are many resources available to students, families, and policy stakeholders; therefore, understanding each perspective is a starting point in knowing what the action area can accomplish. This first principle is currently in place with the statewide transition advisory council. The results and analysis from my study demonstrated that one step further toward the second principle of the common pool resource theory would increase progress.

The second principle establishes that all stakeholders must decide on rules to encourage, expect, and review collaboration practice (Ostrom, 2011). To do this, presence by all parties must occur in an IEP and ISP meeting. All parties must have education on opportunities, resources, and the path chosen by the student to ensure goal development works in a parallel manner, rather than in an opposed fashion (Seong, Wehmeyer, Palmer, & Little, 2014). Also, participation by Vocational Rehabilitation can serve as a catalyst to employment based services, which are also guided by the student. This perspective paralleled in my study results as an area of importance in proactive transition planning.

The third principle of the common pool resource theory should present as a recommendation for implementation and evaluation of reviewed processes. One should

see improved goal development efforts by the student when the student and all stakeholders are included in goal development. Institutional differences between DOE and FSSA exist, but perhaps for transition-age goal development for students with moderate to severe intellectual and developmental disabilities aged 14 to 18, the initiation of common practice may converge toward a unified action area (Basurto, 2013).

The unified action area is built to ensure that students are moving forward and both bureaucratic entities are supporting that path through appropriate resource allocation. Funded resources provided through DOE and FSSA, including the Home and Community Based Services waiver model cannot continue at its current funding stream (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). For that reason, efforts to increase social capacity, integrate supports and find less costly service models are required.

Employment and integrative expectations have furthered by federal policy in two key platforms. First, Medicaid funding will only distribute when states have integrative platforms in place (Novak, 2015). Integrative platforms ensure services do not occur in a segregated setting, nor are they exclusive toward people with intellectual and developmental disabilities only. Second, the Workforce Innovation and Opportunity Act (WIOA; 2014) stated that competitive employment is the expectation. People with intellectual and developmental disabilities will receive paychecks from integrated employers and are expected work to establish a social network through this norm (Hoff, 2014). Rhode Island is an example state for WIOA implementation. In Rhode Island all persons who are enrolled and supported on the WIOA program are set to receive

individualized employment services, beginning with transition-age youth (Novak, 2015). These policy measures expand at the state level. For that to occur all parties must support and review forward-thinking service platforms.

Implementing service platforms requires expectations to be raised, which my interview participants agreed. When parents, teachers, and stakeholders are on board, then increased outcomes are the result (Holwerda, Brouwer, Groothoff, & van der Klink, 2015). A foundation to evaluation is having service standards focused on employment and natural life path benchmarks. Also, utilization of Vocational Rehabilitation must be evaluated help in establishing common rules and practices as a bridge to a needed collaborative network.

While employment status for students with moderate to severe intellectual or developmental disability varies, opportunities for community-based support should also exist (Carter et al., 2013). Opportunities for volunteering, continued integrated education, or supplementary service pairings may reduce costs in either or both bureaucratic institutions. The students and the team should have education on avenues of social pathways and expectations of the corresponding service.

Expectation building begins by understanding what the student desires, and for forward-thinking parameters to come to fruition, self-determination pathways and strategies must be expected and evaluated (Seong et al., 2014). A student understanding and leading their goal development helps to establish a common thread for improved policy implementation. Individual goal development is lost when students are not involved, as my interviews illustrated. It must become a participatory expectation that

occurs through the student, family, and stakeholders. For that reason, attendance requirements by collaborative partners within the action area should transpire.

The IAD framework and common pool resource theory happen within its environmental lens (Ostrom, 2011). My study demonstrated the capacity to utilize in a human service paradigm with the common thread of sustainability. To application of collaboration parameters for transition-age students with moderate to severe intellectual or developmental disabilities, all parties must come together, generate common rules and practices for the action area, and create review procedures to ensure innovative service structures are in place. The quality of life for students with intellectual and developmental disabilities depends on improving collaboration and raising the expectations of what students can accomplish (Wehmeyer, 2015). Having hope in the collaborative system, dependability in processes, and recognition of self-determination opportunities can help to increase these outcomes.

### **Implications**

The research questions within my study all demonstrate the desired path toward positive social change for students with intellectual and developmental disabilities. Individual outcomes led by self-determined values begin by raising expectations. At this time, there are opportunities to harness the paradigm of self-determination and implement the concept in assurances of collaborative policy. Organizationally and through bureaucratic perspectives, avenues to strengthen collaboration must occur. Application of the IAD framework and common pool resource theory could systematically ground the

recommendations from my study to drive positive social change toward students served through goal development in an IEP and ISP funded at both the federal and state level.

### **Individual Application**

The individual application to positive social change that my study illustrates rests on the ability for the transition-age student with an intellectual or developmental disability to drive their supports forward. If a student can articulate their goals in their preferred communication style, then the ownership of services and supports are established early on. Currently, the bureaucratic system sets the parameters, but as my participant interviews demonstrated, there are tangible ways for the student to become more involved.

When a student becomes more involved their ability to understand and guide services and resources, the process becomes more self-directed across both goal development platforms of the IEP and ISP, which helps to reduce program disconnections. Self-direction is empowering for the student, and it creates an investment in services that extends across the boundaries of long-term supports and services (Powers et al., 2012). According to my study findings, self-advocacy efforts are not widespread. When self-advocacy efforts are robust, the developing skills of decision-making emerge, and students can generate service guideposts for change rooted in social inclusion.

Individual application for social inclusion is lacking (Wehman, 2014). My study demonstrated that one of the largest gaps in current service models supporting the transition-age student exists by low expectations. Raising the expectations that students can become employed in some capacity, be part of a broader social network, and

contribute to their society must occur. By looking at strengths to accomplish this task, then goal development should run parallel to that focus. When supports are running in coordination to strengths, positive social change for the student can occur.

### **Organizational Application**

Two organizational levels work to establish goals for the student. Currently, the student may receive goal development strategies from both a school setting, in an IEP, and through a Medicaid waiver model, in an ISP. These two models work separately. My study demonstrated that for positive social change to occur understanding of roles and resources aligned with collaboration must be enhanced. Carter et al. (2014) reiterated this recommendation through a quantitative study analyzing perspectives and collaboration. In the State of Indiana, the movement of understanding collaboration value is a helpful start to drive change forward with systematic parameters and rules.

Ostrom (2011), through both the IAD framework and common pool resource theory, bounds the aspects of sustainability by generating rules and processes. These rules and process must support one goal development strategy. For that to occur, both bureaucratic entities must come together in understanding transition-goals under the broader oversight of long-term supports and services.

### **Empirical Application**

For an individual and organizational application, the goal-driven process for coming together to support the student with a moderate to severe intellectual or developmental disability must have an ease about it. My study interviews demonstrated that goal development must be more aligned and inclusive of all bureaucratic agencies.



Students are not always involved, parents and stakeholders have low expectations, and coordinated efforts of reviewing resources are lacking. Therefore, including all parties, recognizing the desires of the student, and ensuring all people invest in the process are essential goal development strategies.

Creating a cohesive goal development platform supports social change. One way to foster its implementation is rooted in having one unified life-planning meeting merging both goal development strategies. This positive change would become more impactful to all stakeholders in the process and create a shared investment in the student.

The concept of sharing resources and recommendations adheres to the IAD framework and common pool resource theory in reviewing sustainability (Ostrom, 2011). Sustainability of resources can develop beyond ecological resources, and my study demonstrated that the creation of an action area could support all applications to drive positive change for stakeholders.

### **Societal Impact**

Students with intellectual and developmental disabilities have greater capacities than are currently expressed and have more opportunities for employment and inclusion than any other point in history, yet positive outcomes remain lacking (Wehman, 2014). Keith, Bennetto, and Rogue (2015) found that the quality of relationships among people with intellectual and developmental disabilities and the broader community can have the greatest impact on crossing any barriers to social inclusion and prejudice, thus fostering positive social change.

My study demonstrated that creation of quality relationships begins by knowing what the student desires and raising expectations for success. Pathways develop when social relationships foster on strengths. Also, quality relationships emerge by a collaborative team of support.

Simplican et al. (2015) developed an ecological model of social inclusion. This model considers how organizations, families, policy stakeholders, and self-advocacy efforts can help establish a framework for inclusive partnerships. Frameworks that are known and supported by members of social service agencies help to integrate cohesive student program models. In addition to a supportive model, partnerships in the community, and external to social service agencies, are necessary for policy to generate sustainable change (Carter et al., 2014).

### **Conclusions**

For over a century, supporting people with intellectual and developmental disabilities has undergone numerous policy and societal changes. From the development of institutions to the generation of community-based supports, a policy has shaped action by bureaucratic entities. From the Individuals with Disabilities Education Act (IDEA) in 1974 to the Americans with Disabilities Act (ADA) in 1990 and to the Workforce Innovation and Opportunities Act (WIOA) in 2014, all of these policies have created pathways for people with intellectual and developmental disabilities to become integrated and part of their society. Each policy propelling disability support change builds on the other. Components of employment opportunities are included in IDEA and expectations for equal access are included in the ADA and WIOA. Therefore, one must question their

effectiveness among the numerous revisions and policy measures when the overall goal of an inclusive society remains.

My study reviewed collaborative measures from FSSA and DOE to create inclusive services in the State of Indiana. Among each of these bureaucratic entities, the largest policies surrounding Medicaid waiver and special education continue to readjust. The ISP and IEP have two separate goal development platforms working for the same age range, and they remain outdated for necessary forward-thinking measures that foster inclusion. My study identified that collaboration surrounding the IEP and ISP could become a positive step forward so that students with moderate to severe intellectual and developmental disabilities have full access to community and opportunities for natural benchmarks for success.

To achieve inclusive transformation, it requires goals developed in a collaborative capacity and having the student chart their future course. The student's desired course impacts their resources and preferred opportunities. The student's course impacts the sustainability of long-term supports of services. The student's desired course impacts inclusive strategies. Therefore, my study illustrated that supports running parallel amongst two bureaucratic entities must always converge with an enrolled student's interest placed first.

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## Appendix A: Interview protocol

1. Do you represent a perspective guided by Medicaid waiver supports through the Family Social Services Administration or special education through the Department of Education?
2. How have collaboration measures between the Family Social Services Administration and the Department of Education been initiated through the focus of transition planning for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
3. How are collaboration measures sustained between the two service models funded by two bureaucratic entities?
4. In general, relative to transition planning for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities, what efforts promote positive collaboration and similar goal development and fading strategies?
5. Do you have an opportunity to network with fellow stakeholders within the transition process?
6. What do you perceive as barriers to effective transition planning efforts for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
7. What forward-thinking goal development strategies promote collaboration?  
Example sub-points: Employment? Social roles? Volunteering? Networking?  
Other examples of sustainable support models beyond paid support within the local community?

8. What do you perceive as barriers to quality of life outcomes for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
9. How are self-determination strategies applied in which students ages 14 to 18 with moderate to severe intellectual and developmental disabilities lead the generation of the IEP and ISP and their own meeting?
10. What effective strategies are employed within follow-up to a transition meeting?
11. What recommendations do you have to promote collaboration and improvement in transition-based goal development for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?

## Appendix B: Documentation Rubric

**IEP and ISP Common Goal Development Rubric**

Number of Goals Within IEP: \_\_\_\_\_

Number of Goals Within ISP: \_\_\_\_\_

Description of Goals, Strategies, and Objectives	Rubric Score
More than 80% of the IEP and ISP demonstrate common themes	4
60% to 79% of the IEP and ISP demonstrate common themes	3
40% to 59% of the IEP and ISP demonstrate common themes	2
20% to 39% of the IEP and ISP demonstrate common themes	1
Less than 20% of the IEP and ISP demonstrate common themes	0

Themes included within the document(s):

	ISP (Yes/No)	IEP (Yes/No)
Inclusive supports		
Employment strategies		
Self-determination practices		

## Appendix C: Case Study Protocol

**Interviews**

1. E-mail is distributed to FSSA and DOE bureaucratic directors regarding interest in the research topic and the opportunity to interview employees.
2. Follow-up phone calls occur.
3. Permission is obtained from supervisors, and an e-mail of interest is forwarded on to respective bureaucratic policy makers.
4. Interviews are arranged.
5. Permission is obtained for participation and note-taking preference.
6. Interviews occur using Interview protocol (Appendix A).
7. Notes, as the qualitative data source, are transcribed and entered in NVivo.

#### **Documentation Rubric**

1. Contact is initiated with The Arc of Indiana describing the research topic and seeking permission for utilization of the organization's weekly newsletter to gather IEPs and ISPs.
2. Upon obtained permission, training occurs with the Arc of Indiana representative(s).
3. Description of the research topic and flow chart is sent with The Arc of Indiana's newsletter until 20 IEPs and ISPs are obtained by the organization.
4. Permission is signed through The Arc of Indiana.
5. IEPs and ISPs are redacted, then forwarded to the researcher.
6. Researcher collects redacted documents through electronic or physical transfer and secures them in a confidential location.
7. IEPs and ISPs are compared using the documentation rubric (Appendix B).

8. Rubric becomes qualitative data source.
9. IEPs and ISPs are shredded.
10. Rubric scores and themes are entered into NVivo.

## Appendix D: The Ostrom Workshop Permissions

## Permission

Oct 10

Good Morning,

My name is Lucy Klym, and I am pursuing a PhD in Public Policy Analysis and Management through Walden University. I am utilizing the IAD framework and common pool resource theory to look at sustainability of Medicaid Waiver supports through an ongoing interaction of actors within the bureaucratic institutions from the Department of Education and Family Supports Services Administration in Indiana. I was wondering if I could obtain permission to utilize the IAD Framework Figure within my dissertation?

Thank you for the review.

Sent from Windows Mail

Oct 12

Thank you for requesting permission to use the IAD framework figure. You have our permission, provided you acknowledge the original source.

Sincerely,

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## Appendix E: Interview protocol

1. Do you represent a perspective guided by Medicaid waiver supports through the Family Social Services Administration or special education through the Department of Education?
2. How have collaboration measures between the Family Social Services Administration and the Department of Education been initiated for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
3. How are collaboration measures sustained between the two service models funded by two bureaucratic entities?
4. In general, relative to transition planning for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities, what efforts promote positive collaboration and similar goal development and fading strategies?
5. Do you have an opportunity to network with fellow stakeholders within the transition process for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
6. What do you perceive as barriers to effective transition planning efforts for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
7. How do efforts in facilitating volunteerism and employment promote collaboration?
8. How do efforts to create social roles and network promote collaboration?



9. How is Vocational Rehabilitation utilized to promote forward-thinking goal development strategies?
10. What do you perceive as barriers to quality of life outcomes for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?
11. How are self-determination strategies applied in which students ages 14 to 18 with moderate to severe intellectual and developmental disabilities lead the generation of the IEP and ISP?
12. What effective strategies are employed within follow-up to a transition meeting?
13. What recommendations do you have to promote collaboration and improvement in transition-based goal development for students ages 14 to 18 with moderate to severe intellectual and developmental disabilities?