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MORE SEATS AT THE TABLE: AN EXAMINATION OF THE ROLE OF NATURAL
SUPPORTS IN PROMOTING POSTSECONDARY TRANSITION FOR STUDENTS
WITH DISABILITIES IN RURAL MAINE

A Dissertation Presented

by

ELIZABETH STONE-STERLING

Submitted to the Office of Graduate Studies,
University of Massachusetts Boston,
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2020

Global Inclusion and Social Development Program

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WITH DISABILITIES IN RURAL MAINE

A Dissertation Proposal Presented

By

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ABSTRACT

MORE SEATS AT THE TABLE: AN EXAMINATION OF THE ROLE OF NATURAL SUPPORTS IN PROMOTING POSTSECONDARY TRANSITION FOR STUDENTS WITH DISABILITIES IN RURAL MAINE

May 2020

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Students with disabilities who receive special education services are entitled under federal law, the Individuals with Disabilities Education Act, to have an Individualized Education Program (IEP) that includes measurable postsecondary goals and identifies the transition services that are needed in order for the student to reach those goals. Transition planning for students with disabilities in rural areas can be uniquely challenging due to lack of access to transportation, service providers, and accessible programs. Failure to prepare for postsecondary education or employment is correlated with life-long challenges, including

poverty, un/under-employment, and limited educational attainment. Natural supports, in the form of family members, friends, or community members, could be a resource to assist transition planning for students with disabilities but they may not be invited into the transition planning process. The purpose of this study was to investigate the barriers to transition planning in rural Maine today, the role that natural supports have played in transition and postsecondary outcomes for students with disabilities living in rural Maine as well as any barriers that may prevent more fully accessing and integrating these natural supports into transition planning.

This study used qualitative methods to first review the legal and policy context, second draw out the voices of youth with disabilities and third take a retrospective appraisal of the lived experiences of these stakeholders as they supported the transition of students with disabilities to adulthood. Data collected in this study included the voice of youth with disabilities (from multiple sources) and interviews with parents of students with disabilities and special educators who are both responsible for overseeing development and implementation of the Individualized Education Program and serve as gatekeepers to “seats at the table” at transition planning meetings. Key findings in this study confirmed that many barriers to transition planning exist for students in rural Maine – particularly related obstacles to accessing the IEP process, overwhelming responsibilities of parents and educators, lack of knowledge about transition resources, paid services that do not meet students’ needs and divergent beliefs about what is possible for students with disabilities as they enter adulthood. The study also found that rural “Yankee ingenuity” result in creative use of natural supports to meet transition needs – including through the use of family, friends, community members

and interestingly educators who stepped outside their classroom role. These natural supports, however, rarely were physically present at the IEP meeting or explicitly named in transition planning, and special education law and practices failed to promote their inclusion. The voice of youth with disabilities also highlighted that they do not perceive the support of caring adults and that they wanted to be part of the solution through education and support of other youth coming up behind them.

Applying a transdisciplinary approach, these experiences inform recommendations for sustainable ways to promote inclusion of natural supports as a means to strengthen transition planning and postsecondary outcomes for young people living in rural communities in Maine.

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Laws and Regulations Governing Secondary Transition

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Public Law 101-476

Regulations: Assistance to States for the Education of Children with Disabilities – 34 CFR§300

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Purposes – 300.1(a)
 - **Summary of Performance**
Additional Requirements for Evaluations and Reevaluations – 300.305€
 - **IEP Transition Services**
Definition of Individualized Education Program – 300.320
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 - **IEP Team Composition**
IEP Team – 300.321(b)
 - **Transfer of Rights at Age of Majority**
Transfer of Parental Rights at Age of Majority – 300.520
 - **Transition Services Funding**
State Level Activities – 300.704 (b)(4)(vi)
-

State of Maine

Law: **20-A MRSA** (Maine Revised Statutes Annotated)

Chapter 301 – General Provisions

Chapter 303 – Education of Children with Disabilities

Regulations: Maine Unified Special Education Regulation Birth to Age 20 (MUSER) – Chapter 101

CHAPTER 1
INTRODUCTION

Introduction

Seeing Possibility

One day in 2000, I found myself on the back of a tractor, thirty minutes from the Canadian border being driven along a bumpy farm road by “Jim,” a young man with Autism. As we stopped to see greenhouses, pigs, logging operations and more, Jim shared his knowledge; he interacted with other workers, and he demonstrated his passion for farm work. Jim was not accompanied by a job coach, he was not driven by his mother, he was not grouped with other people with disabilities – he was doing what he loved and he was doing it well. Jim was experiencing what it means to be an integrated member of his community.

Getting to that tractor ride was an even bumpier road through the public-school system; a system that told his mother that Jim had “learned as much as he was going to” and needed to exit school despite continuing to be eligible for supports. His parents’ fight to keep Jim’s postsecondary goals at the center of his planning took them all the way to the United States District Court – where they claimed that the school had not provided Jim with adequate transition services so he should not be graduated - but they did not prevail (see *Robert Bell v. Education in the Unorganized Territories*, 33 IDELR 184 (D.ME. 2000)). The

system was about “good enough,” but Jim and his family could not accept anything less than meaningful community integration.

One of the defenses that the school officials had used for their lack of good postsecondary transition planning was that the resources that Jim needed simply did not exist in extreme rural Maine. This was certainly true about paid social services; but with the specter of generational poverty hanging over them, rural Mainers have learned to be resourceful and hard-working. Extremely independent and proud, the region’s citizens are not ones to ask for help, but they know how to support each other, and Jim was one of their own. A neighbor drove Jim to a job shadow twenty miles away. A brother served as a job coach to teach new skills on the farm. A retired teacher continued to work with him on his academic skills. None of these people were identified as needed transition services on his required special education transition plan – but they were all critical to helping him move forward to adulthood. Riding along in the back of the tractor, I began to have an epiphany about supporting young people with disabilities; maybe geographic isolation and poverty among rural students with disabilities were not insurmountable barriers to postsecondary success, perhaps the answer was as simple as looking at the “natural” supports that were hidden in plain sight.

Statement of the Problem

Students with disabilities who receive special education services are required under federal law, the *Individuals with Disabilities Education Act* (IDEA), to have an Individualized Education Program (IEP) that includes measurable postsecondary goals and needed transition services (Assistance to States for the Education of Children with

Disabilities, 2018, section 300.43). Transition planning for students with disabilities in rural areas can be uniquely challenging due to lack of access to transportation, services providers, and accessible programs. Natural supports in the form of neighbors, friends, employers and other community members could be rich sources of support but are generally not invited into the transition planning process. As a result, transition planning in rural areas is often inadequate to ensure successful transition to adulthood for students with disabilities and consequently these young people often remain at home – out of postsecondary education and employment.

Background

Services for students with disabilities. In the 40 plus years since the passage of the *Education for All Handicapped Children Act*, (Public Law 94-142) in 1975 (known since 1990 as the *Individuals with Disabilities Education Act* (IDEA) - parents, advocates and special education teachers have been committed to promoting access to equal and accessible instruction that fulfills the promise of a *free and appropriate public education* (Public Law 94-142, § 602(9)). Despite the legal protections afforded to students with disabilities under special education law, which are also supported by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, for many of these students, completing high school and entering postsecondary education and employment remains a challenge. According to the National Center for Education Statistics (United States Department of Education Institute of Education Sciences, 2017), across the country, only two-thirds of students with disabilities graduate from high school. Even fewer enter employment or pursue a college education. As in general education, special education has

been the subject of extensive research and reform efforts. These have focused on turning the needle on these outcomes through evidence-based practices, specialized instruction, and more robust transition planning (Blackmon, Kohler, Test, & Morningstar, 2015).

While students who qualify for special education services are the subject of this study, there are other students with disabilities who may not qualify for special education services despite presence of a disability. Federal statute (34 CFR § 300.8) clarifies that for the purposes of IDEA, a student must have both a qualifying disability and need of special education and related services. Students may be found ineligible if no need for special education services is demonstrated. In this study, the term “student with a disability” should be understood to specifically refer to students who receive/d special education services. They form a subset of the broader population of school-age or young-adult individuals with disabilities. When that broader group is being referenced, they will be identified as “youth with disabilities” or “young adults with disabilities” except where specifically noted.

What is transition planning? Under IDEA, transition planning is required beginning at age 16 for all students with disabilities who receive special education services. Maine law, *Maine Unified Special Education Regulation Birth to Age Twenty* (05-071, Chapter 101, 2017), surpasses the federal law obligations and requires that transition planning commence not later than 9th grade (p. 97). Hallmarks of transition planning include development of postsecondary education, employment and independent living goals, as well as identification of needed transition services, for inclusion in the student’s Individualized Education Program (IEP). The goal is a coordinated set of strategies and services to promote attainment of desired postsecondary outcomes. The importance of transition planning has been reinforced

in reauthorizations of IDEA. The most recent reauthorization in 2004, in addition to establishing that transition services needed to be in place by age 16, also increased schools' accountability for achieving postsecondary outcomes (Assistance to States for the Education of Children with Disabilities, 2018, section 300.601). Understanding the requirements of the legislative mandates is important to meeting federal expectations for schools and students. Chapter 2 provides a more comprehensive overview of the federal and state laws governing postsecondary transition planning for students who receive special education services, but how do these laws and regulations impact transition planning for an individual student with a disability?

Transition planning in practice. Every student who receives special education services has individual strengths, needs, and goals for the future. Likewise, a disability label must be understood in the context of the individual experiencing it. Transition planning must reflect the uniqueness of each student, and this is signaled first by its inclusion in the *Individualized Education Program (IEP)* that must be developed for every student who receives special education services. This means that while there are accepted best practices, each IEP for a student of transition age should be as unique as the student herself.

Models of best practice to support transition planning vary greatly but one example that includes natural supports is the SPANS (Systematic Plan for Achieving Natural Supports) developed by Trach and Mayhall (1997). This model was developed to assist individuals with significant disabilities around transition to employment. It includes six components: (1) consumer-driven planning, (2) ecological assessment of individual needs, (3) environmental assessment of natural supports, (4) identification of natural supports in

multiple environments, (5) matching natural supports to individual needs, and (6) development of individual natural supports plans (Trach & Mayhall, 1997, as cited in Project 10 Transition Education Network, n.d.). To better understand what this looks like in practice, two fictional examples, drawn from experience, are presented below. The first does not include natural supports, and the second does.

Example one – Jenny. “Jenny” is a 16-year-old girl in the 10th grade, who lives with her family in a small city in New England. Jenny receives special education services under the category “Other Health Impairment” due to the impact of her diagnosis of attention deficit disorder on her ability to access her high school’s general education curriculum. Jenny has difficulty in lecture-style classes and learns better when the course material is presented through hands-on activities. Jenny can be impulsive and has sometimes struggled in social situations. Her current goals are to graduate high school and enroll in the local community college’s program in Culinary Arts. Ultimately, Jenny would like to work as a chef in an upscale restaurant in her city. Jenny’s parents are supportive of this goal but are concerned that she has had little real-world experience to prepare her for the realities of postsecondary education or employment.

Before her annual IEP meeting, Jenny met with the teacher who serves as her school-based case manager to prepare for the meeting. They reviewed the results of a recent transition assessment which confirmed that Jenny’s skills and interests were a good match for a career in culinary arts. They also reviewed the community college’s admissions requirements to help in selecting courses for her junior and senior years. They talked about Jenny’s strengths and needs both in the classroom and out. On the day of her IEP meeting,

Jenny joined the team – which included her regular education and special education teachers, the school principal, her parents, and the school guidance counselor. Based on Jenny’s interests, Jenny’s current IEP includes these two postsecondary goals:

1. After high school graduation, Jenny will attend New England Community College’s Culinary Arts program (education).
2. After completing the New England Community College’s Culinary Arts program, Jenny will work as a chef in Small City, New England (employment).

The team agrees that Jenny will need some transition services to prepare her to reach those goals. They work together, keeping Jenny’s goals as the focus, and identify the following transition services to include in her IEP for the coming year:

1. Jenny will receive specialized instruction in study skills to prepare her for completing college-level assignments (instruction).
2. Jenny will participate in “Job Club” with the school social worker to build soft skills for employment (related services).
3. Jenny will attend the New England Community College open house with her parents in May (community experiences).
4. Jenny will be referred to Vocational Rehabilitation to assist in finding a summer job in a local restaurant (employment activities).

Jenny’s transition services represent coordinated activities that are moving her in the direction of her postsecondary goals. If Jenny is able to complete each of these activities, she, her parents, and her IEP team will have a strong foundation to build upon for her next year’s IEP meeting. Her transition services will be updated to reflect that new information.

Example two – Joey. “Joey” is a 17-year-old student who is in the 11th grade. Joey lives with his mother and grandmother in a rural community in Maine. Joey is identified as a student who needs special education services in the category of “multiple disabilities”. Joey has a chronic heart condition that makes sustained physical activity challenging, and he also has an intellectual disability that impacts his ability to learn at the same rate as his peers. Joey does not like to be singled out for services and has often over-exerted himself lifting heavy items. Joey’s high school has less than 200 enrolled students. He has worked with the same special education teacher for the last three years in his school’s life skills program – where he receives the majority of his instruction. Before his IEP meeting, he meets with his special education teacher. Joey is not sure what he wants to do after high school but he enjoys fishing and spending time with his neighbor, Mr. Dorr, an elderly man who has known Joey since he was small and has always had a good rapport with him. He likes to have Joey go fishing with him and has sometimes offered him money to help him with cleaning up around the yard. Joey knows a lot about the right bait and tackle to use from spending time with Mr. Dorr.

Joey’s teacher has conducted some transition assessments with Joey that highlight that Joey has strengths in his attention to detail and ability to work well with others but also confirm that he does not have any clear postsecondary education or employment goals. When it is time for his IEP meeting, his mom and grandmother attend, as does Joey. They also invite Mr. Dorr to attend because he knows Joey well and has “knowledge or special expertise about the child” (Assistance to States for the Education of Children with Disabilities, 2018, section 300.321). During the meeting, Joey’s mother and grandmother

share that they are not sure what Joey can do for work. They are concerned about him getting overtired due to his heart condition. Mr. Dorr shares about the things that he has seen Joey do well, like handling the fishing tackle and always selecting the right bait for the particular fish they are hoping to catch. During this part of the meeting, Joey is more animated and talks about a new lure that he and Mr. Dorr are hoping to use soon. Mr. Dorr shares that his adult son is the manager of the marine supply store in the next town over. He and Joey go there sometimes to buy lures. Joey's vocational rehabilitation counselor asks Joey if he would be interested in having a paid work experience set up there – which he is. Mr. Dorr offers to drive Joey to the work experience three days per week. Joey's vocational rehabilitation counselor meets with the marine supply store the following week and sets up the work experience. The special education teacher, knowing that Joey will have some difficulty learning the tasks to be completed on the work experience, develops a pictorial guide to completing the tasks similar to one that he uses in school. She also recommends a new program through the local adult education office that provides training on customer service, Joey expresses interest because he likes to spend time around people. Joey's IEP now includes the following post-secondary goals:

1. After high school graduation, Joey will enroll in Rural Town Adult Education's customer service training certificate training program.
2. After high school graduation, Joey will work part-time for a local marine supply store (employment).
3. After high school graduation, Joey will maintain his health through regularly attending appointments with his cardiologist (independent living).

Joey's transition services include:

1. Joey will receive specialized instruction in fractions to assist him with using weights and measurement tools in a marine supply store (instruction).
2. Joey will meet with the school nurse weekly for a blood pressure check (related services).
3. Joey will visit the Rural Town Adult Education Office with his family to get information on the customer service training program (community experiences).
4. With wage support from Vocational Rehabilitation and transportation support from Mr. Dorr, Joey will participate in a work experience at Rural Town Marine Supply (employment).

Jenny and Joey's examples provide a brief look at transition planning as required under IDEA. Early exposure and planning allows time for Jenny and Joey to also change or refine their goals. Through work experiences in their fields of interest, they have the opportunity to learn first-hand about the job tasks involved as well as the supports that they may need to be successful. In the case of Joey, including a natural support in the transition planning process helped make a connection to a local employer as well as to a transportation resource. As Joey works at the marine supply store, he will make connections with other employees leading to additional community integration. As noted in the SPANS model, the natural supports that Joey received were individualized to his needs. As Joey gains skills at his marine supply work experience, it will become clearer what his longer-term needs will be. Including natural supports in ongoing planning and support meetings will help to continue to ensure that Joey's individual needs are met (Trach & Mayall, 1997).

Natural Supports

Since the 1980's, research in the field of inclusion of people with developmental disabilities has identified the importance of *natural supports*. Natural supports can be defined as:

personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships; friendships reflecting the diversity of the neighborhood and the community; association with fellow students or employees in regular classrooms and work places; and associations developed through participation in clubs, organizations, and other civic activities. (California Department of Developmental Services, n.d., p. 1)

The role of natural supports for people with disabilities has been most notable in supporting integration in employment (Nisbet & Hagner, 1998; Storey & Certo, 1996) but natural supports have also been identified as important to the transition planning process. The Kansas Transition Systems Change Project (n.d.) identifies natural supports as a key quality indicator. Natural supports build on the interests and strengths that young people have and build linkages within their communities. These are relationships that are not constrained by the “clash between institutional transitions... (and) cultural or natural guidelines” (Davis, 2003, p. 496).

One consideration in understanding the use of natural supports in rural Maine is the concept of “Yankee Ingenuity”. This term has traditionally been used to reference the ability of the geographically-isolated people of New England (of which Maine is part) to devise

innovative solutions to meet challenges and needs (Price, 2011). “Yankee Ingenuity” is historically-rooted in a self-reliance that arose out of necessity, but it also reflects the abilities of rural communities to meet their own communal needs. One example related to this study is found in fifty-year-old findings from a pilot initiative in a Massachusetts psychiatric children’s hospital (Reinherz, 1963). In the study, college students from Harvard and Radcliffe were trained as volunteer case aides to work with hospitalized children as a way to meet workforce shortages while building bridges for the hospitalized youth between the community and the institution. The researchers found that despite initial reservations by trained professional hospital staff, the children’s “ability to relate meaningfully developed” and they witnessed unexpected growth (p. 546). They concluded that “both volunteers and members of the hospital’s staff can supplement one another’s efforts” which offers an early example of the interplay between natural supports and “Yankee Ingenuity” (p. 546).

Chapter 2 further explores what is known – across disciplines - about the value of natural supports to promote improved outcomes for people with disabilities. As the Maine Department of Education seeks to demonstrate compliance with federal special education requirements, it may be that the use of natural supports in transition planning could be an effective strategy.

Federal Monitoring

According to federal regulations, the Maine Department of Education must report to the federal government concerning compliance on a number of indicators. “Indicator 13” is the indicator that measures whether students with Individualized Education Programs (IEPs) have transition plans. It requires IEPs to have:

appropriate, measurable, postsecondary goals that are annually updated and based upon an age appropriate, transition assessment, transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals and annual IEP goals related to the student's transition services needs. There also must be evidence that the student was invited to the IEP team meeting where transition services are to be discussed and evidence that if appropriate a representative of any participating agency was invited to the IEP team meeting with the prior consent of the parent or student who has reached the age of majority (20 USC 1416 (a) (3) (B)).

Federal monitoring data (United States Department of Education, 2018) reported by Maine during the period of federal fiscal years 2009-2016 reveals a pattern of uneven compliance with Indicator 13, which has a federally required target of 100%, as shown in Table 1.1. This suggests that current strategies for transition planning are not consistently successful and that there is a need to better understand (1) why, (2) whether natural supports could play a role in improving compliance, and (3) if so, how to integrate natural supports into the planning process.

Table 1.1

IDEA Part B – Indicator 13 – Maine SPP/APR

Federal Fiscal Year	Target %	Actual Data %
2009	100	88
2010	100	47
2011	100	60.40
2012	100	36
2013	100	63.36
2014	100	54.29
2015	100	88.96
2016	100	94.38

Source: United States Department of Education, Office of Special Education Programs (n.d.),

<https://osep.grads360.org>

Guiding Frameworks

Research benefits from guiding frameworks or theories. This study is drawn from multiple disciplines as diverse as special education, disability policy, educational theory, psychology, rehabilitation counseling and social work and takes a transdisciplinary approach that promotes the inclusion of non-traditional contributors to the research and aims to answer real-world problems (Bergmann et al., 2012; Pohl & Hadorn, 2007; Polk, 2014). In keeping with the overarching transdisciplinary research approach, several fields of study or theories help to inform how the role of natural supports in transition planning for students with disabilities in rural Maine may be understood. These paradigms include disability studies, social support theory, parent engagement, mentoring, and best practices in transition planning. In Chapter 2, the literature review explores in more depth current research findings

in each of these areas, as well as the additional layer of rurality as a critical lens. Here is a brief introduction to each concept.

- *Disability studies* - Disability studies is a relatively new but growing field that examines the role that disability plays in the lives of individuals. Moving from an early medical understanding of disability to a functional barriers model of disability has meant shifting from seeing the individual with the disability as a problem to fix to a model of understanding disability as a social construct where barriers exist as external to the individual. More recently, some individuals with disabilities have embraced a viewpoint that straddles both the medical and social understandings of disabilities to take ownership of their disability and define for themselves how it is or is not a defining characteristic in their self-concept (Brown, 2011). Within disability studies, other theories - such as Sen's capabilities approach - are examined for their influence on thinking about the access of people with disabilities to quality and meaningful lives (Mitra, 2006).
- *Social support theory* - Social support theory, as applied in the fields of health, rehabilitation, and psychology, recognizes the link between having a supportive network and an individual's health and well-being (Feeney & Collins, 2015). The connection between this supportive network and an individual's ability to thrive and build resiliency in the face of challenges or adversities makes it particularly useful as a concept for understanding the importance of natural supports in transition planning for students with disabilities - many of whom are at risk of being disconnected from social supports after leaving high school.

- *Best practices in transition planning* - Studies over the last twenty or so years, have identified evidenced-based and promising practices in the field of transition planning for students with disabilities. Kohler's (1996) Taxonomy for Transition Planning includes five areas where evidenced-based practices have been located. They are (1) student-focused planning, (2) student development, (3) interagency collaboration, (4) family involvement, and (5) program structures. The use of natural supports may support one or more of these transition strands.
- *Parent engagement* - The value of parental expectations and involvement in the transition planning process has been well documented (Pleet & Wandry, 2009) for its contributions to positive post-school outcomes for students with disabilities. Engagement can include attendance at school meetings, supporting the student at home to build the skills needed for adult living or participating in postsecondary transition planning.
- *Mentoring* – Mentoring pairs individuals with less experience with others who are more experienced so that they can gain skills and advice. This knowledge exchange may occur through structured or unstructured activities. Mentoring shares many features with the concept of natural supports, but may be more time-bound, curriculum-driven, or relationship-based than natural supports. Mentoring is prevalent across disciplines as diverse as business management, education and psychology. While not exclusively applied to youth with disabilities, mentoring as an intervention is often targeted at youth with barriers as a strategy to build skills and community connections (DuBois & Rhodes, 2006).

Purpose of this Study

The purpose of this study is to better understand the barriers that exist in rural Maine today for successful transition planning, the role that natural supports have played in transition planning, transition and postsecondary outcomes for students with disabilities living in rural Maine, and barriers that may prevent more fully accessing and integrating these resources into transition planning and implementation. Data collected in this study included the voice of youth with disabilities (from multiple sources) and interviews with parents of students with disabilities and special educators who are both responsible for overseeing development and implementation of the Individualized Education Program and serve as gatekeepers to “seats at the table” at transition planning meetings.

Research Questions

1. What barriers exist to transition planning for students with disabilities in rural Maine today?
2. In what ways have natural supports contributed to positive postsecondary education and employment outcomes of young people with disabilities living in rural Maine?
3. To what extent are natural supports included in transition planning by IEP teams in Maine Public Schools?
4. What barriers exist to inclusion of natural supports in transition planning under the *Individuals with Disabilities Education Act (IDEA)*?
5. How can stakeholders (parents, special educators, the Maine Department of Education and others) support the inclusion of natural supports in transition planning?

Study Design

This study uses qualitative methods to examine the role of natural supports in promoting postsecondary transition for students with disabilities in rural Maine. It does so by looking at a wide variety of data sources including (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators. When synthesized together this data provides a comprehensive approach to responding to the study's research questions.

The research design is informed by phenomenological inquiry methodology. Phenomenology, according to Van Manen (1990), is a way of describing a phenomenon and also bounding it – or setting limits around the experience - to help determine what makes it different from other phenomena. Creswell (2014) further describes it as a way to determine the essential elements of an experience – in this case, the experience of transition planning for students with disabilities in rural Maine (p. 140). In this study, to understand the phenomenon, the four selected sources of data were analyzed using qualitative data analysis methods and the resulting findings were analyzed within a transdisciplinary approach. This allowed these experiences to ultimately inform recommendations for sustainable ways to promote inclusion of natural supports as a means to strengthen transition planning and postsecondary outcomes for young people living in rural communities in Maine.

Qualitative research is often the best approach when the goal of a study is to understand “the why” behind an experience or phenomenon (Creswell, 2014). In this study, multiple data sources, examined through a qualitative lens are key to answering the research

questions and understanding “the why”. Legal and document analysis, when added to an analysis of the perspectives of youth and the lived experiences of parents and special educators as they support youth as they transition from high school to adult living, provides for a comprehensive understanding of the phenomenon of transition planning for students with disabilities in rural Maine today. Qualitative research recommendations have been followed to promote reliability and validity, but still, as with any qualitative study, caution should be used when addressing the issue of generalizability of study findings.

Positionality

As an individual who is currently active in the field of transition and who is working in a relatively small environment in Maine, awareness of positionality was critical throughout the research study. Through engaging in *Epoché* and the use of bracketing (phenomenological steps discussed in more depth in Chapter 3), a process was adhered to that acknowledged the relationships, experience, and assumptions that existed pre-study, while not allowing them to overshadow the experiences of the individuals who were interviewed. It is not known, however, how the researcher’s role as director of the state vocational rehabilitation agency or chair of the state special education advisory committee may have influenced participation (either positively or negatively) of educators and parents in this study. In developing the approved Institutional Review Board (IRB) protocols for this research, language was included that offered assurances of confidentiality, but Maine is a small state and the Division of Vocational Rehabilitation serves approximately 10,000 individuals with disabilities each year (Maine Bureau of Rehabilitation Services, 2018). While the planned study had originally included interviews of students as well, it proved

difficult to obtain parental permission to interview students. This hesitancy may have been the result of fear (at any level) that this could jeopardize access to a needed service. To ensure the inclusion of youth voice, this study draws on two additional data sources, (1) responses to a statewide survey of Maine high school students, the Maine Integrated Youth Health Survey and (2) document review of feedback and ideas shared by a newly-formed Youth Advisory Group for youth and young adults with disabilities.

Significance of the Research

This research responds to a real-world problem. The findings of this study have relevance today in meeting the needs of rural students with disabilities who are eligible for special education services as they transition to postsecondary life. The study's findings are designed to be pragmatic and presented in a manner that may naturally lead to action. In particular, these findings address three important areas:

Promoting Inclusion

The full inclusion and participation of people with disabilities in their communities is a matter of human rights (UN General Assembly, 2007). Choice of where and how to live and what supports are desired are individual decisions that have historically been made for people with disabilities without their full input or consent (Institute for Community Inclusion, n.d.; Mitra, 2006). A young person with a disability who selects his own choice of natural supports is building community connections (Duggan & Linehan, 2013) and exercising his fundamental right to self-determination (UN General Assembly, 2007, Article 3). This study takes the perspective that the culture of inclusive communities includes the ability of everyone to contribute to solving their own problems.

Promoting Effective Use of Resources

In an era of funding cuts to social service programming, strengthening an understanding of the important role that natural supports can play in improving the lives of people with disabilities takes on increased importance. Poverty and geographic isolation can be factors in marginalizing rural communities (United States Department of Education, Office of Communications and Outreach, 2018), making it challenging for the rural people to give voice to their needs. Development of natural supports is an effective practice that is not reliant on the availability of public funding and can be shaped to the needs and culture of the community. When publicly paid supports are present, natural supports may complement what is available. When appropriate natural supports are available, public funding may be directed to pay for other needed services.

Promoting Compliance and Quality Assurance

Receipt of continued federal funding for special education is contingent on compliance with federal law and regulations. The United States Department of Education's Office of Special Education and Policy oversees special education grant awards to states and requires that each state develop a State Performance Plan every six years and submit an Annual Performance Report (United States Department of Education, Office of Special Education Programs, n.d.). These state-submitted plans and reports promote accountability and transparency by sharing publicly how funding is being used and what the associated outcomes are. Following receipt of the state's Annual Performance Report, the United States Department of Education issues a determination letter to let the state know if they met compliance – and if not, what actions the Department is requiring be undertaken (United

States Department of Education, 2018). Compliance is broken into four categories: (1) Meets the requirements and purposes of IDEA; (2) Needs assistance in implementing the requirements of IDEA; (3) Needs intervention in implementing the requirements of IDEA; or (4) Needs substantial intervention in implementing the requirements of IDEA. These actions may include participation in technical assistance or in extreme cases relinquishment of federal funds (United States Department of Education, 2018). In 2018, for Part B School-Age Children, Maine fell in category (2) “Needs Assistance”, as it was noted that Maine had been in this determination for two or more consecutive years (United States Department of Education, 2018, p. 3). Implementation of practices that strengthen compliance with IDEA’s requirements for transition assist in ensuring that Maine will continue to receive needed federal funding.

Organization of the Dissertation

This study is presented in six chapters. Chapter 1 introduces the study, including background on transition planning for students with disabilities in Maine, significance of the research study, related literature, methodological approaches and research questions. This Chapter provides the context for the study by presenting the legal framework, rural Maine as a physical setting for the study and the positionality of the researcher.

Chapter 2 begins with a review of the federal and state laws and rules and their implications for transition planning. This is followed by a review of the transdisciplinary literature in the fields addressed in this study: special education, disability policy, educational theory, psychology, rehabilitation counseling and social work, and positions the research within these fields. The literature review takes a particular look at how natural supports have

been used to promote positive outcomes across these academic fields and how rurality fits as a lens for the research.

Chapter 3 focuses on the research design, including the methodology, data collection and data analysis. Here, is also found the justification of selection of qualitative research as the best manner to gather and analyze the data needed to respond to the research questions. The Chapter additionally discusses the strategies used to promote qualitative validity (such as triangulation) and reliability (such as use of coding and word clouds). The Chapter concludes with presentation of themes arising from the data.

Chapter 4 presents the study's findings in response to the first four research questions. These findings are drawn from analysis of the four data sources, (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators.

Chapter 5 discusses the findings and in keeping with the transdisciplinary approach, presents recommendations for policy and practice, ideas for dissemination of the findings, and after examining the findings within the context of the current literature, offers suggestions for future research to answer the study's final research question. Lastly, Chapter 6, the conclusion, includes a summary of the study and its significance.

CHAPTER 2

LITERATURE REVIEW

Several fields of study provide the context and current state of knowledge for this study. The study of the process of transitioning from high school to postsecondary education, employment, and adult living crosses many disciplines, and in keeping with a transdisciplinary perspective, this involved examining research in special education law, disability studies, postsecondary transition planning, parent engagement, mentoring, and social support theory. Additionally, two concepts serve as cross-cutting themes across those topics – rurality and natural supports. Relevant scholarship came from journals covering as diverse fields as special education, disability policy, educational theory, psychology, rehabilitation counseling, and social work, among others.

One central theme that ties this work together is the idea of natural supports promoting “independence.” While Wehman and Bricout (n.d., p. 215) state that “every individual needs some level of assistance to succeed,” for students with disabilities it is often incorrectly believed that they will need specialized supports or must demonstrate a level of competency before they are allowed to exert their independence in decision-making about employment and education – as well as in other spheres of their lives. Students with disabilities, who are often surrounded by paid support systems, may find those systems more

limiting to expression of independence when compared to natural support systems, which may not understand disability or view it as a deficit.

To set the context for consideration of natural supports and transition planning for students with disabilities, this chapter begins with a comprehensive examination of the federal laws and regulations governing transition planning for students who receive special education services. This section also includes an overview of Maine state rules to provide clarification on how these rules mirror or differ from the federal guidance.

Transition Planning - Legal Framework

The Individuals with Disabilities Education Act (2004) (PL 94-142) (IDEA) is the federal law that provides the framework and authorization for special education services. The law's accompanying regulations are found in the 2018 United States Code of Federal Regulations (C.F.R.) as 34 C.F.R. § 300 – *Assistance to States for the Education of Children with Disabilities*. These regulations include six sections that address postsecondary transition planning, or preparation of students while in secondary school for postsecondary outcomes: (1) Purposes; (2) Individualized Education Program Transition Services (and definition of transition services; (3) Individualized Education Program Team Composition; (4) Transfer of Age of Majority; (5) Summary of Performance; and (6) Transition Services Funding.

Purposes

The “Purposes” section of the regulation (Assistance to States for the Education of Children with Disabilities, 2018, section 300.1) takes its authority from the Individuals with Disabilities Education Act (2004) and sets out the expectations for what the goals of special education services are. Specifically, § 300.1 (a) states that the purposes include “to ensure

that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for education, employment and independent living.” Provision of special education therefore begins with the end in mind - and those ends reflect the framers’ expectations that youth with disabilities will be able to participate in “education, employment and independent living.” These high expectations are often at odds with the realities for students with disabilities who regularly encounter the bias of lower expectations than their peers without disabilities in school, the community - and even at home (Blustein, Carter, & McMillan, 2016).

Individualized Education Program Transition Services

In its most recent reauthorization in 2004, IDEA reinforced the expectation that every child with a disability who is 16 years or older and receiving special education services must have an Individualized Education Program (IEP) that includes measurable postsecondary goals in training, education, employment - and as appropriate - independent living, as well as the transition services needed to help meet those goals. The regulations define Transition Services (Assistance to States for the Education of Children with Disabilities, 2018, section 300.43) as

- (a) A coordinated set of activities for a child with a disability that (1) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities including postsecondary education, vocational education, integrated employment (including supported employment),

continuing and adult education, independent living, or community participation; and (2) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes - (i) instruction; (ii) related services; (iii) community experiences; (iv) the development of employment and other post-school adult living objectives; and (v) if appropriate, acquisition of daily living skills and provision of a functional vocational evaluation. (b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education. (Individuals with Disabilities Education Act, 2004, section 1401 (34))

Transition services should focus on coordinated activities, moving the individual towards post-school outcomes, and should parallel the high school process for all students with and without disabilities. Coursework is undertaken with the goal of achieving a high school diploma and gaining entry into college or the workplace. The Individuals with Disabilities Education Act (2004), through its transition services requirements, makes clear that success for students with disabilities is tied to functional as much as academic achievement and that certain key elements like community experiences or acquisition of daily living skills are needed for these young people to achieve postsecondary outcomes. Inclusion of the appropriate transition services in the IEP ensures movement towards achievement of measurable postsecondary goals. Postsecondary goals that are outlined in the IEP should be a natural fit with other IEP goals. If the IEP team fails to identify the appropriate needed

transition services to reach those desired postsecondary goals, the IEP is incomplete (Blackmon et al., 2015).

In the federal regulations on “Definition of individual education program (Assistance to States for the Education of Children with Disabilities, 2018, section 300.320), the elements of the program are further described. Transition services states:

Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include (1) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and (2) the transition services (including courses of study) needed to assist the child in reaching those goals. (Assistance to States for the Education of Children with Disabilities, 2018, section 300.320 (b))

Early inclusion of transition services in the IEP is central to ensuring that planning and resources are devoted to preparing for the student’s postsecondary plans. Early exposure - through coursework, work and community experiences - help students with disabilities in rural areas to have a more complete understanding of what it actually means to pursue a career in forensic science, professional sports, or video game development (three current popular fields of interest). If forensic science is a goal but a student with a disability has not had access to rigorous science classes, admission to higher education opportunities in the field is much less likely. On the other hand, a student who is properly supported in more challenging high school coursework may then be able to make an informed decision about whether or not pursuing a career in the sciences is a fit, and the IEP goals and transition

services can be modified in response to what is learned. A community experience with natural supports can be a powerful transition assessment because it reveals areas of competence not seen in the academic setting, and it also can clarify the levels of support that may be realistically needed in a postsecondary setting.

The regulations do not presume a cookie-cutter approach to transition services but rather one that is “based on the individual child’s needs” as well as his/her “strengths, preferences, and interests” (34 CFR § 300.43). Set within the context of the child’s IEP, with its measurable goals, the exact combination of services is left to the IEP team to determine.

IEP Team Composition

The membership of the IEP team - including the student – take on, therefore, a significant responsibility to help craft the content of the IEP when the topic is transition. Section 34 C.F.R. 300.321 (Assistance to States for the Education of Children with Disabilities, 2018), which describes the IEP team, includes a section on transition services participants. That section identifies the following:

1. In accordance with paragraph (a) (7) of this section, the public agency must invite a child with a disability to attend the child’s IEP Team meeting if a purpose of the meeting will be the consideration of the postsecondary goals for the child and the transition services needed to assist the child in reaching those goals under § 300.320 (b).
2. If the child does not attend the IEP Team meeting, the public agency must take other steps to ensure that the child’s preferences and interests are considered.

3. To the extent appropriate, with the consent of the parents or a child who has reached the age of majority, in implementing the requirements of paragraph (b) (1) of this section, the public agency must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services

The key role of the student as a source of important knowledge needed for transition planning is reinforced in these regulations, and subsection (3) makes clear that if another agency is likely to be providing or paying for a service that it also needs to be invited (given proper parental consent). On the surface, this regulation might seem to preclude the participation of an individual who does not represent an agency “responsible for providing or paying for transition services,” so it is necessary to examine the IEP team members as laid out in the (a) general section of the regulation. Here, in addition to including the child with a disability (whenever appropriate), the other required members of the IEP team are identified including parents, a regular education teacher, special education teacher, a school representative who is both knowledgeable about the needs of children with disabilities and the offerings of the general curriculum in the context of the school’s resources, and an individual who can interpret evaluation results. After these five types of participants, the regulation continues with “(6) At the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate.” While the focus may be on the school and related services, this regulation opens the door for the parent (or the school) to invite other individuals including - potential or actual natural supports - into the IEP team, and by extension into the transition planning process.

As the invitation to an outside person to participate in the IEP meeting is based on possession of “knowledge or special expertise regarding the child,” what criteria are used to determine if this exists? Section 34 C.F.R. 300.321 goes on in sub-section (d) Determination of knowledge and special expertise to state that “the determination of the knowledge of special expertise of any individual described in paragraph (a) (6) of this section must be made by the party (parents or public agency) who invited the individual to be a member of the IEP Team.” This rule was reinforced in a March 31, 2008 federal guidance letter issued by William W. Knudsen, then Acting Director of the Office of Special Education Programs, in response to a question on a related topic by the State of Missouri. Writing for the United States Department of Education, Acting Director Knudsen states, “Section 614 (d) (1) (B) (vi) of IDEA and 34 C.F.R. §300.321 (a) (6) of the regulations allow, at the discretion of the parent or the public agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate, to be invited to the IEP Team meeting. The determination of the knowledge or special expertise of any individual described in 34 C.F.R. §300.321 (a) (6) must be made by the party (parents or public agency) who invited the individual to be a member of the IEP team,34 FR § 300.321 (c)” (Knudsen, 2008, para. 2). The Center for Parent Information & Resources (2017), a federally-funded national technical assistance center, offers interpretation that persons who could be invited under this section include a “friend or relative who knows the child” or “others who can talk about the child’s strengths and/or needs” (para. 2). A natural support such as a community member, employer or faith leader would also fit as easily here.

Having established that natural supports are permitted participants in the IEP meeting, it is interesting to note that the regulations speak specifically to parents or the school having the ability to invite these outside resources - not the child. This reinforces the role that parents and educators play as gatekeepers to the IEP meeting and transition planning process. In other sections of the federal regulations, it is clearly stated that the student at the age of majority may play an expanded role in the education process by consenting (or not) or taking other action. In 34 C.F.R. 300.321 (b) (3) (Assistance to States for the Education of Children with Disabilities, 2018), addressing transition service participants, the “consent of the parents or a child who has reached the age of majority” is needed to invite representatives of agencies responsible for providing or paying for transition services.

Transfer of Parental Rights at Age of Majority

Section 34 C.F.R. 300.520 of the 2018 Code of Federal Regulations addresses another area impacting transition age students, that of the transfer of parental rights at the age of majority. The regulations state that “a State may provide that, when a child with a disability reaches the age of majority under State law that applies to all children (except for a child with a disability who has been determined to be incompetent under State law): (i) the public agency must provide any notice required by this part to both the child and the parents; and (ii) all rights accorded to parents under Part B of the Act transfer to the child”. This is another area of the regulations that presumes that students with disabilities have the right to make decisions about their future plans. Transfer of these rights presupposes that planning and discussion have occurred with the student in advance of the transfer (schools are obligated to begin discussion of the transfer of rights one year in advance) so that the student

has had the opportunity to practice decision-making. These opportunities can come in many settings but are particularly likely to arise in the scope of transition services and activities - further reinforcing the importance of meaningful, rich activities that are tied to real-world activities and real-world resources (like natural supports).

Summary of Performance

Another required element for students receiving special education who age out of special education or graduate from high school with a standard diploma is the “Summary of Performance.” According to IDEA, the school has to give the student a “summary of his or her academic achievement and functional performance” (Individuals with Disabilities Education Act, 2004, section 1414(c)(5)(B)(ii)). The Summary of Performance is not meant to be a static report however; the document must also include recommendations for the student on how to meet identified postsecondary goals. The Summary of Performance is situated in the special education regulations (Assistance to States for the Education of Children with Disabilities, 2018, section 300.305 (e)) under *Evaluations* before a section on ineligibility, indicating that the purpose is to ensure that the student does not exit from school (and special education) without a record of her performance and achievements. For students without disabilities, the high school transcript typically serves this purpose, however, for students who received special education, the names of courses taken or levels of support provided can often be unclear, and the Summary of Performance provides an opportunity for the student to have more information about his/her academic - and functional - performance. The richer the student’s transition services and experiences, the more meaningful the Summary of Performance will be.

Transition Services Funding

Federal funding provided to the states for the special education services may be used for funding of transition services. Section 34 C.F.R. 300.704 (Assistance to States for the Education of Children with Disabilities, 2018) identifies that an allowable use of funding is for “Development and implementation of transition programs, including coordination of services with agencies involved in supporting the transition of students with disabilities to postsecondary activities.” Federal approval for states to use this funding is important to note because it challenges the notion that transition planning is an add-on activity that is meant to be delivered only through leveraged resources or if money allows. Schools may be hesitant to spend funding on transition services whose outcomes may be of lesser concern to them than delivery of special education services upon which the school will be measured more directly (like achievement gains in math or reading). This tension between the immediacy of special education needs versus “kicking the can down the road” for students with transition service needs is a powerful force in schools. While funding pressures may make the use of natural supports more appealing, the promotion of use of natural supports should not be driven by a desire to avoid paying for needed services but rather towards sustainability of a student’s needed supports.

Rule of Construction

While not specific to transition planning, one section of the Individuals with Disabilities Education Act (2004) that is often referenced as a check on what may be included in transition planning is the Section 614 “Rule of Construction.” This rule states that “Nothing in Section 614 shall be construed to require: (1) that additional information be

included in a child's IEP beyond what is explicitly required in Section 614; or (2) the IEP team to include information under one component of a child's IEP that is already contained under another component of such IEP" (614(d)(1)(A)(ii)). This language was added in the 2004 reauthorization of IDEA and would seem to direct IEP teams to only include required elements in the IEP. The Rule of Construction may also be used to limit transition planning from expanding beyond the scope of narrow interpretation of the federal and state rules.

Federal laws shape how state rules are developed and may serve as a minimum standard that must be met. While Maine special education law closely mirrors federal language, recognizing the importance of preparing young people with disabilities for adulthood, Maine has specifically chosen to exceed the federal requirements in some areas of transition planning.

Maine Special Education Law and Rules

The Maine Unified Special Education Regulation Birth to Age Twenty (05 - 071 Chapter 101, 2017) or "MUSER" is the state level interpretation of the IDEA. In most areas, MUSER aligns very closely with the federal law and accompanying regulations but there are some exceptions around transition. Most notably, MUSER states that "beginning not later than 9th grade the IEP team will start the transition plan and it will be updated annually thereafter" (p. 97). This is important because it sets a potentially earlier start to transition planning than the federal rules (age 16), one that is tied to high school entrance. Another interesting distinction is the use of the term "transition plan." The federal language (as noted above) speaks about transition planning as an integrated element of the IEP. The Maine language would seem to indicate that another document (the plan) is needed in addition to the

IEP or at a minimum that that the transition plan is something that is incorporated in the IEP differently than described in the federal regulation.

The Maine rules also add clarification, stating that “Nothing in this part relieves any participating agency, including a State vocational rehabilitation agency, of the responsibility to provide or pay for any transition service that the agency would otherwise provide to children with disabilities who meet the eligibility criteria of that agency (34 CFR 300.324(c)” (05 - 071 Chapter 101, 2017, p. 103). This language assists in ensuring that other state agencies serving Maine students with disabilities do not use the special education transition process to shift costs or their responsibility to deliver services to transition-age students. Maine rules also ensure that parents are notified of the provisions of the federal regulations §300.321 (a) (6) and (c) that identify who may be invited to the IEP meeting and what it means for an individual to have “knowledge or special expertise” about the child with a disability (p. 58). This is critical because it directs the school district to inform parents of their rights to invite someone who might be a natural support to the student.

Maine includes a “Rule of Construction” that mirrors the federal language indicating that there is no additional information that is required to be included in the IEP beyond what is explicitly required. Maine rules offer clarification though that “nothing in this subsection shall be construed to restrict the Department in providing interpretation and guidance on the proper implementation of this rule” (05 - 071 Chapter 101, 2017, p. 98).

Postsecondary Transition Planning

Best Practices in Transition Planning

As noted above, students who receive special education services under the Individuals with Disabilities Education Act (2004) must have Individualized Education Programs (IEPs) that include measurable postsecondary goals in education and employment - and independent living (when appropriate). The National Technical Assistance Center on Transition is funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA) and provides technical assistance to states, schools and other stakeholders on best practices in transition. In Gothberg, Fowler and Coyle's *Taxonomy of Transition Programming 2.0* – a transition-planning resource promoted by the National Technical Assistance Center on Transition - there are five areas that must be considered for transition services: (1) Student-Focused Planning, (2) Student Development, (3) Interagency Collaboration, (4) Family Engagement, and (5) Program Structure (Kohler et al., 2016, p. 2).

Student-focused planning means that transition planning starts with the strengths and needs of the individual student in mind and, like the rest of the IEP, is individualized to the specific student. Student development refers to the activities – both academic and non-academic – that are going to create forward movement towards postsecondary goals. Interagency collaboration is the alignment of services for students across youth-serving agencies. Family engagement means that the parents/guardians' voices are invited in and included in the process. Program structures such as policies and a school culture that

promotes transition need to be in place for good transition planning to occur (Kohler, Gothberg, & Fowler, 2016, slide 26).

The *Taxonomy*, which is nationally-recognized as a standard for transition planning, places considerable focus on the coordination of service providers and on the transition from youth to adult-serving agencies (Kohler et al., 2016, p. 7) to the exclusion of natural supports in the coordination of transition services. Natural supports are referenced only briefly – once as a resource for parents to learn about the transition planning process and again among a list of a number of items in a section on student support (Kohler et al., 2016, p. 6). The *Taxonomy* is silent on the role that natural supports could play in IEP plan development and instead focuses on the importance of including agencies that are providing transition services in planning meetings (p. 7). This absence highlights a gap in knowledge and knowledge dissemination as the *Taxonomy* is considered to be accepted best practice in the field.

The focus on the importance of planning for postsecondary living did not just arise out of the special education realm. The independent living movement for people with disabilities also focused on planning for people with intellectual disabilities. In this arena, planning was beginning to happen in new holistic ways that “embrace a broad view of support” with the goal of allowing individuals with intellectual disabilities to select the services that they wanted through person-centered planning (Butterworth, as cited in Schalock, Baker, & Croser, 2002, p. 840). This change in thinking about services for people with significant disabilities has resulted in a new discipline – disability studies (Society for Disability Studies, n.d.).

Disability Studies

Disability studies is a relatively new multidisciplinary field of study challenging the medical model of disability that conceptualizes the person with a disability as broken and in need of restoration to health (Mitra, 2006). Early work in the field included Bogdan and Biklen's (1977) description of "handicapism" as a "set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed differences" (as cited in Connor, Gabel, Gallagher, & Morton, 2008, p. 443). The Society for Disability Studies (n.d.), also a forerunner in the field, was established to "study national and international perspectives" on disability. In particular, the Society and the disability studies field have championed the inclusion and promotion of individuals with disabilities as researchers in disability-related studies (Society for Disability Studies, n.d.; Syracuse University, n.d.). Inclusion is an important concept in disability studies as well as a measure of the progress of society in removing barriers to full participation by people with disabilities. Inclusion for people with disabilities is a recognition of their fundamental right to live, work, and play in society in integrated settings such as schools, places of business, and recreational activities (Institute for Community Inclusion, n.d.).

The passage of the Americans with Disabilities Act in 1990 (section 12101) supported the movement by providing a "national mandate on the elimination of discrimination against individuals with disabilities" (Americans with Disabilities Act, 1990, section 12101 b. purpose). One of the effects of increased inclusion of people with disabilities in the study of disability has been the development of a social model of disability that focuses on functional disability. In this paradigm, disability exists primarily as a social

construct – meaning that it is a product of environmental and societal creation. Barriers to full participation of people with disabilities in society include beliefs about what people with disabilities are capable of achieving, physical construction of public places that is inaccessible and programs that do not permit full participation (Erevelles, 2000). Disability studies’ “examination of disability as a social, cultural and political phenomenon” (Syracuse University, n.d., para. 1), recognizes that while each individual with a disability is unique and contributes to making up a diverse population, that population of people has - as a group – been viewed and treated through the lens of minority status (Syracuse University, n.d., para. 4). One area where disabilities studies has had a significant impact is the field of education.

Disability Studies in Education

A society’s investment in education for its children is an investment in its future. For students with disabilities, who have not always been expected to benefit from public education or to be future members of the workforce, society’s understanding of the value of this investment has not always been clear. In the early days of special education, teachers, who were the front line in schools for students with disabilities, did not necessarily feel prepared to accept these students in their classrooms. Fear of the unknown and limited training were often concerns. This was seen in Patrick’s (1987) study of attitudes towards students with disabilities in physical education classes. Using the *Attitudes Toward Disabled Persons Scale* (Yuker, Block, & Youngg, 1966, as cited in Patrick, 1987) as a pre-and post-test measure of attitudes towards students with disabilities, the study looked at undergraduate physical education majors who took an adaptive physical education course. Exposure to students with disabilities in the course led to a more positive attitude about them. Because

positive regard for students is critical to student success (Bondy & Ross, 2008), it is essential that all teachers who work with students with disabilities believe and demonstrate that students with disabilities can be successful. The establishment of special education in 1974 opened up schools to students with disabilities, but it also created segregation in the public-school system with a two-track system of education. One track for students without disabilities and a special education track for those with disabilities. While the intention is to see these tracks cross and run together for individual students as appropriate, the reality is that by creating the structure of two tracks, segregation is perpetuated and discrimination is inherent. The consequences of this early discrimination can be long-lasting (Connor et al., 2008, pp. 441-457; Erevelles, 2000, p. 25). The disability studies in education field positions itself as a reaction to exclusionary mindsets and practices in education and promotes the attainment of social justice and the creation of a “positive disability identity” (Connor et al., 2008, p. 448) through inclusive education, meaning that students with disabilities should be in regular classrooms not segregated into special education classrooms. Inclusive practices in school can contribute to a natural supports framework in transition planning since the stage has already been set for connections between those with and without disabilities.

Not all educators and researchers have embraced this disability studies in education approach. While considered outliers to most current thought, Anastasiou and Kauffman (2011) challenged the idea that separate special education services are inherently discriminatory and stated that a “disabling context cannot be equated with socially oppressive structures” (p. 377). Moreover, they questioned the social constructionist approach by arguing that the logic of its proponents is faulty. In their view, if disability is an acceptable

state that does not represent a deficit in need of amelioration, then there should be no need for disability-specific services or programs. Anastasiou and Kauffman, as defenders of special education, hold firmly to the belief that some students require services that cannot be provided in integrated settings and therefore, to not provide those services in those settings represents another kind of an injustice. This philosophy is at odds with current best practice in the disability field, where individuals with disabilities have self-advocated for full-inclusion. It may, however, be a way of thinking that continues to be embraced by teachers and other transition-service providers who question the value of inclusion. It is in this context that it is presented here.

The capability approach provides another perspective on disability in education. Amartya Sen's "capability approach" to development defines well-being in terms of the exercise of capabilities (sets of functionings) "to do valuable acts or reach valuable states of being" (Sen, 1993, p. 30). Education is a key component of the capability approach and "is assumed (and expected) to be empowering and transformative" (Walker & Unterhalter, 2007, p. 11). Sen argues that "in analyzing social justice there is a strong case for judging individual advantage in terms of the capabilities that a person has, that is the substantive freedoms he or she enjoys to lead the kind of life he or she has reason to value" (Sen, 1999, p. 87). Freedoms become both a means to an end and the ends themselves. Mitra (2006) examined Sen's approach to better understand how capability intersects with disability. She wrote that "disability can be understood as a deprivation in terms of capabilities or functioning that results from the interaction of an individual's (a) personal characteristics, (b) basket of available goods, and (c) environment" (p. 237). Mitra suggests that the capability

approach can be used to understand what it means to be considered to be disabled. She notes that the capability approach takes into account the economic costs and realities of disability (Mitra, 2006, p. 242) in ways quite unlike the traditional models of disability. Considerations of poverty and financial well-being are critical to discussion of disability as disability is so often linked with poverty. The capability of youth with disabilities to participate in the workforce is predicated on the exercise of their capability to fully participate in education. The capability approach offers a context for understanding the importance of assisting youth to have access to select lives that they have reason to value. Natural supports, in the form of community members, family, and friends become the tools to promote access to full expression of the capability to be a valued community member. When examining factors influencing capabilities of students with disabilities, location is an important variable for its impact on access to services.

Rurality

While rurality may describe a geographic constraint, the term can also evoke images of country life, of simpler times, or of fresh air and water. For others, rurality may be associated with poverty, lower education standards or even the opioid drug crisis. All these views may contain elements of truth, but in this study, it is important to begin with an acknowledgement that rural living may provide both advantages and disadvantages when compared to life in other settings. Advantages of rural life may include closer relationships with neighbors and community members that may extend across generations, increased sense of belonging, or for students - smaller classroom size, leading to increased teacher attention. By necessity, rural people have had to be creative and develop ways of innovating and

making do given the resources available to them. These advantages may have an important role in postsecondary transition planning for students with disabilities as we will see explored further in this study.

For all of the positive qualities of rural life, rural life can intensify or exacerbate marginalization of people with disabilities through environmental and social barriers.

Intersectionality – Rurality and Disability

Rural people may experience marginalization and stigmatization due to prejudicial assumptions about what it means to be a member of a rural community (Sherman, 2006). Students with disabilities not only may be subject to this biased viewpoint but they may be doubly disadvantaged when the longstanding stigma and discrimination that has accompanied disability status is added. Here, an understanding of the concept of *intersectionality*, as developed by Crenshaw (1989), is helpful. Intersectionality is a recognition that oppression of individuals is compounded by characteristics that cross status group. For example, an individual who is transgender and Deaf may experience marginalization that cannot be understood by looking just at her experience of being a person who is transgender nor by exclusively understanding her experience as a Deaf person. Moreover, the combination of the two disadvantages creates unique disadvantages that cannot be understood by just adding Deaf and transgender disadvantage together. Discrimination for rural students with disabilities can take the form of lowered expectations, lack of access to enrichment activities and lack of choice in services and supports (Test & Fowler, 2018; United States Department of Education, 2018). Special education, which is intended to address issues of access to the general curriculum or the need for specially

designed instruction for students with disabilities, is not likely to be able to work to remedy larger discriminatory factors that are due to the intersection of disability and rural status. For example, Mohatt, Adams, Bradley, and Morris (2005) found that the lack of anonymity in rural communities increased stigma when seeking behavioral health services. In this way, the combination of rurality and disability creates unique disadvantages.

Research on Rural Students with Disabilities

The passage of the United States Department of Education's *Every Student Succeeds Act* in 2015 (P.L. 114-95) included a charge to the federal Education Department (Section 5005) to examine itself and its practices to determine if the needs of rural schools are being adequately considered and additionally how the Department could better support the inclusion of the voice of rural schools (United States Department of Education, Office of Communications and Outreach, 2018, p. 1). In 2018, the Department issued its final report in response to that directive. The report noted that one out of five students across the country is living in a rural area (p. 22) and that over a quarter of American public schools are in rural areas (p. 7). While the report included students with disabilities, a limitation of the study was that it did not break out its findings by disability status or special education enrollment. Of particular interest for this study was that, although students in rural areas achieved similar (if not better) educational outcomes when compared to students in other geographic configurations, the population of adults in rural areas without four-year college degrees was 10% lower than in other areas (p. 7). This may indicate some broad concerns about lack of choice in post-secondary options, lack of access to postsecondary education as well as a deficit in adult role models who are college-educated. The study found that like in urban

areas, there were “high rates of childhood poverty, difficulty recruiting and retaining effective teachers and administrators, and limited access to quality health care” but these problems were “exacerbated by the remoteness and small size of rural districts” (United States Department of Education, 2018, p. 7). Transportation was another barrier consistently identified in rural areas (p. 8). Addressing these barriers has challenges unto itself. The report notes that “each rural community is distinct” (p. 8) meaning that there is no one size fits all solution.

These challenges impacting students with disabilities in education were also echoed in recent studies by Hoover, Erickson, Herron, and Smith (2018) and Test and Fowler (2018). The first group’s qualitative study, set in a rural Western state, with a high percentage of English language learners, examined the challenges associated with implementing a “culturally and linguistically responsive special education eligibility assessment” in a rural area and found that “the interconnectedness of diversity, disability and educator preparation often challenges rural districts” in their delivery of educational best practices (p. 92). As in the United States Department of Education’s (2018) report on rural education, Hoover et al. (2018, p. 92) noted earlier findings by Hoover and Erickson (2016) that high levels of staff turnover are a particular problem for rural school districts and that this can result in teachers who have “persistent training needs” (p. 92). To meet training demands, rural schools must redirect resources from other areas where they are needed.

Test and Fowler (2018) reviewed the history of secondary transition via literature and data as a foundation for examining the current state of transition planning and outcomes in

rural areas. Using qualitative data collected from a rural transition community of practice,¹ they similarly found that lack of specialized personnel was a concern when they examined barriers to effective transition services for students living in rural areas. They identified lack of transportation as a primary barrier as it impacted on access to services, employment, and postsecondary options (p. 71). The categories of barriers to successful secondary transition outcomes in rural communities identified by Test and Fowler's community of practice participants included (p. 72):

- Expectations (e.g., parents' and students' lack of knowledge regarding importance of transition planning)
- Opportunities (e.g., few employers in rural areas)
- Personnel (e.g., multiple responsibilities for school personnel due to shortages)
- Services (e.g., distance to or lack of community agencies)
- Transportation (e.g., limited or no public transportation)
- Cultural (e.g., generational poverty)

Test and Fowler (2018) embrace a focus on implementation of data-driven evidence-based best practices in transition as a way to overcome these challenges and increase the likelihood of successful transition for students. Their recommendations also include a call for increased rigorous research that will add to the body of evidence-based practices (p. 72). Hoover et al. (2018) recommendations included strengthening the preparation of rural teachers so that they have the skills necessary to meet the cultural and linguistic needs of rural students with disabilities (p. 100). In conclusion, while considering research on rural students with

¹ Author was a regular participant in this community of practice.

disabilities, it is important to keep in mind that “‘rural’ is not a monolith but a compilation of thousands of unique communities and circumstances” (United States Department of Education, 2018, p. 8).

Natural Supports

Natural supports are an important and potentially underutilized resource for rural students with disabilities as they transition to adult living. The Lanterman Act, a California law passed in 1977, was the first to codify what is meant by natural supports. The Act was intended as a means to guarantee the rights of people with developmental disabilities in California to choose the services that they needed to ensure community inclusion and arose out of early independent living advocacy efforts for people with significant disabilities (Project 10 Transition Education Network, n.d.). Much of the early literature on natural supports has focused on the role of natural supports in supporting employment of people with disabilities. This was due in large part to the work of Nisbet and Hagner (1998), explored later in this chapter, who are credited with coining the term and wrote primarily on supported employment.

Duggan and Linehan (2013), at the request of the Irish government, conducted a literature review of articles published in English since 2000 on the role of natural supports in promoting independent living of people with disabilities. They found 30 peer-reviewed articles on the topic (p. 201). The studies they reviewed were conducted in a variety of countries and included a mix of quantitative and qualitative approaches. The majority of the studies involved a very small sample size of people with disabilities, thus challenging their generalizability (p. 202). In conducting their review, they used a working definition of

natural supports as including “extended family, friends and neighbors” and “individuals who provide informal and unpaid support for people with disabilities within local communities” (p. 199). These individuals who were natural supports functioned as a social network and social support system for people with disabilities.

Through their review, Duggan and Linehan (2013) reinforced the value of natural supports by identifying that “people with disabilities experience social exclusion because they do not have natural supports that enable them to participate as they wish in their communities” (p. 205). Access to natural supports, however, can be challenging due to what they characterize as a “Catch-22” situation where support is needed in order to access natural supports (p. 205). While generally supportive of the value of natural supports, they did recognize research (for example Lemay et al., 2009, as cited in Duggan & Linehan, 2013) that found in some cases that natural supports may “unintentionally impose their own community preferences upon people with disabilities.” An example of this could be if a neighbor, who is available to provide a young person with transportation to a job, only agrees to do so if the youth is going to an area of town that he believes is “safe for people with disabilities” thereby overriding the individual’s preferences and potentially limiting job possibilities. This could be a particular challenge in rural areas where paid supports for youth are already lacking and options for natural supports are likewise limited. The authors note one remedy could be recognition of the need for training and provision of resources for natural supports (p. 206).

Natural Supports in Employment

The concept of natural supports has been most studied in the context of employment for people with disabilities (Wehman & Bricout, n.d.). Nisbet and Hagner (1988, 1998), who are most widely associated with early use of the term “natural supports” in employment, studied people with significant disabilities who participated in supported employment in the community and recognized that “informal interactions flourish at work” (Nisbet & Hagner, 1998, p. 262) and that having a paid job coach could cause “natural sources of support ... (to) be overlooked in favor of external support supplied by the job coach” (Nisbet & Hagner, 1998, p. 263). Hagner, Rogan, and Murphy (1992) further validated this finding, noting that it is “important to participate in the culture to gain social acceptance” (p. 32).

The development and use of natural supports in employment can also be supported through interagency partnerships. Hart, Zimbrich, and Ghiloni (2001) stressed that in developing community-based employment, it is important to look at an individual’s support network and natural supports to assist in employment. Often these supports provide opportunities to think creatively about employment opportunities and move away from the idea that only the agency charged with providing vocational support is responsible for job development.

While natural supports have been much studied in employment, according to Wehman and Bricout (n.d.), they remain “not easy to define or operationalize” (p. 216). They point out that disagreement remains about how natural supports are different from other work supports as well as what is meant by the term “natural”; however, there is general consensus that natural supports are provided by individuals who are not paid service providers

(Wehman & Bricout, n.d., p. 216). Storey and Certo (1996) define natural supports as “people who are not disability service providers but who provide assistance, feedback, contact or companionship to enable people with disabilities to participate independently, or partially independently, in integrated employment settings or other community settings” (p. 63). This idea of facilitating independence is particularly important for transition age youth and is a theme that runs through transition planning for students with disabilities.

Natural Supports in Transition Planning Literature

While the research on the use of natural supports in transition planning for students with disabilities has focused primarily on preparing for postsecondary employment, some recent research has highlighted the importance of natural supports to assist the broader transition to adulthood. This is reflected in the Florida Department of Education’s “Project 10”, a grant-funded initiative to promote secondary transition planning that uses the Taxonomy for Transition Programming (Kohler, Gothberg, & Fowler, 2016) as well as discussion of natural supports (Project 10 Transition Education Network, n.d.). Florida also highlights models of inclusion of natural supports in transition planning. One of these models, the Kansas Transition Systems Change Project (n.d.) identifies natural supports as one of seven indicators of quality transition programming. Another transition model is the SPANS (Systematic Plan for Achieving Natural Supports) developed by Trach and Mayhall (1997). This model includes six components: (1) consumer-driven planning, (2) ecological assessment of individual needs, (3) environmental assessment of natural supports, (4) identification of natural supports in multiple environments, (5) matching natural supports to

individual needs, and (6) development of individual natural supports plans (Trach & Mayhall, 1997, as cited in Project 10 Transition Education Network, n.d.).

The SPANS model was developed as a training tool to assist individuals with significant disabilities to be included in the workplace. The authors studied 19 participants – including school staff – as they worked in teams to use the model’s approaches to build natural supports for 14 individuals with “severe disability” who were exiting school or sheltered employment for employment in the community (Trach & Mayhall, 1997, p. 49). They defined natural supports as being “human or technical resources that are available or can be developed in a setting to facilitate integration, acceptance, and satisfaction, and to promote the goals and interests of all individuals in the setting” (Trach & Shelden, 1993, as cited in Trach & Mayall, 1997, p. 48). Using document review of participant reports and a follow-up phone survey with program participants to collect information on the development and implementation of natural supports, the authors found evidence of 88 natural supports, the majority of which were not reliant on the presence of a job coach (p. 50). Table 2.1 provides a breakdown of the types of natural supports documented. The most often used were training supports at 21.6% and social supports at 20.5%. Physical supports and service supports were equally implemented at 19.3% followed by organizational supports at 13.6%. Interestingly, community supports were the natural support used the least (5.7%) (p. 50).

Table 2.1

SPANS Natural Supports Used

Natural Supports Used	Number of Natural Supports	Percentage of Natural Supports
Training Supports	19	21.6
Social Supports	18	20.5
Physical Supports	17	19.3
Service Supports	17	19.3
Organizational Supports	12	13.6
Community Supports	5	5.7
TOTAL	88	100.0

The SPANS model provides for individuals with disabilities (referred to in the study as consumers) to be taught its techniques (identification of natural work and social interactions) alongside teachers, families, job coaches and employers (p. 52), which helped ensure the voice of persons with a disability was included. This study found that as natural supports were implemented, coworkers of people with disabilities “took the initiative in working more directly with the consumers “(p. 55) instead of relying on a job coach as an intermediary to the person with a disability. The SPANS model and related study are relevant for this study not just because they included teachers and young adults with disabilities but also because Trach and Mayhall (1997, p. 57) found that “fourteen of the program participants stated that the planning meeting was the most helpful factor in determining consumers’ needs and the required supports.” This could transfer very easily into making the special education’s postsecondary planning meetings the most important factor in determining what natural supports will be the most beneficial to a student.

Test, Smith, and Carter (2014) - writing about youth with Autism Spectrum Disorders (ASD) – reviewed recent studies on post-secondary outcomes for students with ASD and concluded that “substantive improvements in post-school outcomes of young adults with ASD are unlikely to occur if responsibility falls entirely on educational and adult service systems” (p. 86). Instead, their analysis led them to recommend inclusion of “the support, resources and relationships of employers, coworkers, neighbors, friends, family and other community” as “an important element in comprehensive transition planning efforts” (Test et al., 2014, p. 86). They recognized the challenge of adding these relationships in to the transition planning process, calling them “among the most promising - and elusive” and acknowledging that “school systems are often unaware of these natural assets” (Test et al., 2014, p. 86).

Carter, Sweeden, Moss, and Pesko (2010) examined challenges to participation in extracurricular activities by students with disabilities and advanced steps that schools could take, using natural supports, to increase inclusion in meaningful extracurricular activities for students with disabilities. Concerned about constraints imposed by self-contained settings at school that “limited choice making” and students who “lack self-determination skills” (Carter et al., 2010, p. 276), Carter et al.’s analysis aimed to promote strategies to include students with disabilities in extracurricular activities. They found that by building on the strengths and interests of the students with disabilities, removing the barriers that existed to their participation, and teaching peers how to best support and engage their classmates with disabilities, new opportunities for inclusion in extracurricular activities occurred for these students (Carter et al., 2010, p. 276). Carter et al. found that using conversations with youth

with disabilities about their postsecondary goals “may help identify extracurricular activities” to join (p. 278) - an interesting inverse to using engagement in extracurricular activities to inform transition planning.

Study on the application of natural supports in transition planning is limited in the literature; but as these studies demonstrate, natural supports can have a positive impact on student outcomes. Building on an individual’s strengths and interests, natural supports help facilitate community connections and inclusion. The presence of natural supports in the transition planning process also leads to broader impacts on the environment – whether as evidenced by positive changes in interactions with the person with a disability by co-workers or classmates (Carter et al., 2010; Trach & Mayhall, 1997).

Parent Engagement

Parents have an important role to play in assisting their children with disabilities to transition to adulthood and can be strong natural supports. In recent years, research has documented the correlation between the level of parent engagement in the transition planning process and student postsecondary outcomes (Landmark, Ju, & Zhang, 2010; Pleet & Wandry, 2009). The National Collaborative on Workforce and Disability for Youth found that “families who learn about and begin the career development process with their youth early will be better prepared to support them in choosing and building a bright future” (2014, para. 2). While engagement can take many forms, a parent’s commitment to the belief that their child can be successful has a particular power.

Carter, Austin, and Trainor (2012) looked at predictors of post-school employment outcomes for young adults with severe disabilities using data from the National Longitudinal

Transition Study -2 (NLTS-2), which collected data on students with disabilities over the 10 years from 2000-2009. Through analysis, they identified variables associated with likelihood of post-school employment. Importantly, they found that “parental expectations at baseline were very strong predictors of student employment after high school,” - and in fact, “parental expectations that a student would definitely get a paying job were associated with fivefold odds of being employed after high school” (Carter et al., 2012, pp. 57-58). Despite these findings, in schools today, the role of the parent - a child’s first natural support - is often minimized or dismissed as students reach the age of majority. Spann, Kohler, and Soenksen (2003), in their study of parents of children with autism participating in a parent support group, found a particular disconnect between the parents’ stated priorities for their children and activities occurring in the classroom that was widest for high school age students. Davis (2003, p. 507) looked at youth with “emotional disturbance” (the term used to qualify some students with significant behavioral or mental health issues for special education services) and found that in addressing the transition needs of these youth, it was important to “emphasize and strengthen natural supports” and engage in “practices that build on the strengths of young people and tie them strongly to their families and communities.” Parental engagement, as a natural support, is an important factor in student success. For transition-age students, however, there can be structural and practical barriers that must be addressed in order to promote inclusion of parents.

Mentoring

Mentoring as an intervention and resource in the lives of young people has been widely implemented and studied in the last 20 years; however, specific studies focused on the

impact of mentoring on youth with disabilities have been much fewer and have had more questionable results due to “methodological flaws” and “difficulty in matching control groups” as well as challenges in isolating the impact of mentoring from that of the other multiple services received by the youth (Britner, Balcazar, Blechman, Blinn-Pike, & Larose, 2006, p. 755). Mentoring shares many commonalities with natural supports but is not an interchangeable term due to its varied goals, modes and location of delivery. Formal youth mentoring is most typically delivered under the auspices of a program (i.e. Big Brothers Big Sisters, Tuesday’s Children) and targets a particular population (for example, youth at-risk of dropping out of school or pregnant teens) with the goal of assisting the youth to improve a skill (such as work-readiness) or outcome (staying out of the corrections system). Evidenced-based mentoring programs also may follow prescribed curricula, have fixed end-dates, and include specific criteria on who may be selected as a mentor. These are all factors that are potentially exclusionary of some youth and potential mentors.

Natural Mentors

A 2005 University of Illinois at Chicago School of Public Health study authored by Dubois and Silverthorn, using data from over 3000 respondents to the National Longitudinal Study of Adolescent Health, found that having a natural mentor may have a significant impact on the lives of adolescents. Dubois and Silverthorn differentiated that “unlike mentors who are assigned by a program, natural mentors come from different areas of the young person’s own life such as their extended family, neighbors, teachers, coaches, religious leaders and employers” (University of Illinois at Chicago, Institute for Health Research and Policy, 2005, para. 2). Because the relationships with natural mentors are within the young

person's own community, the researchers found that there may be more potential for these relationships to lead to other connections in the community (DuBois & Silverthorn, 2005, p. 518). DuBois and Silverthorn's goals included looking at the impact of natural mentoring across many areas of the young person's life. This holistic approach correlates well with the postsecondary transition planning process.

They also looked at the presence of individual and environmental risk. One of the characteristics for an individual to be considered an individual risk was the presence of physical disability (DuBois & Silverthorn, 2005, p. 519). The findings of the study included that among those young people participating, over 70% identified that they had a mentoring relationship with an adult in their life (para. 3). While having a natural mentor did not "meet all the needs of at risk youth" (University of Illinois at Chicago, Institute for Health Research and Policy, 2005, para. 8), the researchers found that youth who reported having a natural mentor had higher levels of self-esteem and life satisfaction, were more likely to find employment, and were more physically active, among other positive outcomes (para. 5). Interestingly, they also established that the length of the natural mentoring relationship was also an important factor in its success, suggesting the high value of natural mentors who are drawn from the young person's own life and community and who have relationships which are not time-bound (DuBois & Silverthorn, 2005, p. 522.)

In a 2016 examination of premature mentoring relationship closures, De Wit, DuBois, Erdem, Larose, and Spencer performed a multinomial logistic regression analysis with a sample of 997 families and found that their study contributed to "an emerging body of evidence (that) has shown wide-ranging positive effects associated with youth involvement

in natural mentoring relationships, including more intrinsically rewarding careers in early adulthood” (p. 70). In another published study the same year, Erdem, DuBois, Larose, De Wit, and Lipman, looked at 501 youth participating in the Big Brothers Big Sisters mentoring program in Canada to determine the impact of mentoring on positive development and youth emotional and behavioral problems. Recruiting young people for the study from enrollments in Big Brothers Big Sisters programs, the researchers checked in on the youth every six months up to 30 months to assess both the mentoring relationship (using the Quality of Mentoring Relationship Engagement Scale) and the youth’s functioning (using the Cognitive-Behavioral Problem Solving subscale of the Coping Scale for Children and Youth among other assessment tools) (Erdem et al., 2016, pp. 470-471). They found that “supportive mentoring relationships can reduce susceptibility to emotional and conduct problems among youth from disadvantaged backgrounds” (Erdem et al., 2016, p. 477).

Zimmerman, Bingenheimer, and Notaro (2002), conducted research with “770 adolescents from a large Midwestern city” (abstract) and found that “54% of the youth had someone age 25 or older whom they considered a mentor” (Zimmerman et al., 2002, p. 231). While it is important to note that two groups of youth with disabilities were excluded from the study - those labeled as “emotionally impaired” and those considered “developmentally disabled” (p. 225), this research did ask participants about their levels of psychological distress via the Brief Symptom Inventory. Zimmerman et al.’s (2002) research suggested that “having a natural mentor appeared to be beneficial to adolescents for both problem behavior and school attitude outcomes” (p. 240). The natural mentors included extended family members, professionals, godparents and godsiblings, friends’ parents and friends’ siblings

among others (p. 231). Of particular interest is the authors' supposition that the professionals (for example a teacher or coach) who became mentors may have done so by moving beyond their professional roles into a mentoring one (p. 231).

While not a solution to all challenges faced by youth, these studies suggest that natural mentors drawn from a young person's connections and community may provide unique benefits and contribute to positive postsecondary outcomes. Analogous to the relationship between natural supports and transition planning, positive outcomes from the inclusion of natural supports in mentoring are encouraging and additional study may further clarify the intersections of the two fields.

Mentoring Youth with Disabilities

As a targeted population for mentoring, youth with disabilities have been the subject of limited study. Available published studies often either focused on a specific disability population (for example, youth with spinal cord injuries) or on a specific mode of mentoring (for example e-mentoring) both of which limit generalizability.

Britner et al. (2006) in their meta-analysis of mentoring programs across the United States serving special youth populations (including youth with disabilities), found that "youth from backgrounds of risk (defined broadly) have the capacity to benefit from mentoring, especially when best practices are employed and strong relationships are formed" (p. 747). Britner et al. (2006) looked at published studies of youth mentoring by adults with and without disabilities as well as by peers with and without disabilities to determine relative benefits and efficacy. They highlighted six studies but were limited as they found that "much of the published research is more methodologically flawed" (p. 755). Despite their

limitations, the studies showed that adolescents with severe physical disabilities who were mentored by adults with disabilities increased their knowledge of strategies to overcome barriers (as did their parents). Rierson-Espino and colleagues (2003) studied youth with learning disabilities, who were trained on how to recruit their own mentors (adults without disabilities), and found the youth were more able to reach their identified goals (as cited in Britner et al., 2006, p. 754). Hernandez, Hayes, Balcazar, and Keys (2001), using participatory methodology, studied the impact of peer mentoring of young people with spinal cord injuries who were matched, while still hospitalized, with other young adults with similar injuries and found that the pairs continued to meet a year later. This demonstrated that the mentoring was still applicable after the youth left the hospital setting (as cited in Britner et al., 2006, pp. 754-755). Another study, which used a matched sample control group design (Welkowitz & Fox, 2000), found that youth with disabilities who were mentored in a school setting by youth without disabilities had no positive gains in academic achievement but did improve school attendance and disciplinary issues (as cited in Britner et al., 2006, p. 755).

Given the small number of published studies on mentoring for youth with disabilities and their associated limitations – small sample size, narrow targeted populations, and methodology concerns – there is a need for additional rigorous research of this topic. Despite these problems, however, mentoring for youth with disabilities does appear to contribute to positive outcomes for youth.

If the literature on mentoring programs for youth with disabilities is limited, there is an even greater dearth of study looking at the value of school-based mentoring compared to mentoring delivered in the community. Westerlund, Granucci, Gamache, and Clark (2006) in

a study of four students with disabilities in a vocational training program found that utilizing peer instruction and coaching helped to link the classroom to the training site where the learned skills were being practiced. Structured to help the students with disabilities through delivery of “nonstigmatizing, natural support” (p. 245), they found that the use of the peer mentors improved the work-related skills of the four students, and they posited that this hybrid school-vocational model might also have future benefits as the four students sought postsecondary employment. Given that students spend the majority of their K-12 experience in the school building, there is a need for additional study of school-based mentoring. Hernandez et al.’s (2001) research on mentoring for hospitalized youth with disabilities demonstrated that mentoring that starts in an institution may not be bound by its four walls. This may have implications for school-based mentoring that could follow the student beyond the classroom into the community.

Mentoring - Additional Considerations

For all mentoring’s benefits, when considering the research on formal mentoring programs, one of the limits is the frequent focus on amelioration of a perceived deficit or anticipated adverse event, such as mentoring to help at-risk students stay in school or mentoring for girls of low socioeconomic status to avoid teen pregnancy. This potential view of youth to be mentored as “less than” is particularly at odds with disability studies theory, which rejects the idea that the individual with the disability must be “fixed” or “changed” to meet the demands of the environment around them. These programs may attract individuals as mentors who are interested in helping but may not necessarily recognize the inherent value and strength in the individual they perceive to be in need of mentoring.

Rhodes (2013) identified ethical principles for youth mentoring relationships that aim to “promote justice for young people” (Section 4). These ethical principles include recognition of the power inequities that are inherent in the mentoring relationship but propose that the increased social capital of the mentor can be used to the benefit of mentees. Another area of concern raised by Rhodes is confidentiality practices and the “insufficient attention” (Rhodes, 2013, section 5) the topic has been given in mentoring programs. As confidentiality and disclosure have particular importance for young people with disabilities, this highlights the need for additional research on mentoring models to address access and inclusion of students with disabilities. Real or perceived concerns over confidentiality in transition planning, are also areas for further discussion in this paper.

Social Support Theory

As students transition out of high school to adult living, issues of future health and well-being are paramount. Social support theory is one framework that helps to link the benefits of natural supports and mentoring with the future-orientation of transition planning for students with disabilities. As described by Feeney and Collins (2015), “close and caring relationships...at all stages of the lifespan” (p. 1) can be linked to an individual’s health and well-being. Social support theory becomes one way of understanding the link between social integration and inclusion and improved mental and physical health (Holt-Lunstad & Smith, 2012). This “thriving through relationships” (Feeney & Collins, 2015, p. 1) may manifest in five distinct states of well-being: hedonic, eudaimonic, psychological, social and physical (p. 4). Each of these components of well-being can be tied to important aspects of the postsecondary transition planning process. Whether the eudaimonic pursuit of purpose and

meaning in one's life or the psychological need for self-determination and self-actualization, or the social connection to community, successful transition to adult living for young people with disabilities requires thriving in each of these domains.

Feeney and Collins (2015) argue that unlike much of the research in social support theory, supportive relationships are not only needed to build resiliency in the face of challenge, but that these relationships serve as “relational catalyst supports” (p. 9) even in the absence of adversity to help individuals thrive. The supportive individual who is acting as this catalyst “facilitate[s] preparation for engagement in life opportunities”; in other words, their support helps to encourage individuals to follow dreams and gain new skills, and it promotes integration and inclusion without having to position themselves above the individual whom they are supporting. Laying on the disabilities studies lens again, the person with a disability does not need to access this relational catalyst support from a “less than” position to overcome the socially-constructed barriers of disability but rather can use the support to move themselves in the direction of their strengths, interests and goals.

“Individuals thrive ...when they are able to fully participate in opportunities for fulfillment and personal growth, through work, play, socializing, learning, discovery, creating, pursuing hobbies and making meaningful contribution to community and society (Deci & Ryan, 2000 and Ryff & Singer, 1998, as cited in Feeney & Collins, 2015, p. 4). While not developed to fit into the transition planning process, and not studied in that manner, it is not hard to see the natural connections between the desired state of thriving with its nod to “growth, development and prosperity” (Feeney & Collins, 2015, p. 3) and the successful transition to adulthood for students with disabilities, which envisions the same. The literature currently,

however, remains largely silent on the application of social support theory to meeting the needs of transition students with disabilities.

Other Considerations

This study is focused on students who live in rural communities. Their specific needs, outlined earlier in this proposal, are often unanswered by studies that have looked more broadly at youth in general, or have tailored approaches to urban youth. While acknowledging differences that may not make the findings applicable to rural youth with disabilities, it is interesting to note that the intervention of natural supports has been validated in other settings. One example is Williams and Portman's (2014) qualitative study of high-achieving African American urban youth and identified six themes that these young people had in common, one of which was the presence of natural support systems (p. 20). Here, the authors considered natural supports as "the resources inherent in the students' family, school and community environment that can be used to support their academic success despite financial or personal hardship" (Williams & Portman, 2014, p. 22). As in studies of youth mentoring with natural mentors, this example highlights the positive outcomes associated with the use of natural supports drawn from the student's community. It also reinforces that even communities that may be considered disadvantaged do have innate strengths and abilities to meet the needs of their members.

Conclusion

This chapter presented a transdisciplinary review of the literature that focused on the fields of disability studies, mentoring, best practices in transition planning, parent engagement and social support theory. Additionally, the concepts of rurality and natural

supports were explored as context for understanding the particular needs of students with disabilities as they transition to adult living in rural Maine. The review began with a comprehensive examination of the federal and state laws and regulations that mandate postsecondary transition planning for students who receive special education services. The review established what is known in the field and importantly, it identified gaps in knowledge that remain. This study is situated to answer, in part, that need for additional research.

Natural supports and related concepts have been evidenced to be beneficial to promoting transition outcomes for students with disabilities. The research supports the use of natural supports in employment and preparation for employment yet is largely silent on the issue of inclusion of natural supports in the school-based transition planning IEP process. Additionally, little attention has been paid to the application of natural supports for rural youth. Research in the fields of mentoring, best practices in transition, parent engagement, disability studies and social support theory all contain promising practices that could inform future practices and policy in the postsecondary transition planning process for students with disabilities in rural areas. This research study sits at the intersection of these fields and answers the need for additional research to better understand the phenomenon of transition planning for students with disabilities in rural areas as understood by the gatekeepers (parents and educators) to that planning process.

CHAPTER 3
RESEARCH DESIGN AND METHODS

Research Design

Worldview – Transdisciplinary Research Approach

This study is informed by a pragmatic worldview. It is designed to respond to a real question/problem facing young people with disabilities living in rural communities and to yield new information and learning that will support the development of policy and practices that promote improved postsecondary transition planning and ultimately strengthen community inclusion for these youth and young adults. A pragmatic worldview, according to Creswell (2014, pp. 10-11), is a way of framing research that allows for varied ways of looking at problems and is not rigidly aligned with one discipline or theory – a paradigm that supports a transdisciplinary research approach, which informs this research project.

Transdisciplinary research, as envisioned by Leavy (2011), Bergmann et al. (2012), Pohl and Hadorn (2007) and others, puts a focus on solving real world problems through the creation of new knowledge as developed by moving beyond the limits of individual disciplines. The principles of transdisciplinary research have informed this research and served as the foundation for its research design and implementation.

Adherence to the principles of transdisciplinary research can be noted in a number of critical points during this study. First, the topic selected is a real-world problem - the

transition of students with disabilities from high school to adult life. In arriving at this topic, I gathered input and feedback from many stakeholders - parents, educators, adult-serving agencies, and employers about the need for such a study. As individuals and organizations who are actively involved in the postsecondary transition planning process in rural Maine, it was important to me that they see value in the study to be undertaken. In this study, I have also strived to use terms and approaches that are understood across stakeholder groups - or have sought to clarify these terms to elicit their essence so that they are accessible to all. Additionally, data has been collected from a wide array of sources, further supporting a transdisciplinary approach.

Using a phenomenological reduction method, which will be discussed further in this chapter, I was able to examine the data multiple ways and through multiple lenses, a process that informed and supported evolution of my methodology as needed. As seen in Chapter 2, my study developed out of a broad look at literature across multiple disciplines as diverse as special education, disability policy, educational theory, psychology, rehabilitation counseling and social work. From its conception, the goal of this research study has been to meaningfully contribute to a systemic response to the unmet transition needs of students with disabilities in rural Maine. As will be discussed in Chapter 5, the recommendations from this study will be actively placed back in the same stakeholder hands from which it arose - namely families, educators and state agencies for further discussion, policy development and additional dissemination. Transdisciplinary research does not require a particular method of data collection but fits well with the qualitative research methods that I have selected as a best fit for this study.

Research Questions

After situating my study within this transdisciplinary framework, I formulated questions which, when answered, would contribute to an increased understanding of the current state of transition planning for students with disabilities in rural Maine and frame areas for action on policy and practice.

1. What barriers exist to transition planning for students with disabilities in rural Maine today?
2. In what ways have natural supports contributed to positive postsecondary education and employment outcomes of young people with disabilities living in rural Maine?
3. To what extent are natural supports included in transition planning by IEP teams in Maine Public Schools?
4. What barriers exist to inclusion of natural supports in transition planning under the *Individuals with Disabilities Education Act* (IDEA)?
5. How can stakeholders (parents, special educators, the Maine Department of Education and others) support the inclusion of natural supports in transition planning?

Qualitative Design

Qualitative research focuses on observing and learning from individuals in their natural settings (Creswell, 2014, p. 185). Unlike quantitative approaches, which answer questions such as “how much” and “how many”, qualitative research is interested in the meaning that those being studied assign to different events and phenomena (Creswell, 2014, p. 185). This design has been selected because qualitative design and methods will yield the best answers to the research questions posed. While qualitative research is not often

associated with generalizable findings, the results of this study may provide descriptive and exploratory data that could support generalization in future studies (Mayring, 2007).

Qualitative Research Approaches

This study is heavily influenced by phenomenological inquiry as a method to gather an understanding of a phenomenon – which in this case, is transition planning for students with disabilities in rural Maine and the placement of natural supports within that that experience (Creswell, 2014). Legal analysis of federal and state laws pertaining to postsecondary transition, document review of published reports, and inclusion of the voice of youth with disabilities and their documented perceptions and needs add to data gathered through interviews of the lived experiences of the gatekeepers to transition planning - parents and educators.

Qualitative research approaches allow information drawn from across a variety of data sources to form the basis for an emergent theory rather than being limited by prescribed theoretical assumptions in advance (Creswell, 2014, p. 196). Phenomenology, according to Van Manen (1990), is a way of describing a phenomenon and also bounding it – or setting limits around the experience - to help determine what makes it different from other phenomena. Creswell (2014) further describes it as a way to determine the essential elements of an experience (p. 140). In this study, the inclusion of phenomenological inquiry along with legal analysis, document review and other qualitative approaches will provide a comprehensive way to understand the phenomenon of transition for students with disabilities living in rural Maine today.

Role of the Researcher

After more than 20 years working with transition-age youth with disabilities, I remain particularly interested in what is needed to move the experience of completing secondary education and entering adulthood beyond the realm of legal and procedural requirements. For nearly all of those years, I have been a member of the State of Maine's State Advisory Panel - advising the Maine Department of Education on the unmet needs of students who receive school-age special education services under the federal Individuals with Disabilities Education Act (2004). Year after year, parents of students with disabilities, disability advocates, and other stakeholders have expressed frustration about the disconnections between best practices in transition planning and actual practices for students. At the same time, anecdotally, as Director of the state vocational rehabilitation agency, I see daily examples of those young people who have successfully transitioned to adult living and independence - and those who have not - and I am aware of at least some of the interventions associated with better outcomes.

The world of transition planning in Maine is not a big one. This is both an advantage and a challenge in this study. In a small state, it is possible to know personally - or have access to - all the necessary individuals, data, and support to conduct research. On the other hand, as a known individual, a concern for me at the beginning of this study was my own ability to put aside my daily role to take up that of a researcher. Vocational Rehabilitation is a key service available statewide to students with disabilities. As the director of the agency, I had to anticipate that vocational rehabilitation services and staff would be mentioned during the interviews. While I was concerned that this might include being asked to intervene in

specific individual's cases, this did not occur. To be prepared, I had developed a script, which included referral to a regional manager of my agency. I also kept in my bag, copies of a guide to which I had contributed entitled, *High School and Beyond: A Guide to Transition Services in Maine* (Youth & Community Engagement Team, Muskie School of Public Service, University of Southern Maine, Comp., 2015). This guide covers a range of topics related to transition planning and has links to additional resources. As a provider of transition services in Maine, I did not feel that it would be appropriate for me to walk away from families in need without offering them some next step.

As I progressed in the interview process, I found that the phenomenological tool of “bracketing” assisted me greatly to address how my extensive experience in the field could influence how I heard what was being shared with me. Identifying and then setting aside my own knowledge and assumptions, through bracketing (Fischer, 2009), permitted me to listen intently to the experience being shared while avoiding an initial filtering of the data due to my own points of reference.

Site Selection

The location for this study is the State of Maine. Maine, located in the northeastern corner of the country, has a population of 1.3 million (of whom approximately 30,000 are students who receive special education services) and in 2010 was considered by the United States Census Bureau as the most rural state in the country (United States Census Bureau, n.d.). The United States Census Bureau (n.d.) describes an area as “rural” by comparing it to what it is not - an urbanized area (50,000 or more residents). For the purposes of this study, the definition of rural will be less about an exact population number and more about an ethos

of rurality - more similar to the definition offered by Merriam-Webster (2004) “of, or relating to the country, country people or life.” Rural areas typically have fewer financial resources and fewer and more geographically spread out service providers. Individuals living in rural areas may be unaware of resources or may have accepted that best practices are not possible due to limited means. The understanding of the role that natural supports can play in transition planning is of particular importance in rural areas because it is not tied to either fiscal resources or the availability of professional providers. On the other hand, natural supports do fit with the picture of close-knit rural communities where individuals must be both individually resourceful and available to assist a neighbor in need.

Institutional Review Board Approval

This study (Protocol # 2018054) is subject to the review and oversight of the University of Massachusetts Boston Institutional Review Board. The Board granted its initial approval of the study on March 27, 2018 after submission of a completed application, proof of successful passage of appropriate Collaborative Institutional Training Initiative (CITI) modules for Social and Behavioral Research Investigators, and development of study protocols and accompanying participant participation consent/assent forms for each population to be interviewed. After the initial period of approval, the Board re-approved the study on March 18, 2019 following submission of updated information on the status of the project. During the data collection, the Board additionally approved a modification on December 16, 2019 to allow for another means of collecting youth voice.

All Institutional Review Board approved materials may be found in Appendix A. These include: (1) Participant consent form for parents; (2) Participant consent form for

special educators; (3) Participant consent for young adults with a disability; (4) Sample interview questions for parents, special educators, and young adults with disabilities; (5) Participant observation assent form (for those under age 18); (6) Parental consent for youth participation in observation; and (7) Sample recruitment notice.

Data Collection

Four types of data have been collected during this study: (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators. These sources of data were selected based on my goal to understand how the lived experience of the transition planning process in rural Maine fit with or contrasted from the legal requirements that mandate and support transition planning for students who receive special education services. I specifically wanted to understand the use of natural supports as an element within that transition planning process and impact on subsequent outcomes. The four data types both build on each other and provide a triangulation of sorts supporting each other and creating meaning that is representative of both subjective and objective realities.

Legal Review

At the commencement of the research study, I reviewed the federal special education law, the *Individuals with Disabilities Education Act*, and applicable regulations. The purpose of this review was to identify statutory and regulatory language concerning transition planning - particularly language that speaks to development of postsecondary goals and identification of needed transition services as well as language that speaks to who is required - and who may - participate in transition planning through the Individualized Education

Program meeting. This review was important to understanding the legal requirements for transition planning and the potential identification of any gaps that exist between these laws and the practice of transition planning. A close reading of the laws and regulations was also necessary to be able to make recommendations on any changes to them that might be necessary to promote best practices in transition planning for students with disabilities in rural areas.

All sections of the *Individuals with Disabilities Education Act* that pertain to postsecondary transition are excerpted from the law and are included in Appendix B. The key sections are introduced in Chapter 1 and explored in more detail in Chapter 2. In Chapter 4, the gap between law and practice is highlighted by comparing the legal requirements to the lived experiences of the individuals interviewed for this study. Chapter 5 draws conclusions and makes recommendations based on those discrepancies.

Document and Artifact Review

One method of data collection was document review. Document review is a helpful way to examine information that has been previously recorded on the topic. This study examined a number of sources of documents and artifacts as noted below:

Federal, state and local reports. Documents that I reviewed included: Maine's special education State Performance Plan/Annual Performance Reports (Federal Fiscal Years 2014-2019) and Local Education Agency compliance determination letters (Federal Fiscal Year 2017). The United States Department of Education's Office of Special Education and Policy oversees special education grant awards to states and requires that each state develop a State Performance Plan every six years and submit an Annual Performance Report (United

States Department of Education, Office of Special Education Programs, n.d.). These state-submitted plans and reports promote accountability and transparency by sharing publicly how funding is being used and what the associated outcomes are. The state's Annual Performance Report, is reviewed by the United States Department of Education and results in issuance of determination letter to let the state know if they met compliance – and if not, what actions the Department is requiring be undertaken (United States Department of Education, 2018). The Maine Department of Education likewise annually monitors and reports on Local Education Agency (or LEA) performance (Maine Department of Education, n.d.a) through deployment in the field of a specially trained monitoring unit. The most recently published (federal fiscal year 2017) *Local Education Agency Determination Letters* were reviewed for the sixteen school districts represented by educators and parents interviewed in this study.

All of these reports are compiled to meet the requirements of the *Individuals with Disabilities Education Act* (IDEA) section 618(a) (for children ages 3-21) and served as backdrop and objective documentation of summary transition compliance for any given school district. Knowing the communities of the special educators and the parents interviewed, I was able to match them with the corresponding determination report. The results of that triangulation are presented in Chapter 4.

Youth Input

Data collection to ascertain youth perspectives involved two important sources, (1) youth perceptions reflected in results of the 2017 Maine Integrated Youth Health Survey and (2) minutes and other outputs of the Youth Advisory Group. These two data sets provided the

research with the voice of youth with disabilities and serve to triangulate findings from other data.

Maine Integrated Youth Health Survey. Since 2009, the State of Maine has been gathering information on the status of youth health across the state. Through a partnership between the Maine Department of Health and Human Services and the Maine Department of Education, the *Maine Integrated Youth Health Survey* is administered to all Kindergarten to Grade 12 students every other year (Maine Departments of Education and Health and Human Services, n.d.). Maine Integrated Youth Health Survey. The results assessed for this study come from the 2017 survey. High school students are surveyed directly following an opt-out consent letter that is sent to parents prior to survey administration. According to the Departments' 2017 fact sheet on the survey, "over 80% of all middle and high schools participated." The survey administrators pay particular attention to ensuring that students who may not be in the traditional school building during the day (vocational and alternative education students - for example) are included.

Survey methodology. The Maine Integrated Youth Health Survey is approved through the Institutional Review Board of the University of Southern Maine and asks high school students to respond truthfully to topics such as nutrition, smoking, drugs, sex, bullying and gambling as well as to questions about disabilities, depression and suicide (Maine Departments of Education and Health and Human Services, n.d.). The questions are tailored to the grade level taking the survey. As noted in the consent letter to parents, students are allowed to opt out of the survey or to skip questions. Survey methodology reported for the 2015 survey (the most recently available methodology report) includes information on the

development of the sampling frame for initial determination of the number of schools per county eligible to participate in the survey. The high school version of the survey is issued to schools in four variations with some questions standard across all survey versions and other questions limited to one or two versions. This approach was designed to produce results that are statistically valid at a variety of levels including; state, public health district, county, school district, and school - as well as to meet other state or federal requirements. For example, only questions that were administered on all four survey versions were included in school district level analysis. Equitable distribution of each survey version was determined using eligible enrollments and numbers of schools by county.

The questions chosen for the survey were selected in part based on questions validated in previous surveys or in other similar surveys (for example other states' student surveys) with guidance from knowledgeable stakeholders. The administration of the survey occurs during a class period where all students would be likely to be present. Confidentiality during and after administration is supported by lack of collection of student names or dates of birth on the survey instrument. Survey results are weighted to offer a more representative analysis, and size of school or targeted population is considered so that results are neither individually identifiable or skewed by outlier data (Maine Departments of Education and Health and Human Services, n.d.). While the survey is intended to be universally offered to high school students, there are noted limitations. One constraint is that the survey does not reach students who are not in school due to drop-out or home-schooling. This does not present a limitation for use in the research at hand, as the focus is on students who are in school and receiving special education services. A limitation that is of more applicability to the

current study is potential underrepresentation of students living in the most rural areas due to sampling size. However, given that Maine as a whole is very rural, the findings of the survey do capture the responses of rural students, even if some number of them are less represented. The survey relies on self-report of behaviors and characteristics - including disability. This means that some students may inaccurately self-report as having a disability. It should be noted that not all students who report as having a disability also receive special education services, so the respondents to the Maine Integrated Youth Health Survey include a broader spectrum of youth with disabilities than the targeted population for this study. This is not believed to be a problem because the nature of the inquiry is qualitative, not quantitative, meaning that the reported perceptions are more useful to this study than specific percentages related to the youth responses.

Survey questions of interest. The Survey contains two questions that are of particular use to this study, (1) Do you agree or disagree that in your community you feel like you matter to people, and (2) I have support from adults other than my parents (Maine Integrated Youth Health Survey, 2017). Youth responses can be broken down by self-reported disability status and compared with the responses of students without a self-reported disability. These questions reflect youth with disabilities' views on how they are included in their communities and who is available to assist them with the transition to adulthood. While surveys typically yield quantitative data, the purpose here was not to focus on the specifics of that quantitative data as much as to gain the impressions and perspectives of the students that were conveyed by the student responses. The survey data and findings is presented in Chapter 4.

Youth Advisory Group. Recognizing the need for youth with disabilities in Maine to have more voice in the policy and programming for services that they receive, a cross-section of state agencies came together to sponsor a new initiative, the Youth Advisory Group. After months of planning, the Youth Advisory Group was convened for their first in-person meeting on the campus of Central Maine Community College, in Auburn, Maine in August 2019. The youth ages of 14-24 had been recruited via a statewide email invitation and survey sent by the Maine Department of Labor's Bureau of Rehabilitation Services. The email described the purpose of the group and the accompanying survey asked the youth questions about their skills, interests, and experience that would make them a good choice for the group. Twenty-five youth and young adults responded expressing interest in the group. No youth who expressed an interest was excluded from participation. All were notified that group participation was voluntary and would have no impact on the services that they received through the Department of Labor – or any other state agency.

At the August meeting, nine youth and young adults were in attendance. The nine present represented a wide range of geographic locations across the state and also a wide range of disabling conditions. The day opened with a review of the purpose of the group - to create a space where youth with disabilities can build leadership skills so that they can self-advocate and offer feedback on state agency policies and practices that impact them and are of importance to them. During the kick-off event, after discussion of confidentiality, the nine youth worked with a pair of facilitators - one a young adult trained in youth leadership and another who was a former teacher and youth program worker. A small number of parents and other adult participants met in a separate room to minimize influence on the youth. The youth

then participated in a number of activities to get to know one another and share issues of concern in their lives. Out of these activities came a number of topics about which they wanted more information or further discussion. The youth also talked over how they would like the group to run and what outcomes they would like to come from their work together.

At their convening meeting, the members identified areas related to post-secondary transition and adult living that are of concern to them (Youth Advisory Group, 2019). They have also identified areas for further development and policy influence. This data has been compiled in a summary manner without inclusion of any personally identifiable information. No individual member may be identified by the notes, themes, and other meeting outputs collected. All members understand that the purpose of the group includes positively influencing policy and practices. Meeting minutes and work product (charts, notes) from the initial convening session were typed up and were made available to the agency representatives who convened the Youth Advisory Group.² This data represents another source of youth voice and when considered along with findings from interviews with parents and educators will form a more complete picture of the status of natural supports in transition planning and outcomes in rural Maine.

Interviews

Face-to-face interviews conducted in the field with special educators and parents are a significant component of the data collection for this study. These populations have been selected because of their direct involvement in transition planning and influence over the consideration and inclusion of natural supports in the IEP meeting and transition planning

² Including this study's author

process. Special education law includes a role for the student with a disability but places the responsibility for invitations to other people, including potential natural supports, to an IEP team meeting on educators and parents (Assistance to States for the Education of Children with Disabilities, 2018, section 300.321). These two groups of stakeholders serve as the gatekeepers to the special education planning process. In keeping with the research approach selected, the interviews were bounded to focus on the transition experience (and the presence and role of natural supports). Because the goal of these interviews was to describe their experience, it was possible to conduct a small number of interviews with each population to be interviewed as saturation was reached in each case (Creswell, 2014, p. 189).

Participant recruitment process. In order to recruit special educators and parents to participate in this research, I first identified the characteristics of the individuals who fit my study, namely that they lived or worked in rural communities, and had first-hand experience of the special education transition planning process - either as educators or as parents of students with disabilities.

Parent recruitment. To recruit parents for this study, I contacted two statewide groups supporting parents of children with disabilities, the Maine Parent Federation and the Autism Society of Maine. Using the IRB-approved recruitment notice (Appendix A), I asked both groups to share the opportunity to participate in this study. This was accomplished in a number of ways. The Maine Parent Federation initially sent an email to parents on their listserv, and later included the recruitment notice in their quarterly newsletter as well as posted it on their Facebook site to generate more interest from parents. The Autism Society of Maine agreed to share the recruitment notice but first requested a copy of the study's IRB-

approval letter. After receiving it, the group posted the recruitment notice on their Facebook site. As I am not a Facebook user, the notice requested that interested parents contact me via my personal cell phone or at my UMass Boston email address. I did not offer any financial incentive to participate in the interview process.

I sought to interview a small number of parents (8-10) with a goal of reaching saturation (Creswell, 2014; Kielmann, Cataldo, & Seeley, 2012). The parent group recruitment notices did generate some, albeit limited, interest. Some parents reached out to request more information about me, or about my affiliation with UMass Boston (clarification that I was a Maine resident) - which I provided. Some parents who contacted me declined to participate or were unresponsive to my follow-up emails or phone messages. As parents did indicate willingness to participate, I set up face-to-face interviews with them at a place, time and location of their choice. I had projected that some “snowballing” of study participants might occur (Creswell, 2014), with parents referring me to other parents of transition-age students. To the best of my knowledge, that did not happen. Ultimately, I was able to interview 10 parents of the 15 who contacted me. Of the five who were not interviewed, four did not respond to follow-up emails and one disclosed that she lived in the largest metro area in Maine, which did not fit with the rural nature of the study. For the parent interviews, seven occurred in the parent’s home and three were held at a community location. One follow-up interview was conducted by telephone after an initial face-to-face meeting.

In addition to contacting parents via the methods above, I also chose to host a vendor table at the annual Autism Society of Maine conference with the goal of recruiting additional parents. At the table, I shared information on the study, had my consent forms on display for

review, and passed out pre-made paper slips with my name and contact information for follow-up contact. I was able to meet a number of educators, parents, and youth during the conference, but many of the parents had children who were too young to be appropriate for inclusion in my study. Many of the individuals (and service providers staffing other tables) expressed interest in the study results and affirmed a need for such a study. While this was validating, ultimately the conference participation did not lead to additional parent interviews.

Educator recruitment. I began the recruitment process initially by sharing an IRB-approved message (Appendix A) with Maine Administrators of Services for Children with Disabilities (MADSEC). This message and an accompanying note from me included information about the nature of the study, its goals, and a brief description of who I am. MADSEC sent the notice out via email message to their membership with an introductory note by their executive director supporting the study. MADSEC members are primarily special education administrators and teachers, and the email generated a number of inquiries. Some (four) of these respondents did not follow up when they were notified that I was seeking a face-to-face interview. Others did agree to be interviewed and a date, time, and location was set that was agreeable to them. With the challenges of the conclusion of the school year, some educators indicated they were interested but were not able to participate. Interviews were during 2018 and the early months of 2019. Of the 12 educator interviews ultimately arranged, three were held at a community location and nine took place at schools where they worked. One interview came about as the result of an educator who was aware of the study and contacted me separately, one was due to a recruitment notice through the

Maine Council for Exceptional Children, three were due to personal appeal in a remote county that had failed to respond to recruitment notices and seven were recruited as a result of directly or indirectly receiving the MADSEC notice.

Conducting the interviews. As each face-to-face interview was arranged, a date, time, and location were set that met the needs of the interviewee. Once at the interview location, there was a period of social introduction and light conversation to put the interviewee at ease and to build rapport (Creswell, 2014; Kielmann et al., 2012). Topics typically consisted of the weather, travel to the interview (road construction, traffic), school activities, vacation plans, etc. Once situated in the room where the interview would take place, I first began by re-introducing the interview topic, reminding them of the estimated length of the interview (approximately one hour) and sharing with the individual the appropriate IRB consent form (Appendix A). I both talked through the form and gave them time to review it and ask questions. During this conversation, I highlighted the purpose of the study, how their information would be stored, and how their identity and the content of the interview would be de-identified in the reporting out of the findings. I clarified that they could stop the interview at any time and could also rescind their consent at any time as well. I also verbally asked their permission to audio-record the interview via an app on my iPad, although permission to audio-record was included in the consent form that they were presented. Once I had determined that all questions had been answered, I presented the interviewee with two copies of the consent form to sign. After they did so, I also signed the form under their signature line and gave them each a copy of the form to keep for their own records. While Finch (1983, as cited in Brannen, 1988, p. 555) noted that women

interviewees are more likely to be able to quickly trust women interviewers, I did not note any difficulty in engagement or establishment of rapport with male interviewees (three educators and two parents).

In my communications with the individual prior to the interview, I indicated that the question/answer part of the interview itself would last approximately 60 minutes, and I reiterated that at the beginning of the interview. The signed consent form stated that interviews could take up to 90 minutes to reflect the additional time beginning and following the “formal” part of the interview used to build rapport or discuss next steps. At the end of some interviews, I was offered the opportunity to see the educator’s classroom or meet additional school staff. Parents likewise often introduced me to other family members including the student with the disability. To help the interviewee begin to describe their experiences, I developed a small number of open-ended guiding questions (Appendix A). Because it was important to my research design to allow for the individual to describe their own experience with the postsecondary transition planning process, I selected a semi-structured interview format and allowed the responses of the parent or educator to take the conversation to the aspects of the experience that were the most relevant to them (Kielmann et al., 2012). Before beginning each interview, I told the person that although I did have some questions to ask, the interview itself was designed to be conversational in nature. This helped to reinforce that the person being interviewed was an equal partner in the process and that they retained the ability to move the conversation towards or away areas of meaning for them. I was particularly cognizant during the interviews with parents that some of the topics that we might cover would be sensitive and would possibly be emotional for them. In

preparation for these conversations, I reread Julia Brannen's 1988 work on the study of sensitive subjects. I noted that "even if a problem is familiar or within respondents' own personal experience, they may lack a ready vocabulary to express themselves" (p. 553). This conversational approach allowed for responses to emerge in the time and manner that the interviewee chose. It also allowed for nonlinear responses. The interviewee could circle back later in the interview to previously mentioned topics to which they wanted to add clarification or further explore. Some parents interviewed, however, in their description of their son or daughter's transition from high school, took a very linear approach and recounted events and their corresponding feelings and reactions tied to a timeline of the child's life. Quite often this timeline reached back to the birth of the young person or to disability diagnosis. This appeared to be a mnemonic device selected to assist in recalling important events as well as recalling their own responses to those events. As each person's responses often generated additional areas for questioning on the topic, I used unscripted follow-up questions to further explore areas not covered by one of my prepared prompts.

While I was audio-recording the interview, I also took notes in a small field notebook where I labeled each interview using the de-identified naming system that I had developed (Kielmann et al., 2012). I used these notes as a way to capture non-verbal gestures, environmental information, and other descriptive details. Although I had estimated the time it might take for a rich description of the individual's experience to emerge, I did not conclude the interview until the person indicated that they had reached the end of what they had to share on the subject. Allowing for these in-depth interviews to be controlled in length by the interviewee was another strategy adapted from Brannen (1988) to assist in promoting a more

equitable power balance in the interview. Once confirmed that they were ready for the interview to conclude, I took a few minutes to thank them for sharing their experience and described for them what my next steps in the research study would be. I reiterated how the data from each interview would be reflected in the study and kept confidential. I also let each person know that I would retain their email address and would offer them the opportunity to receive a copy of the dissertation at completion. Most interviewees expressed interest in reading the final study.

Other information gathered. During the interviews with parents and educators, I invited parents to share documents with me such as copies of student Individualized Education Programs (IEP), *Written Notice* (a required form that serves as minutes to an IEP meeting and notes who was in attendance, among other functions), assessments/reports concerning the students, and personal notes and artifacts.

During the course of the interviews, many parents shared some documents related to their child but asked that I look it over but not keep a copy. Interestingly, when asked, parents did not have readily available copies of IEPs or *Written Notice*. One mother shared a neuropsychological evaluation identifying the child's specific diagnosis and recommendations for treatment, two other parents shared care records from providers that the parents felt documented poor-quality services, one mother provided an email about vocational rehabilitation services and a school report card. Two parents shared artwork created by the young person and one parent shared a copy of a draft resource document that she was in the process of creating for inclusion in a parent center's guide on special education.

Special educators who were interviewed in their schools, described programs and curricula that they used for transition services but did not share student-specific IEPs – undoubtedly due to concerns over confidentiality. Some teachers showed me their classrooms, which had evidence of transition-related activities – such as cooking facilities where students made products for sale in a school store or a rack of free fancy dresses so students with disabilities would have greater access to attend prom. One teacher showed me a binder containing a community-based curriculum for students that he had developed nearly 20 years earlier but no longer was able to use due to the pressure he felt to place an exclusive focus on academic achievement. At another school, a teacher showed me a stack of college applications that she was assisting students in special education to complete – something that she said was new based on changed thinking about students with disabilities and their ability to go on to college.

Data Analysis

I was guided by Creswell's (2014, pp. 194-204) overarching data analysis steps for qualitative research. These include:

1. Organizing and preparing the data for analysis
2. Reading through all the data
3. Coding the data
4. Using the coding process to generate a description of the setting or people as well as categories or themes for analysis
5. Advancing how the description and themes will be represented in the qualitative narrative.

6. Interpreting the findings and results

On to this process, I layered the particular steps of data analysis in phenomenological inquiry, including examination of significant statements, generation of themes and distillation of an essence description (Moustakas, 1994).

Interview Transcription and Bracketing

Following each audio-recorded interview, I took the audio-file of the recording and uploaded it into a password-protected file on my computer where it was labeled using the same system as noted previously, to allow for reliable matching across sources. I next wanted to create a transcript of the audio-file to allow for coding and data analysis. After exploring transcription options, I selected Temi. Temi is a fee for service web-based audio transcription service that uses speech to text algorithms to turn speech files into text. According to their website, Temi has been used by over 10,000 customers including the Wall Street Journal and PBS (Temi, n.d.). The Temi website is *HyperText Transfer Protocol Secure* (HTTPS), which means that all communications on the site are automatically encrypted. Audio files are uploaded via a secure portal on the Temi website. Temi keeps all customer data confidential via TLS 1.2 encryption and when items are deleted from a customer's account they are also removed from their server. All transcription work is done by machine. The accuracy of the transcripts was verified by a subsequent review using an online editor app on the Temi website, which allowed me to re-listen to the interviews while viewing the transcripts and make any needed edits. The finished transcripts were saved in a password-protected file on my computer using previously assigned file names. I then printed a copy of each transcript for use in the next stage of the process.

Epoché/Bracketing

In a phenomenological study, one of the most important steps is the “Epoché” or setting aside of previous knowledge and understanding to allow the phenomenon beginning examined to appear through phenomenological reduction without pre-judgment or assumptions (Moustakas, 1994). While essential to the phenomenological approach, in qualitative research more broadly, the examination and acknowledgement of one’s own biases and limitations is an important part of preparation to engage with the data (Creswell, 2014). This acknowledgment of one’s own self in the research is understood in qualitative research as “bracketing” and is a way to begin to be aware of the difference between how we perceive the world and how others do. It is a letting go of a sense of reality and meaning that is constructed only by understanding the objective or embodied qualities of an object or experience and the embracing of an epistemological meaning-making that includes the perceptions and realities as understood by the individual’s experience of the phenomenon being studied (Fischer, 2009; Moustakas, 1994). While the *Epoché* is similar to bracketing, engaging in Epoché involves a systematic approach to consciously setting aside (temporarily) all knowledge, judgments and personal experiences that could impose one’s own set of understandings as a lens covering and filtering the experience to be examined.

My process for Epoché and for bracketing more generally involved a series of steps that were used both before conducting the interviews, and again before beginning the coding process. These steps borrowed heavily from what in today’s parlance would be considered “mindfulness.” That is, I purposefully took a brief period of time before engaging in the interview to close my eyes, be aware of my breathing, relax my limbs and to prepare my

mind and body to move from the previous activity that I was engaged in to the activity at hand. Once I felt that I had left behind the preceding events and any leftover thoughts or feelings associated with them, then I opened my eyes, consciously prepared to enter the interview activity. I was now prepared to engage in the activity without holding any presuppositions or beliefs in my mind.

During the course of the interviews, I tried hard to maintain this mindful state by focusing on listening intently to the person speaking. If a thought popped up that challenged this “being in the moment,” then I either consciously pushed it out of my mind, or I noted it in my field notebook. This allowed me to quickly dispatch any thoughts that interfered with my mindful state.

During initial coding, I also followed a similar process so that I could allow the transcript to speak for itself without getting bogged down or off-track due to an inappropriate exchange with some element of the dialogue. An example could be reading the parent’s description of working with a service provider and allowing an internal dialogue to arise that questioned the parent’s characterization of the service. Instead, I sought to mindfully listen to the parent’s words, be aware of any thoughts that subconsciously surfaced and push them aside or note my awareness of them and jot down a note in my field notebook about the thought before actively dismissing it from conscious thought.

As a professional who has worked in the field of postsecondary transition for students with disabilities for over 20 years, engaging in Epoché and setting aside my knowledge and experience, initially seemed counter-intuitive since it is precisely my knowledge, experience and interest in the topic that brought me to this study in the first place. I soon realized,

however, that this practice was essential in being able to understand the perceptions and lived experience of the individuals interviewed. If I was not able to remove all my lens of my prior experience as I first listened and looked at what was being shared, the reliability of my findings would be compromised from the outset.

Coding

I followed Creswell (2014) and Moustakas (1994) guidelines for coding the interview transcripts. In this way, I moved from identification of specific elements to identification of more structural themes. As mentioned above, before entering into the first phase of the coding process, I engaged in activities for the Epoché so that I could attempt to consciously undertake the activity with a clear mind. I began by reading each interview transcript thoroughly from beginning to end, my field notebook was available as a resource to me. When this was completed, I wrote down some broad “buckets” of topics that were introduced in the interviews. These included:

1. Barriers and challenges (Blue)
2. Outside agency (paid) transition supports - excluding the school (Orange)
3. Parent supports/Natural supports at the individual level, and social inclusion (Green)
4. Community supports/Natural supports provided by employers, organizations or groups - including cultural supports (Yellow)
5. IEP Postsecondary transition planning process/School-based supports and creative school programs (Pink)
6. Significant statements (Purple)

I assigned a color to each of these six areas and returned to the printed transcripts to color code them by hand based on these broad areas. This activity provided me with a visual picture of the interview and also permitted me to see at a glance across interviews which topics were more represented in which interviews. For example, an educator who reported multiple examples of providing school-based transition supports would have an interview coded with many more sections in pink (the color associated with that topic) than an educator who did not. The category of “significant statements” was used as a second color to draw attention to particular places where there appeared to be something of important note. In this way some coded areas of the transcript were coded with one color and other areas with two colors (Kielmann et al., 2012).

The next step in the coding process included re-reading the interviews while paying particular attention to the areas where I had earlier identified a possible “significant statement.” In this re-examination I now created my next list of codes; these ones were grounded in the content of the interviews themselves. This second phase of coding resulted in identification of over 30 topic areas that could be arranged into five clusters. They consisted of the following:

Second pass topics.

- Teachers as supports (natural) beyond the classroom
- Mismatched Services
- Poverty/Generational poverty
- Access to services
- Parents needing to understand all/complexity of services

- Disability-specific needs - lack of understanding or access
- Being overwhelmed (Parents and Educators)
- Paying/Retaining supports
- Transportation/Driver's Ed
- Creative solutions
- Navigating the system
- Lack of targeted services/specialized knowledge
- Teachers who have disability as part of their lives outside school
- Unified sports
- Social Inclusion
- Teachers' beliefs about the family
- Housing needs
- Contributing to resources
- Parent isolation
- Knowing the community
- "Theories"
- Candidness/honesty/directness of educators
- Role independent
- Teachers' underlying beliefs
- Competing over programs
- Teachers' vision of link from secondary to postsecondary
- Competing with other marginalized populations

- “Rich Activities”
- Lack of STEM (Science, Technology, Engineering and Mathematics)
- Desire to remain in one’s community
- Accepting less than what is needed
- Lack of connection to requirements
- School advisory period
- School leadership
- Frequent staff changes

Second pass – coding clusters.

Cluster 1: Unmet needs (both within and outside the school)

Cluster 2: Access

Cluster 3: Beliefs and vision for the future

Cluster 4: Inclusion and support

Cluster 5: Community and creative solutions

I then returned to the transcripts to recode the interviews according to the second level of five topic clusters. It should be noted here that I purposely chose to develop a set of codes that included codes that could be applied to both the parent and educator interviews. This approach was selected because I was interested in understanding where the transition experiences of parents and special educators overlapped and where they diverged.

Word Cloud

In addition to my coding process for each of the interview transcripts, I also used the content of each transcript to create an individual word cloud. A word cloud is a visual image

that is created based on the frequency of words that appear in a document. This visual can be a helpful tool in qualitative research, particularly for preliminary analysis and determination of reliability as it offers a representation of the narrative content. McNaught and Lam (2010) reviewed two previously completed studies, and applying a word cloud product (Wordle), they were able to arrive at comparable findings (p. 636). Moylan, Derr, and Lindhorst (2013) in a review of new technologies found that use of graphic visualizations was useful for a preliminary review in qualitative social work studies. Both articles cautioned, however, that the word cloud has limitations such as inability to identify multiple speakers or potential for loss of meaning when words are reported out of the context in which they were used (McNaught & Lam, 2010, p. 641; Moylan, Derr, & Linhorst, 2013, p. 5).

Recognizing the limitations of the tool, I selected the use of word clouds as an additional introductory means to represent my data. Word clouds can be created via an online website. I used <https://www.wordclouds.com> which is a secure site that allows you to input narrative content that is then immediately analyzed resulting in a generated visual image. Examples of the word cloud product created with this study's data may be found in Appendix C. I named each word cloud image with the same labeling system as the transcripts for ease of matching. Once completed, I visually compared the coded interview transcript with the word cloud image. I noted confirmations as well as areas for additional data review.

Theme Development

In keeping with Creswell (2014) and Moustakas (1994), the next stage of my analysis of the interview data was revisiting the coded transcripts and five clusters to determine if it

was possible to regroup the data to arrive at themes that appropriately capture the content.

Out of this process, three themes emerged:

1. Access and unmet needs
2. Beliefs and vision for the future
3. Inclusion, community, and creative solutions

When added to the data collected and analyzed from my other data sources, these themes provided context to situate the findings to answer the study's research questions.

Other data analysis. Analysis of my other data sources was conducted using the following strategies. For legal analysis, I gathered legal citations from all applicable state and federal laws. Each was examined for language pertaining to transition services. Taking careful notes, a chart was created using the language from each citation to allow for a visual legal roadmap. Document review of state and federal reports, transition guides, and other printed material was conducted through examination of each document. A field notebook was used to record notable points on each document and descriptive information about the source. The analysis of youth voice was accomplished in two parts, (1) the data from the Maine Integrated Youth Health Survey was extracted and a graph was created from the data – allowing for easier analysis of the data and (2) the data from the minutes and outputs of the Youth Advisory Group was reviewed, notable points highlighted, and then the data was coded and placed into three main categories (1) Transition topics, (2) Youth group operations and (3) Goals. These categories supported analysis of the data both as an individual source and later during triangulation of the data.

Verification of Findings

Many steps were taken to ensure the reliability of the study's data and findings. Creswell (2014) states that reliability is important in qualitative research so that findings can be understood to be stable and trustworthy. For interview data, strategies like pairing the use of computerized audio transcription with secondary manual transcription, development of codes and secondary codes, and the use of word clouds allowed the data to be checked for that stability across various modes. The use of direct quotes from interviewees also supports the authenticity of the data by allowing the person's own words and lived experience to speak to the reader.

Strategies used in legal analysis included examining special education laws and rules at both the federal and state level - and as included in different sources - to ensure reliability of interpretation and meaning. Extensive and careful notes were taken during this process. Review of the methodologies of the Maine Integrated Youth Health Survey provided confirmation of valid practices. Documentation of youth voice was further aided by a comparison of the minutes of the convening of the Youth Advisory Group with information included in a chart created for this study to ensure accuracy.

Validity strategies in qualitative studies may look very different from techniques used in quantitative studies. In this research, a variety of sources were used to help triangulate the data. Educator interviews and parent interviews looked at the same issues from different angles (Creswell, 2014, p. 201) and found some common areas of alignment. Perspectives of youth provided support and context to findings derived from interviews. Also important for validity, I identified my own positionality within the study and made a conscious effort

through application of bracketing and Epoché to identify and minimize bias. During the life of this research study, I have also regularly been in contact with many other parents and colleagues from the transition field both in Maine and nationally who have been interested to talk with me about progress and findings. These conversations with subject matter experts have provided additional means to verify the findings presented in the following chapter.

Triangulation of data sources. Data collected from the interviews was analyzed in conjunction with the document review, youth voice, and legal analysis to arrive at findings that accurately reflect the rich data sources that gave rise to them. When a notable data point was identified, data from each of the four data sources was analyzed to see if supporting data could be found. If no supporting data existed from the other data sources existed, the data point was again reviewed to see if it merited inclusion based on the strength of the original source data. This process led to the exclusion of some data, for example, in a few interviews the topic of pets and support animals as natural supports was raised and discussed. While this was interesting data, it did not align with the definitions of natural supports nor did it fit with data available through legal analysis of IDEA's transition services or with data from the Youth Advisory Group and so therefore was set aside. The findings from this study reflect an integration of the four methods of data collection and are intended to answer the study's research questions in a transdisciplinary manner.

Conclusion

In this chapter, I described my research design, worldview, data collection methods and process for data analysis and the reasons for my selection of those approaches. I offer an overview of phenomenological inquiry as it applies to my study and I defend my choice of

qualitative research as the best method to answer the research questions posed in this study. I also included information on my protocols and IRB approval process and addressed challenges faced in data collection.

The four data types that I used for this study - (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators - when synthesized together led to the numerous findings that will be presented in Chapter 4 and discussed in Chapter 5.

CHAPTER 4

FINDINGS

Introduction

This chapter presents and analyzes data collected from a number of sources to begin to answer the first four of this study's five research questions:

1. What barriers exist to transition planning for students with disabilities in rural Maine today?
2. In what ways have natural supports contributed to positive postsecondary education and employment outcomes of young people with disabilities living in rural Maine?
3. To what extent are natural supports included in transition planning by IEP teams in Maine Public Schools?
4. What barriers exist to inclusion of natural supports in transition planning under the *Individuals with Disabilities Education Act (IDEA)*?

In keeping with the methodologies laid out in Chapter 3, data presented here is drawn from a variety of sources in line with a transdisciplinary framework of qualitative research to arrive at findings that answer the research questions. Data examined includes (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators. School level IDEA monitoring data from the districts represented

by the parent and educator interviews are reviewed along with data that reflects the voice of youth – who are the object of the transition planning. Through review of two sources of input – the qualitative perceptions of youth with disabilities as captured in the Maine Integrated Youth Health Survey and the output of the initial convening of the Youth Advisory Group – the voice of youth emerges clearly to bring into focus the transition needs of youth through their own understanding as they pertain to natural supports. Face-to-face interviews with the gatekeepers to transition planning – educators and parents - highlight their lived experiences concerning transition planning and are presented both through their own words and in collective reflections. These interviews revealed often extremely candid admissions of their challenges, successes and failures. The use of multiple data sources results in findings that create a comprehensive response to this study’s research questions and reveal how natural supports currently fit in the transition planning for youth in rural Maine today. A complete chart of these findings is found in Table 4.1.

Findings

In each finding, quotes and summary statements arising from the interviews are indicated as coming from either parents or educators. Each interviewee is identified using the format P (for parent) 1, 2, 3 and so on or E (for educator) 1, 2, 3 etc. The findings presented in this chapter are organized as detailed in Table 4.1.

Table 4.1

Findings Table

Research Question #1
What barriers exist to transition planning for students with disabilities in rural Maine today?

1.1 Access to the IEP table is limited by physical, structural and programmatic barriers
1.2 Parents and educators feel overwhelmed by responsibilities
1.3 Parents and educators lack knowledge of transition resources
1.4 Existing paid services do not meet students' needs
1.5 Parents and educators may not share common beliefs and expectations

Research Question #2
In what ways have natural supports contributed to positive postsecondary education and employment outcomes of young people with disabilities living in rural Maine?

2.1 Young people with disabilities belong in their communities
2.2 "Yankee ingenuity" results in creative natural support solutions
2.3 Parents experience support when connected to other parents
2.4 Siblings acting as natural supports promote inclusion
2.5 When asked, communities offer support to schools and students
2.6 Educators often act as natural supports for students and families

Research Question #3
To what extent are natural supports included in transition planning by IEP teams in Maine public schools?

3.1 Natural supports rarely have a seat at the IEP table
3.2 Parents are more likely to come to IEP table when good rapport with educators exists
3.3 Community experiences inform students' transition goals

Research Question #4
What barriers exist to inclusion of natural supports in transition planning under the *Individuals with Disabilities Education Act* (IDEA)?

4.1 Special education law and practice fail to promote inclusion of natural supports in transition planning
4.2 Parents and youth are unaware of the role natural supports could play in transition planning
4.3 Natural supports are missing from pre-service and in-service training for special educators

RQ 1. What Barriers Exist to Transition Planning for Students with Disabilities in Rural Maine Today?

The process of preparing for adult living is complicated for all young people and their families, as they wrestle with issues around independence, decision-making, and changes in family dynamics - but for young people with disabilities and their families, these natural challenges are complicated by discussions of access to services, readiness for adult-living, fears about safety and security. Schools, which see their work coming to a close, also struggle with development of a transition plan that they will only see through to graduation. Importantly, stigma about people with disabilities and their capabilities may limit their choices (Connor et al., 2008, p. 443). As families and schools struggle with these issues, they also face many external barriers that impede good transition planning. This study identified the following barriers:

Finding 1.1. Access to the IEP table is limited by physical, structural, and programmatic barriers.

Transportation. In a rural state, it is not surprising that parents and teachers both identified transportation as a barrier to planning for and accessing transition services - particularly work sites in the community. As one mother said gesturing out to the woods and fields around her house, “Transportation is the big issue, and you can see where we live, you know, it’s a beautiful place, but you can’t walk anywhere” (P4). Educators expressed frustration when transportation challenges scuttled access to opportunities for students with disabilities. One educator highlighted the impact that lack of transportation can have on employment opportunities

So, the thing I worry about a great deal is getting a student who was supported, a job, because transportation out here, if a parent can't transport them - any level of regional transportation or private transportation, we have never found that to be something you can depend on (E6).

Public transportation, if it was available at all, was often very limited in hours, which made it impractical to rely upon for travel to jobs. In one touristy area, free seasonal transportation was available, but it was limited to the summer and early fall, where it was helpful only for summer work placements. Likewise, taxis, even if accessible, were not a long-term solution due to the long distance and high cost. Some educators believed that their students would never be able to drive, and transportation solutions needed to be long-term. Educators recognized that for some families living in poverty, the issue of transportation was not just limited to the student and his/her transition activities. One educator explained, "Some of my students' families [have] very limited means as far as transportation for themselves, much less trying to [transport their sons/daughters] - particularly if it a job shadowing thing" (E7). One teacher (E9) noted that lack of funding was one factor among others that limited her ability to support her students in transition activities. While she sometimes transported students in her own vehicle, she explained, "I would love to do more field trips and hands-on experiences. The money's just not there." She went on to say,

At my school, it's a half a mile to get to the main road, which is no big deal because we walk it, and that's not a big deal. However, the closest thing I have [to provide a work experience] is at the restaurant. Stores are like several miles away, but they're little bitty stores. So, when I want to do like a work assessment or something like that,

I'm limited to teach those skills because I have our kitchen, I have our custodian, and I have our secretaries. So, if they [the youth] aren't interested in anything like that, they're kind of stuck doing that because I want to build those skills. I don't have a lot of options in that area. So, for us, being rural, it really does limit any type of work experience, unless an outside agency takes them, and then you're dealing with the transportation (E9).

An educator who was able to set up a work experience for a student in a hardware store, in a larger town in his region, relied on the student's family to support the 40-mile round-trip, but recognized that would not have been possible for many families. The educator went on to observe that for his students, rather than reach out for natural supports, "they don't do it, they just don't go" (E11). Other educators echoed the sentiment of the need to rely on families. Youth weren't able to get to work unless you have a driver or parents who don't work. One teacher found a partial solution to transportation for community activities during the school day by using Ed Techs to transport students.³ Another teacher found, after significant trial and error, that they could rely on a Vocational Rehabilitation-funded job coach and a local taxi company as two consistent means of transportation to get students to work experiences in the community.

Parents felt equally limited by transportation issues. One elderly mother whose young adult daughter had been recommended to participate in day programming was told that, in order for her daughter to participate, she would need to drive her nearly an hour from their

³ In Maine, Ed Techs (or Educational Technicians) are certified para-educators who often work with students with disabilities

rural home – which did not make sense to her as the program was only four hours per day. While fighting to get transportation for his son, a father had to drive his son back and forth to work. This amounted to four hours of driving a day. Given that the father was self-employed, this significantly impacted his ability to work. The family was ultimately awarded transportation services, but only after significant loss of income. Another parent of a daughter with a disability noted that needing to provide so much transportation came at another cost. She explained,

I was like running around all over the place to get all these things coordinated for her... It was awful, and the other kid [her sibling], he's like, you know, his grades are going down the tubes and stuff, and I'm not even noticing because I'm so busy driving her (P3).

Driver's education. Access to and participation in driver's education was a recurrent theme across the interviews from both teachers and parents. For students who wanted, or had the ability, to drive, access to driver's education was key to increased independence. One educator noted that supporting students in driver's education had many challenges. Passing the written test was one hurdle, but so was getting enough driving hours. One educator noted that not all young people with disabilities are ready to take driver's education at the same time as their peers, and therefore, they may miss the traditional window for taking the course. She related, "Some kids aren't ready to take driver's ed until they graduate, and up here without driver's ed, you're sunk" (E10). A parent whose son has taken driver's education, still felt uncertain about the impact of his Autism diagnosis on the social aspects of driving and how this would impact his future. She said,

He's not driving, and I'm not sure that he will. He's taken driver's ed, but a huge barrier for us as a family is trying to figure out how to get him to and from jobs. He can use the bus service, and we'll plan to use it (P5).

Transportation safety. When a third-party transportation provider was available, not all parents were willing to allow their child to access that service due to significant safety concerns. One young man with limited verbal ability was dropped off mistakenly at a methadone treatment center - resulting in a frightening period for both the young man and his family with effects that continue. As his father said, "when you have a disabled child, that's your biggest fear" (P9). Another parent related that when third-party transportation arrived to pick her son up, she noticed that the van was in poor repair with balding tires. On another day, the driver took her son to his work experience site but failed to pick him up at the end of his shift. The family was only contacted hours later. The experience irrevocably destroyed the parent's trust in the transportation provider. She related,

We will never use [the transportation service] ever again. We will not. It was just a really, really scary bad experience. They were not very kind on the phone when we were calling to complain...We feel it's been a nightmare a lot of the time (P2).

Both families identified a need for better training for drivers who are transporting people with disabilities, who may not be able to articulate their needs or contact information.

Limited by special education law. Special education law, which is intended to protect the rights of students and families, sometimes instead caused barriers to working together to address student needs. One example reported by educators was the adoption in Maine of a federal guidance letter provided by the Office of Special Education Programs (Knudsen,

2008, para. 2). Compliance with this guidance changed the long-standing practice of schools inviting outside providers to attend IEP meetings without necessarily having notified the parents in advance. The guidance clarified the expectation that parents must give consent in order for schools to invite outside resources to participate in the IEP meetings where transition planning occurs. While the interpretation was a win for parents' rights, it also had a chilling effect on schools' willingness to reach out to needed providers of transition services, because now they had to obtain permission from parents in advance – something that sometimes proved challenging. It was easier not invite them at all and rely on parents who may or may not know about the outside providers. One long-time educator, who identified Vocational Rehabilitation as his “go-to person for organizing transition” put it like this,

The law changed recently. At least my understanding of it is the parents or the student have to actually invite VR now, and unless there's a real need for them to be at that IEP meeting, we haven't pushed it (E6).

Another teacher echoed this belief, when discussing inclusion of other parties in the IEP meetings, “We'll encourage parents to invite, you know because of the special ed law. It's not something that we do” (E7). The impact on transition planning for students may be that important transition resources may be missing from the IEP meeting – unless parents know to invite them.

The paperwork required by special education law presented a barrier for educators who wanted to devote more time to serving students. One educator reported, “[W]e do have an inordinate amount of paperwork, and every time the state makes an adjustment on these

IEPs, they think it's minor, but it forces us to re-transcribe [the plan]" (E4). Another educator added, "It's really exasperating" (E1).

Some educators reported that they completed the special education paperwork and conducted transition planning to comply with the law but had limited experience with successful outcomes. This led to a lack of belief that the transition plan would be meaningful. One educator noted that other public agencies (such as the Department of Health and Human Services) were not held to the same standard as the schools if they failed to deliver identified transition services (E1). A review of IDEA provided confirmation that the law's scope of authority is limited to state agencies that receive grant funding to deliver special education services (Individuals with Disabilities Education Act, 2004, section 1411).

Timing of eligibility for special education services also made a difference in the transition services that a student received. A girl who was diagnosed with an Autism Spectrum diagnosis relatively late, at age 14, was also late to receive transition planning services in a manner that would allow her to close some gaps before the completion of high school. As her mother described, "We didn't know that (she) had all this stuff until after she turned 14. Like all along we've been talking about college... Even with the accommodations, there's no path for her to get the skill she needs" (P3). This mother decided that she would take her daughter out of her local school and instead try an alternative school, that was not required to provide special education services. Instead, the school crafted an Individualized Service Plan (ISP), which is a school-level personalized plan for learning, but without any of the federal protections of IDEA. She explained,

Because of all the way all these special education laws are written now, I'm glad that she had the ISP (Individualized Service Plan). It was really sort of a placeholder, and the person that wrote it was good and very quick on the uptake, and at least there wasn't a whole bunch of paperwork rigmarole like an IEP where you can be in a meeting like the lone parent and across the table there can be 12 adults who've all pre-met to pretend to listen, and like they know what resources they've got and they know the law (P3).

The mother asked the special education teacher in the ISP meeting what support she could expect for transition planning for her daughter. She recounted,

She said, 'nothing'. And I said what do you mean? [The special educator] said 'well if, she needed all that...she would have it by now'. And I think she meant she was entitled to like case managers and stuff and that's when I really started stepping up my game and really pushing for the case manager because they just assumed that if she had issues, she would have been supported by now. That just wasn't the case (P3).

Oddly, this mother was told that her daughter did not need services at age 14 because if she had needed them, she would have already received them.

The structure of the IEP meeting itself was daunting to one mother, as was its limits in scope. While many paid providers were present, she did not feel that it led to positive outcomes for her son, "The transition planning has always left me in a quandary. Like that is such a joke. There's nobody looking at transition plans...Have you ever heard of it?" (P2).

Teachers recognized that the special education process and IEP team meeting can be extremely stressful for young people who are meant to be its beneficiaries. One teacher recounted,

I always meet with my cases anyway just because we need to align the goals on the transition plans with their measurable goals and everything has to be tied in. So that's the way I've always operated. I always say (to the students), please come to your meeting because this is about you being successful. Sure. Your adult life. And some of them, you know, (are) overwhelmed, because you know, they get a bunch of adults sitting around the table, and we're all talking about (them), but some of them are competent enough to sit in there, which is good. They really should be part of the process because it's about them (E3).

IDEA creates the framework for delivery of special education services but variations in practices and interpretations of the law can result in inconsistent application and understanding. Families and students can be overwhelmed and confused about their roles and responsibilities. Processes that require extra work on the part of educators may be sidelined in the face of more immediate demands.

Socio-economic factors. While many parents described the financial strains and stressors of trying to meet their children's needs, none was asked directly about their family's income and none shared that poverty was a reality in their lives. This contrasted with the educators interviewed, many of whom identified poverty as a key issue for families with whom they worked. To educators, indicators of poverty included qualifying for free school lunch and qualifying for MaineCare, the Maine version of Medicaid. One educator explained,

We are like 78% Free and Reduced (Lunch). Like, we're huge. We are a poor community. We have a lot. One of the benefits I guess is we have a lot of families on MaineCare, and so they can access the services. MaineCare is a big component in accessing those outside agencies. Whether that is a positive or not - that we need that kind of access - I don't know (P10).

One educator who has lived and worked in a rural area of the state for years noted the generational impacts of poverty - in particular exposure to trauma. After attending a recent training on the impacts of trauma, he reflected,

I felt good coming back from it. But it's just, I guess the sad thing about it...I realized that it's 50% of my day... trauma response. Either parents or their kids or parents and the kids. The cycle of poverty, you know, is quite evident... Kids are growing up in completely toxic environments (E4).

One educator made the connection between the poverty work by Dr. Ruby Payne and what she saw in her classroom every day, and this encouraged her to try to inspire her students to focus on their futures. Another educator identified that family income impacted community integration. She noted that she had students in her classroom who had never eaten at a restaurant or traveled out of state. The experience of working in a high poverty district also had its consequences for educators. As one educator shared about the coastal community where he had worked, "There's a lot of sadness. Honestly, I was happy to leave because of the enormous sadness about me. Just kind of a bleak, beautiful place but not a lot of opportunity" (E12). Whether explicitly stated or not, poverty is a reality for families in rural Maine. Educators see the impact of poverty in the lives of their students with disabilities

whether by limiting opportunities or by more actively adding trauma and need to already challenging situations. When poverty is a barrier it can impede access to transition resources and supports.

Rurality. Where transition resources were available in theory, attracting them to remote areas often proved challenging. One educator remarked, “Because of our location, you know, it was very hard to get Vocational Rehabilitation counselors on site” (E2). Remote locations, budgetary concerns and low wages impacted availability of skilled providers, and often transition services were the first to go. Budget cuts forced one school district to eliminate a transition specialist position and instead move the employee to an open social work position where she could bill the state for services provided – thereby generating income to pay for the cost of the position. With no other staff to provide services, transition students bore the brunt of the change. In another district, there was a similar story. An educator stated, “I guess my frustration was that...I never had transition specialists” (E12). When students had low incidence disabilities, there was an even greater challenge in finding qualified staff. Describing the difficulty in finding staff with American Sign Language skills, one educator remarked, “When you get into really specialized services in a small area, that’s hard” (E11).

Educators also highlighted that frequent changes in school leadership had a negative impact on carrying out educational programming. One educator (E4) noted that there had been six special education directors in recent years in his district. As another stated, “The recruitment and retaining of key administrators, superintendents, and special ed directors is key. I had three superintendents in one year” (E11). Turnover of administrators , and the

resultant lack of leadership, may impact quality assurance, follow-through and professional development for educators in the district – potentially leaving students’ needs unmet.

Finding 1.2. Parents and educators feel overwhelmed by responsibilities. Parents and educators also both reported being overwhelmed. Educators named multiple reasons - lack of supports and resources, educator turnover, demands of the jobs, and needs of the students, among other reasons. One special educator who was attempting to implement creative transition planning solutions in her classroom, described her feelings as a new teacher,

I feel at times that I’m more of a case manager than I am a teacher, and I have an amazing team in my room. It’s definitely a team effort, you know, we’re all, everybody does, everybody teaches, there’s so many things that have to be managed in terms of resources and programming. I have right now to meet the needs of the 14 students on my caseload. I have 25 classes that I grade, and we have eight periods in a day...We have tons of resources and tools, different curriculums that we can access, but then I have to do all the grading and all the progress notes and all the IEPs, and making sure the data is being collected or collecting data, so again, the case management part of it is, is huge. This is my second year and I’m thinking to myself, I’ve wanted to run screaming from the building. At least, you know, it’s just in the last year, in the last few months, I’ve been wanting to. It’s just very overwhelming (E2).

Another educator empathized with parents who participate in the transition planning process, stating “[It’s] overwhelming for parents to sit in there” (E4) Parents also used the

word “overwhelmed” to describe some of their experiences seeking transition supports. One parent shared, “I’m so overwhelmed just getting him to get to work with brushed teeth and shaved and clean clothes on. Some of those things feel like, oh my God, I’ve got to have a full-time job just figuring it out” (P5). Parents also talked about the challenge of trying to meet all the needs of their child with a disability while balancing other family and work demands. One parent (P2) admitted,

I admire these parents who have the opportunity or take the opportunity to quit their jobs and take their kid to college and support them. You see, you know, some great kid, lucky kid, graduated from college with cerebral palsy or is blind because his mother quit her job and went to college with them. I mean, I’m not a bad parent, but I can’t do that. No... I have another son I need to support (P2).

Day-to-day challenges can mean that educators and parents do not have the extra time or emotional resources to invest in providing the level of services or care that they may wish they could. Learning about transition services and opportunities may fall behind in priority to immediate daily needs.

Related to feeling overwhelmed was the absence of visible champions to support transition planning and outcomes. A special educator, who was not sure how to solve the need for better transition services, pointed to a need for change at a higher level. She recounted, “We need to have a legislative movement of saying, ok, we have these individuals that need to have support. We need to honor that, and we don’t do that. So, we need to have people standing up for these kids” (E9). When this educator was concerned about changes coming that would impact students, she reached out to parents to educate them about the

proposed change and encouraged them to advocate for their children. She would say, “If you think this is wrong...you need to contact your legislator and it needs to be changed” (E9).

Special education is focused on individualized services for each student with a disability, and advocacy typically occurs at the student level. When there is a need for systemic change, there are not always ready champions or systems to support change.

Another area that contributed to feelings of being overwhelmed and without supports was the lack of social relationships that exist for students with disabilities. Many parents described the lack of social relationships during the transition years as a significant barrier to transition planning for adult living. One parent described his daughter’s situation,

She did field hockey, basketball. She was a wicked three pointer. But that was her only social. Now to let you in on a little insight, she didn’t have any best buddies - you know, to call, and nobody to call her. She told the social worker that worked with her early on that she wished she had a brain like the other girls (P7).

Educators, likewise saw the need for improved social relationships at school and following transition from high school. One educator stated,

One of the biggest areas that I worry about in transition is the social piece, that social/recreation because we’re kind of far flung and rural. Some of the social skills and social connections that our students make during their social years are easily lost in the transition after graduation... So I worry about the disconnection that happens after graduation for those kids (E7).

Parents and educators reported feeling overwhelmed and lacking in supports. Youth with disabilities reported on the Maine Integrated Youth Health Survey that they too feel that they

are lacking supports. This feeling of being overwhelmed and without ability to access resources was one of the most frequent themes across the data collected.

Finding 1.3. Parents and educators lack knowledge of transition resources. One of the barriers that seemed to create the greatest amount of frustration was lack of knowledge about existing resources and services. Parents were frustrated that the schools did not have more information, and educators were frustrated that they did not have the support of outside agencies - and sometimes their own schools - to assist them in getting that knowledge. One father of a daughter with an intellectual disability summed it up, “I guess it’d be nice sometimes to have somebody come in and say, ‘hey, here’s what we can do.’ I mean, she qualifies for Section 21 and Section 26, so she’s got these services, but can’t avail herself of them [due to lack of understanding of how to access them]” (P7). Another father, although pleased with the school, stated “I don’t think the school knows enough about the post-grad. They’re focused on life skills, you know, cooking and cleaning” rather than on larger issues like where a young person will live and work (P9). Incomplete knowledge led one mother to spend extensive time pursuing resources that turned out not to be available. She explained,

The reason that we were denied [Social Security benefits] was because he wasn’t at a high school, and he wasn’t 18 years-old yet, and all this other stuff. I was like, oh, so it is a ton of paperwork, and I did all that willingly, and then it was just like, no, sorry. So yes, I wish that had had more information to go on so I knew what to expect... I’m still learning every day what’s going on (P4).

Not being able to access one service had ripple effects for parents. As one mother (P10) highlighted,

Until recently, she didn't have a case manager. They didn't even tell us about resources, and time is passing. She didn't have MaineCare, so we didn't really know what supports there were...and so she's never had ABA [Applied Behavioral Analysis]. Nobody's ever come to the house. We tried to line up behavioral professionals to come to the house and teach her a routine. But the specialized stuff, there's just a real dearth of people that are informed. She's on a waiting list for people to come out and teach her life skills... Finally, the insurance started covering autism two years ago, and I went through this 34-page questionnaire [that] I finally gave up on. And we got this report like this is all the stuff we can do for you, and I said, great, let's do it. And then they started backpedaling, like, oh well, you know what we really would like to do is, we'd like to offer this class for (her) and two other kids, do you think you could arrange this?... I know I sound frustrated but I'm saying, we're educated, we have money, we have health insurance...and she's not thriving, and there's not much help, and she's not going to be where she needs to be at 18 (P10).

Another mother, of a son with epilepsy and other disabilities, reported,

We didn't have case management or any services until, I think, he was 17 or 18.

Years ago, I didn't know they were available. Nobody ever told me that I could get case management services for someone like (my son) (P2).

Looking back, one mother reflected that it would have been helpful to have an IEP meeting that was focused on the immediate period following high school graduation. She explained,

I mean it would have been nice if maybe during some of his IEP sessions, if there were reps from [programs]. I could sit in on an IEP meeting and... then we could at least be gathering information...there'd be a broader group of people that could talk to his [son's] strengths. You know, if we were sitting at one of his IEP meetings, and there was a specific focus on what the next six months look like after graduation, where are other kids thriving, if maybe the life skills teachers knew where all the other kids were and could share that information and say, you know, knowing (your son) and knowing his personality, I bet he'd do great here. There wasn't any of that sort of connectivity whatsoever (P8).

During one interview, a teacher pulled out a number of informational handouts and pamphlets to demonstrate the resources that she uses to support transition planning and explained which ones for which services but then added, "I'm not an expert in all this so I'm trying to connect them to people who are" (E2). Turnover of teachers and demands in and out of the classroom, create challenges for teachers who need to understand transition resources.

Members of the Youth Advisory Group identified that they – as young people with disabilities - also lacked information on transition resources and indicated that one of their desired goals for the group would be to get educated on transition resources (Youth Advisory Group, 2019). Parents and students bear the brunt of this lack of consistent knowledge, as the responsibility to understand complex systems is often shifted on to them.

Lack of belief in the transition planning process. Not all teachers believe in the value of the transition planning process as a means to effect good transition outcomes. As one educator said, "there's nobody checking...I know, as a special educator, I have to write a

good transition plan for high school kids, and I understand that when I'm sitting there talking to the parents, it's like, you know, I want to say to them, 'No, don't worry about this'... This is all on you" (E5). Despite her lack of faith in the outcomes related to transition planning, she still believed in the process's value for her students with more significant challenges as a way to instill hope for their futures. "If they didn't have that transition plan, they wouldn't have anything because nobody's helping those ED [emotional disabilities] and ID [intellectual disabilities] kids that aren't your top 10 students get through high school... There's nobody in the state that I know of that follows up on a single transition plan to see how kids are doing" (E5). This sense that there is no accountability at any level for transition planning, expressed by both parents and schools, may influence their willingness to invest time and resources in creating individualized and meaningful plans.

Many educators and parents hold the belief that there are no or few jobs in their communities, and particularly that there are few jobs that a young person with a disability could do. As one educator commented:

We don't have a lot, you know. We have a big potato farm but you only pick potatoes at certain times of the year. We have a lot of people out here and not a lot of job opportunities unless you head towards Portland... Will Hannaford [large grocery chain] hire our students? ... It's very limited resources for students who have learned a lot and have refined their fine motor and their gross motor skills. We don't have a lot of opportunities out here now (E7).

A father, however, saw an opportunity to develop employment in the community, if only resources could be better aligned to support local efforts. Knowing how much his daughter

wants to be employed – and how many employers are looking for workers - he envisioned his community pulling together at a grass root level to develop someone local to assist with job development. This is an approach that he felt the community would be more invested in rather than relying on “big brother” – as he put it - to solve the situation for them. This idea of solving problems through development of local solutions often involves tapping into natural supports.

Finding 1.4. Existing paid services do not meet students’ needs.

Misalignment of services. Parents and educators also consistently highlighted the mis-match or misalignment of services as a significant barrier to transition planning and services. Sometimes the disconnect between the need for a particular service and its availability was in part due to the student having a low-incidence disability or a provider’s lack of disability-specific knowledge. Other challenges were due to the service being targeted to the wrong age segment. One example of the latter came from a mother whose son with cerebral palsy and seizures has frequent falls. He was referred for “fall prevention” services with an occupational therapist and physical therapist but the protocols included removing scatter rugs and bathroom mats from the home that could be tripping hazards for elderly people but presented no difficulty for him.

Community integration services for young people entering adulthood were not always tailored to meet their needs. This sometimes created a disincentive for youth participation since they may have few same age peers present or the activities offered may be of limited interest to this age population. One father shared that about his daughter, “She’s not comfortable, because at one point we went down to see [a post-secondary program] but [my

daughter] is very quick to size up the types... [such as] somebody more severely handicapped - she's very uncomfortable" (P7). A mother of a young man with Down's Syndrome described transporting her son at a distance so that he could attend a transition program and have interactions with same age peers. She explained, "In [our] area, a lot of these day hab programs are, you know, people that are in their forties and fifties. We wanted him to be with his peer group" (P8). Another mother stated,

There are like 200 agencies for people with cognitive disabilities, and they're like 'oh, [my son] could go to this place but I'm like, these people have a below 60 IQ. They don't even know who the Red Sox are. [He] is going to want to talk about the Red Sox. He's going to want to talk about the latest book he read about some historical event, and there's nobody that can have a conversation with them in there. That's going to be really frustrating (P2).

During an interview, one parent produced a psychiatric hospitalization discharge summary and in-patient neuropsychological evaluation for her child and drew attention to the provider's stated concerns that the young person's needs were being poorly met by current academic and therapeutic services. The provider went on to recommend residential placement at an out-of-state facility – something that the parents were currently considering.

Transition from youth to adult services and supports. One key element of transition comes when students with disabilities age out of children's services and seek services through adult-serving agencies. Parents experienced challenges for their sons and daughters as they moved from children's services to adult services. The movement from child-serving programs to adult services providers was identified as a challenge by many interviewed,

particularly finding the right supports to meet a student's individual needs. One exasperated educator shared,

I think it was a couple of years ago, I got completely frustrated with all the outside agencies and the reports to them, and I invited them all here on campus. You know, we tried to do what we could (for the student), but we never found the right support system. She fell into, you know, drugs and alcohol and all kinds of things. But it wasn't for lack of trying. We pulled out every stop, every counselor, every agency, anyone that had ever worked with that student in house. It just didn't work (E4).

An experienced teacher (P9) identified the gap between child and adult services as a significant barrier to transition planning. She stated, "It's that transition piece between adolescent services and adult services which is difficult, and it gets hard for the parents [to] make the decision when they actually go over to the adult services because you lose services" (P9). She described wanting to have both youth and adult services at the table but finding it challenging to make that happen and not understanding the reason for the difficulty. Not knowing how the services were intended to fit together, she was stymied as to how to move forward. This concern was also reflected by the Youth Advisory Group who identified the need to understand more about the transition process as it related to agencies providing vocational rehabilitation or independent living services (Youth Advisory Group, 2019).

Workforce challenges. Transition services that are built around paid supports are greatly impacted by changes in the area's economy. Even when young people have been approved for/or had funding for services, parents noted that a tight labor market - added to the geographic challenges of rural communities - had negative impacts on the quality and

quantity of available providers. Frequent turnover, particularly in lower paying jobs (ed techs, job coaches, in-home supports) was commonly reported. An educator in a remote coastal school district reflected on students that he had who were “eligible for everything, you know, all the section numbers”, a reference to Medicaid waiver services to support people with disabilities. He explained,

If anyone was going to do that work, they would have plenty of work but it required people usually traveling over an hour to get here, and they would start, but then after a while the winter made it really hard. The roads are hilly, and you know, kind of dangerous driving. So, people drop out (E12).

Attracting and retaining ed techs was also noted as a challenge by that educator. He recounted,

I mean you can come clean houses for \$30 an hour, you know, and I'll pay you \$15 an hour to be an ed tech... They have to take multiple jobs. They leave and go to the grocery store (to work) (E12).

Turnover in professional positions also negatively impacted student transition planning. An educator described Vocational Rehabilitation services as a “revolving door”. One father shared, “We have had no success with [Vocational Rehabilitation]. Nice people, but you can't have that kind of turnover and have a good meaningful program.” (P7). A mother of a young adult with multiple disabilities echoed similar concerns. She said, “We had Voc Rehab. We've had, I think, four counselors - so there's been no consistency with that” (P2). The mother also shared that individuals who have been recommended to provide in-home support have turned out to have a variety of problems. She explained,

The first time they went to put a person (to work) in our home for Section 28, we had it all set up... And like three days before she was supposed to start in our home, I was reading the newspaper, and she was in there driving on a suspended license, and her car was unregistered. And I'm like, ugh! So, I called the agency, called the case manager (and said) this is what I read in the paper... So here's this person they were going to put in our home that was driving on a suspended license, and she was supposed to be able to transport (my son). And it was like, oh, my God (P2).

The next support person was good and worked with the family for two years but then when she graduated college, the family faced a repeat of their earlier staffing challenges when a woman was referred as a replacement. The mother explained,

I googled her name and she had been convicted of theft... I called them, and I said, 'she's not coming to my home.' This is a convicted felon, convicted of theft. Like don't you do background checks" (P2)?

What the mother found was that criminal background checks were only required every three years and depended on employee self-report if an incidence arose between checks.

For another parent, the staffing turnover impeded realization of her son's transition planning. She explained,

We talked about what an ideal sort of postgraduate situation would look like, but we're never able to access services. You know, there's a lot of turnover in the DSP⁴ world, so we weren't able to get consistent people to help. So, we know what great

⁴ Direct Support Professionals (DSP) assist individuals with intellectual disabilities to increase independence at home and in the community.

would look like, but we haven't been able to get there. We were blessed with some really fabulous DSPs but we've had some not so fabulous...They didn't approve pay increases for the DSPs which means the labor pool just kept shrinking and shrinking (P8).

Parents stressed that letting staff into their homes to work with their children required a high level of trust. One father recognized the role that low pay had in attracting individuals to the field. He related,

The pay scale for those poor fellas! So, there's a high turnover. It's really hard to find a good caring person. You're trusting these people...You're giving these people keys to your house. You know you're relying on (the agency) to do a thorough background check. It's kind of frightening. First time you put them in a car with some person who you just met, you know, it's hard... (P7).

For families who had no ability to influence pay rates for the individuals who worked in their homes, there was a tension between recognizing the low wage that carers received and at the same time wanting to see their son/daughter receive high quality services

Finding 1.5. Parents and educators may not share beliefs and expectations for the student. In the interviews for this study, parents and special educators expressed a number of beliefs about both what could be possible and what they believed were the reasons behind why students with disabilities did or did not achieve the successes that they thought possible. Some of the beliefs were specific yet might potentially limit student opportunity in significant ways - such as one teacher's statement that "very few of my kids will probably ever get a driver's license" (E2). That teacher's belief that disability often rules out driving

might result in her discouragement of students taking driver's education, or she might only look for community-based experiences that are close to a student's home or may overlook resources that could support driving and greater independence. Other beliefs evidence the reason behind a parent or teacher's commitment to young people, such as the parent who when explaining why she and her husband continued to push for opportunities for their daughter stated, "We're not trying to feel like we're ignoring certain facts. It's just that you don't want to put somebody down and (limit) their potential. You don't know until you try it" (P6). In this section, those beliefs are highlighted so that their potential impact on transition planning, use of natural supports and student outcomes can be better understood.

Teachers' beliefs about parents. During the course of the interviews, some educators revealed underlying beliefs about the motivations and actions of the parents of their students and how these impacted transition planning. Many of their beliefs centered around families' economic instability and concerns that families did not want their child with a disability to be working – preferring them to access disability benefits instead. One teacher recognized that "living paycheck to paycheck" and "trying to get food on the table" may overshadow long-range aspects of planning for transition (E2). Another educator, noting that poverty is a big factor in her school district, expressed her belief that some families may want their child with a disability to continue to live at home after high school graduation - in part to support the household with Social Security benefits. Her concern was that her students would "probably really not do anything that productive" (E5).

A long-time educator, reflecting on what he has seen over the years, added, "Nobody comes out and says it, but it sure seems like it. They're worried about jeopardizing the SSI"

(E6). He went on to add about his students, “They’re going to sit at home and that’s a decision that seems like the family to me” (E6).

Educators also held concerns about the perceived culture around some traditional occupations, like fishing. For example, one educator stated,

They have cash, but they also have a lifestyle, and I don’t want to stereotype, but they’re not really managing their money. They have brand new cars, trucks and new boat, (but not) a sense of saving for the future kind of things. Then if someone gets hurt, it’s catastrophic because they don’t have income. My concern really was around the females. There was a whole culture around them not leaving (the community) or getting a license. That would never be encouraged. ... It was free labor you know.

They would be stern men in a boat and they would take care of stepmother’s children (E11).

Teachers also expressed that they believe that parents’ pride gets in the way of their acceptance of the services needed for their children’s transition planning and that this often goes hand in hand with a fear of letting state services into the home. One teacher expressed her concern,

I have had parents that are on the higher economics spectrum that have looked at me and said, “well, we don’t need those services. We can provide.” Like, you don’t understand, no matter how, how much money you have, you really do need to have these services ... So yeah, some of it’s a pride thing too. Eventually, they get the services (E9).

Another educator commented,

I think there's a lot of pride that goes along with taking care of your own... I see parents rejecting services because I think they take it as a sign of weakness, and then I believe that there is also the, you say anything about DHHS⁵ and the wall comes up. There's a concern about they're going to take my kids away from me... So DHHS can have a negative connotation with a lot of folks. So, like when I'm talking about services and stuff to them, like I don't even mention it. I think positioning it, like when I talk about case management, I position it as if it's like having a life coach, and I'll talk about how, like all the NBA players and all the sports people, you know, it's a big deal to have a life coach, somebody that basically helps you with goals and helps you with making decisions (E2).

Another teacher said,

I'm trying to work with a family now. The adult referrals go through DHHS and just even saying DHHS, it's like, 'I don't want them'. That stigma of DHHS involvement. I think they could call it something else, when you want to access it. We have a lot of people helping so when we are trying to get them involved in a positive way that defensiveness is still there. 'I don't want them to come into my house.' We find that a lot with outside agencies. They don't want anybody in their house because they may have had a DHHS referral, and there may have been questions, and they may have been on a (family services) plan (E10).

⁵ Maine Department of Health and Human Services

In another situation, an educator felt that a parent's fear of sharing a student's Social Security number was the barrier to accessing a work experience program through Vocational Rehabilitation.

Related to beliefs about Social Security benefits, teachers also expressed some strong feelings related to the role of parents in communicating what it means to have a disability.

One teacher stated,

This young lady came in and just was bragging about her new diagnosis, and just that whole mindset of you know, I want to be disabled, rather than trying to become more, so people get frustrated with that. I do too. That's learned behavior from family, I would guess... I think that there's a choice, if you had a choice between staying home and doing your SSI kind of thing after you graduated or having at least part-time employment, I think they'd be just fine with sitting at home (E6).

Teachers see their vision for a child's future can be very different than the vision that parents may have and that this may reveal itself through the transition planning process. One teacher, while describing the reaction of parents to her development of community-based work experiences, found that some parents were conflicted about whether time in community settings would take away from opportunities for inclusion with peers in the school setting.

Parental expectations for their youth. During the interviews, parents often shared that they had been told that they needed to change their expectations about what their sons and daughters would be able to do after high school. One mother cried as she described giving up her hope that her daughter, who had expressed wanting to be a veterinarian, would

attend her alma mater. She reported a conversation between her daughter and her daughter's case manager around vocational interests.

[The case manager] was saying, 'What are you interested in? Do you want to work at Domino's [pizza chain] or something?' It was the first time anybody was like, the vision for my daughter is aspiring to work at Domino's. It's one thing if I knew all along (P3).

Assumptions about what a young person's path will be can also negatively impact the transition planning process as time and resources are directed towards a post-secondary goal in which the student with a disability is not invested. This was the case for one mother who always assumed that her very intelligent son would attend college. It was through this lens that she advocated for him in IEP meetings, only to have him announce following a college visit that he had no interest in going away to college – and in fact never had.

It was me that was thinking about it more than him... I just assumed that he would, but then it's like , okay, well, that's not what you want to do. Then let's find something else... Once I, once we, both realized that wasn't gonna happen, we just tried to find another path, which is fine. It's not all that easy actually (P4).

Transition planning is intended to be a process that builds on student experiences and gained knowledge. In the situation above, an assumption about what a young person wanted to do after high school, shaped the IEP's transition goals and supported activities like visiting colleges to the detriment of other work-based learning activities that might have prepared him more for future employment in his field of choice. Time is a limited variable in transition

planning – ultimately high school graduation day will arrive or a student will age out of services.

Beliefs about disability. While disability labels can represent a wide range of functional limitations, equally varied too are the beliefs about what it means to have a disability. For families and educators who are invested in the lives of youth with a disability label, their understanding of disability can greatly shape their interactions and expectations. One educator who was relatively new to teaching expressed that she believes that a number of her students “have cognitive functioning and executive functioning problems...from early childhood trauma” and “now that they’re able to be in a more stable environment,” they are able to make progress. She stated that she didn’t like to talk about disability and preferred to frame it for her students as being “differently-abled,” recognizing that everyone has strengths and challenges (E2). Parents, too, shared their theories about disability. One mother questioned the spike in Autism diagnoses in recent years,

My personal theory, and this is just a personal theory, is a lot of kids that are getting late diagnoses of Autism, it may not be classic Autism. Because you know, it used to be like 20 years ago, they knew that people who have Autism are non-verbal, they didn’t make eye contact, they rock back and forth (P3).

This mother believed that other diagnoses like Fetal Alcohol Disorder may be in play for some of these children. With eligibility for services dependent in many cases on diagnosis from a medical professional or categorical determination by an IEP team, disagreement with or investment in a disability label can be the difference between access to services or not. As one mother put it about her son, “He was unable to go to college because he has epilepsy, and

we couldn't have him attending college without someone there with him, and they don't provide those services. Because of the epilepsy, you never know when he's going to fall" (P2). Medical diagnoses can often determine what services are available to assist a young person through transition. When labels limit access to preferred services, post-secondary goals and plans can be derailed.

RQ 2. In What Ways Have Natural Supports Contributed to Positive Postsecondary Education and Employment Outcomes of Young People with Disabilities Living in Rural Maine?

Finding 2.1. Young people with disabilities belong in their communities. One of the most consistent expressed beliefs among parents and special educators was the idea that young people with disabilities belong in their communities where they have natural supports and connections. The purpose of transition planning in special education is, therefore, they believe to help support that end. One educator described why her district attracts families with children with disabilities,

We had a family that were wanting to buy a house...and so they called and I said, well, you know, come on in and visit. And they said, we're buying in your district because absolutely no one else took the time to welcome us, to show us around...You know, I want you to know that we want you, so that's where we are (E7).

One parent explained, "We're trying to get local. My whole thing was - that's nice up there but it doesn't help her...Maybe she meets somebody that they could become friends, but they're living in (distant community) or wherever and that's not going to produce any social (connections)" (P7).

Finding 2.2. “Yankee ingenuity” results in creative natural support solutions.

For all the challenges, barriers and competing beliefs that can often make transition planning for special education students in rural areas such a minefield, there can be an equally powerful counterforce in the commitment to students with disabilities on the part of their families, schools, and communities. Creative solutions - which many times feature natural supports - may even be an expectation and part of the ethos of rural Maine life. As one educator put it, when developing transition services, her school was not “without our own Yankee ingenuity down here” (E7). “Yankee ingenuity”, or the idea that New England people are self-reliant and can find inventive and creative ways to solve problems, may have been a necessity born out of harsh winters and remote, isolated living, but it lives on as a romanticized view of the resourcefulness of rural Maine people. When educator interviews occurred in schools, teachers were often proud to show off their classrooms and highlight areas that demonstrated creativity and that they were building transition skills – such as bulletin boards that featured work-based learning or student projects in independent living skills. One interview started with a look at the many dresses that the teachers had collected to allow their students from homes with limited means to attend the upcoming school prom.

One mother left this interviewer with a draft copy of a new parent guide that she was completing on behalf of a parent group, along with copies of related guides that had recently been published. This mother was keen to ensure that other parents had more information than she had had during her son’s transition process. Rather than accept that no guide existed that met her needs – she used her own experience to create a resource for others.

Creative ideas were not limited to parents and educators. Youth and young adult members of the Youth Advisory Group also generated many innovative ideas as to how they could support transition planning for students with disabilities. These included advocacy and sharing their stories – but also mentoring younger students with disabilities who are just entering the transition process and creating a game to teach about disabilities (Youth Advisory Group, 2019).

During one interview a special educator (E2) paused to inquire if the interviewer was “from Maine originally”, and then went on to say, “well, you know us, Maine independent!” While the shadow side of a belief in independence and Yankee ingenuity can be a reluctance to ask for help and perhaps a crushing sense of impotency when unable to develop effective solutions on one’s own, the examples shared by parents and educators, during the interviews and the ideas generated by the Youth Advisory Group demonstrated the ability of rural Maine people to often create and sustain effective solutions.

Finding 2.3. Parents experience support when connected to other parents.

Natural supports – Building parent-to-parent connections. One way that teachers described helping to build rapport with parents was by helping them build natural supports and connections with other parents. A teacher who expressed that in her school “we have great relationships with our families”, highlighted that, even in the absence of a parent support organization, “a lot of the parents know each other because we’re a small community, and they grew up together” (E10). A teacher who said that she has “really worked to develop a really good rapport with my parents even if they don’t come to

meetings,” noted her concern about parents not having the supports that they need. She explained,

It does concern me. I don't really know that other than their family members that they know in their neighborhood, (they have any supports). I really try to introduce my families to each other when I get a chance. I'm like, hey, come on, this is so and so's parents. Because I think that sometimes if those parents get to meet one another where they both are dealing with a child with, you know, somewhat similar needs, one might know about resources, maybe that the other one doesn't and can also be a support and encouragement from one another (E9).

One educator went a step further and started a parent support group. She recounted,

We started our parent group about a year and a half ago to provide just this. So many of the parents were kind of flying solo and filling out the dreaded MaineCare paperwork, filling out the waiver form, figuring out how to get a community-based case manager, figuring out how to interface with Voc Rehab. Trying to figure out how to do the estate planning that might be necessary. And so, all of those pieces feel more manageable when you're doing them with the group of people who's done them before. And especially this past year, we've had the four students who were graduating, at least two of those parents or families have been through the process and could share their experiences with the freshman and sophomore parents who are coming in. And so, it made it a lot more manageable, and I'm hoping that that kind of informal support...can help one another through this process... One of the parents

whose son just graduated said, ‘I don’t mind coming back as a guest speaker in the future’ (E8).

A parent who described being very overwhelmed by the needs of her daughter saw a turning point when she was connected to another mother in the community who had children with disabilities. “She basically came and taught me what it was like to be a parent of special needs kids... She was much further along the parenting curve” (P2). One parent also mentioned that she had found some other parents to be supports via social media, but also felt some hesitancy due to not being able to verify the identity of those participating in the Facebook group. One group that she did find particularly helpful included a number of well-educated parents who traveled to conferences on disability topics – something that she wished she was able to do but was not due to her children’s needs.

A parent, who described her son’s transition process as completely lacking in natural supports, decided to change that for other parents. She started a local chapter of a statewide parent organization and created some of the resources that she wished that she had had herself. She explained, “This is my hope for other parents like me, that they can have a resource. They’ll know where to go. They’ll know what to do” (P4). Her affiliation with the parent organization also allowed her to meet other parents and for her and her son to join in with them on community outings.

Finding 2.4. Siblings acting as natural supports promote inclusion. Siblings can play a unique role as natural supports for their sisters and brothers with disabilities, offering them age-appropriate experiences. Their inclusion in IEP meetings, however, was rarely reported. One parent stated about her daughter’s participation in her brother’s IEP meetings,

“I’m not sure if there’s even a need, she’s very involved in his life”. She then relayed an example of how the sister’s participation in the high school basketball team had led to her brother’s inclusion as team manager, something that continued after both siblings had graduated high school (P8). For most parents though, the conversation about sibling involvement focused on long-term care and needs. For example, one parent reported, “Right after he turned 18, we applied for guardianship, and she wanted to be a guardian as well. We didn’t ask her or anything. Really helpful” (P9). Another parent told her son, “But you know, as we’ve talked, I said I’m not going to be here forever, and you can’t expect your brother to take care of you?” (P4)

Sometimes siblings may have mixed feelings about the supports that their siblings with disabilities receive. A mother reported that both of her sons work together at the family business but that the son without a disability sometimes gets frustrated that his brother leaves work regularly for supported activities in the community. The mother said that she told that son, “you have your family to come home to, what does (her son with a disability) have?” (P1). Another father reported that his son with a disability built a strong network at school through his sister without a disability. “All her friends talk to him...going down the hallways. I feel like that was a huge benefit” (P9). A young man with a complex disability has a brother who has been paid to provide respite services. His mother shared that the young men are very close, and her son with a disability has expressed fear that his brother will “go off and leave me” although the brother has said that he will “never let (him) go into a home.” The mother continued,

He needs to be with people his age. You know (my son without a disability) will take him places, but he can't, he's not trying to be responsible for (my son with a disability) either. He loves him, and he loves to take him places but sometimes it's hard. He plays frisbee, and he wants (his brother) to get down for some of that, but like this morning, I think he had seven seizures (P2).

Educators also had some experience with siblings, although rarely as part of the IEP process. One educator shared,

I did have a family...who made assumptions about an older child will be (the student's) guardian. And finally, the kid showed up at the IEP meeting and was like, "Just so you know, that's not happening." A weird dynamic, and I think that there are assumptions made for siblings. One of my recent graduates - there is also that assumption - and the older sibling has said, "Yes, I'll take it on." But again, I'm not sure that they really understand what that means because when you are 22 and you say, "Yes, I'll take care of my sibling with a disability." It's a different perspective (E8).

Finding 2.5. When asked, communities offer support to schools and students.

Many parents recognized the importance of natural supports to their child's successful transition to adulthood even if the natural supports did not participate in the formal special education transition process. One parent whose son had had many opportunities to build community relationships said,

We've gone to a lot of parents' seminars and workshops, and one of the things that stuck with me from one of the instructors was the best way to keep your child safe is

to get them out in the community, make sure people know who they are. Isolation is dangerous for our children. You know, because if he was walking the street and nobody knew who he was, he would be ignored. But if (her son) is walking the street by himself, there's probably half a dozen people that would pull over and go, (son), 'hey, how you doing? Are you okay?'. They would. You know, we live on this street, everybody knows (my son). There's a lot of love where we're at and just in the community. There's people everywhere we go. Like nobody knows me, but I go to Hannaford's, and he's hugging and high-fiving people he knows. (P8)

Many educators and parents identified community members such as neighbors and friends, local employers, or community organizations as being natural supports for transition, however, inclusion in the IEP transition planning was rare. Educators who know the community well, often are key to making those connections. One educator expressed that her school made connections with a local farm to support students who had an interest in agriculture, took students grocery shopping, set students up with horseback riding lessons, and encouraged students to pursue interests through vocational schools. Building these community connections, she believes are key to promoting community integration. She explained, "We really try to hit on what is going to bring this child a rich environment, expose them to different activities, and how do we, how are we going to help them hold down a job?" This teacher worked with a chef from a local restaurant to come in to the school and work with the students. When asked about including the chef in IEP transition planning for the students with whom he was working, the teacher indicated that she would

not name the individual on the IEP but instead would focus on including the opportunity of learning to cook in the transition services (E7).

One educator felt that her small rural district was very aware of the resources in the community and the related opportunities. A large local vegetable producer worked closely with the school to provide work experiences for students, including those with disabilities, with transportation provided by the school. Another student worked with a local welding business, one with significant needs worked at a thrift shop, and another with autism worked at a farming supply business. She said, “We try to get them into the community as much as we can” (E10) She then went on to talk about the employers. “They’re very good to the school district, and we have a lot of community businesses that are very willing to give our kids opportunities to learn skills. We’re very fortunate that way” (E10). In a rural area of the state with a strong farming community, an educator noted that many of these farms hired her students (E2). Another educator identified that

Local businesses and community members have been the most helpful in planning.

I’ve also found parents’ connections to local businesses and community members as super helpful. We’ve had kids in businesses either doing job shadows or doing work internships with checklist and rubrics that help you know whether or not they’re gaining some of those soft skills of dependability and hygiene and social skills and those kinds of things. The way that community members and businesses have been the most helpful is just by opening their doors to us and allowing us to come in.

We’ve had students in a convenience store, grocery store, a couple cafes and restaurants. And this summer we have a student who is going to do some building and

grounds work at a college. All of these businesses, for the most part, if you start the conversation with, “hey, I want to help kids get the skills they need to gain employment after high school, can you help us out with that?” I’ve never had anyone say “no.” So that kind of communal responsibility has been really key in making sure kids get these experiences. (E8)

Parents also felt the value of the community to support their child’s transition. One family identified the support of a neighbor family as “top of the list.” The couples’ children have been close and their son with developmental disabilities considers the neighbor’s son his best friend. As the mother said, “he’s their second son.” The neighbor’s son wrote his essay on his college application about their friendship. The mother noted that “there is an amazing relationship between the two of them. It’s been in existence since we moved here. We’re going over there to watch the Superbowl” (P8). For another family, it was the support and connections of a friend who helped their daughter’s transition by setting up and underwriting a work experience with a non-profit organization in the community.

[The parent’s friend] was extremely influential and dropped a few hundred on a stipend. He was on the board so she could be hired through this stipend. It was to see what she could do. Well this was the summer leading up to her junior year, and it went well, and the (organization) saw that, and (said) maybe we can work something out. So she was able to work (P7).

After a couple years of part-time work there, the father said that the organization leader told him,

We love her. She's like family. There were a couple young women out there who have taken her under their wings, so it's kind of like a job coach. When she graduated, they all walked off work in their work clothes, brought beautiful flowers (P7).

This family also used other community connections to connect their daughter with social and volunteer opportunities. The mother relayed that,

I have to tell you that the community is so supportive of her and in so many different ways and having known her from school and sports. She volunteers at the thrift shop every Monday afternoon with me. She does an excellent job. So, a woman came in and she said, come down and see our community center. And so, I signed her up for a knitting meeting with this group of women. I didn't go with her. I said, "this is something you need to do." Well, they're a bunch of mothers or grandmothers. She's very comfortable with older people. They're just mothering her. They gave her a surprise 21st birthday. They gave her gifts. They gave her money. Oh, my goodness, she's making a sweater! It's nothing with her own peers but that's alright. She doesn't want to miss it. Just like she doesn't want to miss volunteering at the thrift shop (P6).

Despite the strong support that the family has experienced, they recognized that it is not available for all young people. "We're very fortunate that we know people. But I think of the other people who might not have the whatever it is that [we] have, the advocacy, or they get under your skin type. It's not just about (our daughter), it's about anybody who needs service" (P6).

One mother of an adult son with autism noted the importance of the local community in making his transition work. Using the family's connections, and matching them with her son's interests, they were able to set up volunteer and community-based activities and then use paid supports to provide transportation and other needs. She described the positive response of individuals "from away" when they see her son working in the wreath shop - a seasonal position that came about because the mother contacted the owners and asked if they would consider taking him on to work. In another vein, with support, he was able to pass his hunter safety class and go out moose hunting with other family members. They give back together too, regularly donating and posting pictures of them doing so on social media – something that has earned her son many Facebook "likes" (P1).

When natural supports are developed through community connections, students with disabilities have access to new opportunities to pursue interests, explore careers, and build connections leading to stronger community inclusion.

Programs for people with disabilities. Some parents found support with programs exclusive to people with disabilities. These programs, although not integrated, may facilitate access to the community via paid supports. As one mother noted, the physical needs of her son's friends make it impossible for her to host them in a casual get-together with her son in her home so she relies on a local program with staffing to bring the young men together for weekly bowling, "He does see them each week, which is nice and his aide sometimes sends a photo of them" (P8). Another young man benefited from access to funding to provide a direct services provider who could take him into the community and assist him in accessing college courses in the community.

Finding 2.6. Educators often act as natural supports for students and families.

During the course of the interviews, some educators shared that they are supporting students with disabilities through the transition process in ways that extend well beyond the scope of their roles in the classroom. One way is by serving as a role model and sharing information about their own lives. One educator recounted,

I try to use my kids, the experience of my son in college. He's going to be a junior next year.... You try to help them realize the reality of what's coming, that their school is going to end in two years, and what are you going to do because you['ve] got to do something. You're not going to want to live with your parents, and your parents aren't going to want you to live with them (E5).

For a teacher who is “living a fishing life”, she felt that sharing her family’s experience was critical for students who also were planning on following that path.

I feel like all the kids that come through my room or on my caseload, they need to know me as a person too. I have, you know, kind of a unique connection because of what our family does. My husband is a fisherman...and so we've lived a fishing life. And so I can really make a connection with that. Those relationships, it's really what it comes back to for us. I think we can because we have good relationships with them. They actually listen to the things we have to say to them (E3).

“Being honest.” Teachers also expressed that they felt it was important to “be honest” with the young people with whom they work, to provide some guidance that might be more candid than the typical teacher-student relationship.

I think that kids, they appreciate honesty, and I think you can be honest and be nice. . . I'll be real honest with them about transition stuff. I'm like "You know what, the world doesn't care that you had a crappy childhood. The world doesn't care that you have a disability. I'm sorry to say but as a whole, the police officer isn't going to care, the employer isn't going to care, so you need to learn how to take ownership of your life and learn skills that are going to help you to be able to go out there and function in a way that is acceptable... if you don't believe in them, they know. Yeah. They know if you don't believe in them (E2).

Educators who embraced this direct style of speaking to students, did so as a way to transition to a new relationship with them – one that was intended to provide the foundations for ongoing natural supports and community connections outside the classroom walls.

Going the extra mile. One educator recounted his efforts to set up innovative tutoring programs in the evenings so that students might have an extra shot at strengthening their academic skills (E12). Another used her previous work experience in residential care and joined parents on visits to day programs and residential treatment centers, "checking them out, giving my opinion" (E9). Another educator, who knew that transportation was a challenge for some parents shared, "If the family is having a hard-time say getting to [the nearest city], we sometimes help with that" (E10).

One educator described providing the students with a pizza party at the end of the school year and giving them little rocks with inspirational messages on them.

I'm going to tell them that hopefully it's in the bottom of your backpack and when you're feeling really low...you'll pull out that stone from me and you'll read it and

you'll say (my teacher) wanted me to pick myself up and brush myself off and you know, go on (E5).

Sometimes Ed Techs proved to be invaluable resources and links between the school and the community. In one school district, the Ed Techs donated their own money to meet student needs. A teacher recalled that the Ed Techs in his school made sure that students had food for the weekend and that they hugged the students every day so the students felt loved. Feeding families, is another way that schools show their commitment to the community. One educator remarked, that summer food programs consistently brought whole families in to the school. In one rural school they found that non-teaching staff could also be a tremendous asset to support transition planning. When they were short of job coaches, they looked to retrain a district bus driver after noticing that the bus driver had the characteristics, they were looking for in a job coach.

Due to the nature of their work, special educators are often privy to very sensitive information that often found them taking on issues outside of the traditional teacher role. As this educator described,

Parents are very trusting of us. ... It's not uncommon for the same parent to call me six or eight times a day. Yes. Yesterday, you know, it was a 55- minute call with a parent. Legitimate things, kid has been sexually abused. In a class, it became a topic, and it's causing anxiety, and (the student) is hiding in the bathroom for 15 minutes. I'll follow up on that (E4).

One way that educators acted as natural supports involved their ongoing participation in the lives of their students post-graduation. Whether it was the teacher who invited former

students back each year for a Thanksgiving meal in the classroom or the teacher who regularly talked with parents of graduated students. One educator noted,

I can't think of anything more upsetting than having a student walk out of here and sit at home for six months waiting for the next thing.... I have one young student who graduated a year ago, and she was scheduled to go to (a postsecondary program) but there was a gap. I know her mom, and she came to me and said, are you ok if my daughter volunteers in your kitchen? So, until she started at (the postsecondary program), she volunteered. She wasn't sitting at home, she was using good language skills, and interacting appropriately.... A parent comes in and says, "I have a need," we will step up (E7).

An educator who pursued grant funding for a two-seated adaptive bike for one of her students found that its impact went well beyond access to community activities.

Something magical happened that I had not anticipated. He rode that thing around inside the school and on the track. I got the student a little horn and so now everyone is like, can I give him a ride? So, accidently, everybody's like, I want to ride that bike, that cool bike and so everybody's fighting to get a chance to go around the school with this kid. (E8)

For one teacher, going the extra mile for her students with disabilities meant educating herself on topics outside the school doors. She enrolled in a certification course to be able to work as an employment specialist for people with disabilities and learned about supported housing options so she could partner with local parents to help advocate for increased housing opportunities for youth with disabilities.

RQ 3. To What Extent Are Natural Supports Included in Transition Planning by IEP Teams in Maine Public Schools?

Finding 3.1. Natural supports rarely have a seat at the IEP table.

Natural support participation in the IEP meeting. Parents and educators described a wide range of participation in the IEP meeting, and likewise there were varying experiences with inclusion of individuals from outside the school in the IEP meetings. Case managers, behavioral health professionals, vocational rehabilitation counselors, and state agency representatives, were among the paid supports that were identified by parents and educators as being the most regular outside individuals to attend. The presence of many paid supports is not always perceived as helpful. One mother related,

The team meetings were huge because we had PT [physical therapy], OT [occupational therapy], speech people, Voc Rehab, vision rehab - because he's visually impaired...and so we had the huge team of people when we were sitting around at IEP meetings, and I felt like it was a really negative experience. Like they're making a plan but there's not anybody that helps you see that through, and as a parent you're trying to get your kids through school (P2).

Educators related that they encourage parents to invite others to participate in the IEP meeting. One educator recounted that when parents gave their consent, the school always invited Vocational Rehabilitation or case managers or in contentious situations – advocates. Natural supports, however, were rarely at the table, “They don't really bring [other] parents. They don't really bring friends” (E12).

Another educator saw outside agencies as a connection to natural supports in the community. She said,

We're fortunate to have the [Vocational Rehabilitation] transition counselor come in a couple times per month... And for us as a community connection piece, that one's huge. So that's our [workplace] situational assessments, that's our workforce support pieces, it's our visits to colleges. That's our number one go to. If we have a very complicated situation and family, we ask them to attend IEP's, and they will if we need their input (E3).

One parent also saw paid supports as a route to connect with the community.

We went through Vocational Rehabilitation services. We had a woman that he met with prior to graduating high school, and it's a good program but you have to know how to navigate it. She was really helpful because this is what she does for a job... They meet with us, decide what he likes and what he would like to do for a job eventually. And then his person goes out and seeks [trial] employment for him.... His last assessment was at the animal welfare society, and he loves animals. So they take him to places that they think he might like. Vocational Rehab services pays him, and the place of employment gets a wonderful volunteer. So, it's a win-win for everybody. What he did last time is - he particularly likes dogs - so he was walking dogs, cleaning cages and filling dog treats and things like that, and it was wonderful because they pick him up and drive him there. (P4)

One educator who regularly encouraged parents to bring others as supports to the IEP meetings stated,

They were encouraged to bring whatever teams they wanted, you know, clergy, neighbors, family, relatives, anybody. That's not always the case, because a lot of special ed feel intimidated by that. I encouraged that. I said, 'you need to feel supported, that you can have someone you can talk to after, after this', but oftentimes they would just be shell-shocked. They didn't know, especially if it's their first time.

(E11)

Another educator said, "We invite case managers, so they're involved with anyone that has a current role or future role or needs to get up to speed. We always invite all of them to the meetings, and they come." When this educator was asked about individuals in other roles, she added, "they pretty much have a professional affiliation, and they're actually trained to help the student and the parent move forward with...a work plan" (E7). An educator in a school that had actively promoted more community involvement in transition planning measured success like this, "Good news, we're starting to see as many college apps as SSI apps" (E4).

A mother who had to pursue a due process hearing while her son was in high school in an effort to get his needs met, related that since that time she has become an information specialist with a disability organization and regularly gets invited to attend IEP meetings with students at the same school that her son attended. She sees big improvements in the school process as a result of her advocacy on behalf of her son. She said, "I'd like to think we made a difference" (P1).

Youth perceptions of inclusion. For natural supports to participate in transition planning, they need to be identified and understand their role but according to the results of

the Maine Integrated Youth Health Survey (2017), there is an even more foundational need – for youth with disabilities to believe that they matter to people in their communities.

This research looked at the responses to the survey question, “Do you agree or disagree that in your community you feel like you matter to people? (Maine Integrated Youth Health Survey, 2017). This question was selected as it brings the direct voice of youth - speaking on the subject of natural supports available in the transition to adulthood - into this research. The responses to this question by youth who either self-reported as having a disability or “being limited in any activity because of a disability or long-term health problem including physical health, emotional, or learning problems expected to last 6 months or more” were compared with the responses of youth who did not self-report disability or long-term health problem. The findings are shown in Figure 4.1. Student responses on the question of do they feel like they matter to people in their community were markedly different for youth with and without disabilities. Less than half (49.39%) of youth who reported having a disability indicated that they felt they mattered to people in their communities compared to over two-thirds (67.22 %) of youth without a disability. This number crept up only slightly to 50.89% for youth who indicated that they were limited in an activity because of disability or long-term health problem and compared to over 63% of youth who did not identify as having a limitation due to disability or long-term health issue.

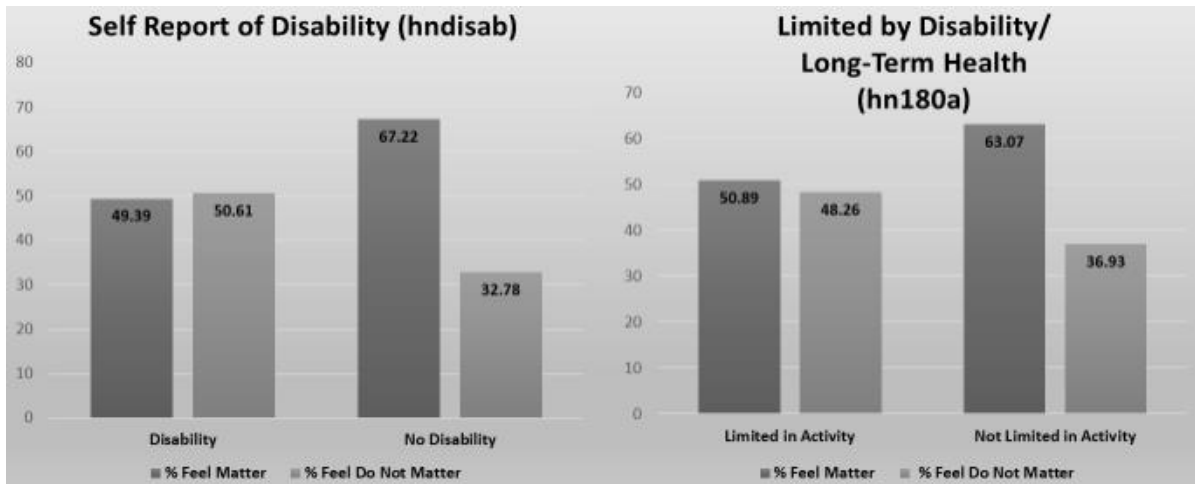


Figure 4.1. Students who feel like they matter to people in their community.

This data reinforces that young people with disabilities do not perceive that they are valued members of their community. Whether correct or not, this belief is a barrier to identification of natural supports for inclusion in the transition planning process. Youth who do not believe that community cares about them are unlikely to identify community members as natural supports and resources.

Finding 3.2. Parents more likely to come to IEP table when good rapport with educators exists. Parents are a first natural support for a student with a disability and special education law is clear that the parent is a required member of the IEP committee (Assistance to States for the Education of Children with Disabilities, 2018, section 300.321) and yet, a parent’s regular attendance at IEP meetings is not an element that is monitored during the state-level special education review of school districts (Maine Department of Education, n.d.b). Educators and parents who expressed the ability to partner together to promote transition planning each identified a strategy that helped to make those partnerships possible. One strategy was starting early to build the relationship between the special educators and the

parents. One teacher noted that her school had good attendance at IEP meetings by parents and students because the high school special education team goes to the middle school to meet with the students and parents during eighth grade IEP meetings and builds rapport with them before they arrive on the high school campus. Commenting on beginning the transition connection before high school, another educator said, “We attend the transition meeting in eighth grade, those eighth-grade teachers don’t know what a transition plan is, so we go” (E1). An educator with a long history in her district found it important to start those relationships even earlier. She explained,

I get connections with them even when they’re in elementary schools. ... I try really hard to get to know the parents, and prior to that, so that by the time they get here for the high school, it’s not so scary, and I know exactly kind of what I’m getting. But they also have a sense of who I am, and they understand what the program is, and things like that. So, I worked really hard. I mean, I can only do that because I’ve been there forever... That has helped over the years building that rapport (E9).

Another educator, who also embraced starting early, reported that she begins to think about a student’s transition to adulthood, as soon as she meets a child entering Kindergarten in her district. She reflected, “I’m looking at the parents and saying, ‘we’re going to plan for your child to be here for 20 years’” (E7). That same educator linked the early partnership with parents to transition involvement at the high school level. She explained,

We rarely have any difficulty getting parents to come to the table. They not only come to IEP meetings, they call IEP meetings. We invite our students no matter what their handicap is. Sometimes we interview them ahead of time and present their

questions or talk about what they're interested in... But parents are always interested, always involved (E7).

Educators who were successful in partnering with parents were both intentional about their actions and found ways to build rapport that often extended beyond the high school doors.

Parents and the IEP meeting. In every interview, parents and educators spoke about the importance of parent involvement in the IEP meeting in order to support transition planning. One educator with 50% parent involvement in IEP meetings described personally driving out to pick parents up at their homes. Many teachers used parent participation in the IEP meeting as an indicator of their connection with the families of their students. One educator said,

We have 100% parent participation really for parents as far as the high school kids. If they're not in attendance...then we meet with them one day before it. We don't have a line outside of our door at parent conferences (non-IEP) because we have more communication with parents than (anyone at the school) (E4).

Interestingly, even when parents were not satisfied with the transition planning process or outcomes, they often expressed a positive regard for the school and specific teachers who they believed had gone above and beyond to establish early and strong rapport with them. One mother who felt that the focus of the IEP meetings "was sort of like we were going to talk about what was going on in the school ... not what happened after" and that teachers "didn't necessarily know" about transition services, still said about her son, "He was beloved at [] High School, I'll tell you that...We're still in touch with his teachers. He still gets invited back into his life skills class" (P8). Another parent, who saw much of her son's

planned transition services face barriers following his graduation, reported that she felt that she had had good input into the IEP transition planning process and IEP meetings. She explained,

I led the IEP meetings basically. I went in with my agenda all typed up and wants and needs and things that I thought he was excelling in, and you know, perhaps programs that he needed more than others, and they were very respectful, and we had very productive IEP meetings (P4).

Describing school for his daughter as “putting the square peg in a round hole”, a father detailed his disappointment in the transition planning process for her, but noted,

We’d have transition meetings...and I’m not trying to throw sticks and stones at the school... The school was very supportive, but they weren’t sure where to go... They were grasping at straws. What do we do with her? (P7).

Another mother (P3) noted that one special educator particularly, was “super, super knowledgeable, she invested a lot in keeping up with evidence-based therapies, and she was a godsend.”

Teachers also saw the importance of building rapport with parents - particularly so they would have better participation in the IEP meetings. One teacher (E7) stated,

When I talk about parent involvement, if a parent says, I can only meet you at 7:00 in the morning, we’re all like, okay, we’ll be there. If a parent says, I can’t make it until 4:00 on Friday afternoon before a long weekend, we’ll say ok. So it is not unusual to be in this district on Friday afternoon before a long weekend and have an IEP meeting that’s not going to get out until 5:30 or 6:00, and people will stay. Parents will come.

They'll find out we're not all that threatening. We're not that frightening. We're concerned about their students, and then it just improves over time.

Many teachers noted that they stay in touch with families for years after students exit their school programs and others mentioned that they build rapport by connecting with students and families well before the student enters their classroom.

Finding 3.3. Community experiences inform transition goals.

Community as natural supports in transition planning. Very few parents or educators described consistent efforts to include natural supports from the community in transition planning and services. But those who did often identified these community connections as the most helpful resources in transition planning. One educator found that the small size of her rural community helped to support these natural supports. She explained,

Our community is small, and one of the benefits is that I grew up and also worked in the community. I know community partners so when I looked for internships for students, as a high school teacher, I was able to go on the personal and professional level. (P10)

Another educator worked in his school to develop a co-op program to build opportunities for real world experience for students with disabilities as they prepare for postsecondary education and employment. He explained,

As far as community connections, you know, we tried to connect kids to work down here. We have been trying to increase our work co-op opportunities for students this year. We have more than ever. They actually took the whole fall and had a legitimate viable work thing where they had to create a portfolio. They were scalloping,

lobstering. They had to keep logs, and there was a financial piece. There was a banking piece. There was an accountability piece where they had to come in and work on resumes... It's all about finding their real interest (E4).

According to the teacher, the co-op experience naturally informed postsecondary goals on the IEP and helped students to be more realistic in their plans. He recounted,

A lot of our kids want to go into fishing. They don't understand like the cost of fuel or the cost of maintenance and repairs and paying your crew and at the end of the day how much money do you really have? Those are things that they don't really understand. That's a great piece that has been built into this co-op (P4).

One experienced rural educator recalled a time when education placed more emphasis on inclusion of community in transition planning.

There was a thing with the State Department of Education, and it must have been in 1980 or 81, something like that. It was community-based learning, and it was a workshop kind of thing. Three- or four-day workshop. Basically community-based learning at that time was a nationalized certified program that allowed us to work with the community without the community getting in trouble with the Department of Labor. I was doing the vocational evaluations (E6).

This teacher went out and met businesses and got to know their needs as part of the certification. He described that although the program changed over time, he continued to build on those community connections. "We went to Kiwanis the first time and talked to them, and they said, sure this sounds good to us. You know, they were all willing to do it... I think I only got turned down twice from the businesses." Later he realized, "that the best

thing that I could do is just focus on what are you going to do after high school and see if you can put some supports in place for that. This educator noted that “these experiences” were finding their way “loosely” into transition plans. She added that this was because the point of the activities was not to force a student onto a particular career track but rather to expose them to the world of work in the community. Speaking about one recent graduate she said, “I think the work experience has helped her gain the confidence that she needs to pursue (college)” (E8).

Supports in the community can also help young people with disabilities find out if the academic or vocational path that they are on is the right one. An educator explained that many students want to be veterinarians but they do not understand the number of years of schooling that is required. They have often benefited from forming relationships by volunteering at the local animal shelter where they can learn about a broader range of careers involving animals. Other educators spoke about co-op opportunities in distinctly Maine occupations like commercial fishing, scalloping, and lobstering that led to richer transition plans while making lifelong connections for students in the community.

A special educator in one of the most rural school districts was looking ahead to building stronger relationships with the community through a post-graduate program. She said,

I’m new so I’m just kind of developing this but I’m actually looking at taking what we call ‘job skills’ in the classroom but getting them out there to experience it. I want to make it more of an experiential learning opportunity and allow for community

integration. Our plan for next year is once a month, I'm taking students to visit area businesses (E2).

This teacher had already seen the value of getting students out in the community after a visit to a discount and salvage store.

You don't realize sometimes how little opportunities these kids get because the boys that went came back flying into the school. They were so excited to go to (the store), and the people there took them on a tour, and they explained things, and they showed them all around (E2).

In one district, one way that the community supported special education transition planning was by looking beyond a special education label. An educator explained,

The community partners will accept not just special education students; it's for all students. I think that's really important that the community is so supportive for all students. It's not really - we have special ed services and kids that learn in a different way - but it's not viewed as they have to go to special education. We have a lot of inclusion (E10).

One educator noted that there are specific advantages to being in a rural community when it comes to community connections, particularly with employers. She explained,

I think that's one of the advantages of rural areas, there's a whole bunch more spaghetti suppers for people that have had an accident or lost their job or whatever, disease or illness, and I think that's the same thing that I see. If there's something that you can do for a kid and you can explain it...and you got the opportunity here to help this student, it's a no-brainer (E6).

Some educators also expressed that they saw transition planning that was tied to the real world as the key purpose of education. One stated, “[There’s no real sense in learning math and English if you’re not going to apply it, and the best way to apply it is through employment” (E6). Another described his process of starting with the student’s goal and transition plan and building the rest of the IEP around them. He explained, “They are the driving force of our IEPs... We see a lot of kids, especially here, that want to go in to commercial fishing so we write transition goals for them that are embedded in the community and embedded in co-op” (E4). Another teacher put it like this: “You can’t have a transition experience unless you really have an experience you’ve got to do” (E6).

RQ4. What Barriers Exist to Inclusion of Natural Supports in Transition Planning Under the *Individuals with Disabilities Education Act (IDEA)*?

Finding 4.1. Special education law and practice fail to promote natural support inclusion. Throughout the interviews with educators, very little mention was made of the constellation of individuals who make up the IEP team. Educators spoke of openness to have parents invite others including natural supports but did not regularly express concerns when supports were not there. Some educators pointed to a federal guidance letter from the Office of Special Education Programs that clarified that parental consent was needed before inviting outside parties to attend IEP meetings as the reason why they did not issue additional invitations (Knudsen, 2008). Parents and educators defaulted to looking for paid supports or accepted that no support was available

In order to meet federal special education mandates under IDEA, the Maine Department of Education annually monitors and reports on Local Education Agency (or

LEA) performance (Maine Department of Education, n.d.a) through deployment in the field of a specially trained monitoring unit. The most recently published (federal fiscal year 2017) *Local Education Agency Determination Letters* were reviewed for the sixteen school districts represented by educators and parents interviewed in this study. The Determination Letters reflect compliance in four categories: (1) State Performance Plan (SPP) Compliance Indicators, (2) Timely and Accurate Data Reporting, (3) Adherence to IDEA Regulatory Provisions, and (4) Fiscal Monitoring. Not all data points are reported on each variable, only those which are mandated for that particular school's performance according to the school monitoring schedule. The category "State Performance Plan Compliance Indicators" includes Indicator 13, which monitors the "Percent of youth in 9th grade and above or age 16 and above with an IEP that includes appropriate transition services and goals". School and state compliance with Indicator 13, as introduced earlier in this study, is a key reflection of appropriate transition planning. At the bottom of each letter is a notation whether the school meets requirements or needs improvement across all four areas. An example of a Determination Letter may be found in Appendix B.

Of the 16 school districts whose reports were reviewed to support triangulation of this research paper's findings, 12 were listed as "Meets Requirements". Three schools were reported as "Needs Assistance". One school, due to small size, had no report. Of the 16 school districts, five were required to report on the federally required target of 100% compliance on Indicator 13. Of these five schools, four reported 100% compliance and one reported 80% compliance. The school that reported 80% compliance was found to "Needs Assistance". These Determination Letters highlight that in most cases schools report meeting

the requirements of IDEA, however, quality of transition planning beyond minimum compliance levels is not assessed (Maine Department of Education, n.d.a).

Maine schools are supported in their efforts to prepare for special education monitoring through the use of a published *Special Education Required Forms Procedural Manual* (Maine Department of Education, 2019). Section 10 addresses the Post-Secondary Transition Plan and provides direction to the school district on completion of this part of the IEP through guidance such as “Use formal and informal methods of gathering data related to the child’s interests, preferences, aptitudes and abilities as they relate to and align with the skills needed for the child’s given interest area” (Maine Department of Education, 2019, p. 37). Inclusion of the child’s voice and interests are strongly supported throughout this section and guidance for completion of *Section F. Transition Services and Activities*, lists many community examples that schools may wish to consider (exploring internships, community-based work experiences, banking, shopping, recreation activities) to help build on these interests.

On the issue of inviting outside agencies to participate in IEP meetings, a critical component of transition planning, the guide provides interesting guidance under *Section G. Agencies Responsible to Provide or Pay for Services*. Here schools are offered two directives – one if they determine that outside agency services are necessary and another if they determine that outside agencies are not needed to participate in the IEP meeting. This would appear to be in conflict with an earlier statement in the *Procedural Manual* that confirms that it is the IEP team (not the school alone) that identifies if outside agencies are needed (Maine Department of Education, 2019, p. 41). This is important because the language switch

effectively puts the school at the center of the decision-making process on outside agency involvement instead of the more comprehensive IEP Team, which includes the parents and the student (Maine Department of Education, 2019, p. 41). If monitoring is only looking at whether schools invited outside agencies, then there is no opportunity to check for – and promote and reinforce – the ability of parents to also invite individuals to participate in the IEP transition meetings.

IDEA is clear that parents and educators can invite “at their discretion” other individuals with special knowledge about the child or expertise to join the IEP team meeting (Assistance to States for the Education of Children with Disabilities, 2018, section 300.321). A review of Maine’s current monitoring special education monitoring manual, revealed no mention of natural supports (Maine Department of Education, 2019).

Likewise, models such as the Taxonomy for Transition Planning 2.0, which are considered to reflect best practice in transition planning, are largely silent on natural supports and so are unable to reinforce how or why they should be included to support transition planning (Kohler, Gothberg, Fowler, & Coyle, 2016). The Taxonomy focuses instead, on promoting interagency collaboration and the inclusion of paid supports in the transition planning process (p. 7).

Finding 4.2. Parents and youth are unaware of the role that natural supports could play. Even when a strong natural support like a sibling was present, parents did not naturally see a role for the sibling in the IEP meeting. During the interviews, one parent described how a sibling had helped her brother with a disability to be more included in the school, but when asked about whether this same sister attended her brother’s IEP meeting,

the parent answered that she did not and then turned to the researcher to ask why the sister would be included. This illustrated the limited connection between the presence of a natural support and her inclusion in the student's IEP meeting for transition planning.

Youth perception of the role of natural supports. One of the questions posed to students by the Maine Integrated Youth Health Survey was “I have support from adults other than my parents” (Maine Integrated Youth Health Survey, 2017). This question was selected as it brings the direct voice of youth - speaking on the subject of natural supports available in the transition to adulthood - into this research. The responses to this question by youth who either self-reported as having a disability or “being limited in any activity because of a disability or long-term health problem including physical health, emotional, or learning problems expected to last 6 months or more” were compared with the responses of youth who did not self-report disability or long-term health problem. The findings are shown in Figure 4.2. On this question of adult supports, just over half (56.65%) of youth with disabilities reported having an adult other than a parent that they turn to for assistance. This compared to over 70% of youth without a disability who indicated they had support from adults other than their parents. When looked at through the lens of youth who reported a limitation in an activity because of disability or long-term health problem, these numbers got even worse with only 51.74% indicating that they had support of an adult outside of a parent compared to nearly 68% who did not identify as having a limitation in activity due to disability or long-term health issue. Overall, this data indicates that youth with disabilities do not perceive having access to adult supports, something that would have significant implications for development of natural supports.

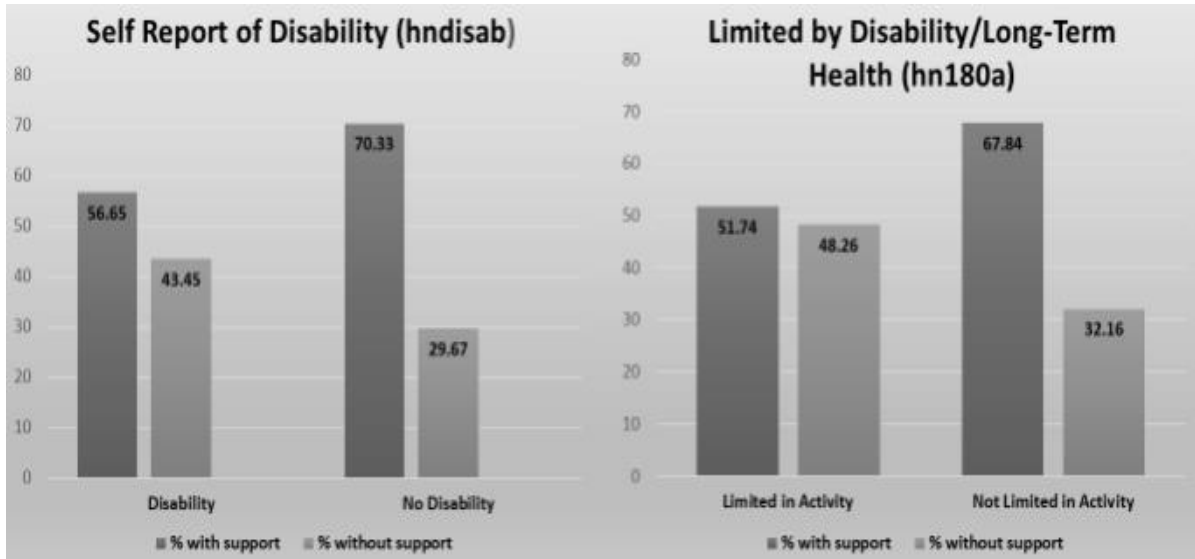


Figure 4.2. Students who have support from adults other than parents.

This finding was further supported by the data generated at the initial convening of the Youth Advisory Group (2019). As seen in Figure 4.3.

Transition Topics	Youth Group Operations	Goals
<ul style="list-style-type: none"> • Vocational Rehabilitation • Independent Living • Transition process • Visible/invisible disabilities • Understanding available resources • Rights and responsibilities • HIPAA • Disability self-disclosure 	<ul style="list-style-type: none"> • Youth-led • Meet monthly • Meet via video-conferencing • Day-long meetings • Less presentation, more discussion/sharing • Collaborate with youth groups from other states • Create a social media group to stay connected 	<ul style="list-style-type: none"> • Create a game to learn about disabilities • Share transition stories • Be a youth voice • Break down silos • Communicate with legislators • Mentor other youth heading into high school • Get educated on transition resources

Figure 4.3. Youth advisory group – Report out on initial convening.

The Youth Advisory Group generated a list of topics about which they either wanted more information or further discussion. Not surprisingly, these focused primarily on aspects of the transition process to adulthood and included: (1) Vocational rehabilitation; (2)

Independent living; (3) Disability self-disclosure; and (4) HIPAA - the Health Insurance Portability and Accountability Act. The youth also wanted to gain an understanding of (5) Available resources, and (6) Their rights and responsibilities as they reach adulthood. Additionally, the group identified a need to gain more knowledge about disability and disabling conditions - some of which are more apparent than others (Youth Advisory Group, 2019). While “available resources” could include natural supports, the lack of identification of anything specific to natural supports is further indication that youth are not aware of the role that natural supports could play in transition planning.

Evident in the responses from the youth is a clear desire to continue to meet as a group on a regular basis - as often as monthly for a full day. They also discussed meeting remotely via video-conferencing. Meeting minutes reflect that many young people exchanged contact information at the day’s conclusion. This strong desire to stay connected also was expressed through a wish to have a social media group where the young people could continue to talk to each other between meetings. The youth also stated that they wanted the group to be youth-led with a format that allowed more time for talking together in lieu of formal presentations which indicates that they are interested and looking for ways to build supportive networks.

Despite diverse membership and only meeting that one day, the youth were able to set some clear goals and desired outcomes for the group’s work. Some of these goals were focused on assisting others to be successful in transition: (1) Sharing our stories of transition and, (2) Mentor other youth heading into high school. Others were focused on raising youth voice for policy change: (3) Be a youth voice, (4) Break down silos, and (5) Meet with

legislators and write letters to political leaders. The third category of goals focused on educating themselves and increasing their own knowledge of disability: (6) Create a game to learn about different disabilities, and (7) Get educated on transition resources/process (Youth Advisory Group, 2019). These goals show a strong interest in gaining more knowledge about transition resources so that they can both advocate for needed changes and help to smooth the path for those younger youth who are following behind them.

The results of the Maine Integrated Youth Health Survey reveal a significant discrepancy in how youth with disabilities feel valued in their communities when compared to their peers without disabilities. Additionally, their responses indicate that they have far fewer adult supports in their lives than non-disabled peers. The Youth Advisory Group, although newly-formed, represents the concerns of a diverse group of youth and young adults with disabilities in Maine. Through examination of documents generated at their initial convening, such as minutes and flipcharts, these findings highlight that transition and related issues are the main concerns of these youth. These include: (1) sharing stories of transition; (2) learning about transition resources and (3) advocating for their adult needs among others. These findings also demonstrate that these young adults are interested in serving as natural supports to other youth through peer mentoring. Additionally, they reveal a need for a deeper dive into youth experiences through additional study, which is addressed in Chapter 5.

Finding 4.3. Natural supports are missing from pre-service and in-service training for educators. During the interviews, some educators highlighted their efforts to create connections between parents to build support for parents and families but only one educator (who developed a parent support group) linked the rationale for building parent

relationships to transition planning. If consideration of natural supports was missing from educator's regular transition practices, this should not be surprising because it was also found to be missing at both the preservice and in-service levels.

Williams-Diehm, Rowe, Johnson, and Guilmeus (2018) conducted an analysis of transition coursework required for special education licensure and found that while the Taxonomy for Transition Planning 2.0 was occasionally included "family preparation was not addressed in learning outcomes for any syllabi" (p. 21). This is important as family preparation is one location where natural supports would expect to be found (p. 20). This confirms that special educators are not being exposed to the value of including natural supports in transition planning during their education and training as special educators.

The Council on Exceptional Children's Division on Career Development and Transition is a national leader in the field of transition. The Council on Exceptional Children (2013) has established Advanced Special Education Transition Specialist Standards. Natural Supports only appears once in Standards and that is under needed skills related to transition assessments, "Apply transition assessment results to develop natural support systems in post school settings" (Council on Exceptional Children, 2013, p. 1). Even this limited mention of natural supports has little opportunity to influence teacher preparation as Williams-Diehm et al. (2018) found that the Standards only appeared in 21% of the transition coursework syllabi they reviewed (p. 20).

A review of current Maine Department of Education special education initiatives on the Department's website does not reveal any that are focused on transition. This means that rural Maine educators interested in learning more about transition for students with

disabilities – and specifically the use of natural supports in transition planning - must find training through other avenues. Natural supports are a demonstrated best practice to assist individuals with disabilities (Duggan & Linehan, 2013) and yet in both in pre-service preparation and in-service professional development, there is little training for educators to help reinforce their use.

Conclusion

In this chapter, through an examination of a wide-range of data sources from school level IDEA monitoring findings to the documented voices of youth with disabilities to interviews with the gatekeepers to the IEP table: parents and educators, 17 findings were developed that provide a response to this study’s research questions. In doing so, the findings highlight the complex factors that influence transition planning for students with disabilities in rural Maine. Geographic isolation and lack of resources exist but so too do creative solutions that showcase the spirit of “Yankee Ingenuity”.

Youth and young adults who participated in the Youth Advisory Group identified many areas where they wanted a voice including as mentors to students coming up behind them. Youth group members also expressed a desire to better understand disability and the transition process and transition-related resources. Youth group members expressed an eagerness to connect with each other to form a network. In the Maine Integrated Youth Health Survey, youth with disabilities reported feeling significantly less included in their communities and lacking in adult supports when compared to their non-disabled peers. These youth responses highlighted both a desire to help other young people with disabilities and a perception that they themselves were lacking those same supports.

Parents and educators identified significant barriers to transition planning that ranged from lack of access due to geography to parents' and educators' lack of knowledge of transition resources. Natural supports, were identified as present and supporting positive transition outcomes in some situations. Parents, siblings, neighbors, friends and community members were among the natural supports identified and often the type of support that they provided reflected the rural spirit of "Yankee ingenuity". Interestingly, educators also were identified as natural supports when they stepped outside of their school-based roles to support students and families. Parents and educators also identified that sometimes paid supports were used to create a bridge to natural supports.

Despite the presence of natural supports for some students, parents and educators reported only very limited presence of natural supports in the IEP meeting. The lack of inclusion of natural supports in school-based transition planning appeared to be related to both a lack of understanding of the potential role that natural supports could play in supporting transition planning as well the lack of a clear directive to schools – as operationalized through state and federal monitoring - to mandate inclusion of natural supports. Natural supports were found to not just be missing in transition practices but also from teacher preparation curricula and in current professional development opportunities – both of which revealed a gap in training for educators supporting youth in transition planning.

In the following chapter, these findings are analyzed in light of past research. Recommendations for policy and practice changes and future research are also presented.

CHAPTER 5

DISCUSSION

Introduction

Planning for post-secondary life is a required element of special education services for identified students - nationally by age 16 - and by Maine law during the student's ninth grade year. This mandate has been established to ensure that students with disabilities, who will likely face more barriers than their peers without disabilities, are intentionally the focus of individualized efforts to prepare them for adulthood - specifically, post-secondary education, employment and independent living (Blackmon et al., 2015). Young people living in rural areas, however, are challenged by lack of access to the key supports and services that have traditionally been part of best practices in transition planning. Lack of access to transportation, poverty, and lower expectations have all been identified as negatively impacting implementation of positive transitions for rural youth (Test & Fowler, 2018). Understanding the barriers and unmet needs that exist helps to identify gaps in services that natural supports could help bridge.

Natural supports, such as those provided by a neighbor, community member, or employer, have been shown to be effective in promoting success with people with disabilities (Duggan & Linehan, 2013). The use of natural supports in transition planning as an alternate or supplement to paid services has only been studied in a limited way - particularly so in

rural areas. This study aimed to better understand the barriers to transition planning for students in rural Maine as well as to understand the use of natural supports in transition planning in rural Maine today through examination and analysis of data from (1) laws and regulations, including federal and state laws and regulations; (2) documents and artifacts (including federal and state reports), (3) documentation of youth voice and (4) interviews with parents and educators.

In this study, the responses of students with disabilities to questions about natural supports on the 2017 Maine Integrated Youth Health Survey demonstrate that an extremely high percentage of these high schoolers perceive that they have no adult support available to them beyond a parent. This would seem to confirm that the lack of inclusion of natural supports in transition planning is not just a function of gatekeepers failing to include them but also of the actual lack of individuals in the lives of these students who are viewed as supportive to them and who might be invited to an IEP meeting.

Findings presented in the previous chapter help to answer the first four of five research questions posed in this study. These findings are further discussed in this chapter along with analysis of how those findings confirm, add to or diverge from what is currently known in the field. In keeping with the study's transdisciplinary approach, recommendations for policy change and future study conclude the chapter.

Responses to Research Questions

This study was developed through a transdisciplinary lens with a specific focus on exploring the varied viewpoints of multiple stakeholders, set against knowledge and best practices from multiple disciplines, for promoting successful transitions for youth with

disabilities. The study used a qualitative research design that was heavily influenced by phenomenological inquiry - which allowed for the meaning of the phenomenon of transition planning for students with disabilities to be discerned. The study's aim was to answer the following research questions:

1. What barriers exist to transition planning for students with disabilities in rural Maine today?
2. In what ways have natural supports contributed to positive postsecondary education and employment outcomes of young people with disabilities living in rural Maine?
3. To what extent are natural supports included in transition planning by IEP teams in Maine Public Schools?
4. What barriers exist to inclusion of natural supports in transition planning under the *Individuals with Disabilities Education Act* (IDEA)?
5. How can stakeholders (parents, special educators, the Maine Department of Education and others) support the inclusion of natural supports in transition planning?

In Chapter 4, findings were presented to answer the first four of the study's research questions, as seen in Table 4.1. In this chapter, attention also turns to the final research question, that of "How can stakeholders (parents, special educators, the Maine Department of Education and others) support the inclusion of natural supports in transition planning?". Building on previous research in the field and the findings of this study, specific recommendations are presented to implement best practices and to develop promising practices through application of innovative approaches and future study.

Discussion of Findings

Shared Barriers

Rich data collected via interviews with parents and educators demonstrated that rural educational systems and families in Maine face many of the same challenges that Test and Fowler noted in their 2018 analysis of barriers to successful rural transitions. In that study, they identified six domains where transition services were impacted in rural communities (p. 72). These included:

- Expectations (e.g., parents' and students' lack of knowledge regarding importance of transition planning)
- Opportunities (e.g., few employers in rural areas)
- Personnel (e.g., multiple responsibilities for school personnel due to shortages)
- Services (e.g., distance to or lack of community agencies)
- Transportation (e.g., limited or no public transportation)
- Cultural (e.g., generational poverty)

Concerning expectations, this study heard many of these themes echoed during interviews with parents and educators - particularly the lack of availability of transportation and access to services. Concerns about distance from services and problems with transportation were repeated across both parent and educator interviews. Other barriers were mentioned by educators but not by parents. These included cultural and school personnel issues. While educators frequently identified material and emotional deprivations in families; the parents interviewed framed resource challenges in the context of time and energy.

Likewise, educators were attuned to the impact of staff turnover - including school leadership

turnover - but the personnel challenges that families identified tended to be those in service provider agencies. Both parents and educators, however, recognized the need for more specialized knowledge (for themselves and for the larger community) about disability and targeted transition services. Interestingly, this was also a theme that was raised by the Youth Advisory Group members as they also expressed a need to better understand the nature of disabilities and resources that might assist in transition planning.

The issue of expectations for transition was an area where there was the widest divergence. In interviews with educators, many expressed concerns that parents were not holding high expectations for their sons/daughters. This was particularly seen in discussions of post-high school living arrangements and employment. On the other hand, parents seemed to either find educators neutral or benign when it came to helping to promote high expectations - or in some cases too focused on the day to day of the classroom to be able to thoughtfully promote high expectations for adulthood and high-quality experiences.

This study's findings diverged from Test and Fowler (2018)'s study in a few key areas that will be explored in greater detail below. These included: (1) the identified lack for many youth with disabilities of perceived social connections and supports, (2) challenges for parents and educators related to feeling overwhelmed by responsibilities, and (3) the lack of systemic supports within special education itself to implement best practices in special education law.

The responses of youth with disabilities to the Maine Integrated Youth Health Survey's (2017) two questions about the presence of adult supports and feelings that they matter to people in the community revealed that youth with disabilities do not perceive

that they have adult supports other than parents. When coupled with their reported belief that they feel that they do not matter to their communities in the way that their non-disabled peers do, there is a need to learn more about why this is. At a face value level, it suggests that young people with disabilities do not have the connections to natural supports in the community that they need in order to successfully transition to adult lives as integrated members of their communities. This fundamental perception by youth with disabilities is central to feelings of self-worth and meaning and represents an area that has not been the focus of previous study for students with disabilities living in rural communities. It is also a key issue for promotion of natural supports and their inclusion in the IEP meetings. If youth do not have any connections to community members then there is no options of inviting them to the IEP meetings.

Another area where this study's findings differed from Test and Fowler's (2018) study is in understanding that both parents and educators feel deeply overwhelmed by the challenges related to the demands of their daily lives as complicated by assisting a young person with a disability to prepare for adult living. The sense of being overwhelmed can make it challenging to tap the additional emotional resources needed to deal with the large issues addressed in a student's transition – becoming an adult and making independent living decisions. Teachers spoke of facing paperwork demands while attempting to address the needs of students who were dealing with trauma, poverty and the impacts of disability. Parents described financial challenges, time commitments that precluded attending to other needs, and exhaustion from a continual fight to get needed services.

The third area where this study's findings moved beyond Test and Fowler (2018) is in identifying that there are structural elements within special education itself that present limitations to effective transition planning. In interviews, this manifested as statements by educators that they welcomed parents to bring natural supports to the table, and yet they noted that parents did not bring them. Educators referenced IDEA's "new" requirement that parents must give consent before the school invites outside parties to the IEP meeting and seemed to interpret it as releasing the school from responsibility for discussing IEP invitations to outside parties – unless they were ones that the school wanted to invite. Educators did not perceive that inclusion of individuals with a special knowledge or expertise about the youth at the IEP meeting was either a requirement or best practice. Parents, who had not experienced having natural supports at the IEP meeting, did not always understand the value of doing so. At the suggestion that a sibling or friend might attend the IEP meeting, some parents seemed perplexed – even if they had previously indicated that sibling or friend was a strong support.

This exemplifies that federal guidance (Knudsen, 2008) that was intended to promote parental rights in the IEP process, in practical application, is having the opposite result. Lacking the technical assistance and training to stakeholders that is needed, the federal guidance fails to effectively give parents the control the law intended because they are either unaware of whom to invite or why they should. State monitoring of schools' special education programs also fails to capture this issue because the monitoring tool only looks for evidence that agencies responsible for paying for transition services were invited to the IEP

meeting – not individuals whose contributions may not be monetary (Maine Department of Education, n.d.b).

Another key difference between Test and Fowler and the findings of this study involves suggested solutions to identified barriers and challenges facing the transition of students with disabilities in rural areas. Test and Fowler recommend additional emphasis on use and development of data-based decision making to lead to improved transition outcomes for students with disabilities. While not discounting that recommendation, the findings of this study would support a focus on building up the social connections and capital between both the students with disabilities and the parents of these students.

Natural Supports as Remedy

Natural supports, in their varied forms, typically involve unpaid individuals providing assistance in a setting where they would normally occur - presenting an alternative to paid supports (Wehman & Bricout, n.d., p. 216). Natural supports have the advantage of potentially being more sustainable than paid supports due to their lack of reliance on outside funding, but they also may be more useful in promoting inclusion because they are “natural” to the setting and reduce the stigma of the presence of external government-funded supports (Storey & Certo, 1996). Previous studies have shown both the negative consequences of the lack of access to natural supports for people with disabilities – social exclusion (Duggan & Linehan, 2013) and the positive results of access to natural supports – new opportunities for inclusion (Carter et al., 2010).

This study looked at how natural supports are being utilized in transition planning for rural Maine students. Whether or not natural supports are invited to the IEP meeting is a

function of whether parents and educators are aware of the value of including them. Interviews with parents and educators provided an opportunity to learn directly from them about their awareness of natural supports as well as their willingness to include them in transition planning. What this study found was that while many educators expressed that they are open to the idea of parents including natural supports in the transition planning process, they have had very little experience with it and even less with encouraging it to happen. Teachers focused most on getting parents to attend IEP meetings and used a variety of techniques to encourage or facilitate that attendance. Parents also reported little in the way of inviting natural support attendance at IEP meetings and when some supports might be available (for example, older siblings), parents seemed unsure as to the value of including them.

Educators were often more able to name natural supports from the community that had a role in the transition process but rather than encourage their direct involvement in the IEP meeting, they gathered their input to help develop the transition plan. Some educators pointed to a federal guidance letter from the Offices of Special Education Programs that clarified that parental consent was needed before inviting outside individuals to the IEP meeting, as a reason that the school did not invite outside parties to attend school meetings (Knudsen, 2008). The hurdle of the parental consent seemed to put off educators from inviting additional people to the IEP meeting as it would require obtaining the consent. They assume that parents could invite natural supports directly if they wished them to be there but did not encourage them to do so. These findings seem to confirm Test et al.'s (2014) conclusion that natural supports are “among the most promising – and elusive” in the

transition planning process, in large part because “school systems are often unaware of these natural assets” and the role that they could play to support transition. Parents also seem unaware of the benefits of natural supports who know the student well and therefore might provide useful information on potential community links.

Facilitating Natural Supports

Duggan and Linehan’s (2013) analysis of the use of natural supports found that individuals with disabilities experienced social exclusion when natural supports were not available to promote inclusion. They also found evidence, however, that given the roles that service providers were already playing with individuals with disabilities there was an opportunity/need in some situations to have natural supports intentionally facilitated through paid providers or supports, especially when they could “employ strategies to nurture social networks” (Bigby, 2008, as cited in Duggan & Linehan, 2013, p. 204). This study found that some educators did see service providers such as Vocational Rehabilitation as being a conduit to natural supports. The educators connected the student with Vocational Rehabilitation counselors in the school and then the counselors became a bridge to natural supports in the community through activities like work-based learning or college visits. Some families also identified that, due to the level of their son/daughter’s needs, paid supports were needed in order to facilitate peer relationships or community connections through providers who offered transportation, personal, or communication assistance.

This study also identified that educators also stepped out of their classroom to help as natural supports themselves. Seeing themselves as community members as well as educators, they reported undertaking activities such as accompanying parents on program visits,

providing transportation, food or personal support. Educators often opened their classrooms and services up to students after graduation as a way to continue to provide support to the student and family. While not a direct natural support to students, educators also saw that they could play a role in making connections between parents to try to reduce isolation and build supportive relationships. They described introducing classroom parents to one another and as discussed in one interview, the educator created a parent support group to specifically aid in sharing transition resources. Test et al. (2014) identified that school systems are often unaware of natural assets in the community. This study also found that schools were often unaware of resources in the community but so too were students and families. When families turned to the schools for assistance, they were frequently unable to get it. This resulted in frustration for parents and educators. Geographic isolation, financial stressors, and lack of knowledge about best practices in transition planning compound this disconnection.

Intentional Development of Natural Supports

If natural supports are lacking for youth with disabilities in rural Maine, and natural supports are a sustainable cost-effective means to promote community inclusion, then it follows that intentional actions are needed to uncover, create, and implement natural supports. This may be accomplished by a variety of means, but according to social support theory, focusing on efforts to create relationships, is an important place to start (Feeney & Collins, 2015). The Youth Advisory Group members identified a role and value for themselves as peer mentors to go into schools and work with younger students with disabilities. They envisioned a model where they could share their knowledge and lessons learned about transition from their unique position of having their own lived experience.

Peer mentoring, and mentoring more generally, provide a framework for creating relationships with the materials and resources to foster success through support, guidance, and training. Mentoring may be a more formal entrée into the use of natural supports, but as Dubois and Silverthorn (2005) found, a mentoring model that includes natural supports could have a significant impact when developed and drawn from the local community. Specifically, use of natural mentors, from the young person's own connections was correlated with higher levels of self-esteem and life satisfaction (DuBois & Silverthorn, 2005, p. 522) as well as "intrinsically rewarding careers in early adulthood" (De Wit et al., 2016, p. 70). For young people with disabilities, natural supports developed through mentoring by adults with disabilities increased their knowledge of how to overcome barriers (Britner et al., 2006). All of which underscore why development and use of natural supports have a role in improving outcomes for young people with disabilities

Another means of developing natural supports locally is through community-based experiences where youth are able to interact directly with others with and without disabilities in a setting of their own interest. Natural supports, which have been most developed in the context of work settings, promote inclusion by allowing young people with disabilities to "participate in the culture to gain social acceptance" (Hagner et al., 1992, p. 32). Schools (and providers such as Vocational Rehabilitation) that placed students in work-based learning internships and paid work experiences before high school graduation took first steps towards helping youth build those natural supports but, according to this study, failed to build on this social capital by intentionally encouraging further development through inclusion in IEP transition planning or other school events. A parent who described his daughter's coworkers

coming to her high school graduation was a rare example of interaction between a school and a student's network in the community - and even in this case the "special knowledge" of the co-workers went untapped in the development or execution of her transition plan.

This study found that both parents and educators lacked concrete knowledge of best practices or models (such as SPANS or Project 10) in effectively incorporating models to promote inclusion of natural supports in transition planning. This suggests that there is a need to increase training on and dissemination of these models, a recommendation that is discussed below in this chapter.

Cultural Sensitivity

Critical to a vision of what can be, are beliefs, often hidden, that shape the parameters of what is possible. Collectively held beliefs, resulting in stigma and prejudice, have long impacted the scope of what people with disabilities have been able to achieve (Mitra, 2006). People who may be closest to individuals with disabilities, including their families and those in the caring professions are not immune to the power of these beliefs. Goddard, Hoy, and Hoy (2004) found that collective efficacy beliefs, in the classroom, impacted student performance and outcomes. Rural communities have their own cultures that may be misunderstood or judged by individuals outside of them (Sherman, 2006).

During the course of interviews for this study, some educators raised concerns related to traditional lifestyles (such as staying local in very rural communities) and employment in traditional sectors (such as fishing). There were also judgments passed about being unemployed or receiving disability benefits, all of which would seem to confirm the presence of a rural stigma. Rural self-reliance was another area which challenged educators and

parents in accessing supports as culturally, some Maine people are reluctant to ask for help. For these reasons, natural supports drawn from the local community, who have an understanding of the local culture may be able to provide assistance in a manner that is more able to meet students where they are. The rural school district that launched a coop program that connected students with disabilities with local employers working in traditional marine occupations, was an example of how natural supports could be developed with respect for local traditional cultural values.

Limitations

This study generated findings that will add to the body of knowledge on the topic of natural supports in transition planning - but it is not without its limitations. At the outset of the study, youth interviews were planned, which would have provided an opportunity to hear directly from individual youth on the subject of natural supports in their lives and transition planning. A central tenet of the disability rights movement is “nothing about us without us” but one of the two primary limitations of the study arose due to the difficulty in recruitment of students with disabilities to participate in interviews or a focus group as parents were unwilling to consent to their participation (Callus & Camilleri Zahra, 2017). Parents wanted to shelter their child from participation – in case difficult topics would be discussed and, in some cases, due to stated beliefs that their sons and daughters would not be able to contribute meaningful information to the study based on their disability. A number of parents introduced the student to the researcher at the beginning or end of the interview but then “dismissed” them. This lack of expected access to students with disabilities proved challenging and warrants further investigation. Other methods of gathering data from a youth

perspective were sought. These methods included data from youth with disabilities who took the Maine Integrated Youth Health Survey and from records of the students and youth with disabilities who participated in the Youth Advisory Group. These other methods did provide summary data of value, but they did not allow for a neat triangulation of individual level data from the student, educator and parent perspectives. It is also possible that parents' concerns about allowing student participation was also related to the second primary limitation of the study – researcher positionality – since nearly all students with disabilities could be current or future clients of the state vocational rehabilitation agency.

Another possible limitation of this study is the positionality of the researcher. Conducting a study as a researcher while concurrently serving as the director of the general state vocational rehabilitation agency,⁶ it is possible that this impacted parents' or educators' decisions to participate in the interviews. It may also have impacted on responses to questions. Vocational rehabilitation is a key transition service for many students with disabilities in Maine and around the country. Engagement and satisfaction with the service varies, as was reflected in the findings of this study. With no direct questions about vocational rehabilitation included in the semi-structured interviews, parents and educators voluntarily chose to mention vocational rehabilitation. The recruitment notices, follow-up communications with interested parties, and the IRB consent forms for this study all gave parents and educators the opportunity to ask questions at any point before, during, or after the study. The wide range of satisfaction with vocational rehabilitation mentioned in some interviews– as well as the absence of any mention of vocational rehabilitation in others – or

⁶ Maine also has a specialized state vocational rehabilitation agency for the blind with its own director.

direct appeal to the researcher for intervention in a specific situation – support the validity of the findings. Follow up study, however, may benefit from teaming with additional researchers with different roles in the community.

An additional note - this study's interviews only included individuals who were white and English speakers - although other data sources (like the Maine Integrated Youth Health Survey) included a broader representation of youth with disabilities. Given the lack of diversity in Maine demographics (United States Census Bureau, n.d.), this lack of diversity is not surprising, however no targeted attempts were made to specifically solicit inclusion of a more diverse perspective. A future study may benefit from collection of demographic information to identify socio-economic background, language spoken at home, gender, immigration status and other variables that may impact transition planning and specifically the availability of natural supports.

Recommendations

In keeping with the principles of transdisciplinary research, it is important that recommendations are developed that are practical and sustainable and are made in a manner that respects and honors the time and candor of those who participated through development of recommendations for next steps that would be of practical use in the field of transition. What follows are two sets of recommendations, one that takes the findings of this study and uses them to as jumping off points for policy and practice changes and the other that uses the findings to suggest future research.

Recommendations for Policy and Practice Changes

Across systems there are many commonly-held transition practices that have developed over time based often on a particular practitioner's preference or understanding of best practices. These practices may have little foundation in the law or the study of best practices but they may continue on with the assumed authority of both - often as "this is how we have always done it". When there is an absence of new information to challenge these practices or when the new information would require a significant departure from current practices without adequate resources to support implementation, change in practices can be slow or non-existent. Rural areas, that are already under pressure due to limited staff and funding may find themselves lagging even further behind (United States Department of Education, 2018). The following are practice changes that are recommended for adoption based on the findings of this study. These recommendations could be implemented with the support of key leaders and allies as well as encouragement from stakeholders. They would not require statutory or regulatory changes - making them able to be implemented immediately - but the lack of immediacy for change that follows implementation of new rules and regulations, may also play out as a disincentive to timely change.

At some time in the future, the *Individuals with Disabilities Education Act* will be proposed for reauthorization, and there may be opportunities to influence the language and practices in the revised version of the law. At a minimum, there will be opportunities to offer recommendations through public comment. At that time, findings from this study may be useful in making the case for adoption of strategies and approaches that recognize the unique needs of students receiving special education in rural areas - particularly during the transition

process. More explicit directives on inclusion of natural supports and increased flexibility on the IEP transition team make up may help to pull in necessary resources to promote more effective transition planning and ultimately improved post-secondary outcomes for students with disabilities.

Gatekeepers.

Recommendation #1 – Raise expectations through joint training. During this research study, some educators and parents expressed misconceptions about post-secondary education and employment options for young people with disabilities. Many had never considered that supported college and training options existed and others were hesitant based on perceived barriers due to the young person’s disability. Some parents had hoped for college options only to have those dreams quashed. Likewise, beliefs about post-secondary employment options sometimes reflected outdated thinking or a limited understanding of the world of work. Those misconceptions included that young people and families preferred benefits over employment, segregated employment is an acceptable option, and employment opportunities for people with disabilities do not exist in rural communities. Providing opportunities for a cross-section of stakeholders to learn about best practices in transition planning through concrete examples drawn from real Maine stories of transition success in rural communities could work to increase expectations about young people’s futures.

In Maine, one current example of this type of training is “Work and Benefits Navigator training” that is jointly supported through state agencies and delivered by trained disability benefits counselors. In this training, participants learn foundational information about the Social Security Administration’s disability benefits and why receiving them does

NOT need to mean that a person is unable to work. Developing a shared language and understanding of what is possible for young people with disabilities could lead to reduction in the myths about people with disabilities and work.

Other joint training could focus on the value of natural supports to the transition planning process. This type of training could be helpful in bringing teachers and parents together to think about local resources and community members in a new way as supports to improve outcomes for students who are part of the community. Since these community members may also be parents themselves, employers, and leaders, they are also able to carry the message of change beyond the scope of the training. Sponsorship of joint training by the local school, community action agency, Chamber of Commerce, or parent training organization can help to convey that the training is of value to the entire community.

The findings of this study made clear that some educators hold beliefs about families that are living in poverty and who receive social services - particularly Social Security disability payments. If families are viewed as impediments to transition planning by educators, it is almost impossible to achieve the promise of IDEA, since the law expects that parents and schools will both be engaged partners in the process of transition planning process. While not specific to youth or disability, a transdisciplinary-focused approach like *Bridges Out of Poverty* could be an example of a useful organizing framework (Payne, DeVol, & Smith, 2006) for cross-stakeholder training. The *Bridges* curriculum is intended to work at a variety of levels from the individual to the systemic and helps to both increase understanding of the many - often unseen - ways that poverty impacts the decisions and opportunities available to people in poverty. A new language to understand poverty and a

clearer vision of these challenges could help to reduce the judgments that educators may make about families - while also helping to bring in individuals living in poverty to the systems change process (Payne et al., 2006). Tried and tested strategies to make environmental changes that lift individuals out of poverty could also have widespread impact in a rural state where the poorest counties also are the ones with the highest rate of disability among their residents.

Recommendation #2 – Connect parents to build natural support networks. In interview after interview, parents expressed their disconnection from other parents and other resources that could assist them. They often expressed being overwhelmed and did not have the time or energy to go out to organized events. This should not, however, mean that parents are unable to be connected as resources to each other through other means. Relying on local parents who have been through the transition process - or individuals with disabilities who have - to serve as informal navigators could pass on and increase local knowledge. One educator interviewed stated that she had launched a parent support group in her school by accessing a parent whose child had recently graduated. Another mother indicated that things began to turn around for her when another local parent of children with disabilities came to her home to help her learn more effective strategies to work with her children. Another mother talked about the value of connecting with parents via social media. Parents living in rural areas need to have access to parent supports through a variety of modalities.

Schools can be a powerful force in linking parents but often do not do so because of concern about confidentiality. Routinely asking parents during special education team meetings if they are interested in being connected to other parents could allow for parents to

easily opt in to offer or receive parent networking information. In communities where the Parent Training and Information Center has a presence, they could also assist the school in performing this role. An example from South Carolina is “Education Partners”. These “Partners” are individuals who are “experienced parents” and are available to assist parents of young people with disabilities up to age 26. They can provide support in-person or remotely through technology to address issues such as: “(1) Information and training to help parents understand their rights and responsibilities in special education, (2) Information and training to help parents and those with disabilities to develop self-advocacy skills, and (3) Problem-solving techniques to facilitate the collaboration and success of school meetings (IEP, IFSPs, 504) to best identify needed support and services for the student” (Family Connection South Carolina, n.d., para. 7-11). The service is provided under the coordination of the state’s parent information and training center - a federally-funded grant in place in every state.

Recommendation #3 – Move beyond compliance in IDEA transition planning. State level monitoring of schools has focused on ensuring that they meet compliance on State Performance Plan Indicator 13. A review of the State Determination letters found that most of the districts that were represented through interviews in this study with parents and educators were compliant with IDEA, however, the lived experiences of the parents and educators interviewed did not always reflect that same compliance. A recommendation for moving beyond compliance would include adoption of quality indicators of transition planning from established best practices in transition planning along with a focus on inclusion of natural supports. The *Taxonomy for Transition Planning 2.0* is one example of

such a framework. Strategies in the *Taxonomy* support success in (1) Student Development, (2) Student-Focused Planning, (3) Family Engagement, (4) Program Structures and (5) Interagency Collaboration. Examples from Student-focused planning include “Cultural and linguistic considerations embedded throughout the planning process” and “Planning decisions are driven by students and their families” (Kohler, Gothberg, Fowler, & Coyle, 2016, p. 4).

Trach and Mayhall’s (1997) SPANS (Systemic Plan for Achieving Natural Supports) model outlines six steps/elements for promoting effective use of natural supports. These include (1) Consumer-driven planning, (2) Ecological assessment of individual needs, (3) Environmental assessment of natural supports, (4) Identification of natural supports in multiple environments, (5) Matching natural supports to individual needs, and (6) Development of individual natural supports plans (Trach & Mayhall, 1997, p. 47). Pairing the *Taxonomy* with the six natural supports elements from the SPANS would create a comprehensive transition planning system to support development, implementation, and evaluation of high quality practices that included natural supports.

These quality indicators could be available on the Maine Department of Education’s website along with exemplars. Additionally, professional development opportunities that supported adoption and implementation could be facilitated by the Department and made available statewide through in-person and distance training options.

Development of a template for inviting natural supports to IEP meetings would also encourage their inclusion. This template could be included in both the Maine Department of Education’s Special Education Required Forms Procedural Manual and available through the

Parent Training and Information Center. Maine Department of Education's special education monitoring could also document use of best practices and publicly recognize those school districts as leaders in the state.

Student development.

Recommendation #1 – Prepare students for active participation in IEP meetings.

While IDEA requires students to be invited to their IEP meetings, there is no requirement that they attend - and in fact regulations anticipate their non-attendance by offering alternate means for them to offer their input into the transition planning process. Best practices identified by Kohler, Gothberg, and Fowler (2016) highlight the importance of youth voice in transition planning. In order to see student participation and leadership at IEP meetings increase, however, it is also important to prepare students with disabilities to take on a more active role. This can be done through pre-teaching and preparation that begins in the early grades and continues through high school graduation. Curriculum materials that help build these self-determination and leadership skills are available but as this study showed, one of the key components is the expectation from teachers, parents and students - that students will participate in and even lead their IEP meetings. Opportunities to practice self-determination, may mean allowing more latitude in length and pacing of IEP meetings. In the high school years, schools can partner with state vocational rehabilitation programs in many instances to teach and practice these (Pre-Employment Transition Skills) skills as they will also be key to success in post-secondary education and employment.

Recommendation #2 – Intentionally increase students' community connections. In the 2017 Maine Integrated Youth Health Survey, youth with disabilities reported feeling less

connected and important within their communities compared to their fellow students without disabilities. Many factors likely influence the reasons for this at an individual level but stigma, geographic isolation and lack of community inclusion may be understood to play a role. Youth who participated in Maine’s newly-formed Youth Advisory Group also identified the need for more opportunities for connections and peer mentoring between students with disabilities and their near peers. To develop more natural supports and promote community inclusion, there needs to be intentional efforts to build relationships and connections.

Youth mentoring may be one such model to promote networking. The Youth Advisory Group’s suggestion of peer mentoring to build self-advocacy and self-determination is an idea that could be piloted in a couple school districts with support from the cross-agency council for transition that has sponsored it. This group includes the Maine Department of Education and the federally-funded Parent Training and Information Center. Another model of mentoring to promote natural supports may be one that focuses on individuals with disabilities as natural supports in an employment setting. Using best practices in youth mentoring, this researcher has developed a possible model for delivery of employment-focused mentoring for youth with disabilities in Maine. A brief overview of that model, called #aJob4Mentor⁷ follows below.

#aJob4Mentor. As developed and envisioned by this author, #ajob4Mentor Coalition is a proposed collaboration of state agencies (Health and Human Services – Office of Child and Family Services, Education, and Labor), community organizations, employers,

⁷ #ajob4Mentor includes a play on the initials for Maine, “ME” and represents the initiative’s focus on work and mentorship. Follow #ajob4Mentor on Twitter now at @ajob4Mentor

individuals with disabilities and interested others who understand that youth with disabilities need to have the opportunities for work-based learning that are typically available to teenagers through volunteering in their communities and working summer jobs. Missing out on early employment can have significant implications for later employment. Following the great recession of 2008, researchers found that youth who were edged out of the employment market by more experienced adults had continued difficulty to “catch-up” in the workforce post-recession (Fernandes-Alcantara, 2012, p. 25). The #ajob4MENTor Coalition would ensure that this is not the fate for youth with disabilities who may otherwise miss out on youth employment opportunities. The Coalition would also provide education and resources to fight the stigma that youth with disabilities often experience trying to enter the workforce.

#ajob4MENTor Coalition instead would build on the best practices in mentoring today, and research on the needs of youth with disabilities. #ajob4MENTor could become an affiliate of MENTOR – The National Mentoring Partnership, which would provide it access to mentoring materials and resources that will support with the delivery of a unique vocational mentoring model. #ajob4MENTor will target, recruit and train three groups of mentors including (1) individuals with disabilities who are employed, (2) local employers, and (3) “natural” mentors – teachers, community members and other adults who are important to the youth. These mentors will commit to serve as a vocational mentor for a youth for 12 months (a timeframe that has been demonstrated to be needed to allow relationships to form and growth to occur). During the course of the year, the mentor will develop an encouraging and supportive relationship with the youth while assisting in the development of work readiness (“soft”) skills through real-time feedback while the youth is engaged in work-based learning

(job shadows, tours, mock interviews etc.) and paid work in the community. Training for mentors will be culturally competent and will include modules on disability disclosure, accommodations and confidentiality.

To support improvement of employment outcomes in this project, #ajob4MEntor would seek out mentors who may never have thought of themselves as mentors - individuals with disabilities who are employed in the career field of interest to the youth, employers who are interested in promoting youth employment, and “natural mentors” – individuals who already play a role in the youth’s life but who could take on a greater role as a mentor. Natural mentors may be shop teachers, co-workers, or family and friends. Likewise, individuals with disabilities - who themselves have faced barriers to employment and overcome them - can be powerful role-models for youth. #ajob4MEntor would be focused on relationship building and positive adult supports.

In this proposed model, youth would be referred to #ajob4MEntors with the youth’s assent. Following receipt of the referral, #ajob4MEntor would review the youth’s expressed career interests and location to determine a possible mentor match. If a natural mentor can be identified at the time of the referral, #ajob4MEntor would reach out to that individual to offer information about the program and provide training on the mentoring commitment. If no natural mentor is available, the youth would be matched with another mentor with whom he/she shares a commonality of employment interest. Each mentor and youth would be given a resource binder filled with career preparation activities and resources. During the 12 months of the mentoring relationship, the mentor and youth would connect on a monthly basis to share information on career interests, problem solve issues related to employment

that arise and plan for work experience activities. The mentor, through his or her networks (and with Coalition support), would facilitate business tours, interviews (mock or real), job shadows, paid work and other work-based learning opportunities. Mentors may share job leads or provide a reference for the youth. The mentor would support the youth through participation in transition planning meetings that may occur at school or with Vocational Rehabilitation, DHHS or other providers. As many careers require post-secondary education and training, mentors may also facilitate college tours or connections with apprenticeship sites. #ajob4Mentor provides monthly check-ins with each youth/mentor match to assess progress and provide support to resolve any barriers to the relationship or attainment of planned activities. While the hope is that many mentoring relationships will continue following the 12-month commitment, #ajob4Mentor will work between months 9-12 with each mentoring pair to facilitate closure and transition as appropriate.

Recommendations for Future Research

Through this study a number of areas for future research have been identified. As noted in the limitations section, earlier in this chapter, the lack of diversity represented in this study would suggest that future study would be helpful to determine if the experiences of students with disabilities who are “New Mainers”, English Language Learners, or people of color and who are living in rural Maine with their families were similar to those captured in this study. Additionally, this study identified a need for development of more case studies that reflect success through the use of natural supports in transition planning and raise up the voice of youth. As one finding was that parents and educators do not understand how to use natural supports in transition planning, case studies that document the factors and techniques

(including creative home-grown solutions) used to develop natural supports could considerably add to literature and by extension to the practice in rural areas – including Maine.

As shown through literature review for the study, research to date on the topics of natural supports (in the field of disability studies) and mentoring (in the fields of psychology and education) have stayed largely distinct. The intersections between natural supports and mentoring occur in both approaches' focus on amelioration of challenges through sharing of knowledge and resources between two individuals – one of whom has more experience. The commonalities between natural supports and mentoring suggest that additional transdisciplinary research that builds on the strengths of both fields could yield significant contributions to promoting improved youth outcomes, particularly if it includes how youth with disabilities can play a role in peer mentoring, a need identified in this study.

Social support theory with its focus on building “close and caring relationships...at all stages of the lifespan” (Feeney & Collins, 2015, p. 1) may also merit additional research given this study's findings on the disconnection that both students with disabilities and their parents often feel from natural supports in their communities. Research that studies the application of social support theory with youth with disabilities in community settings may lead to best practices that could be key tools in promoting effective application of natural supports in transition planning. Social support theory's applicability across the lifespan would also promote sustainability of relationships. Natural supports formed in the context of school-based transition planning would not need to be time-bound to an individual's life stage.

School-Based Pilot Study

This research study revealed that the educators interviewed had varying levels of knowledge concerning best practices in transition - and they also held a variety of beliefs about disability, poverty, social services and rural living. These beliefs have an impact on the students with whom they work. Future school-based action research on the question “Could inclusion of non-traditional community supports in special education transition planning make a difference in post-secondary outcomes for rural students with disabilities?” could help to illumine targeted areas for training and intervention with these and other educators. As discussed below, it may also be useful in increasing student leadership skills and promoting feelings of connectedness for both students and families. Action research is a growing approach in education inquiry to gather data, test new approaches and promote change (Schmuck, 2009, p. 36). It presents an alternative, a way to do meaningful research while stakeholders participate in finding solutions to their own challenges (Schmuck, 2009). Action research is an iterative model that allows learnings from each cycle of implementation to feed further study (Schmuck, 2009). This type of a model of research allows the three primary research stakeholder groups (educators, families, students) to be both addressed separately and folded in together in subsequent cycles - creating a more complete approach.

An action research approach could begin with the sharing of the findings of this current study and a proposed model for action research model (see Figure 5.1) along with a timeline for implementation with the three stakeholder groups in an identified rural school district. This would build buy-in to move forward with implementation. Natural supports in the community, while important to future iterations of the action research would be

purposefully excluded in this first stage. One reason is logistical (importance of keeping the project manageable) but the main reason is to ensure that the voices of the stakeholder groups that are most directly impacted have a priority opportunity to make their needs and concerns known.

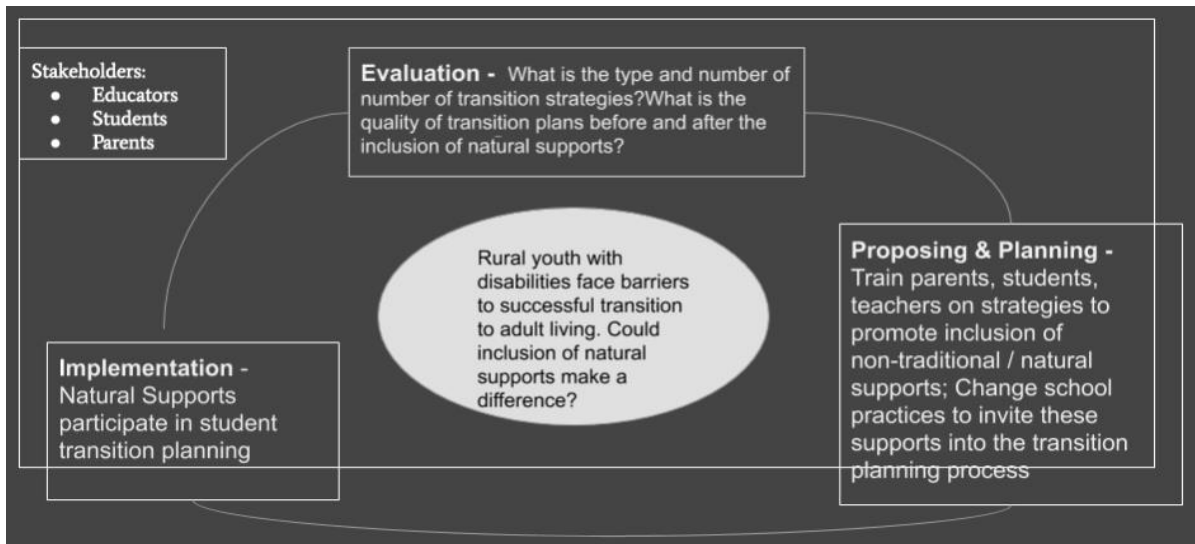


Figure 5.1. Action research model.

Educators. A collaborative action research approach would engage special education teachers in the schools as co-researchers. Invitations to participate in the pilot could be issued to rural high schools (preferably ones that have been identified as being in need of improvement by the Maine Department of Education). Responses to a brief survey sent to these school administrators would assist in site selection and onsite informational meetings to describe the research and answer questions of administrators and teachers. Getting this level of buy-in from the teachers will ensure that teachers are one of the primary audiences of the research. It will also increase the buy-in of teachers who can see that the problem of poor transition-planning for students does not end at the classroom door. Failure to assist young

people to transition successfully translates into the community where the teachers are also residents. Calhoun (as cited in Schmuck, 2009) found that involvement of teachers in collaborative action research also means that the research will be shared more widely than just another dissertation in academia. One of the most promising benefits of this approach was identified by Cooley and Yovanoff (1996, as cited in Schmuck, 2009, p. 145) as the reduction of special educators' sense of isolation in doing this work with students (many of whom may have challenging behaviors and disabilities). For teachers who have limited opportunities for professional development, participation in action research could be a win-win.

Students. Students with disabilities who have no familiarity with the concept of natural supports will require some training on self-determination to be able to advocate for inclusion of the important natural supports in their lives as members of the transition planning process. Building self-determination skills can be done as individual or small group work using a curriculum like “Whose Future is it Anyway?” which is available free of charge from the Zarrow Center for Learning Enrichment (Zarrow Center, n.d.). Building self-determination skills is also a key component of the five *Pre-Employment Transition Services* that state vocational rehabilitation agencies are required to deliver in partnership with schools under the 2014 federal law, *Workforce Innovation and Opportunity Act*.

Parents. Education of parents on the value of including natural supports in their children's transition planning IEP meetings may take place through partnership with the state's federally-funded Parent Information and Training Center. This organization has connections to parents and partners around the state and can build off of other activities in the

region where the selected schools are located. The findings of this research study highlighted that many parents interviewed do not feel connected to other parents - and this perceived isolation can foster real isolation enhanced by rurality and day to day struggles. A concerted effort by the Parent Information and Training Center that was well-advertised through school networks and used parents to reach out to other parents directly - may be more successful in promoting engagement of families.

Constituency building epicycle. The next stage in the action research would be *Constituency Building Epicycle* which focuses on specific activities to engage the three main stakeholders in the action research. Using strategies from collaborative action research, special education teachers will be engaged to serve actively as co-researchers in this initiative. Activities like a gallery walk of student transition outcome data along with posted narrative quotes from this study or results of the Maine Integrated Youth Health Survey - followed by time for pair-share reflection - will help the teachers connect with their own feelings about the data, and work through their own resistance that may arise. Other activities like reading and discussing articles describing best practices in inclusion of natural supports can promote shared learning. In particular, educators may benefit from reading journal articles (from publications such as the *Journal of Vocational Rehabilitation*, *Rural Special Education Quarterly*, and *Career Development and Transition for Exceptional Individuals*) that help to debunk myths about what students with disabilities are capable of achieving as adults. Release time to conduct research-related activities is a way the school administration can offer their support. Teachers from the pilot schools may also meet together to share learning, with each school's teachers getting recognition for their involvement in the

research. Uncovering competing commitments (Kegan & Lahey, 2001) can also help to address the real reasons for resistance. These may include a teacher's fear that his lack of skills in an area may be exposed, or that her participation this time will lead to required further activities.

Constituency-building with students can occur naturally in the school environment but it also will be useful to invite their participation in the feedback that shapes (formative evaluation) what the ultimate form of inclusion of natural supports looks like. It may be that the majority of the constituency-building comes with students at a later date after implementation when they have experience with natural supports from which they can draw. Bringing students from the pilot schools together for activities like the development of transition SNOW (Strengths, Needs, Opportunities, Worries) charts (a variation on the SWOT strategic planning tool) can be a way to help students think and plan for their futures while collaborating with their peers. The charts can then be brought in to IEP meetings to help guide the conversation.

Building a constituency with families can be done through follow-up open dialogue sessions, where parents can talk together about transition planning and also have opportunities to self-reflect on who they would identify as natural supports in their child's life. Learning from other families who have been through the transition planning process, faced similar challenges and who have accessed natural supports could assist with application within their own lives. Creating a family network that is available in ways that meet each family's needs (online, via phone, in person, etc.) would also model how natural supports can be developed and used.

Implementation. Following planning and constituency building, the next step in action research is implementation - and in this case implementation of the practice of including natural supports in student transition planning. The teachers who have been identified as the co-researchers will develop letters that will go to parents and students to encourage them to invite individuals who are natural supports to the students to participate in the IEP transition planning meeting. The letter will include an additional flyer that the parent can share with the natural support to explain the purpose of their involvement and what they can expect at the meeting. IEP meetings happen throughout the year but many typically fall in the spring for transition-age students. This timing will work well as it will allow the fall and winter to prepare for putting the activities into practice. At the conclusion of the IEP meetings, participating parents will be sent a brief survey to gather their feedback on the new format of the meetings. During the meetings, the special education teachers who are the co-researchers will take turns as observers and will use a rubric to collect qualitative data on meeting elements including contributions by natural supports.

Evaluation. Following implementation, and as the school year draws to a close, it will be important to review the pilots with both an eye to formative and summative evaluation - ensuring that all questions, methods, and data collection have been systematic and thorough. The initial inquiry question (Could inclusion of non-traditional community supports in special education transition planning make a difference in post-secondary outcomes for rural students with disabilities?) will be examined in light of the experience of the pilot projects and new learnings gained through the inclusion of the teacher co-researchers. To evaluate the success of the implementation, the type and number of transition

strategies reflected in transition plans before and after the inclusion of natural supports at each pilot school will be examined and quantified. In conjunction with the educator co-researchers, a qualitative analysis of the parent surveys and teacher observations from the IEP meetings will be conducted. Lastly, the participating teachers will be invited to a structured dialogue activity to share their experiences over the life of the pilot. Once all the evaluative data is gathered, the researchers will invite all stakeholders (and the natural supports) to attend a debriefing where the school administration will hear the preliminary findings and results of the initiative.

Reflection/dialogue. Reflection and dialogue will occur throughout the research but before engaging in a future iteration or expansion of the number of pilot schools, it will be important to fully reflect on the experience of the first pilots. Did the inclusion of teachers as co-researchers go according to design? What unexpected learnings emerged? Did students practice new skills as a result? What remains to be done to make this change in school practice sustainable?

Conclusions/next steps following action research. The promise of action research is its real-world solution-focused approach. This fits as a natural extension of this current study which provided a qualitative baseline of the use of natural supports in transition for students with disabilities in rural Maine. It also is well-situated within the framework of transdisciplinary research which also is real-world focused and intended as a transformative approach built on the input of many different types of stakeholders representing different roles and disciplines. The findings of this follow-up action research may allow more targeted training and interventions to meet the needs of particular school districts while building on

some of the promising practices that help to promote improved post-secondary outcomes through inclusion of natural supports. The research will be practical and useful at the local level but a secondary - and nearly equal - byproduct would be the reinforcement of the idea that marginalized rural communities hold within themselves much strength - including the ability to solve their own problems. After the conclusion of the first iteration of the research, the schools, students and families will hold the ability to continue further iterations - with or without additional external support.

Local allies may be discovered who are also prepared to assist with the work. They may arise naturally from the identified stakeholder group, but it is more likely that they may need to be more intentionally cultivated through outreach to like-minded individuals. These allies will be key in working towards sustainable systems change.

CHAPTER 6

CONCLUSION

Possibilities in Action

It's summertime, and Jim has traveled over two hours from his home in rural Maine to a small city where we meet. Jim's mom has helped with the logistics and let me know that Jim likes to go to this restaurant when he comes to town because they have an "all you can eat" pizza buffet. It's the beginning of the lunch hour - and not too busy - which is less overstimulating for Jim. When I arrive, Jim looks up from his pizza to greet me. I grab a slice of pizza too and join Jim and the community support person who has accompanied him on this trip, something they usually do about once a month. She proudly tells me that she has worked with Jim for over 10 years and that Jim has set a busy agenda for them that day. After lunch, they'll stop at a surplus store to poke around for bargains and then head over to a large truck center and salvage yard. Jim knows machinery, and through his regular visits he has also gotten to know the businesses and the people who work there. His support person reports that Jim knows everybody, and Jim nods his head in agreement.

Jim and I try to work out when the last time we saw each other was. Jim's disability can make conversations difficult but today as he works his way through his pizza, we talk about a summer camp program for adults with intellectual disabilities that he has attended for years and where he'll be headed soon. Jim is also looking ahead to an upcoming fall

agricultural fair and describes how he helps out there. We talk about his family, his work, and his community activities - many of which he has continued in the years since he has graduated from high school. I ask Jim if he remembers when I came to visit him on the farm and he does. He lights up as I recall my tractor ride with him those many years ago. The pizza eaten, Jim is ready to get moving again, he has people to see and places to go. We say our good-byes and Jim heads back out into his busy life.

The richness of Jim's life today, as a valued member of his community, a worker, and a loved member of his family represents what is possible for individuals with disabilities living in rural communities in Maine. The seeds for these connections were planted for Jim, by his family, when it became apparent to them that they would not be able to partner with Jim's IEP team to achieve the type of meaningful transition planning that they believed would lead to the positive post-secondary outcomes that they imagined for him. As gatekeepers, his special educators' inability to see possibilities for Jim meant that IDEA's required transition planning was incomplete and ineffective. Jim's parents, seeing a different future for him, had to take it upon themselves to design and implement a pathway for how that might be achieved. The brother who acted as a job coach, the neighbor who drove Jim to a job shadow, and the retired teacher who continued to work on Jim's academic skills all were natural supports who played key roles in Jim's transition; however, there were no seats at the table for these natural supports.

Contributions of This Study

This study presents a snapshot in time of the status of transition planning in rural Maine for students who receive special education services. This study adds to the research on

the role that natural supports play for individuals with disabilities through its examination of the transition planning process for students in rural Maine. Gatekeepers in the form of parents and educators control access to the IEP table and as demonstrated in this study often lack a full understanding of how natural supports could be developed and implemented to enhance transition planning. While confirming many of the barriers found in previous research on transition planning in rural areas, this study also added to the literature by identifying additional barriers, such as: (1) the lack of social connections and supports perceived by youth with disabilities, (2) parents and educators feeling overwhelmed by responsibilities, and (3) structural flaws in special education that discourage development of natural supports.

Additionally, this study highlighted examples of how creative, innovative approaches involving natural supports have been undertaken by some parents and educators to open up new opportunities and connections in their communities for youth with disabilities. It is these new connections that provide promise for adding more seats at the table for transition planning for students with disabilities in rural Maine.

Other Themes from the Data for Future Research Consideration

During the course of the interviews, some topics were raised that were considered to be outside the scope of the study but important to note for possible future study. They included: (1) the impact of the current drug (specifically opioid) crisis in rural America on parent engagement and community needs, and (2) the reported rise in grandparents raising their grandchildren (often related to substance abuse or mental health challenges). As transition planning relies on parent involvement, parents who were unavailable due to

substance abuse - and related incarceration, child welfare system involvement, or as noted by one educator - death - have limited or no ability to participate in transition planning.

The value of animals as supports for young people with disabilities, was an additional area that was raised in interviews - particularly as it applied to increasing youth responsibility through attending to the care of their animals or by providing company in the absence of human companions. Without dismissing the importance of animals as “natural” support or as opportunities for skill building, they fall outside the commonly-held definitions of natural supports and would be better addressed through further targeted research.

Unified sports teams as a model to promote social inclusion of transition age youth was a theme that arose multiple times during the interviews. Unified sports teams are a new model currently being adopted in Maine by a number of school districts. These teams are separate from the traditional junior varsity or varsity tradition, and intentionally mix youth both with and without disabilities. Educators noted positive impacts on social inclusion of students with disabilities in the school following implementation of unified sports teams. This change in social relationships at school may lead to additional natural supports available to students in the transition planning process, and so is of interest to this study, but a full exploration of implementation and impact of unified sports teams is outside the scope of this research. More information on Maine’s unified sports programs may be found at <http://www.mpa.cc/index.php/interscholastic-activities-and-committees/unified-basketball>.

APPENDIX A

PROTOCOL

More seats at the table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine

Investigator: Elizabeth Stone-Sterling, School of Global Inclusion and Social Development (SGISD), PhD Candidate

Background Information

Students with disabilities who receive special education services are entitled under federal law, the *Individuals with Disabilities Education Act*, to have an Individualized Education Program (IEP) that includes measurable postsecondary goals and identifies the transition services that are needed in order for the student to reach those goals. Transition planning for students with disabilities in rural areas can be uniquely challenging due to lack of access to transportation, service providers, and accessible programs. Failure to prepare for post-secondary education or employment is correlated with life-long challenges, including poverty, un/under-employment, and limited educational attainment. Natural supports, in the form of family members, friends, or community members, could be a resource to assist transition planning for students with disabilities but they may not be invited into the transition planning process. The purpose of this study is to better understand the role that natural supports have played in transition and post-secondary outcomes for students with disabilities living in rural Maine as well as any barriers that may prevent more fully accessing and integrating these resources into transition planning.

Research Design and Methodologies

This study will use qualitative methods – law review, interviews, observations and document review – within a phenomenological research study to take a retrospective appraisal of the lived experiences of stakeholders as they transitioned - or supported the transition - to adulthood. Key participants in this study include young adults with disabilities who have transitioned to adulthood, their parents, and special education teachers who are responsible for overseeing development and implementation of the Individualized Education Program. Through application of a transdisciplinary approach, these experiences will inform recommendations for sustainable ways to promote inclusion of natural supports as a means to strengthen transition planning and post-secondary outcomes for young people living in rural communities in Maine.

Data will be collected via four methods: (1) Legal Review, (2) Face to face interviews, (3) Observation, (4) Document review. This protocol will cover types 2, 3, and 4.

Face-to-face interviews: The researcher plans to hold face-to-face interviews with three groups of individuals: (1) young adults with disabilities (age 18+), (2) parents, and (3) special education teachers. The n for each group is planned to be 8 – 20. The researcher will conduct outreach to parents of students who have recently transitioned from high school to adult living to solicit participation in this study. The primary initial means of outreach will be via identified parent groups. Snowballing will support identification of additional parents. Parents will be invited to participate in semi-structured interviews with limited pre-determined questions designed to elicit information to describe their son or daughter's experience of transition from high school to adulthood. Parents will assist in the identification of their adult children to participate in another set of interviews. These interviews will last no more than 90 minutes. Special educators, identified by the parents as participants in their son/daughter's special education services and transition planning will be contacted by the researcher for an additional set of interviews. Ideally, a complete set of interviews will include participation by all three parties; however, each party will have the right to refuse, discontinue or delete their interview. Interviews may be audio-recorded in order to ensure the accuracy of information shared. Interview consent forms are included as Appendices A, B, and C. Sample questions are found in Appendix D.

Observation: A small number (n=3-10) of students with disabilities will be observed in a variety of natural settings (home, community, employment) to assess use of natural supports. The role of the researcher is intended to be non-intrusive and only assent from the youth (if under age 18) and permission/consent from a parent will be obtained so as to maintain the authenticity of the interaction. The student observation assent and parent observation consent forms are included as Appendices E & F.

Document Review: The researcher plans to review educational records and paperwork such as Individualized Education Programs (IEPs) and Written Notice from IEP meetings. These documents will be shared with the researcher by the young adult or family. These records may include information that refers to the student's disabling condition, results of certain educational or psychological assessments and school performance. They may also include identifying information such as student date of birth, home address and student identification number. These records will be maintained in a locked cabinet or password protected computer file depending on their transmission format. The student (age 18+) and parent participation consent forms (Appendices A & B) include language on how these documents will be used and maintained.

Human Participants Information

Participant Data

Participants will be from four groups: (1) Parents of students who are transitioning/have recently transitioned from high school to adult living, (2) Young adults (age 18+) who are/have recently transitioned from high school, (3) special educators from rural Maine schools, and (4) for the observations only, students with disabilities (age 14-20). The focus of this study is on the experience of students in rural Maine so all participants will be current residents of rural Maine communities. While even gender distribution will be sought, it may not be achievable due to participant identification via snowballing and other convenience sampling methods. The range of disabling conditions among participating students and young adults will vary and may include autism, anxiety, depression, mobility disorders, and specific learning disability, among others. All participants will provide informed consent. An example of a recruitment notice is attached as Appendix G.

Procedures for Vulnerable Populations

Young adults and students with disabilities who will be participating in this study will all have identified disabilities that impact one or more areas of functioning. Accommodations will be provided as needed to ensure access to the interviews and consent materials. Accommodations may include things such as provision of additional time, consent materials read aloud, or breaks during the interview among others. Participants will be able to ask questions about the process at any time. Participants will be allowed to have support persons with them during the interviews. In some instances, there may be a need to establish rapport with the individual via a pre-interview meeting. Interview and observation locations will be selected by participants to allow for maximum convenience.

Observations of young people will involve youth under the age of 18. In order to determine if a young person is able to give assent or consent, the researcher will ask both the individual youth as to his/her age as well as the youth's parent. If the researcher determines that the young person is under the age of majority (18), then the youth will be given the assent form for review and signature and the parent will be given the corresponding observation parental permission/consent form for signature. Observations on minors will not occur without first obtaining both forms.

Risk and Benefits

The researcher believes that there is likely to be very limited risk to individuals participating in this study. It is possible that reflection on experiences that the participant views as unsuccessful or negative (for example- lack of support while in high school, failure to obtain

employment, limited community integration) may cause the participant some uncomfortable feelings or slight distress. Individuals will be encouraged to take breaks or have other supports available during the interview.

There is no direct benefit to individuals participating in this study. Individuals may, however, find some benefit in reflecting on their – or their child/student's - transition experiences to inform their future plans. Individuals may also find benefit in the knowledge that sharing their lived experience in this study will add to the body of knowledge on transition planning. Because it is likely that some participants may identify areas where they would like assistance going forward, the researcher will prepare and distribute to participants a resource list that includes contact information for websites and organizations that may be of assistance on topics related to transition planning.

Informed Consent

At the time of initial recruitment, individuals will be told by the researcher that they may choose to participate or not participate without any negative consequences now or in the future. The researcher will meet face-to-face with individuals who indicate interest in participating. At that time, the consent/assent forms will be read aloud to the individual before obtaining their signature. Individuals will be offered additional time to inspect and read the form, as well as offered an opportunity to ask questions prior to signing. Signatures will be obtained prior to beginning any interviews, observations or data collection. The consent/assent forms inform individuals that they may decide to participate or not without any negative consequences now or in the future. The prepared assent/consent forms also indicate exactly how the information they share will be protected and used. All individuals will be informed that they may discontinue participation at any time, even after the interview is over (the next day or week). Participants may ask questions about the process at any time. They can ask to have an accommodation to be able to access the consent/assent forms and it will be provided. Consent forms will request permission for the interview and also specific permission to the audio-recording of the interview. Youth under age 18 will be asked for their assent to observation (and their parent's consent). A copy of the signed assent /consent forms will be provided to participants.

Confidentiality

Participation in this research is confidential. None of the information that the researcher collects will identify the individuals by name – a number will be assigned to each person interviewed and each person observed. The recordings of the interviews will be transcribed by a paid transcriptionist and then both the transcripts and the audio files will be kept in a locked file cabinet or on a password protected computer. Documents collected will be also

kept in a locked cabinet. All data will be destroyed at the completion of the research. Field notes will be stored in the locked cabinet as well as in a password protected computer file. The only persons who will have access to raw data will be the researcher and a paid transcriptionist.

IRB Appendix A

University of Massachusetts Boston
Department of Global Inclusion and Social Development
100 Morrissey Boulevard
Boston, MA. 02125-3393

Young Adult Consent Form for “More Seats at the Table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine”

Dear _____

You are being asked to take part in a research project about the use of “natural supports” in transition planning for students with disabilities who received special education services in high school. Natural supports may be friends, family, community members, or others who help support young adults like you be more included at work, in school or in activities in your community. My name is Libby Stone-Sterling, and I am the primary researcher for this project. I live here in Maine but I am a doctoral student at the University of Massachusetts Boston.

Please read this form and feel free to ask questions. If you have further questions later, I am happy to discuss them with you. You can reach me at (207) 807-9063 or by email at Elizabeth.stonest001@umb.edu. If you have questions about the research you can also contact the chair of my dissertation committee, Dr. Gillian MacNaughton, at gillian.macnaughton@umb.edu.

This study is intended to help us understand more about how natural supports are included in transition planning for students in rural Maine. For this study, I plan to interview young adults like you, as well as parents and special educators. If you decide to participate in this study, you will be asked to complete an interview of up to 90 minutes, at a location that is convenient to you. You may be asked to share a copy of your Individualized Education Program (IEP) or other special education paperwork that you may have that describes transition services that you received when you were in high school.

This study is intended to minimize any risk or harm. It is possible that you may experience negative or distressful feelings while participating in the interview. You may speak with me about any issues of discomfort during the study. If you feel that you need additional support, you may also want to contact a support person like a friend or family member to sit in on the interview with you. You can also stop the interview at any time you wish.

Your participation in this research is **confidential**. Things that you tell me in the interview won't be shared with your parents or special education teachers unless you specifically give me permission to do so. The information gathered for this project will not be published or presented in a way that would allow anyone to identify you. Information gathered for this project will be stored in a locked file cabinet and only the researcher and paid transcriptionist will have access to the data.

The decision whether or not to take part in this research study is up to you. You may stop your participation at any time with no negative consequences now or in the future.

You have the right to ask questions about this research before you sign this form and at any time during the study. You can reach me at (207) 807-9063 or elizabethstonest001@umb.edu. You may reach Dr. Gillian MacNaughton at Gillian.macnaughton@umb.edu. If you have any questions or concerns about your rights as a research participant, please contact a representative of the Institutional Review Board (IRB), at the University of Massachusetts, Boston, which oversees research involving human participants. The Institutional Review Board may be reached at the following address: IRB, Quinn Administration Building-2-080, University of Massachusetts Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393. You can also contact the Board by telephone or e-mail at (617) 287-5374 or at human.subjects@umb.edu.

I HAVE READ THE CONSENT FORM. MY QUESTIONS HAVE BEEN ANSWERED. MY SIGNATURE ON THIS FORM MEANS THAT I CONSENT:

- (1) TO PARTICIPATE IN THIS STUDY, and
- (2) TO AUDIO RECORDING OF THE INTEVIEW.

I ALSO CERTIFY THAT I AM 18 YEARS OF AGE OR OLDER AND AM j OWN GUARDIAN.

Signature of Participant

Date

Signature of Researcher

Libby Stone-Sterling

Printed Name of Participant

Typed/Printed Name of Researcher

IRB Appendix B

University of Massachusetts Boston
Department of Global Inclusion and Social Development
100 Morrissey Boulevard
Boston, MA. 02125-3393

Parent Consent Form for “More Seats at the Table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine”

Dear _____

You are being asked to take part in a dissertation research project about the use of “natural supports” in transition planning for students with disabilities who received special education services in high school. Natural supports may be friends, family, community members, or others who help support a young person’s successful inclusion in activities like employment, education or independent living. My name is Libby Stone-Sterling, and I am the primary researcher for this project. I live here in Maine but I am a doctoral student at the University of Massachusetts - Boston.

Please read this form and feel free to ask questions. If you have further questions later, I am happy to discuss them with you. You can reach me at (207) 807-9063 or by email at Elizabeth.stonest001@umb.edu. If you have questions about the research you can also contact the chair of my dissertation committee, Dr. Gillian MacNaughton, at gillian.macnaughton@umb.edu.

This study is intended to help us understand more about how natural supports are included in transition planning for students in rural Maine. During the study, I plan to interview parents like yourself, as well as young adults with disabilities and special educators. If you decide to participate in this study, you will be asked to complete an interview of up to 90 minutes at a location that is convenient to you. You may be asked to share a copy of your son/daughter’s Individualized Education Program (IEP) or other special education paperwork that you may have that describes transition services that your son/daughter received.

This study is intended to minimize any risk or harm. It is possible that you may experience negative or distressful feelings while participating in the interview. You may speak with me about any issues of discomfort during the study. If you feel that you need additional support, you may also want to contact a support person like a friend or family member to sit in on the interview with you. You can also stop the interview at any time you wish.

Your participation in this research is **confidential**. That is, the information gathered for this project will not be published or presented in a way that would allow anyone to identify you.

Information gathered for this project will be stored in a locked file cabinet and only the researcher and a paid transcriptionist will have access to the data.

The decision whether or not to take part in this research study is voluntary. You may stop your participation at any time with no negative consequences now or in the future.

You have the right to ask questions about this research before you sign this form and at any time during the study. You can reach Libby at (207) 807-9063 or elizabethstonest001@umb.edu. You may reach Dr. Gillian MacNaughton at Gillian.macnaughton@umb.edu. If you have any questions or concerns about your rights as a research participant, please contact a representative of the Institutional Review Board (IRB), at the University of Massachusetts, Boston, which oversees research involving human participants. The Institutional Review Board may be reached at the following address: IRB, Quinn Administration Building-2-080, University of Massachusetts Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393. You can also contact the Board by telephone or e-mail at (617) 287-5374 or at human.subjects@umb.edu.

I HAVE READ THE CONSENT FORM. MY QUESTIONS HAVE BEEN ANSWERED. MY SIGNATURE ON THIS FORM MEANS THAT I CONSENT TO:

- (1) PARTICIPATE IN THIS STUDY, and
- (2) AUDIORECORDING OF THE INTERVIEW.

I ALSO CERTIFY THAT I AM 18 YEARS OF AGE OR OLDER AND AM MY OWN GUARDIAN.

_____ Signature of Participant	_____ Date	_____ Signature of Researcher
_____ Printed Name of Participant	_____ Libby Stone-Sterling Typed/Printed Name of Researcher	

IRB Appendix C

University of Massachusetts Boston
Department of Global Inclusion and Social Development
100 Morrissey Boulevard
Boston, MA. 02125-3393

Special Educator Consent Form for “More Seats at the Table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine”

Dear _____

You are being asked to take part in a dissertation research project about the use of “natural supports” in transition planning for students with disabilities who received special education services in high school. Natural supports may be friends, family, community members, or others who help support a young person’s successful inclusion in activities like employment, education or independent living. My name is Libby Stone-Sterling, and I am the primary researcher for this project. I live here in Maine but I am a doctoral student at the University of Massachusetts - Boston.

Please read this form and feel free to ask questions. If you have further questions later, I am happy to discuss them with you. You can reach me at (207) 807-9063 or by email at Elizabeth.stonest001@umb.edu. If you have questions about the research you can also contact the chair of my dissertation committee, Dr. Gillian MacNaughton, at gillian.macnaughton@umb.edu.

This study is intended to help us understand more about how natural supports are included in transition planning for students in rural Maine. During the research I plan to interview special educators like yourself, as well as young adults with disabilities and parents. If you decide to participate in this study, you will be asked to complete an interview of up to 90 minutes, at a location that is convenient to you.

This study is intended to minimize any risk or harm. It is possible that you may experience negative or distressful feelings while participating in the interview. You may speak with me about any issues of discomfort during the study. If you feel that you need additional support, you may also want to contact a support person like a friend or family member to sit in on the interview with you. You can also stop the interview at any time you wish.

Your participation in this research is **confidential**. That is, the information gathered for this project will not be published or presented in a way that would allow anyone to identify you. In some cases a parent or young adult may have given permission for you to speak specifically about his/her transition plan and services. In those situations the information that you share with me will not be re-released to the parent or young adult. Information gathered for this project will be stored in a locked file cabinet and only the researcher will have access to the data.

The decision whether or not to take part in this research study is voluntary. You may stop your participation at any time with no negative consequences now or in the future.

You have the right to ask questions about this research before you sign this form and at any time during the study. You can reach Libby at (207) 807-9063 or elizabethstonest001@umb.edu. You may reach Dr. Gillian MacNaughton at Gillian.macnaughton@umb.edu. If you have any questions or concerns about your rights as a

research participant, please contact a representative of the Institutional Review Board (IRB), at the University of Massachusetts, Boston, which oversees research involving human participants. The Institutional Review Board may be reached at the following address: IRB, Quinn Administration Building-2-080, University of Massachusetts Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393. You can also contact the Board by telephone or e-mail at (617) 287-5374 or at human.subjects@umb.edu.

I HAVE READ THE CONSENT FORM. MY QUESTIONS HAVE BEEN ANSWERED.
MY SIGNATURE ON THIS FORM MEANS THAT I CONSENT TO:

- (1) PARTICIPATE IN THIS STUDY, and
- (2) AUDIORECORDING OF THE INTERVIEW. I ALSO CERTIFY THAT I AM 18 YEARS OF AGE OR OLDER AND AM MY OWN GUARDIAN.

_____ Signature of Participant	_____ Date	_____ Signature of Researcher
_____ Printed Name of Participant	_____ Libby Stone-Sterling Typed/Printed Name of Researcher	

IRB Appendix D

Semi-Structured Interviews - Sample Interview Questions:

Parents

1. Thinking back to your son/daughter's transition from high school to adult living, who were the people who supported that process?
2. What type of role did they play? What did they do that was helpful?
3. Did this person participate in IEP or other school meetings?
4. Why or why not?
5. Is this person still involved in your son/daughter's life? If so, in what ways?
6. Thinking back, who might have been helpful to that process knowing what you know now?

Young Adults

1. When you think back to when you were in high school and planning for the future, who were the people who were helpful to you?
2. How were they helpful? What did they do?
3. Did this person participate in your IEP or other school meetings?
4. Do you think it would have been helpful to have them attend school meetings?
5. Is this person still involved in your life now? If so, in what ways?

Special Educators

1. When you think of transition planning with students, what individuals or resources have you found the most helpful?
2. Thinking back to students who have recently transitioned from high school to adult living, who typically attended IEP meetings where transition planning was discussed?
3. Do you encourage parents /students to invite individuals or organizations to attend the IEP meeting? Why or why not?
4. When you are developing the transition section of the IEP, would you be likely to include natural (share definition) supports? Why or why not?
5. Are there barriers that might prevent you from including natural supports?
6. (Given participant permission) Thinking back to _____'s transition planning process, do you recall who was involved? What role did they play?

IRB Appendix E

University of Massachusetts Boston
Department of Global Inclusion and Social Development
100 Morrissey Boulevard
Boston, MA. 02125-3393

Observation Assent Form for participation in observation for “More Seats at the Table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine”

Dear _____

You are being asked to take part in a research project about the use of “natural supports” in transition planning for students with disabilities who receive special education services in high school. Natural supports may be friends, family, community members, or others who help support young adults like you be more included at work, in school or in activities in your community. My name is Libby Stone-Sterling, and I am the primary researcher for this project. I live here in Maine but I am a doctoral student at the University of Massachusetts - Boston.

Please read this form and feel free to ask questions. If you have further questions later, I am happy to discuss them with you. You can reach me at (207) 807-9063 or by email at Elizabeth.stonest001@umb.edu. If you have questions about the research you can also contact the chair of my dissertation committee, Dr. Gillian MacNaughton, at gillian.macnaughton@umb.edu.

This study is intended to help us understand more about how natural supports are included in transition planning for students in rural Maine. During the research I plan to observe young people like you in a variety of settings so that I can better understand how people in your life are helpful to you as you prepare for life after high school.

When the observation is taking place, I will keep in the background. Nothing that I say or do will disclose personal information about you. Anything that I learn during the observation will be kept **confidential**. That means I can’t share it with anyone without your agreement.

You have the right to ask me to stop the observation at any time and I will do so. Since you are under age 18, I must also have your parent’s permission to conduct the observation.

You have the right to ask questions about this research before you sign this form and at any time during the study. You can reach me at (207) 807-9063 or elizabethstonest001@umb.edu. You may reach Dr. Gillian MacNaughton at Gillian.macnaughton@umb.edu. If you have any questions or concerns about your rights as a research participant, please contact a representative of the Institutional Review Board (IRB), at the University of Massachusetts, Boston, which oversees research involving human participants. The Institutional Review Board may be reached at the following address: IRB, Quinn Administration Building-2-080, University of Massachusetts Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393. You can also contact the Board by telephone or e-mail at (617) 287-5374 or at human.subjects@umb.edu.

I HAVE READ THIS ASSENT FORM. MY QUESTIONS HAVE BEEN ANSWERED. MY SIGNATURE ON THIS FORM MEANS THAT I GIVE ASSENT (MY AGREEMENT) TO PARTICIPATE IN THIS STUDY.

Signature of Participant

Date

Signature of Researcher

Libby Stone-Sterling

Printed Name of Participant,(AGE)

Typed/Printed Name of Researcher

IRB Appendix F

University of Massachusetts Boston
Department of Global Inclusion and Social Development
100 Morrissey Boulevard
Boston, MA. 02125-3393

Parental Consent Form for youth participation in observation for “More Seats at the Table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine”

Dear _____

You are being asked to take part in a research project about the use of “natural supports” in transition planning for students with disabilities who receive special education services in high school. Natural supports may be friends, family, community members, or others who help support young people be more included at work, in school or in activities in your community. My name is Libby Stone-Sterling, and I am the primary researcher for this project. I live here in Maine but I am a doctoral student at the University of Massachusetts - Boston.

Please read this form and feel free to ask questions. If you have further questions later, I am happy to discuss them with you. You can reach me at (207) 807-9063 or by email at Elizabeth.stonest001@umb.edu. If you have questions about the research you can also contact the chair of my dissertation committee, Dr. Gillian MacNaughton, at gillian.macnaughton@umb.edu.

This study is intended to help us understand more about how natural supports are included in transition planning for students in rural Maine. During the research I plan to observe young people in a variety of settings (such as at home, in the community or at work) so that I can

IRB Appendix G

Recruitment Notice

PARENTS NEEDED TO PARTICIPATE IN STUDY

Are you the parent of a young adult with a disability who has recently exited high school? Are you willing to share the story of your son/daughter's transition from high school to help increase understanding of what the transition process from school to adult life is like for young people in rural Maine?

My name is Libby Stone-Sterling and I am a doctoral student at the University of Massachusetts – Boston. I am currently conducting interviews with parents and other stakeholders across the state. If you would like to participate or have questions, please call me confidentially at 807-9063 or email me at Elizabeth.stonest001@umb.edu. I look forward to hearing from you!

Modification Request – Secondary Data Review

IRB Study Number: 2018054

Title of Protocol: More Seats at the table: An examination of the role of natural supports in promoting post-secondary transition for students with disabilities in rural Maine

Principal Investigator: Elizabeth Stone-Sterling, PhD candidate, School of Global Inclusion and Social Development

Additional Data Source: In addition to other previously approved document review, this research will benefit from inclusion and analysis of minutes, charts, and other work product resulting from a Youth Advisory Group for youth and young adults with disabilities that first convened in August, 2019. The purpose of the group is to create a space where youth with disabilities can build leadership skills so that they can self-advocate and offer feedback on state agency policies and practices that impact them and are of importance to them. The youth and young adults who are members voluntarily joined following an invitation from the Maine Department of Labor. Through their initial meeting and subsequent work, the members have identified areas related to post-secondary transition and adult living that are of concern to them. They have also identified areas for further development and policy influence. This data has been compiled in a summary manner without inclusion of any personally identifiable information. No individual member may be identified by the notes, themes, and other materials collected. All members understand that the purpose of the group includes positively influencing policy and practices.

Value to this Research: This data is available for document review separate from any data about the group's members and will serve to assist in strengthening youth voice in this research study. It will also assist in validating other findings – particularly as themes align or differ from other studies. A copy of this data is available to the researcher through professional affiliation. While the Youth Advisory Group data contains no sensitive

information or personal data, a copy will also be kept under password protection in an electronic file. The document review will not include any interaction with members of the Youth Advisory Group.

APPENDIX B

LOCAL EDUCATION AGENCY DETERMINATION LETTER (SAMPLE)

2017-18 Local Education Agency Individuals with Disabilities Education Act (IDEA) Determination

This report displays the performance of the Local Education Agency (LEA) toward to the compliance requirements of the Individuals with Disabilities Education Act (IDEA) of 2004 as amended. The report is provided in four sections to address key aspects of the requirement: State Performance Plan (SPP) Compliance Indicators, Timely and Accurate Data Reporting, Adherence to IDEA Regulatory Provisions, and Fiscal Monitoring. Values of NA indicate that the indicator was not applicable to the LEA during the reporting period.

DISTRICT East Machias		TARGET	LEA PERFORMANCE	IS THE LEA IN SUBSTANTIAL COMPLIANCE
SPP COMPLIANCE INDICATOR PERFORMANCE	Indicator 4b: Percent of disproportionate representation of racial and ethnic groups in suspensions and expulsions greater than 10 days and policies, procedures, and practices that contribute to the discrepancy	0%	0.0%	Yes
	Indicator 9: Percent of disproportionate representation of racial and ethnic groups in special education and related services that is the result of inappropriate identification	0%	0.0%	Yes
	Indicator 10: Percent of disproportionate representation of racial and ethnic groups in specific disability categories that is the result of inappropriate identification	0%	0.0%	Yes
	Indicator 11: Percent of children who were evaluated within 45 days of receiving parental consent for initial evaluation	100%	100.0%	Yes
	Indicator 13: Percent of youth in 9th grade and above or age 16 and above with an IEP that includes appropriate transition services and goals	100%	100.0%	Yes
	Correction of Previous Noncompliance: Noncompliance for indicators 4b, 9, 10, 11, or 13 is corrected as soon as possible but in no case later than one year from identification	100%	NA	NA
TIMELY AND ACCURATE DATA PROVIDED	Local Entitlement Application completed on time without significant error	100%	100.0%	Yes
	Child Count Data provided on time and validated accurate, complete, and representative.	100%	100.0%	Yes
ADHERENCE TO IDEA REGULATORY REQUIREMENTS AND PROVISIONS	Noncompliance regarding chapter 101 and federal IDEA regulations is corrected within 1 year after identification or as required by agreement with Maine Department of Education	100%	NA	NA
FISCAL AUDIT	Fiscal audit noncompliance is corrected as soon as possible but in no case later than one year after identification	100%	NA	NA

OVERALL DETERMINATION	
<div style="border: 1px solid black; padding: 5px; display: inline-block;">MEETS REQUIREMENTS</div>	NOTE: <input style="width: 100%;" type="text"/>
	NOTE: <input style="width: 100%;" type="text"/>

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