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Teaching Students With Profound Intellectual and Multiple Disabilities

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This is to certify that the doctoral dissertation by

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Abstract

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MA, Muskingum University, 2001

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

In the United States, students with disabilities are protected by federal and state law, with rigorous learning standards mandated for all students. Research on the education of students with severe disabilities has focused on students on the upper end of the severe disability spectrum, but few studies in the United States have addressed the education of students with profound intellectual and multiple disabilities (PIMD). This qualitive, exploratory multiple case study focused on how teachers are providing appropriate and meaningful education to students with PIMD. Theoretical foundations were based on the work of Dewey and Vygotsky, who argued that appropriate education includes elements of communication, self-actualization, and social justice, as well as Nakken and Vlaskamp, who argued for an international understanding of the characteristics of individuals with PIMD. The conceptual framework was developed in response to issues of student identification, ethical practices, and legal mandates. Data were collected from interviews with four teachers from the Midwestern United States who teach students with PIMD, and examination of formal educational documents. Data were analyzed using hand coding to identify categories and themes. The resulting themes included a lack of teacher preparation and access to guidance for teaching students with PIMD, as well as the importance of meaningful relationships and activities for these students. Analysis indicated a mismatch between the characteristics of students with PIMD and current educational standards and expectations. Findings may provide special education teachers with insights that promote a broader vision of meaningful education as they recognize, dignify, and respond to the unique educational needs of students with PIMD.

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Chapter 1: Introduction to the Study

In the United States, the Individuals with Disabilities Education Improvement Act (2004) and the Every Student Succeeds Act (2015) are the essential federal mandates that ensure an appropriate education for all students with disabilities, "regardless of the severity of their handicap" (Education for All Handicapped Children Act, 1975, Sec. 612 A, B, C). These mandates prompted individual states to establish extended educational standards and assessments to address the needs of learners with intellectual disabilities who have entwined factors of significantly subaverage general intellectual functioning ranging from IQ scores as high as 77.5 (Vermont Agency of Education, 2013) and below, and a wide range of deficits in adaptive behavior (American Psychiatric Association, 2013; Koriakin et al., 2013; Sulkes, 2020; Tasse, 2018; United States Department of Education, 2017b).

Within the broad definition of intellectual disability, there is a small subset of students with the most profound level of ID, those with an estimated IQ of 20–25 and below (at least five standard deviations below the norm) who have a degree of learning difficulty so severe that they function at a developmental level of 2 years or less, and have any one of more of the following: severe physical disability, severe visual or hearing impairment, epilepsy, or other complex health conditions for which medication is required (Carnaby, 2007). Individuals in this profound range of disability do not have the ability to use symbolic language, such as representations that are used in reading, mathematics, and speech (Antaki et al., 2017). IDEA, however, does not utilize specific IQ as a defining factor in identification of intellectual disability, employing the language

"significantly subaverage general intellectual functioning" (Individuals with Disabilities Education Improvement Act, 2004, § 300.8 [c] [6]). In an effort to operationalize the IDEA standard of intellectual disability to guide decisions about classification, academic standards, and alternate assessment for students with ID, individual state departments of education continue to use IQ as a factor in identification, along with deficits in adaptive behavior. Five states currently utilize a differentiated model to subcategorize intellectual disability into mild, moderate, severe (IQ of 40 and below) levels of intellectual disability, in addition to two states that recognize profound disability as approximate IQ of 25 and below (see Appendix A).

This qualitive study addressed the experiences of special education teachers in school districts in the United States as they seek to provide an appropriate and meaningful education of students with the most profound intellectual disabilities, even as they are provided with little guidance from state and federal standards. Ruppar et al. (2017) stated that the lack of disaggregation and research on the population of students with the most profound level of intellectual disability may result in a lack of knowledge or misunderstanding of their challenging and unique learning needs. The problem addressed in this study was how special education teachers, with little guidance from state and federal standards, are providing appropriate and meaningful education for students who present on the most profound end of the spectrum of intellectual disability. Federal mandates and state-adopted educational standards that focus on the rights and needs of students are largely incongruous with what is known about the characteristics of students with the most profound intellectual disabilities. Teachers in public school

districts who interact with and build educational relationships with these students may lack the information and resources necessary to guide their decisions about curriculum planning, goal setting, daily practices, and desired outcomes as they seek to enact the intent of IDEA and the meaningful education of students with profound disability. I sought to add the praxis-centered voices of teachers to the body of research on profound intellectual and multiple disabilities (PIMD), particularly in relation to gaining insights that can lead to understandings and practices that will assist teachers in their work with children and young adults with profound disabilities.

The challenge presented by Walden University in the mission of positive social change requires that scholarship should result in the "improvement of human or social conditions" by promoting the "worth, dignity, and development of individuals, communities, organizations, institutions, cultures, and/or societies" (Walden University, 2021, Social Change section, para. 1). Under the Every Student Succeeds Act (ESSA), the number of students who meet the legal requirement for the most significant cognitive disabilities is designated at or below 1% of the total number of tested students, as evidenced by the allowable number for alternate assessment (United States Department of Education, 2017b). The educational experiences of the special education teachers and their students with profound disabilities are largely unknown, and knowledge about the specific goals and practices of teachers who have these students on their caseloads is limited (Ruppar et al., 2017).

The implications of this research may reach educators and curriculum directors at the district and state levels by increasing awareness of this low-incidence subset of

students, the work that is being done by teachers in the field, and the needs of these teachers as they seek to educate students having PIMD. The findings of this study could create space for transdisciplinary conversations in school districts, inform course development in higher education and seminar presentations for in-service educators, and be used to create written resources to assist educators in providing not only legal but also meaningful and effective schooling for children with profound manifestations of intellectual disability.

This chapter is an introduction to a study of public school students who have PIMD. The background addresses the characteristics of individuals with PIMD from educational, medical, and psychological viewpoints as well as the general framework of special education services for these students in the United States. The problem statement articulates the challenges presented as teachers seek to educate students with PIMD in a manner that facilitates growth and meaningful experiences for each student. The research questions guiding this study are presented, as they provided the focus and guided the methodology employed through all stages of this study. I describe the theoretical and conceptual frameworks for this study, delineating the need for both frameworks to address the complex nature of PIMD. Finally, this chapter includes a brief description of the qualitative, multiple case study methodology and the related limitations and assumptions. The potential social significance of the work is also discussed**.**

Background

Children with disabilities have been included in public education in the United States for over 40 years, officially beginning with President Ford signing into law the

mandate of the Education for All Handicapped Children Act (Public Law 94-142) in 1975 (see Education for All Handicapped Children Act, 1975). The law included language that has been broadly accepted and implemented in the United States, providing the catalyst for the continued support and expansion of special education services that support appropriate learning experiences for all students (United States Department of Education, 2007). Inclusion in the educational process became the imperative for all students including those with severe disability (Education for all Handicapped Children Act,1975). Although special education law was determined at the congressional level, much of the work of advocacy and service improvement for the education of students with disabilities has relied on the parents (Deno, 1972; Itkonen, 2007), termed by Itkonen (2007) as the "politics of passion" (p. 9).

While passion fueled the movement for access to education, consideration of the processes and outcomes of education came to the forefront with adoption of ESSA of 2015, requiring that all students, regardless of disability, be instructed in rigorous common educational standards and tested yearly to ensure that the standards are being mastered (Every Student Succeeds Act, 2015). Extending federal law further, the 2017 Supreme Court case of *Endrew F. v. Douglas County School District RE-1* (2017) was explicit in its finding that "states must provide children with disabilities 'access' to education that is meaningful" (p. 33). The Supreme Court affirmed the rights of students with disabilities to meet goals that are developmentally appropriate and take into account each child's unique capabilities and circumstances (United States Department of Education, 2017a).

With legal impetus, public schools in the United States are now considering the right to a meaningful education and are working to implement appropriate educational experiences for students with disabilities that will allow all children to make educational progress, regardless of their physical or cognitive condition (United States Department of Education, Every Student Succeeds Act, 2017). Most recently as a part of ESSA, the inclusive practice of Universal Design for Learning (UDL), first defined in the Higher Education Opportunity Act of 2008, has become the main conduit for the education of students with disabilities (Every Student Succeeds Act, 2015). UDL is a scientific framework that guides educational practice to provide flexibility in the way information is presented in a classroom, providing students with multiple means of engagement to access and understand instruction, and removes barriers that inhibit the education of all students in inclusive settings with their nondisabled peers (Ross, 2019).

In 2009, individual states began to develop Common Core State Standards to establish consistent learning goals for all students. It was required that these standards must be linked to real-world knowledge and skills that would be needed to ensure that all students, regardless of their zip code, would graduate from high school with a readiness to engage successfully in college or a career (Common Core State Standards Initiative, 2020a). In 2015, under ESSA, the United States legislated Common Core State Standards for students with disabilities (Every Student Succeeds Act, 2015). With this mandate came the criticism that the educational reforms were having a significant influence on children's learning and development, yet they had not been thoroughly researched or substantiated as effective (Bartlett et al., 2015), and that there was too heavy a reliance on

standardized assessment and a narrowing of the curriculum that marginalized children with severe special educational needs. Bartlett et al. (2015) recognized tension between legislated curriculum and practice and the principles of social justice for students with special educational needs. Dukes and Darling (2017) observed that a gap existed between the way the standards were being interpreted administratively and the actual work that was being done to develop appropriate academic and life skills for students with disabilities.

Although elementary and secondary schools in the United States are now being held accountable for the education of students with disabilities and the interventions provided to them, examination of Common Core State Standards indicated that there were few linkages between classroom resources or materials to implement content standards with students with severe disabilities, and those that were found were linked to alternate assessment rather than instruction (Dukes et al., 2017). While acknowledging that content standards were intended to provide a guide for curriculum content, Dukes et al. (2017) concluded that "alignment between the standards and curriculum for students with severe disabilities is still in need of work" (p. 152), and that further development of this alignment focusing on the goal of a personally relevant curriculum could be of great benefit for teacher practice. Dukes et al. concluded that little information is available through state Department of Education websites or those of local school districts regarding core academic standards and students with severe disabilities.

It is reasonable that most special education services and educational supports are focused toward the larger number of students with mild to moderate disabilities who

make up nearly 70% of students served under IDEA (United States Department of Education, National Center for Education Statistics, 2016). Disability, however, exists on a spectrum of need (*Endrew F. v. Douglas County School District RE-1*, 2017; Piotrowski & Houp, 2019; University of Hawai'i at Manoa, n.d.), and opportunities for professional development and curricular and strategic support are limited for teachers who work with low-incidence populations (Collins, 2007; Pennington, 2017). The goal of the current study was to recognize the students whose disabilities lie at the most profound end of that spectrum and illuminate the challenge that they present for public education. This is a challenge that is missing from U.S. educational literature and preparation, and may be unknown to most policymakers and educators.

There are two intertwined strands of standards-based education in the United States mandated by ESSAP: high academic standards such as the Common Core State Standards and a focus on college and career readiness (Malin et al., 2017; Morningstar et al., 2017; United States Department of Education, n.d.). Morningstar et al. (2017) examined the impact of academic factors addressed in state academic standards as well as nonacademic and foundational skills that are not included within state standards on students with disabilities, and acknowledged that the research framework omitted explicit consideration of the unique learning needs of students with severe disabilities as well as the level of support that would be needed to ensure their education. Morningstar et al. set out to ascertain what was needed to strengthen and complete the framework to include factors of college and career readiness for students with severe disability.

Findings of the Morningstar et al. (2017) study included skills such as waiting their turn, raising hand, note taking, following directions, self-determination, self-advocacy, scheduling and organizational skills, use of mnemonics, graphic organizers, and utilization of assistive technology that would allow students to receptively and expressively relate relevant topics, interests, and feelings to others. These skills, when juxtapositioned with characteristics of students with profound disabilities, indicate discrepancy of capability. As the educational experiences of students in the United States need to be designed to develop college and career readiness (Every Student Succeeds Act, 2015), education for students with severe disabilities must be designed to equip them with the knowledge and skills to prepare them for participation in the life of their communities, and to this end must utilize a life span perspective (Moljord, 2017).

In defining any level of intellectual disability, both cognitive and adaptive abilities must be considered. Educational content standards and testing focus on cognitive and academic skill attainment with a major emphasis on English/language arts and mathematics (Common Core State Standards Initiative, 2020b; Myers, 2018). Adaptive behavior deficits, necessary in the identification of a student with intellectual disability, refers to the social, conceptual, and practical skills that are utilized by people in daily life (Tasse, 2018). Moljord (2017) stated that the understanding of adaptive behavior is critical in the development of curriculum for individuals with intellectual disability because of its role in “providing a framework for person-referenced education goals” and to utilize a focus on an “essential dimension of human functioning” (p. 649).

The descriptions and characterizations of severe disability illustrate the challenge presented under the current broad educational understanding of severe disability. In the United States, students with profound disabilities are identified under broader categories in IDEA. There is currently no definition or description in the U.S. educational system that characterizes a very small subgroup of students with the most pervasive and profound disability, known in European nations as profound intellectual and multiple disabilities (see Individuals with Disabilities Education Improvement Act, 2004). The definition and characteristics of students with the most profound disability were a foundational consideration in the current study. Therefore, the population was defined more specifically through other recognized medical, psychological, and educational lenses that provided greater levels of disaggregation.

Broad Picture of Student Identification in Education

Carnaby (2007) utilized a collection of resources from the World Health Organization (WHO), the American Psychiatric Association, and analysis of research from 1994 and after in an attempt to clarify the condition of PIMD. Carnaby suggested that individuals who would be considered as having PIMD present with an intelligence quotient less than or equal to 20–25 (at least five standard deviations below the norm), have a degree of learning difficult so severe that they function at a developmental level of 2 years old or less, and have any one or more of the following: severe physical disability, severe visual or hearing impairment, epilepsy, or other complex health conditions for which medication is required. In addition, individuals in the profound range of disability do not utilize symbolic language or representations (Antaki et al., 2017).

In the United States, there is no category or acknowledgement of PIMD in the legal documents governing special education. Data from the National Center for Education Statistics regarding the number of students in the United States receiving services for disabilities through 2014 revealed that there was no disaggregation for children with PIMD; they are included under the same broad categories of intellectual disability or multiple disability (United States Department of Education, National Center for Education Statistics, 2016). Additional inquiry directed to the National Library of Education: Office of Special Education and Rehabilitative Services, IDEA Data Center with a similar question regarding the awareness or acknowledgement by the educational system of the special category of students on the most profound end of the spectrum of disability yielded similar results. Data for students who would be included in the European definition of PIMD are not disaggregated (National Library of Education, personal communication, January 3, 2018).

The current emphasis on inclusive education further compounds the complexity of providing meaningful educational experiences for students with PIMD. Browder et al. (2014) stated the following:

> Students with the most severe disabilities- those who need the most intensive supports- are not well represented in the research literature. More research is needed on students who have emerging systems of communication, sensory, and physical impairments combined with severe intellectual disabilities and severe behavior disorders. (p. 49)

Gilmour (2018) suggested that an overemphasis on inclusion can result in equating the setting where a child is educated with the actual gains a child is making. In its *Endrew F. v. Douglas County School District* (2017), the Supreme Court determined that a child's educational benefit in their educational setting must be considered. Gilmour concluded that educational settings for children with disabilities may be determined by bureaucratic *shoulds* for inclusion rather than on a student's actual access and progress in personal educational goals.

Studies regarding the strategies and successes of inclusive practices for students with severe disabilities have been based on the impact of education on students in the general category of intellectual disability. These more general studies have supported the findings that students with moderate and severe developmental disability can learn mathematical content that aligns with their grade level, including problem-solving, by utilizing technology, graphic organizers, and manipulatives (Browder et al., 2014; Spooner et al., 2018), as well as demonstrate success in achieving conventional literacy (Erickson, 2017). When these research findings are examined in the light of medical and psychological definitions of severe disability, there is incongruity in the characteristics of what is considered severe; a disharmony emerges between medical and psychological understanding and educational interpretation of student characteristics. This research demonstrated that a lack of common understanding of the characteristics of PIMD may often lead to "erroneous expectations of positive results of research or successes in practice of therapies, support programs, or best practices for individuals with PIMD" (Nakken & Vlaskamp, 2007, p. 84).

Although well intended, strategies that are a part of the UDL, if not understood in the context of PIMD, could increase the possibility of disappointment, isolation, and educational neglect. Nakken and Vlaskamp (2007) warned that embracing an encompassing, absolute rule of full, equal participation for all students could limit rather than broaden the options, choices, and freedoms for individuals with PIMD and their families. Where acknowledgement and definition of a category of disability is not present, it may indicate that guidance in developing educational responses to the disability may be lacking.

Defining the Population Outside the Educational Realm: The Health Care Taxonomy of Profound Disability

The population of individuals who live with the most global and profound disabilities is beginning to gain focus from the health care industry, which has become aware of the disparity in health care and outcomes of those with disabling conditions (Krahn et al., 2015). In an effort to provide standard language and an internationally shared conceptual basis for the definition and measurement of health and disability, WHO designed a framework known as the International Classification of Functioning, Disability and Health (World Health Assembly, 54, 2001). The World Health Assembly approved the adult framework in 2001 and published a companion framework for children and youth in 2007 (see World Health Organization, 2007).

The areas of functioning that are represented by this framework include the functioning level of the body, the activities of an individual with a disability, participation in society, and environmental factors that might include barriers and

facilitators of functioning (Ustun, 2007). Krahn et al. (2015) noted that adoption of the International Classification of Functioning model has been slow in the United States, in part because it offers a social model of disability while the medical community in the United States subscribes to a medical model. The use of a medical model in the understanding and treatment of students with disabilities has been a factor in U.S. public education, and was a basis for the system of reform proposed and championed by Deno who established the basic ecological model used for U.S. Public Law 94-142 in 1975 and IDEA in 2004 (see Deno, 1972; Hallanhan & Kauffman, 1994; University of Minnesota Institute on Community Integration, 2013).

In the United States, the American Psychological Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) that provided a definition for individuals who present in the profound range of disability, which correlates closely with the International Classification of Functioning model. A constraint of this publication is that its use is limited to professionals in the mental health field, and has not been adopted as a tool in the field of education. The DSM-5 includes specifiers for various levels of functioning that are defined on the basis of adaptive functioning and not IQ scores, because when a person reaches the lower extremes of the IQ range, testing for IQ become less valid (American Psychiatric Association, 2013). In the severity level of *Profound*, three domains are identified: conceptual, social, and practical. See Table 1 for full descriptive identifiers.

Table 1

Intellectual Severity Level: Profound

Conceptual domain	Social domain	Practical domain
Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goal-directed fashion for self-care, work, and recreation. Certain visuospatial skills, such as matching and sorting based on physical characteristics may be acquired. However, co-occurring motor and sensory impairments may prevent functional use of objects.	The individual has very limited understanding of symbolic communication in speech or gesture. They may understand some simple instructions or gestures. The individual expresses their own desires and emotions largely through nonverbal, nonsymbolic communication. The individual enjoys relationships with well-known family members, caretakers, and familiar others, and initiates and responds to social interactions through gestural and emotional cues. Co-occurring sensory and physical impairments may prevent many social activities.	The individual is dependent on others for all aspects of daily physical care, health, and safety, although they may be able to participate in some of these activities as well. Individuals without severe physical impairments may assist with some daily work tasks at home, like carrying dishes to the table. Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support. Recreational activities may involve, for example, enjoyment in listening to music, watching movies, going out for walks, or participating in water activities, all with the support of others. Co-occurring physical and sensory impairments are frequent barriers to participation (beyond watching) in home, recreational, and vocational activities. Maladaptive behavior is present in a significant minority.

Note. Adapted from American Psychiatric Association, 2013). *Diagnostic and statistical manual of mental disorders (5th ed.), p. 36.*

https://dsm.psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596

Despite the detailed description provided in the DSM-5, the educational community in the United States does not include the presence of most severe disability as a unique and challenging academic enigma, but instead utilizes a broad classification of intellectual disability without clarification of severe or profound manifestations of this type of disability (Every Student Succeeds Act, 2015). This American Psychiatric Association mental health resource could be helpful to the educational community as professionals seek to improve cohesive service to individuals with disabilities. Although students with profound challenges may lack some of the capacities identified by the DSM-5, these descriptions could serve as an appropriate starting point in identifying a student's adaptive behavior capacities and strengths, adding to the deficit in understanding of adaptive behavior stated in IDEA (see Individuals with Disabilities Education Improvement Act, 2004). Identifying competencies is necessary in developing the goals, methods, and activities that characterize an individualized educational plan for children with PIMD (Elder et al., 2018).

Great Britain and Scandinavia, leaders in the fields of philosophy and education related to children with profound disability, share common conceptual frameworks and language in their work with individuals with disabilities modeled on the WHO definitions of disability. Vorhaus, a contemporary researcher of moral and educational philosophy, utilized data from the SALT Review, commissioned by the government of the United Kingdom, which provided characterization of students who are included in the scope of PIMD as follows:

> Pupils with profound and multiple learning difficulties have complex learning needs. In addition to very severe learning difficulties, pupils have other significant difficulties, such as physical disabilities, sensory impairment, or a severe medical condition. Pupils require a high level of adult support, both for their learning needs and their personal care. They are likely to need sensory stimulation. . . [and] communicate by gesture, eye pointing, or symbols. . . . Their attainments are likely to remain in the early P scale range throughout their school careers. (Salt, 2010, p. 14)

Because the focus of the current study was on issues of education, the P Scale definitions referred to in the Salt Review may be the most informative and helpful understanding of the segment of disability of concern. The P Scale system is used throughout the United Kingdom to specify performance attainment targets and performance descriptions for students with special educational needs (Gov. UK. Department of Education, 2017) who are performing below the standard of the national curriculum (Reference Department for Education, 2010), much like the more general alternate educational content standards used by many states in the United States. See Table 2 for P Scale descriptors that are associated with students having profound disabilities.

Table 2

Performance Descriptors

P-Scale Level	Descriptors
P1(i)	Pupils encounter activities and experiences • May be passive or resistant • May show simple reflex responses • Any participation is fully prompted
P1(ii)	Pupils show emerging awareness of activities and experiences • May have periods where they appear alert and ready to focus their attention on certain people, events, objects, or parts of objects • May give intermittent reactions
P2(i)	Pupils begin to respond consistently to familiar people, events, and objects • React to new activities and experiences • Begin to show interest in people, events, and objects • Accept and engage in coactive exploration
P2(ii)	Pupils begin to be proactive in their interactions • Communicate consistent preferences and affective responses • Recognize familiar people, events, and objects • Perform actions, often by trial and improvement, and they remember learned responses over short periods of time • Cooperate with shared exploration and supported participation

Note. Adapted from "Gov. UK. Department of Education, 2017). Performance (P Scale) attainment targets for pupils with special educational needs (SEN)," p. 5.

Clarity regarding the characteristics of the population who have profound disability is critical for a shared understanding of this topic. For these reasons, the definitions and terminology utilized by European nations to denote the population of citizenry who live with PIMD were used throughout the current study. This study was needed because the body of research that enables greater knowledge and understanding of individuals with profound disability and their education has largely focused on the culture and practices of health care and special education in European nations. Information that is readily available to teachers in the United States has most often addressed the education of students with higher IQ and ability levels, often leaving teachers without guidance or precedent as they seek to provide services for students with PIMD.

Through this study, I hoped to elicit the knowledge and experiences of the teachers who are charged with the face-to-face challenge of providing appropriate educational experiences for learners with PIMD. The results of this study may provide special education teachers, researchers, and policymakers with a broader vision of what teaching looks like in cases of PIMD in public schools, as well as the strategies that are being used in goal setting, curriculum planning, and teaching practices and strategies. The research may add to the knowledge base of public education for students with PIMD, perhaps adding a deeper understanding of the professional development, coursework, training, and support that could benefit teachers regarding their work with students with profound learning needs. The goal was to improve the experiences of teachers and their students as they work toward educational practices that enhance the dignity, capacity, and happiness of those engaged in the work of special education in PIMD.

Problem Statement

Signed into law in 1975, Public Law 94-142, reauthorized as IDEA in 2004 (Education for all Handicapped Children Act, 1975), mandated and ensured the education of all students with disabilities in the United States, prompting many states to establish extended educational standards to address the needs of exceptional learners. Extending federal law even further, the 2017 Supreme Court case of *Endrew F. v. Douglas County School District RE-1* (2017) was explicit in its finding that "states must provide children with disabilities 'access' to education that is meaningful" (p. 33). However, in the laws and mandates that guide the United States educational system (IDEA, ESSA), there is no specific recognition or definition of the especially challenging subgroup of students who are identified under the 14 broad categories that create eligibility for special educational services, those with PIMD. As a result, they are eligible for specialized instruction, but there is little guidance for educational practice, as evidenced by published state standards for students with severe intellectual disability (see Appendix B). As a result of little guidance from state and federal standards, the current multiple case study focused on how teachers in school districts in the United States are providing appropriate and meaningful education to students with the most profound intellectual disabilities.

Educational Standards and Curriculum

Every U.S. state has established or adopted accessible educational standards to address the needs of learners with disabilities under the mandate of Every Student Succeeds Act (2015). In seeking to place earlier research on Common Core State Standards and College and Career Readiness for students with disabilities within the

context of students with severe disabilities who benefit from alternate achievement standards, Morningstar et al. (2017) concluded that more research is needed to determine how "state and local educational agencies are aligning essential characteristics of CCR [College and Career Readiness] with the AAS [Alternate Achievement Standards] for students with severe disabilities" (p. 200). Further, Morningstar et al. noted that special educators of students who utilize alternate achievement standards (that is, students with severe intellectual disabilities) struggle to use effective planning methods and align students learning needs with standards, and that a model needs to be created that will facilitate the work of teachers as they develop interventions, supports, and supplementary services that will nurture success for students with severe disabilities. Case study outcomes can facilitate deeper understandings of processes and practices within a context (Harrison et al., 2017), which in the current study was an educational context. Although the creation of a model as suggested by Morningstar et al. was beyond the scope of this study, the data from this study gathered from teachers who are on the front line of educating students with PIMD may support later work to construct such a framework.

Chapter 2 of this study includes an in-depth examination of the alternate achievement standards for each state and the District of Columbia, which revealed an organizational understanding that children with PIMD may experience standards-based curriculum as a context in which to embed the developmental goals of engagement, communication, and self-actualization. Although a broad conceptual understanding of these standards allows teachers to adapt their application for the extremely low incidence of children with PIMD, ambiguity remains as to what the curriculum and educational

process should look like and what strategies and methods may help in the furtherance of engagement, communication, and actualization goals.

In their systematic review of research on curriculum for students with moderate and severe intellectual disability, Shurr and Bouck (2013) concluded that over a 15-year span, only 2–3% of all articles published in key journals regarding students with moderate to severe disabilities were found to have curricular-focused articles. Moreover, Shurr and Bouck found it problematic that of that 2–3%, most did not provide clearly defined context or focus for students with moderate to severe disabilities. Building on the work of Shurr and Bouck, Moljord (2017) concluded that curricular research for students with intellectual disability from 1994 to 2016 followed a predominantly cognitive academic approach, reflecting the current special education ideology of UDL, standards-based education, and access to the general education curriculum for students with intellectual disabilities.

Moljord's (2017) finding of a cognitive–academic curricular focus for the education of students with disabilities supported the hypothesis suggested by Shurr and Bouck (2013) that cognitive academics surpasses the foundational functional life skills in research for students with ID. This cognitive and academic focus may be occurring as a result of the entire range of intellectual disabilities being included in the review, instead of only moderate and severe intellectual disabilities (Moljord, 2017). Recognition of subgroups within the intellectual disabilities category may elicit consideration of an issue that must be considered ethically as well as academically. Being able to read and write may be considered functional life skills of the 21st century. However, "for a proportion of

the [intellectual disabilities] student population, the aim of being literate and numerate may be out of reach. For some students with [intellectual disabilities], focusing on sensorimotor stimulating and communication are essential" (Moljord, 2017, p. 656). This nexus of academic standards, philosophy, and ethics was critical to the need in the current study to employ both theoretical and conceptual frameworks, which are introduced later in this chapter.

Published Curricula and Profound Disability

Educational standards, or learning goals, are established to set the expectations for students. Once these standards are determined, the work of curriculum development lies in creating an organized plan to teach students so that they may reach these goals. Several curricula have become available to meet the needs of children with profound needs while still aligning with state academic content goals.

The Unique Learning System is an online, standards-based curriculum designed with three differentiated difficulty levels to accommodate a range of students with significant disabilities, with online, picture and symbol-supported instruction as primary tools. The curriculum is aligned to the procedures used in statewide alternate assessments (Ahern, 2011). A review of information provided on the Unique Learning System website, program materials, and an online blog for teachers who use this program indicated that there is a gap in all materials at the *Participation Level/Level One* (students with severe cognitive challenges) level. "[T]hose of us serving primarily or only students with severe/profound disabilities still will be unable to use many materials without significant adaptations" (Ahern, 2011, para. 3). The vision of the Unique Learning

System may be glimpsed through the following information from the Unique website regarding literacy: Unique covers "all of the vital pillars of reading instruction-phonemic awareness, phonics, fluency, vocabulary and comprehension" and "meet grade-level extended standards with comprehensive ELA (English Language Arts) instruction" (News to You, 2021). The expectation that students will develop these literacy skills is not consistent with the characteristics of students with PIMD, particularly in the conceptual domain, in with these students are involved in "physical world rather than in symbolic processes" (American Psychiatric Association, 2013, p. 36).

Another published curriculum focusing on students with significant cognitive abilities is the *MEville to WEville* curriculum, a research-based K-12 emergent literacy and communication program developed for students with "the most significant multiple disabilities" (Erickson et al., 2005, p. 46). This curriculum, like Unique, is based on the premise that students with moderate to severe disabilities can learn and use common literacy strategies including letter identification, concepts of word, letter, and one-to-one match between spoken and written words, and phonological awareness to learn new words, develop expressive language, build comprehension of vocabulary and stories, and to have opportunities to express themselves in writing (pp. 49-50).

Like the state extended curriculum standards, these curricula were created to ensure that students with severe disabilities receive appropriate instruction, and that teachers have access to curriculum materials that have integrity for their intended student population. These resources are invaluable for use with students who fit the broader category of intellectual or severe disability, but they require students to have the capacity

to utilize symbolic understanding. As discussed earlier, students with PIMD are characterized by their lack of symbolic language, communication, and understanding.

An exploratory review of educational databases and sources dealing with profound disability yielded insights into research that is being conducted to further the knowledge of meaningful and practical educational strategies. These studies are nearly all being done in Scandinavian countries where students are being treated in residential or day-treatment facilities (Bunning et al., 2013; deBoer & Munde, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; Jansen et al., 2012, 2016; Ten Brug et al., 2015). The few articles that have been published in the United States have focused almost exclusively on medical and psychological implications of PIMD rather than educational applications (Blain-Moraes et al., 2013; Darling & Circo, 2015).

Studies originating in the United States have not addressed the experience of teachers in the United States who are responsible for the appropriate and meaningful education of students with PIMD. The broad range of abilities that is connoted by the term *severe disability* results in a marked absence of resources designed to support the educational undertakings of teachers who work with students with PIMD. Efforts to interpret educational standards and design curriculum using best educational practices for students with profound disability will require that explicit distinctions be made between the broad educational categories of intellectual disability and multiple disabilities and the specific group of individuals with PIMD. Roemer et al. (2018) found that a number of qualitive studies concerning individuals with severe disabilities used a definition of severe disability that resulted in the researchers focusing their work on participants with

higher cognitive abilities than those of people with the level of profound disability indicated by PIMD. The research methods used in many of these studies are not suitable for people with PIMD (Roemer et al., 2018). Students with PIMD are dependent for their education on professionals who have knowledge about their individual needs and preferences, who know what possibilities may exist, and who will support them in exploring those possibilities (Wessels & van der Putten, 2017). Wessels and van der Putten (2017) also asserted that providing appropriate support is difficult because valid and reliable instruments that can be used for individuals with PIMD are "scarce" and "do not lead to a valid estimation of a developmental level" (p. 2).

Purpose of Study

The purpose of this exploratory multiple case study was to investigate how special education teachers are providing appropriate and meaningful education to students with PIMD, students with profound manifestations of disability, with little guidance from state and federal educational standards. The intent was that this research would increase awareness of the subgroup of students with PIMD whose needs, strengths, and educational goals fall outside of the range of traditional educational practice in the U.S. public school system through glimpses of the work of the public educators who engage with them. This examination was undertaken via the lens of knowledge, experiences, and practices of the special education teachers who work with these individuals in the light of federal and state educational mandates. Narrative inquiry and structured interviews, augmented by educational record review, were used to collect data on current educational practice.

Research Questions

1. What are the lived experiences of teachers of students with profound intellectual disability who teach in public school districts in the United States regarding challenges and successes in their teaching practice?

2. What kinds of curriculum, activities, and practices do teachers of students with PIMD utilize in their teaching to fulfill the federal mandate of meaningful education, and from what sources are these tools (curriculum, activities, practices) obtained?

3. How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?

Frameworks of Study

Historical and contemporary educational theorists laid a theoretical foundation for meaningful and democratic education, contributing to human growth before the emergence of contemporary educational law and legal mandates that gave consistent structure to the practice of public education. The conceptual framework was developed to give form to the practice of education in the light of current understandings of student identification, legal mandates, and ethical practice.

Theoretical Framework

In beginning a study on the education of students with profound disability, it is helpful to refer to the work of Dewey on experiential and interactive learning, as well as the work of Vygotsky on social interaction. The theoretical framework for this study was based on the extensive writings of Dewey for whom a significant premise of education

was that social interaction and reciprocity are at the center of human growth and the life of society. Further, Dewey (1893, 1899, 1902, 1909, 1916) and Vygotsky (1978) shared the ideology that appropriate education must include the elements of communication, self-actualization, and social justice.

An additional, more contemporary theory that was important to the examination of profound disability was that of Nakken and Vlaskamp who argued for an internationally accepted, specific identifier for individuals who have profound intellectual and multiple disabilities (Nakken & Vlaskamp, 2002, 2007; Vlaskamp, 2005; Vlaskamp & Nakken, 1999). The key characteristics of the most profound manifestation of intellectual disabilities proposed by Nakken and Vlaskamp have been described in British journal publications dating back to 1999 (Vlaskamp & Nakken, 1999). Without a common definition and understanding of this population, there will be limited recognition that educational goals and quality-of-life decisions may be very different from those of the wider disability population, and appropriate treatments and interventions may be underdeveloped.

As these theories are applied to the work being done with students with PIMD to provide a full and appropriate education, special education teachers have a unique and important role in the development and implementation of educational goals and practices within an environment of educational complexity (Lavian, 2015). Striving for continuous improvement and greater efficacy in the work with children with PIMD, educators have offered valid, insightful, and practical voices to achieve the educational goals set forth in federal law (Pickl et al., 2016). The examination of contemporary definitions, legal

decisions, and moral and ethical considerations was added to this foundation of theory composing the conceptual framework that undergirds the work of educating students with PIMD in public school settings.

Conceptual Framework

The conceptual framework included three aspects of profound disability that must be considered in the integration of education and PIMD. First, a clear and shared definition of the population must be established to facilitate communication between professionals and disciplines, promote best practices for the specific population (Soorya et al., 2018), and avoid invalid expectations for intervention (Nakken & Vlaskamp, 2007). The legal considerations involved in public education for students with disabilities must be understood and applied, but for students with profound disability, foundations of personhood and ethical practice are of great significance in educational decision-making (Vorhaus, 2015). Although the theoretical framework for this study was based on the work of educational theorists, the conceptual framework was developed to give form to the practice of public education in the light of current understandings of student identification, legal mandates, and ethical practice. The research questions of this study were designed to probe the work of special education teachers in the United States as they seek to provide appropriate and meaningful education of students who present at the most profound end of the spectrum of intellectual disability with little guidance from the state and federal standards. Chapter 2 includes a more detailed description of each of these three contemporary issues in the public education of students with PIMD.

Nature of Study

This research was a qualitative exploratory multiple case study supported by narrative inquiry. Data were collected through structured interviews and educational record review. I chose a multiple case study based on two premises: that of Eisenhardt (1989) who wrote that this approach could be relevant when researching new areas for which existing theory may be insufficient, and that of Yin (1994) who asserted that case study allows for deep and detailed investigation of a research question.

The cases that I investigated were part of a subset of teachers in the United States chosen based on their experience with students having profound disability. Geographic area was of interest because one of the goals of standards-based education is based on the premise that "it's critical that, collectively, we raise the bar so that every student in this country—regardless of socioeconomic status, race, or geographic location—is held to high learning standards" (United States Department of Education, n.d., para.1). For this reason, cases were recruited from various segments of the United States with the goal of discovering the experiences of a wide range of educators who share a common population of learners. The experience base of the teachers chosen for this exploratory multiple case study was critical, with the single focus of the practice of special education teachers who are responsible for the education of students with characteristics of PIMD, a population that is addressed in Department of Education mandates as comprising less than 1% of the student population in the United States (United States Department of Education, 2017b).

The primary source of data collection was interviews that were conducted with kindergarten through Grade 12 teachers in school districts in the United States who are responsible for the education of students on the most profound end of the disability spectrum. Triangulation was achieved through review of two types of educational documents supplied by the teachers being interviewed. Educational documents included Multifactored Evaluations (MFEs) and Individualized Education Plans (IEPs) with names redacted to ensure confidentiality of students.

Definitions

Child with a disability: "Child with a disability means a child evaluated…as having an intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as 'emotional disturbance'), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services" (Individuals with Disabilities Education Improvement Act, 2004, § 300.8).

Intellectual disability: "[S]ignificantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance. The term 'intellectual disability' was formerly termed "mental retardation" (Individuals with Disabilities Education Improvement Act, 2004, 20 U.S.C. 1400, § 300.8).

Multiple disabilities: "[C]oncomitant impairments (such as intellectual disability-blindness or intellectual disability-orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. Multiple disabilities does not include deaf-blindness" (Individuals with Disabilities Education Improvement Act, 2004, 20 U.S.C. 1400, § 300.8).

Profound intellectual and multiple disabilities (PIMD): The subgroup of students with moderate to intensive disabilities having the following characteristics:

- Although it is impossible to attain an accurate IQ score for these students, it is generally agreed that PIMD indicates a probable IQ of below 20 (Blain-Moraes et al., 2013; Roemer et al., 2018; Ten Brug et al., 2015).
- People with PIMD need extensive supports to engage meaningfully in life and to participate in the ordinary daily activities of people without disabilities (Hughes et al., 2011).
- People with PIMD require extensive physical and medical care (nursing, feeding, mobility, positioning, or breathing support) and are completely dependent on others for activities of daily life (Rosenbaum, 2008).
- People with PIMD do not have a meaningful or reliable way to express thoughts or feelings; it is very hard to interpret what they communicate, and this communication may occur through noises or movements that are unique to them. In addition, they may lack verbal understanding and communicate at

a presymbolic level (Blain-Moraes et al., 2013; Hostyn & Maes, 2013; Roemer et al., 2018; Ten Brug et al., 2015).

- Individuals with PIMD have severe motor disabilities and low levels of alertness (Roemer et al., 2018; Wessels & van der Putten, 2017).

Special education teacher: In some states, the term *intervention specialist* has been adopted to define educators with degrees in special education. Under IDEA, a highly qualified special education teacher must fulfill two requirements: having at least a bachelor's degree and holding full state certification as a special education teacher or passing the state special education licensing exam (Individuals with Disabilities Education Improvement Act, 2004).

Student: A child enrolled in kindergarten through Grade 12 in a school district in the United States. Because the population of concern in this study was students with disabilities, it should be noted that under IDEA, special education students can be funded until the day of their 22nd birthday if the students meet eligibility requirements.

Assumptions

One assumption of this research was that participants who met the inclusion criteria of the purposeful sampling strategy used in the study would have basic knowledge of the discipline of education in general and special education, in particular to recognize the development level, characteristics, and trajectory of a student with intellectual disabilities (see Collins, 2007; Tyler et al., 2003). Other assumptions were those that are commonly applied to qualitative research, including beliefs that participants

would answer interview questions candidly and honestly, and that the inclusion criteria would ensure that relevant data were collected.

Scope and Delimitations

The study's focus was narrow in the definition of the specific population being investigated and in the teachers who were interviewed. Although the issues being addressed in this study had national implications, the sample size for this study needed to be manageable. According to the National Center for Education Statistics, as of 2013–2014, 53% of all school districts in the United States were ranked as rural, 18% were identified as town districts, and 29% were urban/suburban districts (United States Department of Education, National Center for Education Statistics, 2016). In light of these statistics, recruiting the sample from various points along the urban–rural spectrum of districts in the United States fit the framework of an instrumental case study, which allows a researcher to investigate a specific issue (see Crowe et al., 2011) that may be applicable in many areas of the United States. In applying Campbell's 1986 (as cited in Polit & Beck, 2010) proximal similarity model to support congruence of collected data, my target population needed to share demographic characteristics of certified teachers of students with PIMD who are currently working with students of the PIMD population.

Limitations

Threats to External Validity

Extraneous Variables

Anticipated in this study were the following factors that could have impacted responses: treatment environment (home-based, resource room, general education

setting), current level of burnout or job satisfaction, gender, years of experience, and type of undergraduate degree. Demographic questions were included in the structured interviews related to these variables, and the patterns that emerged from analysis were discussed in the study.

Testing Reactivity

The problem of testing reactivity may be present in qualitative aspects of a research design (Gibb, 2011). I reduced the likelihood of testing reactivity in my study by utilizing an expert panel to help identify any language or wording in my interview plan that might have influenced a respondent to shape their answers to provide the socially desirable answer or confirm the suspected desired response. In considering this issue of testing reactivity, I also considered the possibility that respondents might have been reluctant to be fully forthcoming on topics of their knowledge and the potential moral/ethical philosophies that they hold in regard to students with PIMD. Because the study participants were in-service teachers, there was an ethical balance that I needed to achieve. The ethical issues were not related to the highly vulnerable and protected population that they serve, but rather to the teachers' willingness to offer transparency. Teachers of students with PIMD may benefit from this research through means of having their viewpoints considered, serving as advocates for students with PIMD and their families, and propelling the work for resources to meet the legal and ethical mandates in the education of students with PIMD. Despite these potential benefits, I considered that there could have been concerns among these educators when they were asked to provide written or recorded data concerning their knowledge and feelings concerning their job.

Confidentiality was ensured to minimize any fear of judgment on the part of teachers. Interviews took place via telephone outside of work hours and outside of the participants' workplaces. Recorded interviews were transcribed, numbered, and erased once the complete transcripts were verified, eliminating the connection between the respondent and their comments.

Construct Validity

The most significant source of construct confusion that I anticipated was that of defining the population. PIMD is not a distinct classification in the United States, and students with this level of disability are identified under one of several broad categories. I was careful to clearly define and give explicit examples of the student characteristics for the population referred to in the study. Although the population will always be somewhat heterogeneous, construct clarity served to narrow the definition so that valid data could be collected.

This study was strengthened by my position as both a practitioner and a researcher, and that the research was not done in my location of employment. My professional experience helped build the interest, trust, and transparency with my participants, which was an asset to the study. I balanced subjectivity and objectivity of perspectives in two of the ways suggested by Onwuegbuzie and Johnson (2006). First, after the interview process, I utilized a retired, trained practitioner in the area of PIMD to check my interpretations of transcribed data from interviews. In addition, throughout the process of data collection, I utilized dynamic participant review, repeating back what I had heard the participant say and seeking clarification or agreement with my

understanding. Through these strategies, I was able to utilize insider–outsider legitimization throughout the data interpretation process.

Threats to Internal Validity and Credibility

Because issues of moral and ethical values are interwoven with legal mandates in the work with individuals with profound intellectual disabilities, there are two types of researcher bias of which I sought to be especially cognizant. First was confirmation bias, as I chose to study an issue that is salient in my professional practice, and that, based on literature review and confirmation from other educators, appears to illuminate a gap in special education for students with profound learning challenges in school districts in the United States. It was necessary for me to defer my suspicion that a gap exists, and explore the knowledge base through my research design to determine whether existent literature and the experiences of other educators supported or disconfirmed this gap. Awareness of my tendency toward confirmation bias helped me to acknowledge and follow the lead of both corroborating and contradicting data (see Stapleton, 2019).

The second issue that I needed to be attentive to in my study was that I could not judge respondents' thoughts and reflections based on my value system. I could not allow the emotional and philosophical construct of human value to influence this study. I know that the work of special education is not based only in moral and ethical value judgments (although those do provide a historic foundation), but also in the constitutional and legal rights of individuals in society, and in the law governing special educational practice. Having a well-established interview protocol was important in ensuring that my interview questions remained aligned with my research questions and that interviews, while

allowing for open-ended discussion, did not stray too far from the central purpose (see Stapleton, 2019).

Issues of Trustworthiness

Data saturation (or inadequate data saturation) has an impact on the quality of research, yet is very complex in qualitative studies, focusing both on richness of information and reaching the range of participants who best represent the research topic (O'Reilly & Parker, 2012). Because interviews were a part of the data collection in this study, saturation was facilitated at the research design stage by determining a semistructured interview protocol that involved asking multiple participants the same questions and adhering to similar lengths of interviews (see O'Reilly & Parker, 2012). Additionally, I was able to recruit teachers who would often be absent from public school district records (e.g., those who are contracted by local school districts to work itinerantly through educational service centers or in public separate schools). In my reporting of data, I utilized transparency about my choices and limitations in recruitment.

Qualitative methodology is used to understand and address complex challenges in the world (Bansal et al., 2018), shaped by the practices of in-depth, descriptive questions, life experiences of individuals, and contextual understandings (Creswell et al., 2007). As I conducted interviews, I was aware of the importance of the voices and perspectives of my respondents regarding the subject of the education of students with PIMD. Education that fulfills the legal and moral mandates of meaningful experience cannot be examined outside of the context of human relationships and experiences. Clear and rich

documentation and interpretation of these human factors have been included in my discussion.

Significance

The mission of positive social change requires that scholarship result in the "improvement of human or social conditions" by promoting the "worth, dignity, and development of individuals, communities, organizations, institutions, cultures, and/or societies" (Walden University, 2021, Social Change section, para. 1). There is a need to address the issue of the value, dignity, and worth of human beings outside of the parameters of economic potential and asset/liability considerations. School reform and accountability are most often the solutions offered for educational challenges, yet in the sphere of PIMD, the law alone is unable to provide a structure of reform and accountability. What is needed is a strengthening of daily, ongoing, meaningful educational experiences that will lead into posteducational life for individuals with PIMD in a positive effort to balance the often disillusioning interactions between these individuals and the support team that surrounds them (Rossetti et al., 2016). Teachers and therapists need resources and assurance that there is structure, meaning, and value in the work that they do (Griffiths & Smith, 2016). Families need to be supported (Axelsson et al., 2013; Jansen et al., 2012). Students with PIMD need to be assisted in living with dignity, happiness, and optimal self-actualization (Darling & Circo, 2015; Hostyn & Maes, 2013).

This research may partially fill a gap in the knowledge about the experiences of special education teachers in the United States as they work to provide appropriate and

meaningful educational experiences for students with PIMD, and do so with little guidance from state and federal mandates. This low-incidence student population is perhaps the most challenging group to educate because of the entanglement of moral, ethical, social, personal, economic, and educational issues that are embodied within the individual (Blain-Moraes et al., 2013; Curtis & Vehmas, 2016; Griffiths & Smith, 2016; McFerran & Shoemark, 2013; Simmons & Watson, 2014). The outcomes of practice are not easily measurable, and like other educational endeavors they include not only the student but also their family, service providers, and community, and may impact the national perspective (Axelsson et al., 2013; deBoer & Munde, 2015; Jansen et al., 2012; Vorhaus, 2015).

Summary

In the United States, free, appropriate public education is a legal mandate. In the case of students with profound disability, this legality becomes entangled with the equally important but more nebulous mandates of ethical and meaningful educational practice. Research in European nations has expanded the base of knowledge regarding enhanced quality of life and enriched practices and relationships for individuals with PIMD, but these studies have been conducted in the settings of residential care facilities and separated educational institutions (Bunning et al., 2013; deBoer & Munde, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; Jansen et al., 2012, 2016; Ten Brug et al., 2015). There is a gap in the research concerning how special education teachers approach their work of fulfilling federal mandates to provide appropriate and meaningful

public education for students with PIMD with little guidance from state academic content standards.

The work of neuroscientist Kurt Fischer focused on the transdisciplinary effort to connect “mind, brain, and education” (Immordino-Yang & Fischer, 2007, p. 3) with the goal of integrating brain science and the insights of teachers to cross-inform understanding and educational practices. The goal of the current study was to bring the voice of public school teachers into the conversation of special education for students with PIMD. My hope was this study would elicit information from in-service educators regarding their experiences with providing appropriate and meaningful education to students with profound disability, and have the added benefit of providing the teachers involved in the study a means to reflect on their practice, experiences, beliefs, and needs as they work with the small population of students with PIMD.

This chapter provided an introduction to this exploratory multiple case study, including the background, purpose, focus, and frameworks of this research. In Chapter 2, I examine historical and current special education laws in the United States, translation of those laws into the standards-based practice in public schools, the unique characteristics and needs of the PIMD population, and current research in the field of PIMD.

Chapter 2: Literature Review

In the United States, there is a comprehensive history of legal mandates, public laws, and court decisions that have shaped and governed the practices of public education of students with disabilities. These legal declarations have included language regarding appropriate, rigorous, and meaningful education for students regardless of the severity of their disability. There is one small subset of the special education population that has been inadvertently left out of the expanding base of knowledge and research regarding educational practice in the United States, however. Hidden within broad categories of intellectual and multiple disability, students who manifest the most profound characteristics of these disabilities are conventionally unrecognized in the United States educational system. There is little guidance from state or federal standards to guide the practice of special education teachers in school districts in the United States as they seek to provide an appropriate and meaningful education of students with the most profound intellectual disabilities, and there is minimal research that can lead to understandings and practices that will assist teachers in their work with children and young adults with profound disabilities.

Clarifying the Population

In the United States, educational research, curricular guidelines, content standards, and educational practices for students with severe to profound needs apply to the entire spectrum of students with intellectual disability, typically recognized as having approximate IQ scores of 70 and below, though including a top range of up to 77.5 (see Appendix A for full list of intellectual disabilities qualification by state). Although

appropriate for most students with intellectual disabilities, the language of common standards, evidence-based intervention, and evaluation is difficult to reconcile with the population of students with PIMD. This population is a very small subset of students with the most profound level of intellectual disability: those with an estimated IQ of 20–25 (at least five standard deviations below the norm), who have a degree of learning difficulty so severe that they function at a developmental level of 2 years or less, and have "little to no symbolic language" (Antaki et al., 2017, p. 581).

Students who would be considered as having PIMD are dependent on others for all aspects of life: nourishment, self-care, movement, medical interventions, and life experiences in multiple settings (home, school, hospital, children's treatment center, community-based settings; Rosenbaum, 2008). These children are typically nonverbal, demonstrating idiosyncratic means of communication that are difficult to interpret; presymbolic (Blain-Moraes et al., 2013; Hostyn & Maes, 2013; Ten Brug et al., 2015); present with an intelligence quotient at least five standard deviations below the norm, less than or equal to 20–25 (Blain-Moraes et al., 2013; Carnaby, 2007; Hogg, 1992; Ten Brug et al., 2015); have a degree of learning difficulty so severe that they function at a developmental level of 2 years or less; and have any one or more of the following: impairment to vision, hearing, or movement severe enough to affect the person's ability to adapt to day-to-day-living" (Hogg, 1992, p. 475); or "severe physical disability, severe visual or hearing impairment, epilepsy, and other complex health conditions for which medication is required" (Carnaby, 2007, p. 88). Students with this level of disability are very different learners with needs that vary from the descriptions noted in current

literature as severe disability (Dukes & Darling, 2017; Roemer et al., 2018). Without acknowledgement of students on this profound end of the disability spectrum, little guidance exists to frame the philosophy and structure the practice of the unique educational needs of these students (Morningstar et al., 2017).

Because the U.S. educational system has no definition of the subgroup of students with PIMD, there is little guidance to frame the philosophy and structure the practice of the education of students with this level of disability (Individuals with Disabilities Education Improvement Act, 2004, §300.8 [c] [6]; Ruppar et al., 2017). The legal considerations of common academic standards, evidence-based intervention, mandatory testing for all students, and meaningful developmental appropriateness are a complicated quartet to navigate. Failure to delineate this very small subgroup of students with disabilities may also lead to inadequate preparation of teachers who are responsible for this complex task, and may increase the risk for academic neglect (Nakken & Vlaskamp, 2007). Bartlett et al. (2015) suggested that these educational mandates for students with severe disabilities may serve to further marginalize the population by narrowing the curriculum through standardization.

The lack of disaggregation and research on the population of students with the most profound level of intellectual disability may result in a lack of knowledge or misunderstanding of their challenging and unique learning needs (Ruppar et al., 2017). The problem addressed in the current study was how, with little guidance from state and federal standards, special education teachers in the United States who are responsible for students with PIMD provide appropriate and meaningful education to these individuals.

An exploratory review of educational databases and sources dealing with profound disability yielded insights into research that is being done to further the knowledge of meaningful and practical educational strategies. These studies are nearly all being done in Scandinavian countries where students are being treated in residential or day-treatment facilities (Bunning et al., 2013; deBoer & Munde, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; Jansen et al., 2012, 2016; Ten Brug et al., 2015). The few articles that have been published in the United States have focused on medical and psychological implications of PIMD rather than educational applications (Blain-Moraes et al., 2013; Darling & Circo, 2015). Few, if any, articles have addressed the experience of teachers in the United States who are responsible for the appropriate and meaningful education of students with profound disability. Further research and application in developing, teaching, and aligning curriculum and evaluation for students with profound disability in the United States is needed (Dukes et al., 2017).

Although international research and practices exist to support ethical and meaningful educational applications for these students, that research is still making its way into the knowledge base of mainstream public education in the United States (Courtade et al., 2015). The purpose of the current exploratory multiple case study was to investigate how special education teachers are providing appropriate and meaningful education to students with PIMD, students with profound manifestations of disability, with little guidance from state and federal educational standards. The intent was that this research might increase awareness of this challenging subgroup of students whose needs, strengths, and educational goals fall outside of the range of traditional educational

practice in the U.S. public school system through case studies of the work of the teachers who facilitate their public educational experience.

This literature review follows three major trajectories: the social, political, and educational history of PIMD; philosophical and ethical considerations of practice; and the impact of these historical and philosophical foundations on current educational practice. I first address these contexts through an examination of the social and political milieu in which special education practice in the United States is situated. This section addresses societal attitudes, complications of shared governance of education, the impact of special education legislation on the interpretation of educational expectations for students with PIMD, and the problem of identification in PIMD practice. The second section addresses issues related to personhood, human dignity, and basic human rights in the consideration of educational practice for individuals with PIMD. The third section focuses on recent research that addressed the establishment of evidence-based educational practices that may enhance well-being, maximize communication, and address meaningful academic access to educational curriculum, transdisciplinary and inclusive educational models, and interpersonal reciprocity. Following the literature review, I discuss my chosen methodology and provide justification for the use of the exploratory multiple case study approach to the problem of profound disability in the educational environment.

Literature Search Strategy

In order to understand the complexities of issues related to the education of children with severe and profound disabilities, I structured my literature search into six distinct segments: historical and current special education laws and policies since the

1970s, translation of law into educational practices in public schools (development of extended standards and evidence-based intervention), the unique characteristics and needs of the PIMD population (need for definition), factors surrounding special education teacher staffing and training (licensure and attrition), the impact of self-efficacy on the performance of teachers of students with profound disabilities, and, current research on teaching practices for students with PIMD.

I gathered most of the current scholarly literature through searches of multiple databases in the Walden University online library, focusing primarily on education databases such as Education Source, ERIC, Academic Search Complete, and SAGE Journals. Applicable literature sources were collected from the reference portions of articles that were particularly salient to my topics.

Keywords for all searches conducted through the Walden University Library included exact terms or permutations that included*: profound disability, severe disability, profound intellectual multiple disabilities, PIMD, intellectual disability, special education, personhood, teachers, education, teacher preparation, attrition, assessing people with profound intellectual disability, low-incidence population,* and *evidence-based practice.*

To deepen my understanding of the legal history and current status of federal mandates that impact the education of students with PIMD, I accessed and read the original documents on which special educational practice is based: PL 94-142, IDEA, Americans with Disabilities Act of 1973 and subsequent amendments, as well as court records regarding Supreme Court case *Endrew F. v. Douglas County School District RE*

1. This search included work by Deno, whose framework for inclusive education is foundational to educational access for students with disabilities.

In an effort to gain an understanding of how individual states are facilitating education and accountability, I examined the work of Morningstar et al. (2017). Morningstar et al. acknowledged that their framework of study did not explicitly consider the characteristics of students with severe disabilities, which led me to conduct a state-level review of available online materials seeking information about how the Common Core Standards are interpreted for students with the most profound cognitive disabilities. The Google Chrome search engine was utilized in this search, beginning with a search of the state Department of Education site for each of the United States, as well as the federal District of Columbia. From information gleaned from the Department of Education websites, a deeper search was conducted using a variety of search terms including: *extended standards, extended content standards, core content connectors, extended evidence indicators, Dynamic Learning Maps, Essential Elements, grade band extensions, alternate achievement standards, alternate eligible content, Unique Learning System, curriculum framework,* and *alternate learning progression.* When online materials could not be located or accessed, I contacted personnel at the respective state departments of education for clarification.

Theoretical Foundation

The theoretical foundation for this study lies in the extensive writings of Dewey (1893, 1899, 1902, 1909, 1916) exploring his theory of experience, and Vygotsky (1978), for whom a significant premise of education was that social interaction and reciprocity

were at the center of human growth and the life of society. Further, these theorists shared the ideology that appropriate education included the elements of communication, self-actualization, and social justice.

Theorists Dewey and Vygotsky are diverse voices who have contributed theoretical foundations for the goals, methods, and priorities that may be applied to the curriculum and practice of educating children with profound disabilities. Dewey was an advocate for child-centered instruction that allowed for high levels of self-actualization (Dewey, 1916) and was a proponent of school reform. His emphasis on the practical aspects of schooling including active experience (Dewey, 1916), language development (Dewey, 1899, 1916), the value of shared experience (Dewey, 1909), and democratic principles (Dewey, 1916) in education bear many of the same marks as the current struggle to ensure appropriate and enriching educational practices for all students.

Vygotsky contributed to education an understanding of intertwining biological and behavioral components of development (Vygotsky, 1978). Like Dewey, Vygotsky's work emphasizes the development of language and socialization, as well as education as a process rather than a means to an end product. These theorists established a foundation of essential elements on which to build educational ideology and practice to guide the implementation of public education for children with profound disabilities. Historic theory offers further insights to guide the current development of educational programs for students who were, until very recently, thought to be outside of the realm of meaningful education (Deno, 1970). Dewey suggests that the passions of a child must be identified and utilized (Dewey, 1916). Dewey and Vygotsky provided strong cases for

providing a means for children to experience and initiate active motor experiences that occur in the context of socialization; a premise that has been supported in current literature (Calveley, 2017; Giles & Fresne, 2016; Pence & Dymond, 2015; Ten Brug et al., 2015). Vygotsky's theories on the topics of language, communication, play, and memory require us to pursue ways to stimulate, strengthen, or support these skills in children with profound disability.

An additional theory that is important to this work is that of Nakken and Vlaskamp (Nakken & Vlaskamp, 2002, 2007; Vlaskamp, 2005; Vlaskamp & Nakken, 1999) who argued for an internationally-accepted, specific identifier for individuals who have profound intellectual and multiple disabilities. The key characteristics of PIMD proposed by Nakken and Vlaskamp have been described in publications dating back to the 1980s and 1990s (Hogg, 1987; Realon et al., 1990; Vlaskamp & Nakken, 1999).

Nakken and Vlaskamp (2007) theorized that, without a common definition for this population, individuals in this marginal group are overlooked in discussion about human rights, value, and inclusion. Without a common definition and understanding of this population, there will be limited recognition that educational goals and quality of life decisions may be very different from those of the wider disability population, and appropriate treatments and interventions may be underdeveloped. This cautionary message was affirmed by Roemer et al. (2018) as well, noting that many research studies use definitions of severe disability that encompass a higher level of cognition than that of individuals with the widely accepted understanding of PIMD. Ruppar et al. (2017) affirm the complexity of teaching students with severe disabilities, and establish the connection

between appropriate teacher preparation related to the unique roles and expertise needed and the influence of that knowledge on the quality of education for students with severe disabilities.

In the last 50 years, the mission and ideology of public education has been stretched to include children who were once believed to fall outside of the bounds of meaningful education, gaining an initial entry into public schooling with P.L. 92-142. For children with the most profound disability, laws governing the provision of education have been established, yet meaningful implementation of the law through curricula reform at the state level and educational practice at the direct instructional level are still progressing, but continue to be underrepresented (see Appendices A and B; Spooner & Browder, 2014). The work of Dewey, Vygotsky, Nakken, and Vlaskamp may serve as infrastructure for the analysis of contemporary research that is being done to continue to further the humanistic and educational edict of appropriate education for all children.

As foundational premises including child-centered curriculum, active experiences, the importance of communication, a democratic approach to education, and the importance of recognizing the unique characteristics of learners with profound disabilities are gleaned from historic theory and applied to the work being done with students with PIMD in an effort to provide a full and appropriate education, intervention specialists have a unique and important role in the development and implementation of educational goals and practices (Collins & Ludlow, 2018). Striving for continuous improvement and greater efficacy in the work with children with PIMD, educators offer valid, insightful, and practical voices to achieve the educational goals set forth in federal law.

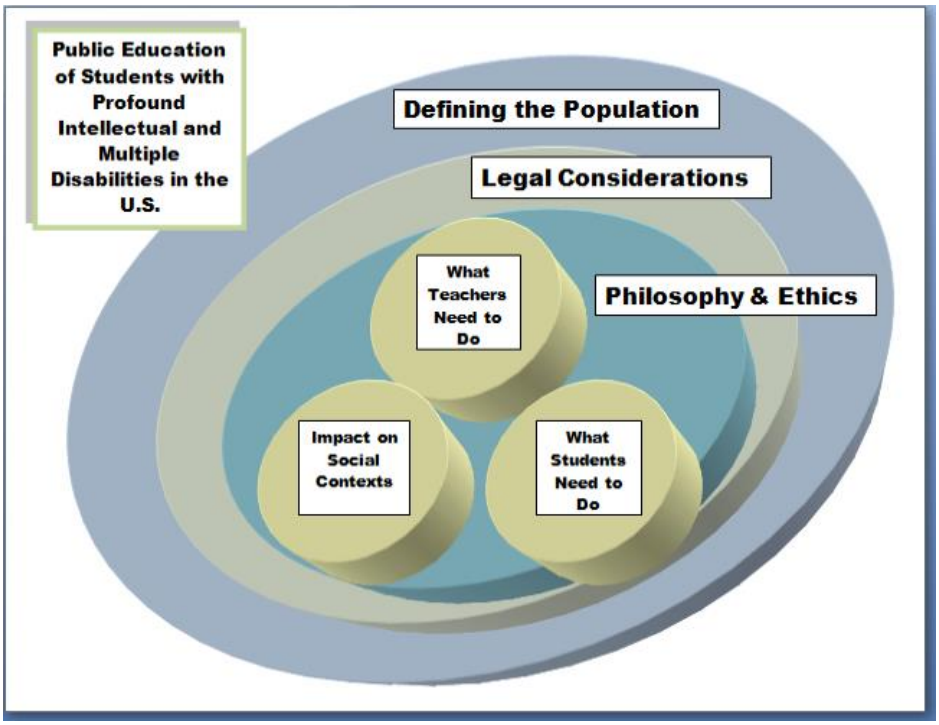
Conceptual Framework

The theoretical framework of this study was rooted in the work of established figures in education, and the conceptual framework provides a systematic flow and focus for the understanding of the topic of PIMD in the United States educational system. Kivunja (2018) defined a conceptual framework as the "total, logical orientation and associations of anything and everything that forms the underlying thinking, structures, plans and practices and implementation of the research topic…" (p. 47). Kivunja went on to explain that a conceptual framework is the structure that encases "all the concepts and ideas that occupy your mind as you contemplate, plan, implement, and conclude" (p. 47) a research project.

Figure 1 illustrates the conceptual framework that undergirds the work of educating students with PIMD in public school settings. Each part of this graphically presented framework illustrates the constituent topics of investigation that will comprise this study.

Figure 1

Conceptual Framework



The conceptual model created to shape the direction of this study begins in the outside oval: *Defining the Population*. The definition of PIMD globally and in the United States is the critical foundation of this work. These students comprise a small subgroup of the intellectual and multiple disability categories recognized in the United States educational system. Despite their inclusion in these broader categories, students with PIMD have very specialized needs requiring unique educational considerations (Antaki et al., 2017; Bartlett et al., 2015; Carnaby, 2007).

After defining the PIMD population, the second oval, *Legal Considerations*, examines the relatively short history of special education policy in the United States

including early mandates and laws, and continues to current Supreme Court cases that clarify not only the requirement of education, but of meaningful education for all students (United States Department of Education, 1983; *Endrew F. v. Douglas County School District RE-1*, 2017). When juxtaposed with the characteristics of learners with PIMD, the substantial challenges in fulfilling these mandates to provide a meaningful education may be considered. This section of the study supplies a legal justification for further understanding of the PIMD population, whereas the inner oval of *Philosophy and Ethics* addresses the moral and ethical considerations of educating students with profound disabilities. Although moral and ethical considerations may drive legal mandates, these issues become particularly salient at the level of educational practice; how schools and teachers address the unique needs of students with PIMD, how they conceptualize the value of a meaningful education for these children, and how the activities of education are carried out.

The three broad outer ovals provided the context for this study; the inner circles provided a practical component to the work. *What Teachers Need to Do* addressed the issues that teachers face in attaining and applying knowledge of PIMD, creating appropriate, evidence-based goals, and carrying out daily activities of meaningful education that contribute to the highest levels of student self-actualization and quality of life possible. The second circle, *What Students Need to Do* was based on the idea that for individuals with PIMD, educational experiences, personal care, and even social interaction are done *to* them rather than *with* them, inviting deeper study of Dewey's work on active education; that students must be engaged (Dewey, 1893, 1916). In current

legal terminology, educational experiences should be meaningful to the student and should strive to find a manner in which they may have a voice in the world (*Endrew F. v. Douglas County School District RE-1,* 2017).

The circle of *Impact on Social Contexts* was critical because the education of students with profound disabilities does not occur in a vacuum, impacting only the student. Individuals with PIMD are dependent on others to facilitate nearly every aspect of their lives, engaging the social contexts of family (Gardiner et al., 2018; Reichman et al., 2008), school (Almalki & Abaoud, 2015; Anaby et al., 2018), and community (Carter et al., 2016; McGowan et al., 2018). The teacher and educational teams who work with these students are also invested personally in the social contexts of their team, the student's family, and their own professional discipline (Cooper-Duffy & Eaker, 2017).

This conceptual model guided this exploratory multiple case study to explain significant factors in the instruction of students with PIMD. This portion of the study served to evaluate whether the Turnbull and Stowe (2017) characterization of the "work on the books" being translated to "the work on the street" (p. 223), and what factors impact educational practices, curriculum, and meaningful interpretation and implementation of the mandates of special education.

The quest of the United States education system to address students with disabilities has followed a mindset of growth over time:

- moral considerations (Training of Professional Personnel Act of 1959, Public Law 86-158: *Expansion of Teaching in Education of the Mentally Retarded*)

- educational access (Deno's *Cascade of Services* model, 1970; Education for All Handicapped Children Act, Public Law 94-142, 1975)
- equity (United States Department of Education, 1983, *A Nation at Risk: The Imperative for Educational Reform*)
- meaningful practice (*Endrew vs. Douglas County School District RE-1*, 2017)

As knowledge increased, more specific and standardized educational practices were sought to meet student needs (Courtade et al., 2015). At this time in the United States, there are robust state and federal mandates in place and research journals filled with studies being conducted to continue the trajectory of growth that began in 1959. The inclusion of low-incidence populations, like that of PIMD, in the knowledge and practice regarding the education of students with disabilities is a needed step in the growth of special education in the United States.

Literature Review

The right of all children to a free and appropriate education is a hallmark of the United States educational system (United States Department of Education, Office for Civil Rights, 2010). In the last 50 years, United States public education has been challenged by the legal and ethical issues surrounding the education of children with PIMD (*Endrew F. v. Douglas County School District, RE-1*, 2017; *Board of Education of Hendrick Hudson Central School District v. Rowley,* 1982; *Florence County School District Four v. Shannon Carter,* 1993; *Cedar Rapids Community School District v. Garret F.,* 1999). With the passage of U.S. Public Law 94-142 in 1975 and the Individuals with Disabilities Education Improvement Act (IDEA) in 2004, issues

regarding the responsibility of public schools to provide appropriate educational opportunities for all students regardless of disability, the most salient legal issue regarding special education, has been settled, although battles continue to be waged over ethical issues, as well as the manner in which the mandate is carried out.

In the United States in the early 1900s, it was common for all individuals with developmental disabilities to be institutionalized; to "receive services in large public institutions or [to be] cared for by their families with very little financial and social support from the government" (Davis et al., 2000, Introduction, Background, para. 8). Despite widespread institutionalization, there is evidence that the issue of education for this population was beginning to be considered. The Walter E. Fernald State School, a combination state hospital/educational institution for individuals with intellectual disabilities was established in 1848 with "high optimism" regarding a "forward-looking educational regime" (Dybwad, 1960, para.1). Dybwad reported that it became clear that the expectations could not be fulfilled and treatment was reduced to custodial care. In 1896, special classes for the mildly retarded in Providence, Rhode Island were introduced, with classes for the moderately retarded (trainables) being established in the 1920s (Dybwad, 1960). The first Public Law 86-158 (Training of Professional Personnel Act of 1959) enacted August 14, 1959 by the U.S. Senate and House of Representatives, appropriated money for the "Expansion of Teaching in Education of the Mentally Retarded, making grants available to assist…in meeting the costs of training such personnel" (Training of Professional Personnel Act of 1959, 1959, August, p. 346).

According to Davis et al. (2000), concerns regarding institutionalization began to come to the forefront in the 1960s, and by the 1970s legal challenges to the practice were causing a movement away from the locking away of people with mental or intellectual challenges. Data disseminated by the United States Department of Education, Office of Special Education and Rehabilitative Services (2010) states that, as late as 1967, state institutions were home to almost 200,000 persons with significant disabilities, providing only minimal food, clothing, and shelter. Education and rehabilitation were typically ignored. The same source indicates that in 1970, schools in the United States educated only 1 in 5 children with disabilities of any kind. Many states had laws that excluded students from public schools who were "deaf, blind, emotionally disturbed, or mentally retarded" (United States Department of Education, Office of Special Education and Rehabilitative Services, 2010, p. 3).

Establishing the Rights of Students With Disabilities

The timeline of educational progress moved ahead, beginning most determinately with Public Law 94-142, the Education for All Handicapped Children Act, in 1975. This law ensured that schools could be held accountable for providing services for all children, regardless of disability (Wright, 2010). First published in 1970, Deno's conceptualization of reform for the reorganization and delivery of public school special education services, known as *Deno's Cascade of Services*, had been recommended and adopted by the Council for Exceptional Children in 1974 (Deno, 1978). When Public Law 94-142, 1975, (reauthorized in 2004 as the Individuals with Disabilities Education Improvement Act), was passed, Deno's Cascade served as the primary model for the requirement for Least

Restrictive Environment (LRE) and the paradigm for decisions regarding the placement of students on the continuum of special education settings.

Deno's *Cascade* provides a visual model of the range of special educational services that could be utilized to meet the array of educational supports required by students in public school systems. The model includes an upper six levels, sequenced from least to most restrictive: participation in the general education classroom with regular accommodations and therapies as needed, general education classroom with supplemental instruction, part-time special class, full-time special class, separate schools, and homebound services (Deno, 1970). The seventh level of special education services references students who are housed in hospital or residential facilities and those who require non-educational services such as medical and welfare care (Deno, 1970).

A perplexing and enduring conundrum became apparent with the implementation of Deno's Cascade. The lower half of the Cascade, Level 7, encompassing students who would fit the definition of PIMD, was considered to be outside the realm of public education. Children in this level were assigned to facilities or settings governed by health, welfare, or correctional agencies (Deno, 1970, 1978). Public Law 94-142, however, included the requirement that "a free and appropriate public education will be available for all handicapped children for all children between the ages of three and 18 not later than September 1, 1978" (Education for All Handicapped Children Act, Public Law 94-142, 1975, §612). It is critical to note that for the first time in legislative mandate, this document included the radical language "regardless of the severity of their handicap" (Education for All Handicapped Children Act, Public Law 94-142, 1975, 20 USC 1412,

Sec. 612 A, B, C). The educational opportunities for students in Deno's Level 7 remained unclear. Never before had public education faced the challenge of addressing children who were profoundly disabled. As late as 1978, in her discussion of *zero reject*, Deno offered interpretation of the law by stating that with the most severely disabled children, a school district could prove that a child had a degree of learning incapacity that he could not benefit from learning opportunity (Deno, 1978, p. 50). There was no specific manner of proving this degree of disability in Deno's interpretation. Further, Deno's model, which laid the foundation for equity and responsibility in special education service provision, highlights the dissonance that surrounded the education of students with severe disability. Deno's interpretation of the law varied from the language of PL 94-142. The wording of PL 94-142 legally removed the discretionary power of the public school to determine which students could be excluded from appropriate public education.

Although established in 1975, interpretation of PL 94-142 has evolved through amendments and reauthorizations, concurrently with progress in social policy and technology. Moving into the realm of current philosophy and practice in special education, the rights ensured under NCLB and IDEA have now evolved to the point that we, as a nation, have come to focus on the provision that children with disabilities be educated in the least restrictive environment appropriate to meet their unique learning needs (Individuals with Disabilities Education Improvement Act, 2004, § 612.[a] [5]).

In recent years, least restrictive environment (LRE) has come to mean more inclusive educational settings for most students with disabilities with a focus on equal opportunities and maximized potential (Tahir et al., 2019). Student placement in inclusive

or more restrictive settings, however, is impacted by factors beyond student-centered attributes. External factors such as state of residence and geographical characteristics of a region have been found to have a significant influence on special education placement settings (Kurth, 2015; Powell, 2011). Specifically, inclusive practice has not increased for students with intellectual disability (Brock, 2018). For individuals with disabilities served by special education services, inclusion secures opportunities for students with disabilities to learn alongside their nondisabled peers in general education classrooms, promoting diversity, equitability in educational opportunities, and even laying a foundation for a more inclusive and knowledgeable society (Tahir et al., 2019).

It is within this historical perspective that this work will approach the education of children with PIMD. Vorhaus (2016) offered the following introduction to his own work on the PIMD population:

> Books on disability would fill many libraries; books on profound and multiple disabilities a few shelves; and books devoted to exploring the lives of profoundly disabled people, and the experience of those who care for them and work with them, rather less than that. (p. 1)

This same gap exists in regard to research on meaningful, appropriate, and legal practices in the education of students with profound and multiple disabilities in the United States public school system.

Beyond IDEA

Standards-Based Education for All

In 1983, the National Commission on Excellence in Education released an *open letter to the American people*, *A Nation at Risk: The Imperative for Educational Reform*, to report the quality of education in America to the American people (Gardner, 1983). In this document, the commission recommended that, "schools, colleges, and universities adopt more rigorous and measurable standards, and higher expectations, for academic performance*" (*Gardner, 1983, Recommendation B). This *Imperative for Educational Reform* became a part of the impetus for the establishment and adoption of common educational standards and common core expectations for teaching and learning in United States' public schools (Common Core State Standards Initiative, 2018a). The needs of educationally disadvantaged students were addressed in the report by the acknowledgment that these students, *"*may require special curriculum materials, smaller classes, or individual tutoring to help them master the material presented" (United States Department of Education, 1983, p. 24).

Twelve years after the publication of *A Nation at Risk*, President Obama signed the bill known as the Every Student Succeeds Act. Key components of ESSA include the requirement that all students in America, including children with disabilities, be taught to high academic standards that will prepare them graduate from high school and to succeed in college and careers (United States Department of Education, Every Student Succeeds Act, 2017, para. 6). ESSA sets forth specifically that it is the responsibility of individual states and public school districts to ensure the mandate "to measure progress against that

goal and maintain a critical focus on educational equity and excellence for all, the law maintains the requirement that states administer to all students annual statewide assessments…" (United States Department of Education, Every Student Succeeds Act, 2017, para. 6). The law emphasizes the requirement that *all* students are tested, offered appropriate accommodations when needed, and held to *the same* high standards. Although the mandates of ESSA are reasonable and intended to promote excellence and equality for all students in the United States, carrying out these mandates with the population of students with PIMD proves problematic (Collins & Ludlow, 2018).

Ruling for Relevance

Extending the federal mandate of ESSA even further and adding an important but challenging layer of complexity, the 2017 Supreme Court case of *Endrew F. v. Douglas County School District RE-1* was explicit in its finding that "states must provide children with disabilities 'access' to education that is meaningful" (p. 33). The Supreme Court affirmed the rights of students with disabilities to "meet developmental goals" (5Ai), and the responsibility of school districts to support:

> high-quality, intensive pre-service preparation and professional development for all personnel who work with children with disabilities in order to ensure that such personnel have the skills and knowledge necessary to improve the academic achievement and functional performance of children with disabilities, including the use of scientifically based instructional practices…" (*Endrew F. v. Douglas County School District RE-1*, 2017; Appendix 3a)

Despite this broad general and legal acknowledgement of the specialized needs of students with disabilities, educational goals and measures of success for these children may be difficult to reconcile with those established for children who do not have disabilities (Cramer et al., 2017). A review of documents designed to guide public education, particularly those to ensure equity to students with disabilities, reveals that in the United States there is largely an absence of understanding and acknowledgement of the needs of students with PIMD. Educational practices logically focus on reading and mathematical literacy, for students with profound manifestations of disability, a focus on sensorimotor stimulation and communication are essential skills to be addressed (Moljord, 2017).

Evidence-Based Intervention

An additional challenge presented by ESSA is the inclusion of financial incentives for states to use evidence-based practices (EBP) and interventions to improve student achievement. The mandate of evidence-based practice is mentioned at least 54 times (some documentation cites 61 instances, see Laughter, 2018) in ESSA. ESSA identifies four tiers of research evidence to assist states and local school districts in selecting appropriate interventions based on the strength of evidence of statistical significance available to support the practice. The importance of utilizing evidence-based practice is iterated by Laughter (2018) asserts that “this is a matter of equity…we surely have a pedagogical and moral imperative to employ [EBPs] if we are able to do so” (p. 1).

Designed to assist university teacher preparation programs, Browder et al. (2014) produced a report on evidence-based practices for students with severe disabilities. In this document, Browder et al. (2014) defined the population of students with severe disabilities as "students who needed an alternate assessment to participate in the states' assessment systems" (p. 6). This important work, however, is a demonstration of the importance of a clear definition of profound disability, with PIMD as an entity distinct from other manifestations of severe disabilities presenting on the higher end of the disability spectrum.

Although a comprehensive and helpful document pertaining to teacher education practices for a majority of students with severe disability, the Browder et al. descriptions of evidenced-based practices lack full relevance in light of the definition of PIMD. Evidence base in the area of "skills and academics" includes an emphasis on "preparing students to show progress on state standards" (Browder et al., 2014, p. 8) and teaching students the skills they will need for functioning independently in adult settings, such as daily living, having a job, and community skills (Browder et al., 2014, p. 8). The Browder et al. study emphasizes the importance of teaching students skills of self-management, goal setting, choice-making, self-directed learning, picture-based self-instruction, student problem-solving, goal setting, and community and job skills; all practices applicable to less severe manifestations of intellectual disability. Browder et al. noted that their review omitted the topics of "sensory, motor, and health-care needs of students," as these topics focused on "practical guidelines rather than EBPs for teachers" (p. 9).

It is important to the scope of this this study to understand that many practices cited by Browder et al. (2014) related to in-depth, evidence-based strategies for instruction have a research base with students with profound manifestations of disability in current European literature. Research on their application for students with PIMD, however, has not been extended to include application for students with profound disability in the United States.

For example, Browder et al. (2014) showed evidence of success with the use of peer tutoring for students with disabilities. Peer tutoring is described as being used to teach money skills, oral reading, and comprehension skills to students with severe disabilities. Although this content application does not apply to students with PIMD, Nijs et al. (2016) provide research findings that demonstrate that intentional peer interaction is more motivating and encouraging, and elicits higher levels of verbal and non-verbal attention from individuals with PIMD. Likewise, one of the EBSs of Browder et al. is the use of read-alouds, which has been found to increase correct answers to comprehensions questions, conversation about pictures, and even independent reading skills. Although these suggested benefits hold little promise for students with PIMD, the success of a similar practice of using read-alouds that include tactile objects has been documented with the PIMD population (Ten Brug et al., 2015).

Although not explicitly extended to the work with PIMD, the Browder et al. (2014) study demonstrated an understanding of issues that are critical to students at all levels of intellectual disability. The importance of the provision of a purpose and means for communication was echoed in the PIMD literature (Darling & Circo, 2015; Fisher et

al., 1996; Griffiths & Smith, 2016; McFerran & Shoemark, 2013; Simmons & Watson, 2014; Smebye & Kirkevold, 2013). The authors also cited collaborative teaming, use of assistive technology, inclusive practices, and utilization of paraprofessionals as evidence-based instructional practices for students with severe disability; practices that also have a research base with students with PIMD (Blain-Moraes et al., 2013; Bunning et al., 2013; Hostyn & Maes, 2013; Jansen et al., 2016; Munde & Vlaskamp, 2014).

In the study's discussion of limitations, the Browder et al. (2014) stated that "students with the most severe disabilities…are not well represented in the research literature. More research is needed on students who have emerging systems of communication, sensory, and physical impairments combined with severe intellectual disabilities and severe behavior disorders" (p. 49). This limitation is an echo of an earlier work by Browder et al. (2014) and Browder and Cooper-Duffy (2003) on the topic of evidence-based practices for students with severe disabilities: "[there is] sparse literature with students with complex, multiple disabilities" (p. 159). When considering this 2014 study, directed toward the mid-to-upper range of intellectual disability, however, it becomes apparent that appropriate knowledge and strategies are existent in U.S. special education literature. At this time, there is no research evidence to connect that which is known about the education of students with less severe forms of intellectual disabilities to the practices of education for students with profound disability.

Common Core and Extended Educational Standards

An important consideration in the discussion of education for all students is that of Common Core State Standards for academics. The passing of IDEA in 1997 required

the first alternate assessments, but at that time the alternate assessments offered to students with significant cognitive abilities were not linked to academic standards. Instead, alternate assessment measures reflected the practice of functional curriculum for students with this level of disability (Quenemoen, 2008).

Promulgation of Common Core standards, a movement in education that began in 2009, before the mandate of ESSA, came as a result of an "uneven patchwork of academic standards that vary from state to state and do not agree on what students should know and be able to do at each grade level" (Common Core State Standards Initiative, 2018a, para. 3). In the creation of these common standards, the complicated relationship between federal and state governments is apparent. The common core standards are a state-level initiative that was coordinated and designed by a collaboration of state school chiefs and governors, as well as teachers, administrators, and other experts (Common Core State Standards Initiative, 2018a). The group of state governors at the helm of the development of the Common Core is known as the National Governors Association (NGA), which indicates both a state and federal component to the creation of these standards.

The goal of the Common Core was to equalize the playing field for students attending public schools, ensuring that all students have access to high standards of education regardless of the state where they live. Under ESSA, states are permitted to adopt and implement their own academic standards and apply these standards to *all* students (United States Department of Education, Every Student Succeeds Act, 2017). Common Core is one option for schools to meet this requirement (Common Core State

Standards Initiative, 2018b). As of 2018, “forty-two states, the District of Columbia, four territories, and the Department of Defense Education Activity have voluntarily adopted the Common Core” (Common Core State Standards Initiative, 2018a). The next challenge to face state departments of education would be to establish the means for students with disabilities to have access to their state’s academic standards, whether Common Core or another set of standards (Individuals with Disabilities Education Improvement Act, 2004, §300.160). In response to this challenge, many states began to work together to establish guidelines to assist teachers in this task. The two most encompassing collaborations were The Core Content Connectors and the Dynamic Learning Maps Consortium.

The Core Content Connectors (CCC) were devised to operate as a starting point for instruction based on the Common Core State Standards, identifying the “key knowledge and skills from the Common Core State Standards that are needed to make progress in later grades” (Sabia, n.d.). Twenty-four states and the District of Columbia are currently using the CCC as the pathway for students with cognitive and intellectual disabilities to access the common core. With the characteristics of students with PIMD in mind, a review of the most basic level of CCC was undertaken. When possible, the CCC associated with the Common Core State Standards for Kindergarten were examined, as these would be the most basic level of academic expectation.

The first Common Core State Standard for kindergarten mathematics is that a student would “Know number names and the count sequence: Count to 100 by ones and by tens.” The Core Connectors for this standard identifies a pathway for meeting the

standard, beginning with “Rote count up to 10,” “Rote count up to 31” and “Rote count up to 100” (“National Center and State Collaborative: Core Content Connectors by Common Core State Standards: Mathematics Kindergarten,” 2014). In the area of Reading/Language Arts, the first Common Core Connectors are for reading fluency, “During shared reading activities, point to text: from top to bottom of page, left to right, or to match a spoken ‘orally read’ word to the written word” (“National Center and State Collaborative: Core Content Connectors by Common Core State Standards: English Language Arts-Language Reading Standards for Foundational Skills grades K-2,” 2014).

These examples demonstrate that the provisions made for students with disabilities to have access to the general education curriculum at an appropriately rigorous level cannot be accessed by students with PIMD for whom the abstract concept of numbers or the written word, which require visual and cognitive attention and understanding, do not hold meaning. It may be envisioned that assistive technology devices could be programmed and utilized to allow a student to press a button that would count for them, or that hand-over-hand assistance would enable a student to meet the pointing goal with full physical prompting, perhaps fulfilling the letter of the law. These practices highlight a gap between legislated curriculum and content standard acquisition and practices and principles of appropriateness and social justice that has been noted in research (Bartlett et al., 2015; Dukes & Darling, 2017).

Although the underlying skill of cause and effect (striking a button and having an auditory effect) is appropriate for a student with PIMD, the cognitive intent of the skill remains unmet due to the limitation of the student’s ability to utilize symbolic processes.

This necessitates reflection on the findings of *Endrew F. v. Douglas County School District RE-1* (2017) that students have the right to access to an education that is *meaningful*, and that students with disabilities have the right to meet *developmental* goals, not to be supplanted with motor goals.

Philosophical and Ethical Considerations of Practice in PIMD

Although the focus of this research is to gain clarity and more fully lay a foundation for understanding the praxis component of education for students in the United States who have complex educational needs due to issues of PIMD, it is impossible to consider issues in education while ignoring the philosophical and ethical questions that are inherent in working with students who have profound disabilities. The usual considerations of public education: leadership, purpose, curriculum, teacher training, buildings, accountability, and funding serve to answer questions of what should be included in education, and how it will be provided with efficacy and fairness (Sebastian et al., 2019). In the realm of PIMD, all of these considerations remain, yet are made more complex and intense by questions of "love and care, dignity and respect, dependence and independence, human capabilities and the value of human beings" (Vorhaus, 2016, p. 2) in regard to vulnerability of the population.

Personhood: The Value and Moral Status of Individuals With PIMD

Curtis and Vehmas (2016) acknowledged that it is not possible to sustain the argument that humans, through biology alone, inherently have a higher moral status than animals using standard philosophical theory. Even cognitive and emotional capacity, facility for aesthetic appreciation, or ultimate potential cannot determinately separate

humans from non-humans, particularly in circumstances of PIMD. The authors argued that full moral status as a human being is a function of "a deeply held belief, common in all classes and cultures from around the world today" (p. 41). It is this moral imperative that inspires advocates and lawmakers to seek educational opportunity for all (United Nations Department of Economic and Social Affairs Disability, 2006).

The work of Vorhaus (2015) explored the issue of human dignity in individuals with profound and multiple disabilities (PIMD) as it relates to basic and legal entitlements. The basis for these basic and legal entitlements rests on the premise that "people are entitled not only to mere life but to a life compatible with human dignity…" (Vorhaus, 2015, p. 464). Vorhaus made the ardent statement that those with profound disability have the right of "belonging to and not suffering rejection from humanity" (p. 476). That statement carries with it a sobering consideration for educators and policy-makers as it is considered within the context of belonging and not being rejected from educational experiences and opportunities.

Educational theorist Vygotsky's is known for his work on the Zone of Proximal Development, which explores the independent capabilities of a learner as well as how that capacity expands with assistance (Vygotsky, 2011). Expanding the premise of this theory, Vorhaus (2015) stated that simply because an individual may always lack capability when acting alone, they deserve the same rights, even if they benefit only with the assistance of more able helpers. Through this language, Vorhaus offered the foundational belief that independent ability and mastery are not necessary factors in education, but that it is acceptable for individuals to function indefinitely within the zone

where they require the assistance of more capable others. The WHO also addressed the qualifiers of *performance without assistance* and *capacity with assistance*, which are particularly useful in educational decision-making (World Health Organization, 2001).

Finally, Vorhaus aligned with the work of Dewey on student-centered goals, offering a paradoxical idea that having high treatment goals for all students, translated into current educational jargon as the "ability of all children to achieve at high levels" (Desravines & Fenton, 2015, p. 133), may actually diminish the recognition of human dignity of those with PIMD. Vorhaus (2016) suggested the risk that a proposed goal that is perceived as lesser than that of the general population is less desirous or important. *High levels of achievement* focuses on cognitive capability, and capability does not accurately capture the essence of what individuals with PIMD are able to contribute to the community around them (Vorhaus, 2016). This perspective indicates that any goal that furthers a growth mindset for practitioners working with individuals with PIMD; any goal that furthers student growth and fosters appreciation for human contribution, has irreducible value.

Researchers have undertaken the philosophical and ethical considerations that are challenges to the practices of education and could hold promise for the work of public education. Blain-Moraes et al. (2013) authored a study based on the social interactionist perspective of personhood that explored biomusic as a technology that may increase perceptions and awareness of co-presence and reciprocity, and thus enhance the quality of life of individuals with PMD and their primary caregivers. Sensors were attached to a subject's fingers that can pick up electrodermal activity (EDA), fingertip skin

temperature, blood volume pulse (BVP), and respiration. These readings can be converted into computer-generated musical elements, which, when synthesized and presented audibly, allow caregivers of those with PIMD to perceive co-presence and physiological responses to their presence and actions; a unique communication from the individual with a disability that severely limits communication in relationship (Blain-Moraes et al., 2013).

This work by Blain-Moraes et al. (2013) speaks to the issues of quality of life, dignity, and personhood which form the ideology of service to and relationship with individuals with profound disabilities. Blain-Moraes et al. found that relationships were enhanced by the auditory manifestation that the individual with PIMD responded to the actions of caregivers, creating awareness of reciprocity. Although involuntary, the music provides a manner in which the individual with PMD may contribute an essence of relationship to those who care for him. Application of this study to the practice of public education could potentially introduce a viable way to determine responses, preferences, and choices of students with PIMD, a strategy to address the challenges of goal assessment.

Respect for Human Dignity

In his memoir about a young man with profound disability, Nouwen (1997) wrote, “Adam’s humanity was not diminished by his disability” (p. 50). Vorhaus (2015) asserted that it is of great significance that human beings be treated with dignity, irrespective of their actual or potential functioning. The construct of human reasoning and rationality highlights the deep vulnerability of those with PIMD as they may be recipients of the

view that they, “might somehow not merit the respect owed to those possessing the dignity of reason” (Vorhaus, 2016, p. 87). Vorhaus (2015) was challenging in his assertion that respect for human dignity resides not only is what is done, but in how it is done.

Affection and Assisted Self-Actualization

Deno (1972) argued that individuals with disabilities were worthy of equal educational opportunities because of moral imperative, and that, “the primary goal of education should be self-actualization of the individuals served” (p. 2). The concept of self-actualization carries with it of fulfillment of potential, but also a tacit belief in the pursuit of happiness, which must extend to those with PIMD (Vorhaus, 2016). For individuals with profound multiple disabilities, the ability to seek out experiences that may lead to self-actualization and increase happiness may be minimal due to physical and cognitive limitations (Darling & Circo, 2015). Instead of being internally driven, opportunities for happiness may need to be provided by external sources. Legislative and judicial mandates to ensure meaningful experiences for individuals with disabilities further the belief that every person has a right to strive for their potential, and speaks to the importance of human relationships to promote assisted self-actualization (Hostyn & Maes, 2013).

Continuing the idea that human relationships affirm the personhood and dignity of those with PIMD, Griffiths and Smith (2016) used the term “attuning” to describe a mutual process where an individual with PIMD and a communication partner achieve mutual valuing that can be observed and documented by careful observation of

idiosyncratic gestures, facial expressions, body movements, or vocalizations. Hostyn and Maes (2013) made a similar argument asserting that "supportive relationships are a crucial determinant of the well-being and quality of life of people with profound intellectual and multiple disabilities" (p. 189). One element of this dissertation study was to gain understanding of teachers' experiences and practices as they interact and communicate with persons with profound disability.

Pursuit of Happiness

At the most basic level, in accordance with Article 23 of the United Nations Convention on the Rights of the Child (United Nations General Assembly, Human Rights, 1990), children with disabilities have the right to live a full and decent life. Few would argue that the concept of a "full and decent life" for a child includes happiness. Children with profound disability have limited independent ability to attain objects or experiences that bring them heightened happiness (Darling & Circo, 2015). They are dependent on caregivers and educators to provide those stimuli. The challenge of ensuring a "full and decent life" in the context of PIMD is complex. "[T]hese persons do not appear to manifest thoughts and feelings in ways that can be reliably interpreted" (Blain-Moraes et al., 2013, p. 159). Outward indications of contentment and happiness may be quite idiosyncratic for individuals with PIMD, and it may be very difficult to have assurance that they are being interpreted accurately. A variety of caregivers stated that the most frustrating and challenging aspects of being with and working with people with profound disability is the uncertainty, the *not knowing*, what they are feeling or experiencing (Blain-Moraes et al., 2013). Individuals with PIMD offer very few

voluntary initiations of communication and, when given, often give an interlocutor "virtually no information at all on which to base a response" (Antaki et al., 2017, p. 581). It is important to understand whether educators encounter the same difficulty of "not knowing" as they work with students.

To increase the possibility of an individual with PIMD experiencing the highest possible level of happiness, caregivers and professional service providers must be proactive in the effort (Darling & Circo, 2015). Educational practice may be understood to have the underlying goal of increasing happiness and self-actualization in students with profound disability. One of the recurrent themes in the literature is the importance of caregivers and service providers having long-term relationships with a child with PIMD, a fundamental and requisite factor in knowing the student well (Darling & Circo, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; McFerran & Shoemark, 2013; Munde & Vlaskamp, 2014; Simmons & Watson, 2014). The issue of longevity of relationship with students with PIMD may also impact educational decision-making.

One tool that may provide some framework for educators as they seek to interpret the emotions of a person with PIMD is the Reinforcer Assessment for Individuals with Severe Disability (Fisher et al., 1996). Tools such as this rely on caregivers who have extensive knowledge of the individual with PIMD to give actionable input. The importance of having a transdisciplinary team is discussed later, but in an effort to most effectively and positively serve an individual for whom communication is very difficult to interpret; information must be gathered from several sources, when possible. No one caregiver, whether parent, teacher, therapist, or other service provider, should be charged

with the full responsibility of determining the conditions or impacting the quality of life for another (Mietola et al., 2016). In the current climate of outcome-based education and accountability, reference to the works of Dewey and Deno reinforce the verity that subjective ethical and moral implications of education are irreducible (Deno, 1972; Dewey, 1909).

Communication

In 1966, the United Nations Human Rights Office of the High Commissioner adopted the *International Covenant on Civil and Political Rights*; a document that declared that "…everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice" (United Nations Human Rights Office of the High Commissioner, 1966, Part III, Article 19, Number 2). Long before this document, Dewey and later Vygotsky, theorists on whom this current study rests, were convinced of the necessity of communication in education. Dewey (1916) believed that education should teach people to respond to each other; should deepen a child's ability to reach out into his world, to share activity. Responding and reaching out are dual processes that need to happen, even within the complexity of profound disability. Dewey frequently construed communication in the light of between-person relationships; Vygotsky's perspective had an operative connotation, recognizing communication as elemental in the within-person development of cognition (Vygotsky, 1978). For Vygotsky, communication and cognitive growth were fully integrated processes, which suggests that intensive intervention and

mindful opportunities to strengthen the communicative ability of individuals with PIMD may be the key for optimal cognitive growth, a perspective echoed in current literature on profound disability (Darling & Circo, 2015; Fisher et al., 1996; Griffiths & Smith, 2016; McFerran & Shoemark, 2013; Simmons & Watson, 2014; Smebye & Kirkevold, 2013).

Communication may be most challenging and frustrating in cases where an individual presents on the most profound end of the spectrum that exists in PIMD due to the deeply compromised capacity for typical means of communication (Griffiths & Smith, 2016). Hostyn and Maes (2013) and Antaki et al. (2017) identified one characteristic of individuals with PIMD as their engagement in "presymbolic communication…[which] may be idiosyncratic, and difficult to understand and interpret" (Hostyn & Maes, 2013, p. 190). For students with PIMD, there exists the danger that their personhood may be deeply concealed by their physical, medical, and cognitive challenges because their lack of formal linguistic codes places extreme demands on communication partners (Griffiths & Smith, 2016).

Antaki et al. (2017) stated that profound problems in communication for those with PIMD "put in jeopardy their personhood and their place in the social world" (p. 581). Reaching into the literature on dementia, sometimes used as a proxy for understanding PIMD, researchers have written that purely task-centered activities tended to diminish personhood whereas close emotional bonds served to sustain personhood (Lawrence, 2007; Smebye & Kirkevold, 2013). The challenge for educators is to find ways to build these emotional bonds with children who are behaviorally unresponsive and are unable to manifest thoughts or feelings in any outward manner, prohibiting the

construct of reciprocity in relationship (Calveley, 2017) that was foundational in Dewey's theory. Echoing the early work of Dewey, Moljord (2017) stated that in educating students with profound disabilities, "sensorimotor stimulating and communication are essential" (p. 656).

In light of children with profound disabilities, Dewey's words resonate, "To be a recipient of communication is to have an enlarged and changed experience" (Dewey, 1916, p. 5). If one goal of education is growth, then it follows that communication facilitates growth. Vygotsky shared the perspective that "higher psychological functions may not be attained without speech playing a significant role. (Vygotsky, 1978, p. 22-3). Continuing his thoughts on communication, Dewey asserted that "living together educates" (Dewey, 1916, p. 6), and from this ideal it may be surmised that children with profound disability deserve to be the recipients of the communication efforts of others, and perhaps those "others" may be enlarged and changed as they become recipients, themselves, of the communication efforts of individuals with profound disability.

Academic Considerations in PIMD

Including Communication in Practice

A key component in the study of communication is that there must be both a sender and receiver of verbal or non-verbal information for communication to exist (Griffiths & Smith, 2016). Nordquist (2020), expanded on that definition by declaring that communication involves an interplay of "conversation, delivery, and feedback…the audience's reaction and participation" (para. 3). The educational interventionists who strive to facilitate a richer quality of life through communication for children who are

preverbal or averbal may discover a greater depth and purpose in their practice through awareness of Nordquist's addendum; focusing on the audience's reaction and participation.

It would be nearly impossible to address any element of educational practice for children with PIMD without mention or awareness of the presence and importance of communication, as communication offers greater possibility of autonomy and personhood for these individuals (Blain-Moraes et al., 2013; Calveley, 2017; Griffiths & Smith, 2016). Like relationships, communication is integral and foundational to all human exchanges. Because of the deep integration of communication into every aspect of curriculum and teaching activity (McFerran & Shoemark, 2013) in this section I will attempt to focus on specific, overt practices to develop communication in children with PIMD while acknowledging that no element of communication stands alone in the wholistic practice of education.

When striving to enhance communication with individuals with PIMD, two considerations are elemental: focusing on creating an environment that offers opportunity to engage and scaffolding of communicative initiations and efforts on the part of the student (Calveley, 2017; Griffiths & Smith, 2016; McFerran & Shoemark, 2013; Munde & Vlaskamp, 2014). Because symbolic language is typically unavailable to this population, sensory stimulation is an essential component of communication. Everyone possesses sensory preferences that encourage or discourage engagement with the environment and the people in the environment. Preferred activities "facilitate a

higher rate of intentional communication" for children with PIMD (Bunning et al., 2013, p. 41).

A basic and practical question is how to recognize preferred activities in children with alertness and response patterns that may vary significantly from interaction to interaction. Due to the complexity of communication with students with PIMD, relationships that are allowed to develop over time are necessary so that both the student and the interventionist may learn to attune to one another, build a history of shared experiences, and engage in familiar routines that increase the probability of engagement (Calveley, 2017; Griffiths & Smith, 2016; McFerran & Shoemark, 2013; Simmons & Watson, 2014). Ruppar et al. (2017) found that teachers of students with PIMD needed to operate from a deep and "extensive base of knowledge about individual students" (p. 128). It is important, too, to refer to the work of Dewey in his insistence that education must be child-centered, and that goals for each child must be individualized (Dewey, 1916; McFerran & Shoemark, 2013). This is reiterated by Ruppar et al. (2017) in their finding that one of the characteristics of an expert teacher for a student with severe disabilities is their ability to individualize and adapt curriculum to customize learning experiences for each student. In PIMD, communication goals may include heightened or extended periods of alertness (Munde & Vlaskamp, 2014), spontaneous initiation (McFerran & Shoemark, 2013), and even "some progress" (which is an unacceptable goal for nondisabled students) is a reasonable goal for children with profound PIMD (Simmons & Watson, 2014).

Revisualizing Literacy Standards

As discussed previously, the goal of the extended standards adopted by many states is to ensure that children with special educational needs are offered equitable opportunities to achieve at high levels academically. As we view education through the lens of PIMD, we again must consider that goals must be dynamic and individualized, though having appropriate rigor for the student being served. In one state's core academic standards, the language of "adequate exposure" is used in regard to the goal statements (Ohio Department of Education, 2012, slide 17). The standardized testing measure for children with PIMD in this state includes engagement tasks as a part of the Alternative Assessment (Ohio Department of Education, 2019). In a state by state examination, only three states include presymbolic standards in their aligned content standards for students with severe disabilities (see Appendix B for a summary of findings by state). Although the verbiage of these standards is subjective, they do open the possibility that exposure and engagement may be legally and ethically appropriate goals, allowing children with significant disabilities to experience the core as it is conceptualized. This idea was applied to the area of reading/language arts, which encompasses an extensive portion of the educational experience.

In their study of family engagement and interaction, Axelsson et al. (2013) explored the position that children with PIMD show evidence of enjoying experiences and activities similar to their nondisabled peers. Children with significant disabilities were found to have a lower level of overall engagement than their nondisabled siblings in most family activities, they also discovered that the "activities that engaged the children

to a higher or lesser extent were the same in both groups" (p. 530). Similarly, Hostyn and Maes (2013) reported case studies that demonstrated that individuals with PIMD enjoyed "humor and small teasing between clients and support workers" (p. 198). These findings add to the work on curriculum development for students with PIMD by suggesting that activities that provide enjoyment and engagement for typical children should be offered, also, to children who have limited response repertoires.

Ten Brug et al. (2015) studied and refined a practice known as multisensory storytelling (MSST) that would allow students with PIMD carefully designed opportunities to hear and to use their senses to explore, handle materials, and respond to literature. In regular storytelling, the educational focus is typically on comprehension. For those students with PIMD, exposure to literature and storytelling "is not only about the content of the story or understanding the words, but also about listening to the sounds and feeling the words and atmosphere of the story" (Ten Brug et al., 2015, p. 190). The practice of multisensory storytelling (MSST) may be adapted and utilized across domains. One element of this style of reading aloud is repetition, which may serve as a catalyst to build what Vygotsky termed *natural memory* and believed to be an important factor in cognitive development (Vygotsky, 1978). This interactive form of read-aloud provides access to the educational core curriculum. It allows children with PIMD to share an experience (stories and language) that is an integral part of the general education classroom and enjoyed regularly by most students. Finally, it provides a catalyst for active learning, as championed by the theories of Dewey and Vygotsky (Pardjono, 2016).

Access to Mathematics

A second focus of traditional educational curriculum is the area of mathematics. Based on the defining characteristic of children with PIMD functioning at a presymbolic level of understanding, it is reasonable to strive to present a mathematics curriculum that centers on basic understandings rather than skill acquisition. In recent years there has been a surge in studies into the integration of music and mathematics, and music may be the key to building a bridge into the mathematics standards for our students with profound disability.

Giles and Fresne (2016) cited brain research that has shown that listening to and making music can help form connections along neural pathways of the brain, and that regular participation in music increases the number of brain areas that are activated during musical activity. Further, music and mathematics development have been shown to follow "similar, qualitative changes in the development of meaning-making: perception, recognition, recall, and conception" (McDonel, 2015, p. 7). This research meshes well with the work of Vygotsky on the integrated biological and behavioral components of higher cognitive development (Vygotsky, 2011).

Further research ties music to the active learning component of Dewey and Vygotsky's writings: "Music enriches the mathematical learning environment by making activities more pleasurable and promotes learning through active participation" (Edelson & Johnson in Giles & Fresne, 2016, p. 22). Engaging the mathematics standards through the portal of music offers entrée into the goals of social communication and heightened levels of engagement through music-making and the related discipline of

music therapy. McFerran and Shoemark (2013) suggested that the power of music for children with PIMD lies in the "combination of attentive, responsive, and creative being with the other person over time" (p. 1). Musical interaction calls forth both turn-taking and "speaking" at once with another (McFerran & Shoemark, 2013, p. 8)). It requires patience and waiting to elicit action rather than soothing passivity. Familiar songs and musical experiences also allow teachers, peers, or other caregivers to supply an auditory memory cue for a child who lacks the cognitive capacity to independently access positive memories (Brown & Palmer, 2012).

Finally, for children with PIMD, all experiences serve overlapping functions. Besides access to mathematical concepts, utilizing music as a part of core instruction reaches even into the domain of personhood. "…participating in the study of music, including active participation in making music, instrumental or vocal, contributes to the overall development of being human" (Giles & Fresne, 2016, p. 24).

Inclusive Environments

One aspect of the experiences of teachers of students with PIMD includes the setting where the students are being served. Inclusion in the least restrictive environment has become law, but there is a continuum of service settings and delivery models allowable under IDEA, much like the early model of Deno (1970). Although the societal practices and expectations for education and for children with disabilities were very different in the time of Dewey, he understood and wrote extensively on the issue of democracy in education (Dewey, 1916). He believed that living together is, in itself, educational, and that opportunities for giving and taking, social reciprocity, should be

evident in public education (Dewey, 1916). More contemporary, Deno's most influential work was pivotal in the movement to provide educational rights and inclusive opportunities to children with disabilities (University of Minnesota, n.d., para. 2).

The principles of these theorists have been validated by current law and practice requiring that students with disabilities be educated in the least restrictive environment and that school utilize practices of Universal Design for Learning (Individuals with Disabilities Education Improvement Act, 2004, § 612[a] [5]; Every Student Succeeds Act, 2015, § 1177-23[xiii]). How to provide appropriate inclusive services for children with PIMD is perhaps the most difficult scenario for educational teams to assay due to the multitude of factors that must be considered regarding the student, his family, and the broader educational community. This heightens the responsibility of teachers who work with students with PIMD to include that of advocacy for the student (Ruppar et al., 2017).

Drawing from a study of family life, Nijs et al. (2016), provided insights into the social relationships of children with PIMD with their peers that have consequence in the realm of schools. Children with PIMD in school settings often have needs that are believed to be too complex for meaningful participation in the general education classroom. This is an issue that requires a deep look at the capabilities of a child and the goals for their inclusion (Collins & Ludlow, 2018). In the Nijs et al. (2016) study, a review of past literature revealed that being with typically-developing peers elicited more *awake-active-alert* behaviors and communicative efforts in children with PIMD.

Bunning et al. (2013) studied the experiences of children with PIMD who were involved in an inclusive classroom compared to those in a segregated classroom with

only peers who also had PIMD. The authors discovered that teachers and assistants were more involved with students in the special education classroom, but the children themselves were placed in the room with greater physical distance between them, limiting the potential for peer-to-peer interaction. In the mainstream setting, there was a peer communication partner available to the child with PIMD 69% of the time.

Despite the mandate for inclusive education, there are concerns regarding the impact of inclusion on students without disabilities. Studies on inclusion examined the impact of the practice almost exclusively on the students with disabilities, while excluding the experiences of nondisabled students in the studies (Gilmour, 2018). Gilmour (2018) cited surveys and qualitative studies that call into question whether it is possible for general education teachers to meet the needs of the majority of students while still meeting the complex needs of the included child in a way that makes inclusion beneficial for him or her. In an effort to nurture a positive attitude toward inclusion, deBoer and Munde (2015) found that contact between the children needs to be "frequent, pleasant, interactive, focused on common goals, meaningful, respectful, and long" (p. 184). There should be openness about the challenges and goals of inclusion for both the child with PIMD and general education peers, where all parents are offered information and opportunities for greater awareness. Finally, as Deno's advocacy indicated, if inclusive practice is to work, there must be acknowledgement of the legal mandates, ethical considerations, and there must be support from school authorities (Deno, 1972; Geer & Deno, 1965).

Discovering Reciprocity

When inclusion is considered in the world of education, the focus is generally on the impact for the child who has a disability (Gilmour, 2018). When typically-developing peers are considered, there are often concerns about whether having children with significant needs in general education classrooms will have a negative impact on the education of the nondisabled students (deBoer & Munde, 2015; Sira et al., 2018). Regardless of this area of concern, even for the students with disabilities there must be a balance between inclusive practice and individualized direct instruction for children with PIMD for them to have opportunities to achieve selected goals (Gilmour, 2018).

An important question that may be not be considered by educational teams concerns what positive impact inclusion could have on the lives of the general education students, school, and communities that embrace the inclusion of children with PIMD. Dewey (1916) believed that children in schools need to be connected to others who can deepen and broaden their knowledge and understanding. They need to learn to respond to others; should have the opportunity not only to benefit from school, but also to have something to contribute (Dewey, 1916). Deno added to this philosophy decades later in her discussion on inclusive public education as a place where children learn that human differences are accepted and respected, not ridiculed or feared (Deno, 1972). Perhaps the process of education, learning together, and having opportunities to communicate with one another contribute as much to the growth of those who are viewed as providers as to those with PIMD.

Blain-Moraes et al. (2013) shared a subtle finding that adds to this discussion. The authors found that when caregivers could describe their relationship with an individual with PIMD as "warm," a term that presumes familiarity and time spent together, that the individual with PIMD was "clearly valued and cherished" (Blain-Moraes et al., 2013, p. 168). Raghunathan (2014) reported:

> We know that the desire to love and care for others is a hard-wired and deep-seated because fulfillment of this desire enhances our happiness levels. Expressing love or compassion for others benefits not just the recipient of affection, but also the person who delivers it. (para. 4)

It is important that society recognize that relationships with individuals with disabilities have the power to enrich the lives of others rather than diminishing them.

Discovering the Foundation Through Research

As stated earlier in this chapter, the voices of teachers who work with students with PIMD in the United States are missing from the current research. Kurt Fischer, director of the Mind, Brain, & Education Graduate School of Education at Harvard University is a proponent for partnerships between the diverse disciplines of neuroscience and education, stating that,

> Building links among mind, brain, and education requires…interactions of researchers and practitioners. As those links grow, questions and insights from educational practice will inform and enrich brain and cognitive science just as

much as scientific findings will inform and enrich educational practice. (Immordino-Yang & Fischer, 2007, pp. 145-6)

In a similar way, the worlds of medical research into PIMD, European studies of enrichment and well-being, and the field of education and teaching in the United States, though diverse, may together hold the potential to impact the lives of students with PIMD, and cause ripples that could influence their families, schools, and communities in positive ways.

The foundation of this partnership of shared knowledge may be strengthened by beginning to examine the components and practices of teaching special education to students with profound disability in an outcome and accountability-based educational culture. In seeking to give voice to the educator's experience in teaching children with PIMD, a starting point may be found in Bandura's theory of self-efficacy. Bandura's understanding of self-efficacy beliefs may inform the work that needs to be done to promote meaningful and effective practice in the field of profound special education. Bandura posited that individuals need to believe their actions lead to positive effects if they are to exercise incentive and persevere in challenging circumstances (Bandura, 1993). This belief is particularly important when looking at a teacher's work with students with PIMD, because measurable outcomes on the part of students may be minimal (Ruppar et al., 2016).

Teacher burnout in the field of severe disability is high, often related to feelings of inability to establish and instruct students in meaningful curriculum (Williams & Dikes, 2015). Building on Bandura's theory, Zee and Koomen (2016) found that feelings

of self-efficacy impact both teacher and student outcomes. On the teacher side, empirical evidence suggests that teachers with higher levels of self-efficacy persist longer when work is challenging (Zee et al., 2016), remain motivated and committed to a task, make greater efforts to involve students in educational activities in a meaningful way, and help students realize higher goal attainment (Love et al., 2019), and benefit from heightened levels of warmth, responsiveness, and enthusiasm in teacher-student interactions (Guo et al., 2012). This research may be closely linked to the previously reported findings that meaningful work with individuals with PIMD typically involves long-term relationship (Darling & Circo, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; McFerran & Shoemark, 2013; Munde & Vlaskamp, 2014; Simmons & Watson, 2014). Educator feelings of self-efficacy may impact instructional quality and educational experiences for students in the public school system by reducing teacher burnout.

Research Design and Approach

In this study I explored both the instructional practices and teacher perceptions of their work of intervention for students with PIMD in the public education system of the United States. Topics including teacher knowledge of PIMD and the sources for that knowledge, service models, goals and curriculum, evidence-based practices, and teacher experiences comprise the data that form a basis for further work in the areas of identification, standards, and sustainable, and meaningful educational practice. This work has been undertaken in an effort to address the unique challenges of providing legal and ethical educational experiences for individuals with profound disabilities. My approach best matches the pragmatic and transformative-emancipatory philosophies.

A pragmatic philosophy provides a strong foundation for case study research (Fishman, 2013). Understandings and viewpoints regarding profound disability are diverse when considering the different facets of work undertaken by medical and mental health practitioners, educational policy-makers, and that of teachers who engage with students face-to-face. The questions being asked in my study, and the inferences drawn from the responses, may contribute to the basis of knowledge to create a framework for the education of students with PIMD that works, meeting the mandates of law, the needs of educators, and the legal, moral, and ethical rights of the students being served.

In examining the transformative-emancipatory philosophy, I felt that my research could not be separated from a social justice perspective, as its aim includes clarifying factors in the education of students with disabilities that may require additional work to provide the supports needed to fulfill the mandate of legal and moral mandates of meaningful and appropriate education. Informed by both transformative and emancipatory frameworks, this study may serve as one tenet of the goal of educational improvement that will strengthen the work of furthering the personal development and public understanding of the marginalized subgroup of students with PIMD.

The information that I sought to attain on the current practice of teachers for students with PIMD could have been examined through quantitative means, including conducting reviews of the number of students who participate in state testing through alternate evaluations and their scores, focusing on levels of inclusive practice, and looking at responses to my research questions through a fully quantitative lens. The results would provide useful information that would fulfill the purpose of adding to the

knowledge base regarding the education of students with PIMD in the United States. As Creswell explains, this information would provide a “large, general surface picture” of the topic (Creswell, 2013) that is needed due to the lack of a defined definition or framework of practice currently in the U.S. view of special education in public schools, but this perspective would not have given voice to the teachers who are in the field, working with the PIMD population.

It may be theorized that the meaningful education that law requires for this very small, yet complex population of students may require heightened commitment of time, close proximity, specialized knowledge, and personal investment on the part of the teacher or team who is responsible for their education. Creswell explained that qualitative data will provide an in-depth picture and rich details of the subject (Creswell, 2013, March 1, min. 1:32), and this depth and detail is critical when trying to address legal mandates while understanding the challenges of providing meaningful educational practice for these learners, the outliers for whom educational goals, community participation, quality of life, and self-actualization must be defined very differently than for the other students with disabilities.

Justification for the Methodological Paradigm

This study was focused on a problem set that confronts a very small minority and under-recognized group of students. In advocating for case study in the field of psychotherapy, Fishman (2013) stated that case studies “have the capacity to link directly to the work of practitioners because these studies are grounded in the same type of setting in which clinicians function, that of the single case” (p. 403). Likewise, the story of

educating students with profound and multiple disabilities, is similarly complex and highly individualized.

As characterized by descriptors of performance used in the United Kingdom in regard to students whose disabilities place them at the most profound end of the disability spectrum, these students generally require full prompting and support for participation in activities and experiences of education, responses to familiar people, events, and objects may be inconsistent, and communication is likely to be idiosyncratic and marked by gestures and vocalizations that must be interpreted through familiar caregivers (Gov. UK. Department of Education, 2017). Multiple case study promised to capture the depth reflected in deep and individualized educational work with students with PIMD.

Clandinin (2013) believed that justification of the methodology of case study utilizing narrative inquiry must include the examination of three contexts: personal, practical, and social/theoretical. Personal justification in case study was important because this methodology requires a researcher to enter into a trust with those being studied. I was attentive to what brought me to this study; aware of potential biases and filters through which I might listen to those participants who granted an interview. I came to this research as a seeker. After many years of working with students with PIMD in one-on-one settings, attaining certification in severe disability, seeking to provide meaningful educational experiences, and being charged with the fulfillment of educational mandates with my students, I found myself wondering at times “What really matters?” “Why does it matter?” and “To whom?” This study was a personal quest for those answers.

The practical justification was more objective, and was grounded in the need to understand deeply the experiences of teachers of students with PIMD in the United States It is these teachers who are charged with the task of creating meaning for individual students in the context of educational mandates for growth, rigorous curriculum, and tested accountability. Further, it was my hope that this multiple case study would allow greater insight into the needs, experiences, and insights of teachers of students with profound disability that may be matched to current research being undertaken with this population in other parts of the world.

Finally, the social/theoretical justification came from the dearth of practical, actionable research in the United States that could serve to add to the disciplinary knowledge of the work with students with PIMD and the federal mandates acknowledging that all students deserve and are entitled to meaningful educational experiences that have the greatest power to elicit personal growth. Through the voices and experiences of teachers in the field, it may be possible to gain a deeper sense of the interface between federal mandates and the moral, ethical, and practical issues encompassed in the education of those with profound disability, as well as their place in educational and social communities.

Summary and Conclusions

Education mandates in the United States pertaining to the education of at-risk and marginalized learners date back to 1975. In the 43 years since the passage of the landmark PL 94-142, revisions, improvements and assurances of law have been steadily changing special educational practice in all parts of the United States. For a vast majority

of students, these changes have created more appropriate, equitable, challenging, and responsive learning environments.

A void continues to exist in the understanding, visualization, and implementation of meaningful educational experiences for students with the most profound intellectual and multiple disabilities in the United States, however. Factors including the low incidence of students with PIMD, the idiosyncratic nature and complexity of their medical, personal, and educational needs, lack of definition of the disability, and lack of evidence-based practices, which would facilitate the establishment of an educational taxonomy contribute to the often inadequate or inappropriate education that is provided for these students. Medical research, as well as studies pertaining to meaningful practices that lead to better quality of life are available, but there is a prominent paucity of research regarding the perceptions and practices of teachers in the United States who work on the front lines with these students, attempting to reconcile special educational mandates with the needs of their students.

Throughout the historical, legal, philosophical, and praxis literatures, there are foundational themes including the purposes of education, the rights of individuals with PIMD to be regarded with dignity, to enjoy the same human rights as their nondisabled peers, and to have access to a meaningful educational experience. European nations have established taxonomies that can contribute to the knowledge base of United States policy-makers and educators, but public, inclusive special education frameworks for students with PIMD must be visualized within the unique context of American culture, tradition, educational philosophy, and law. Before this can occur, research must be undertaken in

an effort to understand this challenging population through the eyes of those who know them and serve them, including their teachers who view their students through an educational lens that includes best practice, individualization, goal setting, curriculum, and adherence to the law regarding educational standards and accountability.

The challenge of service to others and of positive social change requires that scholarship should result in the "improvement of human or social conditions" by promoting the "worth, dignity, and development of individuals, communities, organizations, institutions, cultures, and/or societies" (Walden University, 2021, Social Change, para. 1). There is a need to address the issue of the value, dignity, and worth of human beings outside of the parameters of economic potential and asset/liability considerations. School reform and accountability are most often the solutions offered for educational challenges, yet in the sphere of PIMD, the law alone is unable to provide a structure of reform and accountability. What is needed is a strengthening of the daily, ongoing, joyful, and often disillusioning interactions between individuals with PIMD and the support team that surrounds him. Teachers and therapists need resources and assurance that there is structure, meaning, and value in the work that they do (Collins, 2007; Griffiths & Smith, 2016). Families need to be supported. Students with PIMD need to be assisted in living with dignity, happiness, and optimal self-actualization (Hostyn & Maes, 2013). It was the goal of this study to add educator insights to the structure of legal mandates that form the practice of special education of students with profound intellectual and multiple disabilities.

In Chapter 3, the research design and rationale for this study are delineated. Decisions regarding population selection, data sources and triangulation, data collection and analysis, and issues of ethical protections are described in an effort to address the research questions with credibility and integrity.

Chapter 3: Research Method

The purpose of this exploratory multiple case study was to investigate how special education teachers are providing appropriate and meaningful education to students with PIMD, students with profound manifestations of disability, with little guidance from state and federal standards. The intent was that this research would increase awareness of this challenging subgroup of students whose needs, strengths, and educational goals fall outside of the range of traditional educational practice in the U.S. public school system. This study addressed the knowledge, experiences, and practices of the special education teachers who work with these individuals in the context of federal and state educational mandates. Narrative inquiry and structured interviews were used to collect insights into current educational practice. In the methods section, I explain how the study was conducted and present the research questions that were answered to increase the understanding of the complexity of public education for students with the most profound disabilities.

Research Design and Rationale

Research Questions

1. What are the lived experiences of teachers of students with profound intellectual disability in public school districts of the United States regarding challenges and successes in their teaching practice?
2. What kinds of curriculum, activities, and practices do teachers of students with PIMD utilize in their teaching to fulfill the federal mandate of

meaningful education and from what sources are these tools (curriculum, activities, practices) obtained?

3. How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?

Research Method: Multiple Case Study

A literature review was conducted to explore the work of educating students with profound disability in the United States. I discovered that very little scholarly information was available related to this subgroup. The journals dedicated to severe disability and articles addressing profound disability in educational settings were focused on the entire spectrum of students who are defined under IDEA as having moderate to severe disabilities (approximate IQ of 70 and below). There appeared to be a gap in the literature regarding children who fall outside the general understanding of this subgroup of students. When reviewing the work of Deno (1970), whose spectrum of services was central in establishing special education mandates in the United States, it became clear that students in Level 7 of the Cascade, though no longer outside the realm of public education legally, were still beyond the reach of education on a practical level.

Upon recognition that there was a gap in the literature related to profound disability, I determined that a qualitative approach would be appropriate to study the topic of interest. Specifically, I chose a multiple case study for its focus on the case. Eisenhardt (1989) wrote that case study is appropriate when examining new research areas or those where existing research is inadequate. Yin (1994) stated that case study is

an approach that supports investigation of the question with depth and detail. I employed the study of multiple cases to provide a stronger basis for interpretation and analytical generalization (see Yin, 2010). The goal of this study was not to draw conclusions about the PIMD population, but rather to understand and describe the practices and insights of special education teachers in the United States as they provide appropriate and meaningful education to this challenging subgroup of students, while having little guidance from state and federal standards.

Design of Study

This qualitative exploratory multiple case study design was supported by narrative inquiry undertaken through structured interviews. From the available scholarly research, as well as examination of state and federal educational guidance, I discovered a paucity of guidance on the population of U.S. students with PIMD. Narrative inquiry was an appropriate entry point into the study, as the method supports a "Deweyan view of experience" (Clandinin, 2006, p. 14), which embraces the premise that stories and images from the lives and educational experiences of students as told through their teachers may illuminate the characteristics and issues of educational practice for those with profound disability. Yin (2014) defined a case study as an "empirical inquiry that investigates a phenomenon in depth and within its real-life context" (p. 18). According to Yin's definition, case study was an appropriate design for the current study to explore the special education laws, mandates, and ethical foundations and the application of these guidelines in the real-life intervention with students. Interviews allow the researcher and

the participant to join together in exploring the participant's understanding of the issues in question and their articulation of these personal insights (Pessoa et al., 2019).

To mitigate bias and maximize validity, data triangulation was achieved through semistructured interviews accompanied by review of two types of educational documents supplied by the teachers. Fusch et al. (2018) stated that triangulation requires that a researcher explore a phenomenon at different levels of engagement and from different perspectives. To triangulate my data, I pursued all three data sources, examining similarities and differences that may have arisen. Through the integration of interviews that addressed the teachers' words and thoughts, and two separate sources of documentation that linked their work to the mandates set by law, I examined the stories that teachers told of their work in everyday, dynamic contexts with the constraints and opportunities that their educational settings and students present. I was attentive to embed my research and findings in the action and life of educational reality (see Denzin & Lincoln, 2017).

The research approach was based on the pragmatic and transformative-emancipatory philosophies. A pragmatic philosophy has the potential to address the problems of everyday life and to use established principles to envision a path for the future (Legg & Hookway, 2020). The goal of understanding and transforming the practice of special education for teachers of students with profound disabilities is multileveled and is rooted in historical understandings and mandates. Proponents of the transformative-emancipatory paradigm maintain that the importance of research lies in its ability to transform practices and improve lives (Chilisa & Kawulich, 2012).

Understandings and viewpoints regarding disability, the impact of students with disability on public education, and student characteristics are diverse when considering the different facets of work undertaken by educational policymakers compared to that of teachers who approach students face-to-face (Graham, 2015; Gregory, 2018; Kearns et al., 2015; Robinson, 2017).

The questions asked in this study and the inferences drawn from the responses may contribute to the framework for the effective education of students with PIMD, meeting the mandates of law, the needs of educators, and the rights of the students being served. Utilizing the transformative-emancipatory philosophy was important because the research is enmeshed in a social justice perspective, as its aim includes clarifying factors in the education of students with profound disabilities that may require additional work to provide the supports needed to fulfill the mandate of legal and moral mandates of meaningful and appropriate education. This study focused on a problem that confronts a very small minority and underrecognized group of students.

Role of the Researcher

This study was initiated due to my role as a special education teacher. I am an insider, similar to the subjects I interviewed, sharing the role and many of the experiences of the participants. The interviews used for data collection in the study, however, were gathered from special education teachers with whom I had no professional connection or responsibility. In the language of Adler and Adler (1987) on membership roles in qualitative research, I would be considered a peripheral member researcher. Although Adler and Adler explained this role as being marginal or superficial in in the phenomena

being studied, understanding, but not participating in the practice of the participants, Dwyer and Buckle (2009) expanded the concept, writing of a space between being an insider or an outsider in research. Finding myself occupying this space, I allowed my role as a researcher on the topic of the educational aspect of PIMD to shape my inquiry, finding balance through the duality of being an insider in the work of teaching but an outsider in the communities and circumstances of the participants.

This study was strengthened by my position as both a practitioner and a researcher, particularly because my research was not done in my own location of employment. I believe that the reality of having been there myself gave me a level of legitimacy and elicit trust and transparency needed from my respondents (Dwyer & Buckle, 2009).

The status of insider brings with it challenges in reducing the possibility of bias. Dwyer and Buckle (2009) warned that the participants could make "assumptions of similarity," and may be less clear in their remarks (p. 58). I needed to be aware of my own potential for subjectivity, not allowing my own experiences to cloud my perceptions. Galdas (2017) suggested that the issue of bias in a qualitative study could be mediated by the intentional practice of the researcher to be transparent and self-reflective when conducting research. I sought to carefully balance subjectivity and objectivity of perspectives, and did so in two of the ways suggested by Onwuegbuzie and Johnson (2006). First, descriptive validity was strengthened by recording and transcription of interviews, followed by multiple comparisons of each audio recording and written transcript to ensure that the interview conversation accurately captured not only the

spontaneously spoken words of the interviewee, but also the intent that the participant's voice indicated that they were striving to convey. Following data collection and interpretation, I used a peer reviewer (an individual with a terminal degree and trained in the field of qualitative research) to examine the relationships and conceptualizations I made between the three data sources to gain outsider review of the data. Through these strategies, I was able to utilize insider-outsider legitimation in the interpretation of the collected data.

Because issues of moral and ethical values are interwoven with legal mandates in the work with individuals with profound intellectual disabilities, I had to be particularly cognizant of possible confirmation bias in my data collection, analysis, and presentation of research. I chose to study an issue that is salient in my professional practice, and that, based on literature review and confirmation from other educators, appeared to be illustrative of a gap in special educational practice in U.S. public schools (Shurr & Bouck, 2013). It was necessary for me to consistently defer my suspicion that a gap truly does exist, and explore the knowledge base through my research design; gathering verbal and documentation data to describe and more fully understand the phenomenon.

The practice of grounding my analysis of three data streams (interview, record review of Individualized Educational Plans and Evaluation Team Reports) in legal mandates and maintaining a growth mindset rather than a confirmatory mindset was imperative. Documents that standardized the sequence of questions that I asked during the interview process, as well as specific data collected from records were submitted to mentors and experienced qualitative researchers for comment, revision, and approval.

Methodology

Participant Selection Logic

Participant selection for this study was purposeful. Ishak and Bakar (2014) stated that purposeful sampling is useful when a researcher needs to locate members of a specialized population and when seeking particular characteristics for in-depth investigation. Special education teachers in United States public school districts who work with students with the low-incidence disability of PIMD are part of a specialized population, and comprised the participant pool for this study. A literal replication strategy was used in recruiting participants in an effort to find typical themes in relation to the topic of inquiry (Gibbs, 2012b). Potential contacts for participants who met inclusion criteria were sought through employment channels and further vetted through phone conversations and email exchanges. Specific recruitment procedures are described later this chapter.

The number of interviews that need to be conducted in case study has traditionally been determined by data saturation. Data saturation (or inadequate data saturation) has an impact on the quality of research. Hagaman and Wultich (2017) reported that, when given a relatively homogenous group, common themes could be identified with 16 or fewer interviews. Francis et al. (2010) suggested an approach that requires that at least 10 interviews be conducted and coded. After those 10 interviews, three additional interviews should be conducted. If no new themes emerge in the final 3 interviews, the stopping criterion has been reached. Similar to the work of Francis et al. (2010), Ishak and Bakar (2014) suggested that the number of interviews be determined by repetition of the stories

and themes of the participants. They suggested that four interviews could be undertaken and coded, and then two more participant interviews could determine whether saturation has been reached, evidenced by no new information being attributed to the final participants.

Marshall et al. (2013) stated, “Case studies are among the most difficult types of qualitative research to classify” (p. 13). In trying to quantify an appropriate number of cases in a study, Creswell et al. (2007) recommended no more than four or five. Marshall et al. (2013) further recommends three to five interviewees per case study. Given these precedents, the goal for this exploratory study was to interview at least four participants and code the data from these interviews. After coding was complete, I conducted two additional interviews. Those two additional interviews did not reveal any significantly unique information or codes, so I was able to assume saturation of this bounded population.

Data Saturation

Even when the number of interviews had been established, data saturation was still considered. A qualitative data set must be large enough to reasonably assure that diverse and important perceptions are captured, but not so large as to become repetitive and unmanageable (Mason, 2010). In the interviews used in this study, saturation was facilitated by a semistructured interview protocol that involved asking multiple participants the same questions (Guest et al., 2006). Because the collected data was coded and analyzed throughout the study, it was possible to determine when new information and additional codes were no longer being supplied by participants (Guest et al., 2006;

Simon, 2011). Additionally, through discussion with school district special education directors and public websites, I was able to locate and include a teacher who was absent from public school and Board of Developmental Disability records; one contracted by a school district to work itinerantly through an educational service center. This added diversity to the sample and represented a strata of teachers within the target population who have a different knowledge profile than teachers who work directly for traditional school districts (Bernard, 2018).

Instrumentation

For this study, semistructured interviews with special education teachers were the primary data collection instrument. The probe questions for the interviews were established based on the research questions for the study. Two university researchers were contacted to obtain insights and suggestions on the interview protocol. The suggestions they offered were incorporated into the protocol Specifically, one of the researchers elaborated on the need to be aware of the possibility that subjects may demonstrate frustration with their experience in teaching students with PIMD, and it is necessary that I be positioned to recognize and accept heightened emotion, yet value the insights offered. An additional concept for consideration that was raised was the mandated principle of UDL for students with intellectual disability. The framework of UDL is to increase the potential of inclusionary classroom practices to support all students, regardless of ability, in mastering learning goals (Rao et al., 2017). Despite mandated UDL practice under ESSA, few empirical studies exist on its use with students

with intellectual or other severe disabilities (Rao et al., 2017). The researcher vetting the interview protocol wrote the following:

> The general tenor of public education as reflected in the Universal Design for Learning paradigm presumes a certain level of cognitive and language facility leading toward college readiness. Do the teachers of PIMD students accept and identify with that "anyone can learn" orientation? Do they feel frustration when educational philosophy fails to align with the very limited cognitive and language ability of this population of students?

This tenet of inquiry was included in the section of the interview protocol regarding *Impact of Federal and State Laws and Mandates*. Interview protocol and research question alignment document are included in Appendix E.

The final pieces of data that were examined were educational records in the form of Evaluation Team Reports (ETRs) and Individualized Educational Plans (IEPs), with all names redacted. These documents are often used for training purposes, and in this data collection, student identities, geographic locations, and all information that could identify a student was safeguarded. Under the Individuals with Disabilities Education Improvement Act, 2004, Part B, §300.304-300.311, federal guidelines require that every student suspected of having a disability must receive a full and individualized evaluation to determine eligibility for special education services and to determine the educational needs of the student. This evaluation must use a variety of assessment tools and strategies to gather functional, developmental, and academic information about the child that will subsequently be used to develop the student's Individualized Education Plan. Federal

Guidelines for IEPs are described in the Individuals with Disabilities Education Improvement Act, 2004, Part B, §300.320-300.328. These guidelines require present levels of academic and functional performance, academic and functional goals that are aligned with alternate academic achievement standards, and a statement of the "special education and related services and supplementary aids and services, based on peer-reviewed research to the extent practicable, to be provided to the child," and accommodations that are necessary to measure "academic achievement and functional performance" of the child (Individuals with Disabilities Education Improvement Act, 2004, Part B, §300.320-300.328). Specifically, the ETR and IEP data sources were examined for information regarding functional and developmental data of the student, functional goals that are aligned to alternate academic achievement standards, and what peer-reviewed research is being utilized to measure the functional performance of the child. Records Review checklist is included in Appendix F.

Procedures

Procedures for Recruitment

For this study, participants included special education teachers who work with students having profound and multiple disabilities. The participants were selected using purposeful sampling in an effort to identify cases that could yield rich information and effectively use limited resources (Patton, 2002). Organizations that might employ research participants were identified through internet searches and networking with professionals in the field of special education.

Organizational representatives, who in the realm of special education typically include school superintendents, special education directors, or school principals, were contacted through telephone or e-mail exchange to inform them of the research plan and seek formal organizational cooperation, allowing potential participants to be recruited from their organization (see Appendix C). Documentation of Institutional Review Board approval was included in this message. The authorizing representative was not informed of employees who chose to participate to insure participant transparency and confidentiality. During this process, one administrator asked which employees would be contacted, to which I replied that I was unable to compromise a teacher's confidentiality, but that only teachers with special education credentials would be contacted, and that if any child abuse was disclosed, mandated reporter guidelines would be followed. Potential contacts for these interviews were gained through organizational websites that identified employees and their roles in the district or organization. Once potential educators were identified, phone, text, and e-mail were used to begin the process of initial outreach to the potential participants. In the initial conversation, a basic description of who I am and what the purpose is for the study was provided, as well as confirmation that their organizational representative agreed to permit participation.

If participants verbally indicated their interest in the study and willingness to participate, a follow-up email was sent to the potential participants. This letter outlined the purpose of the study, the procedures to be followed, the manner in which confidentiality of participants would be protected, risks and benefits of participation, and a statement of informed consent (see Appendix D). Potential participants were asked to

return the signed letter of consent via email. Once six participants were identified and consent received, phone interviews were scheduled. Due to restrictions created by COVID-19 safety and personal distancing protocols, interviews took place over the telephone. Once we commenced each interview, I reviewed with each participant the content of the consent form that was provided and signed prior to beginning data collection. Validity for the interview method of data collection must be two-faceted. First, there must be validity in the method of data collection (Kuzmanic, 2009). To ensure this, interviews took place through private phone conversations. I personally conducted all interviews, which consisted of a single interview session with each participant and interview times ranging from approximately 16 to 40 minutes. Timing was flexible following the lead of the participant. Participants were asked for verbal and written permission to digitally audio record the discussion to provide an accurate record that was revisited by the researcher. Transcription occurred after the interviews through use of Temi digital transcription software, which was then checked against the audio recording to ensure accuracy. Participants were reminded that if they chose to exit the study at any time, their wishes would be respected and transcripts would be destroyed. None of the participants chose to withdraw from the interview. At the end of the interviews, four of the participants were asked to submit their redacted ETR and IEP documents, per their consent agreements. Two of the interviewees, one who had less than a single year of special education experience and one who was uncertain how to redact information and transmit documents, were informed that their participation had allowed me to reach data saturation, and that they did not need to take the extra step in submitting documentation.

Considerations for Interviews

It was important in the initial phase of data collection, the interviews, to establish rapport, which can be facilitated by two strategies, affiliation and empathy (Prior, 2017). Affiliation refers to a commitment on the part of the researcher to foster mutual trust, respect, and the co-construction of knowledge with a participant as well as the recognition of a shared understanding. Researchers need to recognize that they are, "carrying out research *with* their participants, not *on* them" (Prior, 2017, p. 2). The second requisite was that of empathy, with both partners knowing that they are sharing the experience, not judging it (Prior, 2017). During the interview process, participants were assured of both confidentiality and that they were discussing an experience shared by other teachers of students with PIMD.

Procedures for Document Review

The Document Review (Appendix F) outlines the focus of the selective review method that was chosen to increase opportunities to gain a more complete understanding of the population and specific research questions posed in this study. As in the interview phase, no identifying information was collected and only numbers were used to organize related data sources, which helped in the clarity of data comparison in the study.

These final tenets of data triangulation, the records reviews, were most closely tied to the objective information that is legally required to be included in ETR and IEP documents. These documents provided insight into how students with PIMD are identified in school districts, types of services that are offered, settings where they are being served, and the types of goals established by parents and educators for the students'

growth and development in the public school system. Because of the protected nature of students with disabilities, all identifying information was redacted before document review. It was communicated to research partners that information was not being collected to gain insights about any specific student, but about the PIMD student population as a whole. The boundaries of the information attained from this review are presented in Appendix F. The goal of this document review was to evaluate documents in a manner that adds to empirical evidence of the practical response to the education of students with PIMD in the public school setting.

Testing Reactivity

The problem of testing reactivity or observer effect, which is the reality that the researcher and research participants respond to each other during the research process, and that those being interviewed may change their behavior or responses as a result of being interviewed (Liang, 2015; McKechnie, 2008), may be present in qualitative aspects of a research design. In an effort to reduce the likelihood of testing reactivity in my semistructured interviews, I utilized an expert panel to help identify any language or wording in my interview plan that could influence a respondent to shape their answers in a particular manner, perhaps to give an answer that they believe is what they *should* feel or say. I also considered the possibility that respondents might be reluctant to be fully forthcoming on topics of their own knowledge and the potential moral/ethical philosophies that they hold in regard to students with PIMD. To moderate this possibility, I reiterated the confidential nature of the interview, and disclosed my identity as an

insider who has also wrestled with the intricacies of educating students with profound disability. Each interview yielded a high level of candor from participants.

Muhammad et al. (2015) found that "matching researcher identity with that of the interviewee minimized social distance [and] mistrust" (Discussion, para. 3). Muhammad et al. (2015) suggested that it is helpful in reducing reactivity if researchers' identities intersect with the identity of community partners (Reflection on Researcher Identity, para. 1). Confidentiality was discussed with participants and then carefully practiced to minimize any fear of judgment. Interview data were analyzed at the group level and pseudonyms were used in order to de-identify participants. When participants were quoted in the study, these pseudonyms were also utilized to mask identities. Interviews were taped, transcribed, and numbered; audio was erased at completion of this study eliminating the connection between the respondent and their comments. Collected paper documents will be stored for a minimum of five years in a locked box in my home, and will then be destroyed.

The process for the storage and disposal of the interview data was shared in the letter of consent (Appendix D). Interviews were recorded and the digital copy was destroyed after transcription was cross-checked multiple times for accuracy and clarity throughout data analysis and notes were made regarding voice, inflection, and participant demeanor that could have been lost through text alone. The typed interviews contain no mention of participant names, student names, or identifying information about school, district, or location. The typed interviews are being kept in on a password protected thumb drive in a locked box in my home and will be destroyed after five years.

Validity

Establishing validity in an interview method of data collection requires finding balance on the spectrum between pure objectivity and subjective relativism (Kuzmanic, 2009). Kuzmanic (2009) asserted that in the interview process, it is important for the researcher to maintain focus on the perspective of the interviewee in regard to the topic of inquiry rather than on the meaning of the phenomena in isolation. My question format was designed to intermix questions that were straightforward and included a low element of risk for the respondent with questions that required greater transparency and could be perceived as involving a level of relational risk. I anticipated that in the interview process, talking about experiences with students who have PIMD might elicit strong emotions for teachers. While I welcomed and encouraged these stories, it was sometimes necessary for me the redirect discussion to assure that the timeframe was appropriate and that content of the interview remained loosely focused on the research topics. By mixing low-intensity questions with possible high intensity questions, the interview proved more rewarding for both parties. The interview questions for this study were built on the theoretical and conceptual theories of the research. Alignment may be seen in Appendix E.

Data Analysis Plan

I used hand coding for the interview data using a strategy suggested by Gramenz (2014) utilizing three columns: the first for emerging codes, the second for the transcript itself, and the third for notes and further information on categories and themes. The second element of validity, according to Kuzmanic (2009), is the validity of interpretation

of the data. To facilitate meaningful and accurate interpretation, anecdotal notes were handwritten throughout the interviews to supplement verbatim transcription with emergent thoughts or nuances that could be lost in the time lapse between interview and transcription.

In addition to these coding procedures, I used multiple coding-recoding iterations as a means to revisit those that were coded early in the process. It was through this mechanism of rereading that I was able to detect new themes that emerged as later interviews were coded, and to explore the presence of these themes in interviews coded prior to their emergence. Pessoa et al. (2019) observed that in the process of transcribing or analyzing interviews, researchers may realize that certain content of an interview may have been mentioned briefly or superficially by a participant, and not immediately recognized as being connected to the research questions. Revisiting early interview transcripts allowed me to seek deeper understanding, clarity, and consistency in coding.

To begin analysis of qualitative data, transcripts were created from recorded interviews though the initial use of Temi dictation software and followed up by the researcher's comparison of the digital recording and written transcription. After multiple rechecks, coding followed the Gramenz (2014) strategy described above. After this table was prepared, the following practices, adapted from a process outlined by Lofgren (2013), was followed:

1. Each transcript was read as a whole document; initial impressions were noted.
2. Each transcript was read closely, with "relevant pieces, such as words, phrases, sentences, or sections" highlighted. Highlighting occurred when

repeated themes are noticed, new or surprising information is shared, when the respondent indicates that something is particularly important to them, or it relates to information in the literature review. Additional notes were made of overarching themes that continually surfaced during interviews.

3. Highlighted areas were matched with a preliminary code. Patterns of codes were not predetermined, but were emergent and a part of analysis.
4. Once an entire transcript was coded, I looked for codes that were particularly salient or repetitive. I looked for ways to meaningfully combine codes into broader categories or themes.
5. Themes were labeled and compared to the research questions, looking for connections.
6. When possible, visual representation of the themes was created, looking for importance, relevance, and any connections noted between separate interview data.
7. In writing up findings, I utilized themes as headings, and describe the categories and how they are connected. I made no effort to interpret findings at this stage.
8. At this point, I began to plan the discussion of research, which included interpreting results, relating them closely to theoretical and conceptual frameworks and drawing in information from the literature review.

Valuing Participation in Research

Wolgemuth et al. (2014) noted that participating in research through interviews allow participants to feel that they are being listened to, validated, and given the opportunity to experience empathetic understanding. Campbell et al. (2010) further found that when research participants discovered that other participants had experiences that were similar to their own, it relieved their sense of isolation and made them feel connected to a broader community. In the interest of demonstrating to participants the value of their time, candid sharing during interviews, and the effort taken to appropriately redact and submit documentation, as well as simply affirming the significance of their willingness to participate in the research process, at the end of this study, participants will be sent a letter of thanks that will include a synopsis of findings. They will be invited to contact me if they desire more extensive information about the findings of the study.

Issues of Trustworthiness

Lincoln and Guba (1990) explained that trustworthiness is one manner of judging the process of a case study, but is also a way of judging the quality of the narrative, the quality, of the interpretation of stories that are told through case study. Although complete objectivity is not a key goal of qualitative research, resonance is an important counterpart to objectivity and relates to a researcher's ability to impact stakeholders in such a way that they find value in the study and will be able to transfer the findings into their own context (Tracy, 2010) Resonance, however, must be situated in the context of criteria such as rigor, sincerity (reflexivity), credibility, significant contribution to the

field of study, ethics, and cohesion (Tracy, 2010). The criteria of trustworthiness integrates many of these facets of excellence in qualitative research.

Internal Validity

Internal validity has been addressed topically throughout this chapter, including interviewer credibility in a high-context setting, triangulation of three data sources: interview and document review; data saturation, and peer review from research mentors and qualitative researchers with terminal degrees.

External Validity

Issues of external validity include reflexivity, which has been addressed by the transparency on the part of the researcher, discussed in the *role of the researcher*. Transferability may present a challenge in qualitative study, and particularly in case study methods. One strategy in this study to address transferability was the use of interviews with multiple participants with questions structured to facilitate a similar framework for interview content. The selection of participants was sought from a broad geographical and cultural area to allow for optimal variation of contexts for the experience of educating students from an extremely low-incidence population.

Qualitative research is shaped by the practice of thick, rich description. As I conducted interviews, I was aware of the importance of the voices and perspectives of my respondents on the subject of the education of students with PIMD. Education that fulfills the legal, and moral mandates of meaningful experience cannot be examined outside of the context of human relationships and experiences. Clear and rich documentation and interpretation of these human factors have been mindfully included in my discussion.

Qualitative questions were worded with the goal of eliciting not only factual data from participants, but also to encourage story-telling from their experiences in teaching a challenging population. It was the goal that these stories, in addition to the anecdotal notes that are included during data collection, have resulted in the thick, rich description that characterizes qualitative research.

Dependability

Dependability refers, in part, to the stability of data over time or consistency (Gibbs, 2012a). One method that I utilized was the semistructured interview protocol as presented in Appendix E to guide the themes and questions in the interviews in similar trajectories. Another strategy I used to ensure the stability of my interpretation over time was a process suggested by one of the expert reviewers of my interview protocol. His suggestion was that it would enhance dependability by using multiple coding-recoding iterations to make certain that coded themes and interpretations are stable throughout the data analysis process. I used triangulation of three data sources in this study.

Confirmability

Confirmability is the qualitative equivalent to objectivity, dealing with issues of neutrality and reduction of bias (Gibbs, 2012a). Reflexivity was practiced as I acknowledged my role as an insider and an outsider in the research process. As previously discussed, I was attentive to my own researcher biases, particularly confirmation bias. Confirmability was also built through transparency with participants.

Ethical Procedures

Ethical issues are present in qualitative research. Orb et al. (2000) explained that, "The research process creates tension between the aims of research to make generalizations for the good of others, and the rights of participants to maintain privacy" (p. 93). For this research, procedures developed and required by the Institutional Review Board (IRB) were followed, and approval for the study was granted by the Walden University IRB, with an approval number of 08-07-20-0248531. As the researcher, I was ultimately responsible for the ethical treatment of the participants in this study and the data that has been collected (Orb et al., 2000).

Because the study participants are in-service teachers, there was an ethical balance that I needed to achieve. The ethical issues were not related to the highly vulnerable and protected population that they serve, but rather the teachers' own willingness to offer transparency. Although teachers of students with PIMD may benefit from this research through means of having their viewpoints considered, serving as advocates for students with PIMD, and deepening the understanding of the unique teacher needs and competencies necessary to meet the legal and ethical mandates in the education of students with PIMD, it may also have been worrisome for these educators to provide written and recorded data concerning their knowledge of and feelings about their job. To mitigate these concerns, participants were assured of the measures in place to protect their identities: the connection between the respondent and their comments were eliminated and when names were necessary for clarity, pseudonyms were used.

Summary

Chapter 3 included a description of the research methods that were utilized in this study. An introduction and rationalization of the exploratory multiple case study design was presented as an effective method for answering the posed research questions. The pragmatic and transformative-emancipatory philosophies that are utilized in this design were explored for their salience to the goals of understanding current educational practice in the field of profound disability. The role of the researcher with the strengths and cautions of being an insider were considered.

In addition, this chapter included descriptions of participant selection, data saturation, and the semistructured interviews that comprised instrumentation for data collection. Research questions were aligned to interview questions, issues of ethical practice were delineated, and strategies to improve the trustworthiness of this research were presented.

This study attempted to provide answers to the *how* and *why* questions that evolve from the practice of educating students with PIMD; how instruction is carried out, why decisions about goals and curriculum are made; and primarily, what are the stories of the educators who are committed to providing legal, ethical, and life-enhancing educational experiences to students with these disabilities. This research was undertaken with fidelity to the standards of high research quality in an effort to assure that the data can be used to make a difference in the lives of students, families, teachers, schools, and communities that are impacted by profound disability. Chapter 4 addresses the results of this study.

Chapter 4: Results

The purpose of this exploratory multiple case study was to investigate how special education teachers are providing appropriate and meaningful education to students with PIMD, students with profound manifestations of disability, with little guidance from state and federal educational standards. Narrative inquiry and semistructured interviews, as well as review of educational documents, provided the data through which the three research questions were addressed:

1. What are the lived experiences of teachers of students with profound intellectual disability who teach in public school districts in the United States regarding challenges and successes in their teaching practice?
2. What kinds of curriculum, activities, and practices do teachers of students with PIMD utilize in their teaching to fulfill the federal mandate of meaningful education and from what sources are these tools (curriculum, activities, practices) obtained?
3. How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?

This chapter contains the results of the analysis of each of the three data sources. I describe the setting, which includes a brief, contextual explanation of how a national pandemic has influenced the work of four special education teachers in the United States. The demographic section includes a chart that contains the descriptions of students with PIMD given by the participating teachers. This became a valuable tool to check that the

correct population was being explored and as a means to interpret some incongruent anecdotes shared by participants. The process used for data collection is explained, as well as the process for data analysis of each data source individually. I discuss evidence of trustworthiness of analysis, and the separate analyses are synthesized in the results section of the chapter. Key findings of the study are presented in relation to the research questions.

Setting

The data for this study were collected from participants who were teaching students with profound disability during the international pandemic of COVID-19. The impact of this pandemic on the educational systems in the United States has varied by location, but in most cases teachers have implemented models of education in which some students are face-to-face in their classrooms while others are served through remote means. There have been mandates regarding the wearing of masks, personal protective equipment, high levels of sanitization, and recommendations of social distancing from students. Although these conditions had little bearing on the document review portion of this study, the impact of the pandemic on teaching settings, practices, activities, challenges, and successes was discussed by three of the four primary participants and by the two additional teachers who provided interviews for data saturation confirmation.

Although the impact of COVID-19 on the experiences of teachers was outside of the intended scope of this study, the comments of the participants on this issue are discussed to provide additional context to the interview data because in many cases these experiences influenced teacher experiences and practices. Two main issues are addressed

because the participants spoke of teaching with the challenges of COVID-19, including how their roles and typical practices as teachers had changed, and the additional stress and concern over remote teaching.

Ms. Duffy shared that her role as a teacher had changed. Instead of providing direct services to her students, she makes videos that are shared with the students by therapy staff who are permitted to have face-to-face contact with the students. This presents a disconnect because one of her students with PIMD is blind and deaf and displays inconsistent alertness. Ms. Brookes shared her frustration that her ability to teach her students was dependent on technology and the willingness of a students' home caregivers to access the technology that was provided: "I had one parent who faithfully signed in for whatever activities we did, but that was it." Mr. Cox summarized his concerns about the limitations presented by COVID-19: "Well, here's the problem. How do you do remote learning with [these students]?"

Demographics

This multiple case study was conducted with special education teachers who work with students with profound disabilities as defined by the characteristics described in Chapter 1. The participants included educators whose teaching experience ranged from 1 to 20 years in the field of special education according to information that was gathered through semistructured interviews. Table 3 highlights the demographic information collected during these interviews. Pseudonyms were used to differentiate each participant and to protect their confidentiality.

Table 3

Participant Demographic Information and Data Validation

Pseudonym	Degree	Years of experience	Setting	Data validation: screening student characteristics indicating PIMD (teacher report)
Ms. Arnold	Early Childhood/ Special Education	7	Regular Public School/ Self-Contained Classroom: Jr. and Senior High	• Traumatic Brain Injury • Seizures • 11 and 13 year olds with , <1 and <3 yr. old developmental level • Communication: Idiosyncratic and Echolalic • One student: no evidence of hearing
Ms. Brookes	Early Childhood-Grade 3 Regular Education/ Preschool-Age 21 Special Education	11	Intellectual/ Developmental Disabilities Separate School/Teenagers	• Blind and deaf • Severe motor impairment • Communication rare, guttural, and idiosyncratic • Newborn developmental level
Mr. Cox	Special Education K-12	20	Regular Public School/Self-Contained Classroom: 4th-5th grade	• Non-ambulatory • Non-verbal • Rare syndrome • Blind • Fully dependent for personal care
Ms. Duffy	Special Education K-12	14	Intellectual/ Developmental Disabilities Separate School/Primary	• Blind • Communicates through vocalizations • Inconsistent alertness
Ms. Eppley: Data Saturation Only	Special Education	<1	Intellectual/ Developmental Disabilities Separate School/ Intermediate Level	• Requires full care • Tube feed • No standard communication • Low levels of alertness
Ms. Franks: Data Saturation Only	Special Education K-12, Autism	18	Regular Public School K-5/ Self-Contained classroom	• No independent movement except a little in right hand • Feeding tube • Diapering • Non-verbal/ idiosyncratic sounds • Cortical blindness • Generally in sleep level of alertness, can be awakened by auditory input

During my collection and analysis of the interview data for this study, a confounding issue presented in every interview. Students with PIMD, the most profound manifestation of disability, compose a very low-incidence population in schools. All four of the teachers who were full participants in this study, as well as the two who provided interviews for data saturation purposes only, teach at least one student with PIMD, but all have students with less severe manifestations of disability in their classrooms, as well. Although the specific population being discussed was clear and that clarification was reiterated throughout the interviews, there were occasional instances when the teachers answered questions and provided examples based on their work with the larger population in their classroom without focusing on their experiences with the student with PIMD specifically.

Although these instances were redirected when possible and probed for relevance to the single student or students with PIMD, during data analysis comments had to be evaluated to determine whether they applied to the PIMD population of interest, or whether the participant had included a larger population of their classroom in the responses. In these cases, the definition of PIMD and the teacher's reported characteristics of the primary student or students of interest in the interview were compared to the statements given. If it was apparent that the participant comment included students with a wide range of abilities, that comment was not included in the analysis.

For example, one scenario described by Mr. Cox, who teaches fourth and fifth grade students clearly differentiates the target student who, per Mr. Cox's initial

description his student with PIMD as having a rare syndrome causing challenges such as the child being non-ambulatory, non-verbal, blind, and fully dependent on others for all personal care, and regressing; where the goals set for her involve motor strength and range of motion:

> Um, [for] the real low ones I do have [one] I found called Unique Curriculum, and we try to use that…One kiddo, I mean, he does catch on to some things and the same with [another student]. I mean, usually when I'm doing the one group that's reading about a kindergarten level, I'll have her up there just so she can listen.

Another comment was clearly more general: "I've always said if I can just give them enough information to survive on their own…if I can get them enough where they can add simple numbers and even just answer simple questions…" The goals of surviving on their own, performing addition, and answering simple questions do not correspond with Mr. Cox' stated abilities and goals of the student with PIMD, but rather to his broader population, so those comments were not included in data results.

Another example of this need for discretion came from the interview with Ms. Duffy. She reported that she had done a lesson on students' favorite subjects, and one of her students said, '"I like science!' I was like, 'She did always love the experiments.'" This experience did not match the description that Ms. Duffy had provided for her student with PIMD: deaf/blind, communicates through vocalizations, inconsistent alertness. It appeared that she was speaking of another student in her class rather than the

target pupil. For this reason, I felt that it was important to probe her response for greater clarity:

> I'm trying to picture this, because I know you've got some kids that are more capable, and then you've got the really profound kids. How do you gauge their involvement?
>
> Some just, you know, if they're looking, if they're awake, if they seem to be paying attention.

In this manner, I was able to isolate the comments that refer to the teaching of the target student with PIMD from the broader context of the scenario.

Data Collection

This section describes the data collection process undertaken for this study. The initial recruitment process included first obtaining consent from teachers' employing agencies before individual participants were identified. Contacts were sought from 11 educational institutions in the western, southwestern, and midwestern United States. Once contacts were identified, consent was sought from the administrative entity of 9 agencies. The administrative leaders who provided consent for recruitment were all from the midwestern United States.

Once consent was granted that allowed me to contact special education teachers under their employ, 41 teachers were identified as eligible for participation on the basis of their employment as special education teachers. These teachers were contacted via email to their school email address obtained from public staff directories. From these,

four participants agreed to contribute in all three elements of the study and two were willing to take part as interview-only participants to verify data saturation. These individuals returned informed consent through e-mails exchanged with the researcher, and phone contact information was exchanged in preparation for interviews. Public school facilities and state agencies are represented by the teachers participating in this multiple case study, and include two public school districts, one Educational Service Center, and one Intellectual/Developmental Disabilities Agency.

For this multiple case study, I collected data from three sources to allow for triangulation of data, thereby providing a multidimensional perspective of the phenomena of educating students with profound disability in public educational settings and to increase validity and reliability of the data (Thurmond, 2001). I examined Individualized Educational Plans (IEPs), Evaluation Team Reports (ETRs), and conducted semistructured interviews. Each of these methods provided a distinct insight of the work of special education teachers of students with PIMD. I describe the data collection process for each type of evidence in the sections that follow.

To facilitate a consistent format and to build the framework to collect data to answer specific research questions, I used an interview guide (see Appendix E) to structure my interviews. These interviews were conducted over the telephone at times selected by the participants not to coincide with the work hours of their teaching contract. I posed similar questions to each participant, and probing and follow-up questions were used spontaneously to clarify the teacher's comments or to explore topics that they brought up. When their tone indicated hesitancy, I reiterated the expectation of

confidentiality. The interviews lasted between 16 and 32 minutes. With the participants' knowledge and permission, each interview was digitally recorded. Initial transcription was performed by the Temi voice-to-text transcription program, and I then checked each transcript against the original recording to make corrections as needed. The transcripts are verbatim, but the quotations included in this paper have excluded unnecessary utterances (e.g., "um," "yeah," "you know," and "okay" as a filler words), phrases that indicated thinking-aloud utterances that precluded clarity, and substituted general replacement nouns when names were mentioned that could jeopardize the teacher, school, or district's confidentiality.

The final interviews were conducted with two teachers who had agreed to participate in an interview-only portion of data collection. These interviews were completed after the four primary, or full, participants had been interviewed, and they were analyzed after analysis had been completed on the original four. Analysis was undertaken for these final interviews with codes and themes already identified from the initial interviews determined. A line-by-line review was conducted using the same method of open coding followed by axial coding, and then matching was utilized to determine if the codes and themes were congruent with those already identified or whether new topics were introduced. The goal of these interviews was to check for any new or divergent themes or novel ideas that might be raised. In the absence of any new or unique data points, within the limited scope of this dissertation, data saturation would be determined as adequate for the current study.

Data Analysis

Two methods of data analysis were utilized in this study. Data analysis was initiated with the participant interviews. For these transcripts, both content and narrative analysis were used. Content analysis was primarily used as a means to analyze responses from interviewees in relation to the three research questions that are central to this work. Narrative analysis was then used for the purpose of focusing on the stories and experiences shared by the participating teachers. For the two remaining data sources for triangulation, IEP and ETR documents, targeted content analysis was used in accordance with the records review plan in Appendix F.

The process used in analyzing the data contained in the interview transcripts began with reviewing the three research questions to organize open coding topics. All interviews were coded manually. As I read each transcript separately, I created labels to correspond to each separate piece of information, noting the interview number from which the label was derived so that I could return easily to each source at a later time to locate participants actual words. Once initial manual coding was complete, all transcripts were re-read, having all four transcripts side-by-side allowed for continual comparison analysis.

In the next phase of my analysis, I began axial coding by looking for patterns in the open coding labels, and organizing the separate labels under broader themes that began to emerge. Once themes had emerged, I used pie charts to visualize the themes that were most prevalent and salient in the interview conversations.

Research Question 1, Part 1: Challenges

Figure 2

Theme of Challenges by Percentage

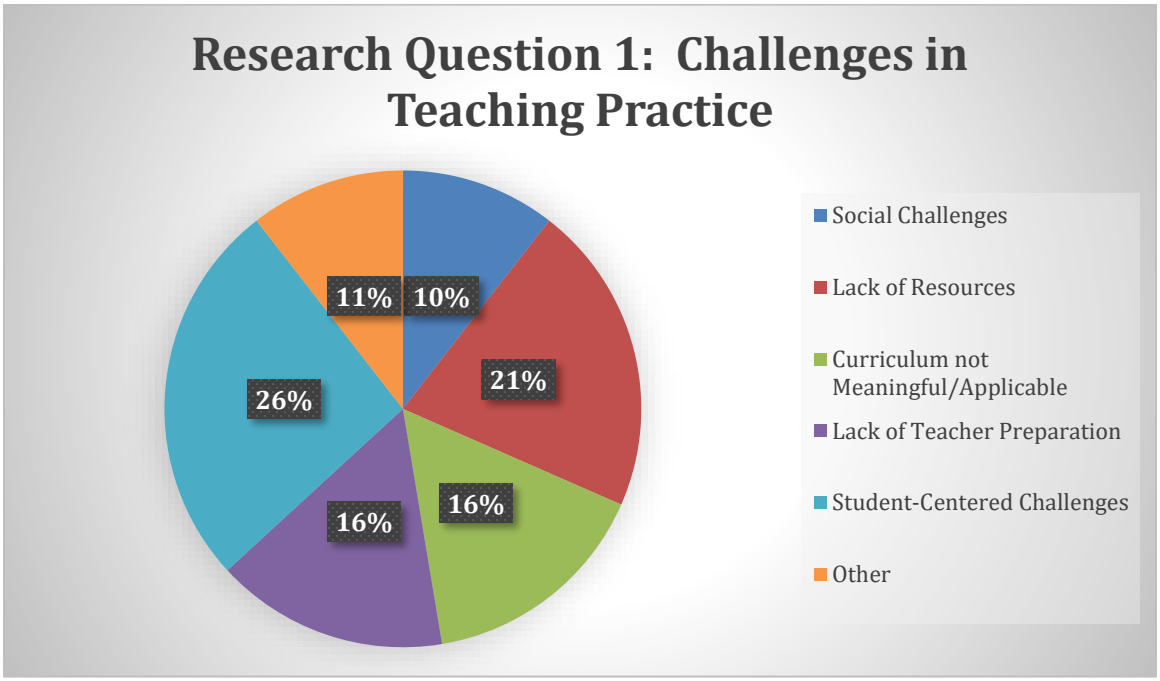


Figure 2 summarizes response themes gleaned from responses to probes related to the first research question: What are the lived experiences of teachers of students with profound intellectual disability regarding challenges and successes in their teaching practice? The goal of this examination by percentage of occurrences was done to determine if there was a preponderance of responses under any particular theme. Each participant typically discussed more than one challenge they face. When analyzing response themes for this question, the statements articulating challenges and those of successes were handled as two separate response sets. All four teachers of the teachers in the original sample were willing to articulate the challenges that they face as teachers of

students with profound disabilities. From their total 19 responses to this first inquiry, 6 categories of response were identified: school and community social challenges, resources, curriculum, lack of preparation, student-centered challenges, and other.

School and Community Challenges

The first category, school and community social challenges, was mentioned by 3 out of 4 participants, and equated to 10% of the responses within the broad category of Challenges pertaining to Research Question 1. These responses introduced the idea that teachers of students with profound disabilities may have a broader view of the educational experience for students beyond the special education classroom. Two teachers discussed the challenges faced as they attempt to integrate students into their community. Ms. Brookes noted the negative response that her students have received on community outings:

> When you're out in public we've actually had people…we were in Kentucky Fried Chicken and we had people leave because we came in. We tried to start a special needs soccer team last year with county soccer and they did not want to include us with pictures, left us off the schedule.

Mr. Cox added his observation that students with profound disabilities are still believed to exist on the fringes of public education:

> And I mean in the community, I'm going to be honest. There's a lot of people when I tell them…what kind of students I have, they, they, to this day, most people don't even know that those students are in a public school. I mean, a lot of

> people still think [separate school for students with disabilities] has the students and they're like, and the question comes up, 'Why are they at your school?'….I think it comes down to, there's a lot of education not being out there for adults to know what schools are facing and what's going on and who's in the class.

Lack of Resources and Curriculum Challenges

Responses to the interview probe regarding teaching challenges included the themes *lack of resources* and *curriculum not meaningful/applicable*. Three out of four participants stated this as a significant problem. Ms. Duffy referred to the disconnect that she has felt between educational expectations and the reality of teaching students with profound disabilities:

> There's ideas that we've done [at our school] that we think help, but it's just hard. It's really hard to, to find it out there. I would say I would get frustrated throughout the years with, you know, different things we had to do that I didn't feel were applicable.

One response requires some context. In the discipline of special education and therapy, the term *habitation* refers to the practice of helping individuals attain, keep, and improve skills and functioning for daily living. Ms. Brookes abbreviated this term in her response regarding teaching challenges:

> I feel like we're more of a hab room than an educational room. There's more to life than academics. Yeah. Sometimes I think I wasn't really cut out to be a teacher because [academics are] the least of my worries.

Another teacher summarized the challenges succinctly, replying, “I get stuck. A lot.”

The final comments under this topic of *challenges* are related to the lack of resources, in this case, time and personnel, during the school day. Mr. Meek stated, “[We] have a couple of students that we’d like to do more with, ‘cause they could probably learn more, but there are so many other ones that have so many needs.” Ms. Brookes spoke of the impact on her work with her family: “It makes you think, you know, working on lesson plans during the weekends and I just, I bring a lot home. And so sometimes you wonder if it’s the right thing for your family.”

Lack of Teacher Preparation

Each participant was asked, very early in the interview, “Can you remember the time that you first became aware that there were students with this very profound level of disability?” Two out of four respondents indicated that they remembered briefly seeing students with profound disabilities when they were elementary-aged children in school. Ms. Arnold remembered the earlier days of special education in the schools, before inclusion was considered or practiced:

> Our school was not very good at bringing them out. They, like, stayed in a room and I think probably when I was younger, I was like, ‘oh, those kids from that room’. It was almost a bad thing when I was growing up. That’s when I became aware.

Ms. Duffy recalled an initial brush with the knowledge of children with profound needs when she herself was a child, an experience that impacted her vocational decision as a young adult:

> I don't remember if it was through my church or through school. I think that we had a field trip [to a facility for children with disabilities] there once, but it wasn't really interacting with the individuals. I just remember going through their large, this large room…so when I started working at [that facility] I was a high school senior and at that point they were doing a summer camp…so it was amazing. I just loved it…my dad told me it was at that time that he felt good about [me] going away to college and picking a major because he could see the passion that I had for it.

Ms. Arnold attained a bachelor's degree in early childhood education and a master's degree in special education. The second story, from Ms. Duffy, who knew upon choosing a college major that she wanted to work with students with severe disabilities, took a degree path for mild to moderate disability. These demographic notations may be relevant in a later synthesis of the findings of this study.

The final two interview participants indicated that they were unaware of students with moderate to severe disabilities until they were in their final college experiences or when they began their first jobs as teachers in the field. Mr. Cox pursued an undergraduate degree in human development, but an acquaintance suggested he sit in on a jr. high special education class before graduation and took the coursework to complete a degree in special education. He noted, however, that he wasn't prepared for students

with profound disabilities when they began showing up in his classroom after 17 years of teaching.

> The [special school] closed up and boom, here we go. [When I was in college] they went over different disabilities I guess, but never really prepared you for what to expect except like in learning disability. For what to do in a multiple handicap [classroom] they don't [prepare you]. It's a whole different ball game.

The final participant, Ms. Brookes, reported that she had received her college degree in primary-level regular education, and then as an intervention specialist. In response to the question of when she first became aware of students with severe disabilities, she explained, "not until I started at the [separate school for students with developmental disabilities], really, because in college they never talked about kids like that. It's always just the ones that need reading intervention."

Within the context of these experiences, the interview data showed that 16% of the responses regarding the challenges of special education teachers centered on a lack of teacher preparation. The statements of the teachers were brief. "This is not what college made it sound like." "In college, they never talked about kids like this." "You're going to have to do a lot of issues on the fly, in that you're not going to come in and have a book [to tell you what to do]."

Student-Centered Challenges

The theme of *student-centered challenges* was discussed by 3 out of 4 of participants, totaling 26% of the interview responses regarding challenges of teaching, with a repeated theme that conveyed that one of the challenges is that teachers who have

acquired a range of 7 to 20 years of teaching experience continue to struggle to know what to do with the students whom they teach. Some of the responses under this theme were general, pertaining to a broad group of students with profound disabilities. Ms. Arnold described her experience as follows:

> I feel like you get stuck when I know I have to teach something and I know there's only so much my kids are going to understand. I think I'm really good at trying to get them to understand that, but there's just certain things they're not going to get, and it's, I just feel like it's useless.

Other responses spoke to challenges presented by specific student characteristics, but could be applicable on a broader scale, such as, "I felt lacking," "it was hard to know if I was reaching him or not," dealing with violent behaviors, and short periods of alertness. One of these struggles was articulated by Ms. Duffy:

> I have [taught kids with the most profound disabilities] in the past, too. I had one [student] that was considered deaf/blind, and so that was very difficult trying to find ways to reach him…I felt lacking. I felt like I could give him a good experience. You know, loving him, giving him something to do. As far as the education part, it was hard to know if I was reaching him or not, because even, you know, he's considered deaf/blind, but could he see anything? Could he hear anything? We really didn't know.

Ms. Arnold described dual frustration with the presence of chronic severe behavior and the perceived lack of administrative support:

> I think if I had this profound disability kid all the time, throwing rocks at me and stuff…this happened a lot. And I'm like, I can't. I can't do this for five years if you guys are gonna let him just like throw stuff at me.

Finally, Mr. Meek shared, "His attention span is like about two minutes. So it's like, what are the things where you can keep him focused for a couple of minutes? By afternoon, he's pretty much done."

The single participant who did not reflect on any student-centered challenges noted strongly that the students do not present the challenge. Instead, she viewed the difficulty lying in societal prejudices against people with disabilities, and a lack of knowledge about what to do with the students; a lack within the educator, not the students.

Other Challenges

When compiling themes under the topic of *challenges*, two additional responses were noted, both by a single participant. The first, lack of administrative support, was articulated in various ways throughout the interview process. Although this single response to the issue of challenges was reported as a part of the data gleaned from responses to the direct probes of Research Question 1, the number of instances where administrative influence on the teaching experience are mentioned indicates that this may be one of the overarching themes of this study, and was explored in a later synthesis of findings. Ms. Arnold first spoke of this concern:

> [My administrator] tries to be diplomatic and I wish she would kind of stick up for us more, but I think she tries to side with the parents sometimes, too. Anytime

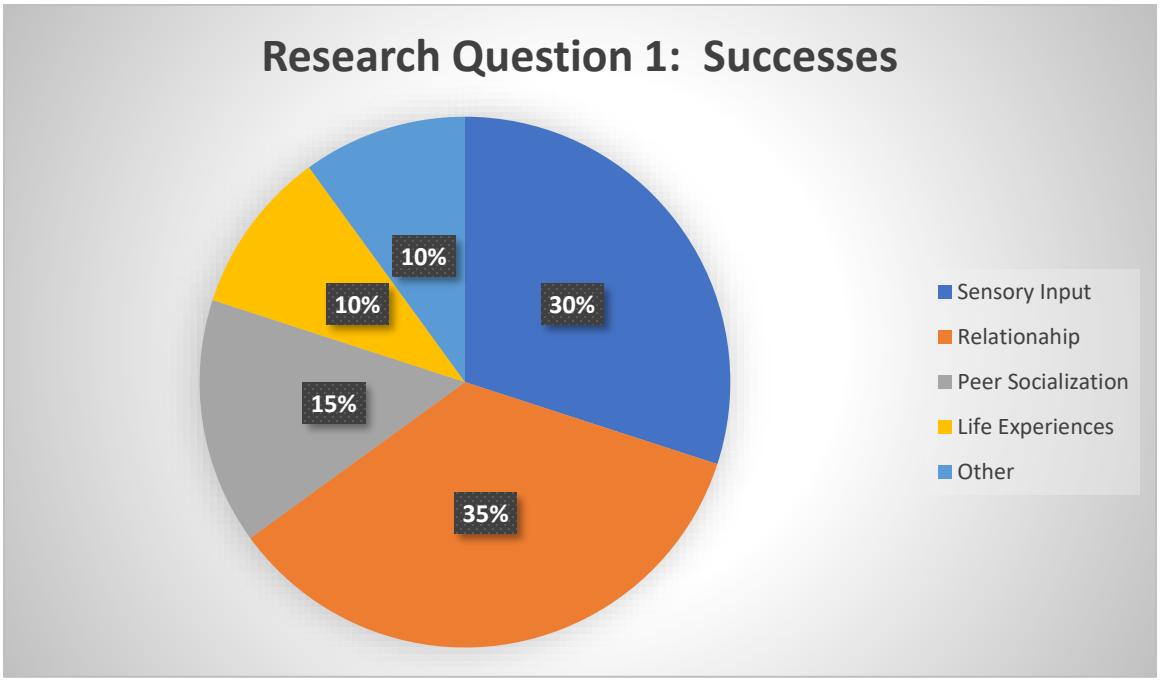
there's a problem or concern, [the administrator] doesn't really care, or it's my fault. We could use a little help.

Finally, under the category of challenges faced by teachers of students with profound disability, Ms. Arnold also spoke of a broad range of frustrations of non-involved families, student health-care needs being unmet, and as a teacher, taking responsibility for cleanliness of body and clothing, appropriate feeding, and dental care. These are challenges that are not unique to teachers of students with profound needs, but add to the complex challenges already faced by teachers in educational settings.

Research Question 1, Part 2: Successes

Figure 3

Theme of Successes by Percentage



Analysis of Research Question 1 was divided into two components, *challenges* described by teachers of students with profound disability and *successes* that they have enjoyed in their work with these students. Open coding on the topic of successes included 20 responses from the participants, with all 4 participants speaking of successes. As in the first segment of Research Question 1 regarding *challenges*, the responses to this probe were examined numerically through percentages of comment. This was done to determine if there was a prevalence of particular undertakings that resulted in feelings of success for teachers who deal daily with small steps of progress. These responses were

grouped into five themes: sensory input, relationship, peer socialization, life experiences, with two additional responses comprising a group noted as *other*.

Sensory Input

Impairments in the sensory system, as well as the need for sensory stimulation have been discussed as a part of the literature review portion of this study. When asked to reflect on successes in their teaching experiences with students with profound disabilities, without any specific prompting, sensory experiences with students were cited in 30% of the response total. These sensory experiences are linked to both academic learning extensions and to behavioral and emotional responses.

Ms. Arnold told the story of a student with profound disability who experienced nervousness around other students and would become very agitated. She converted a storage closet near her classroom into a simple sensory room:

> We cleared everything out, put some chairs and a beanbag, like a sensory corner, an iPad, and a little strobe light that he loves, and music. And we kind of made that his like relax…I don't know that I came up with it. I just kind of followed his lead and you know, it happened to work…sometimes it takes a while to figure things out.

Within the context of relationship, which is discussed later in this analysis, Ms. Brookes discussed the feeling of success when she is able to give students "all the sensory input they need." Ms. Duffy described success as being able to make [a student] comfortable. "I could give him things to explore or things that he liked. He like sensory, like chewing, so I would find different things to put in his mouth or chew." Ms. Duffy

went on to explain that sometimes successes aren't "educational-wise," but rather are strategies to help with student meltdowns. "We get to know the kids and that [one student] likes bird sounds and her favorite blanket. So we give her the blanket and the switch [that produces bird sounds] and let her calm down."

Two of the responses that were included under the "sensory input" theme were related to the successful attempts of teachers to translate academic standards into sensory experiences for their students. Mr. Cox described the process of trying out different textures and trying to find sensory input that the student likes. Ms. Duffy also spoke of tactile input, as well as utilizing any visual input that could be discerned:

> I always try to find a way to make it different for my learners, you know? If there's a book we're reading, I try and do different things. I have one young lady who uses a light box, so I would print something off for her on the transparent sheets and have that on there for her. I would cut out felt and string and made the hat and the coat for a winter book feel different textures. So I would just try and do different things for everybody, but still around the standard.

Ms. Duffy's final response related to academic content required some probing to clarify my understanding. "I really enjoy doing science with them, 'cause I do a lot of experiments in class and they to seem to like that, especially my young lady who can vocalize." Because this teacher had shared that her students have profound disabilities, I asked how she gauges their involvement. Her response included the idea that as a teacher, she looks at "a little bit of everything":

> Some just, you know, if they're looking, if they're awake, if they seem to be paying attention. If it's something that has a smell or a texture to it, then we can go around and show everybody; some can smell, some can feel, some can just look.

Relationships

Comprising 35% of the responses to the probe about successes in their teaching practice, the importance of relationships in successful educational experiences was the most prolific topic among participants. In some of these replies, the issue of building a relationship with students was connected to success in teaching endeavors; in others, the presence of relationship was an end in itself, and the relationship stands alone as the success in teaching students with profound disability. In other words, some respondents viewed relationship as a window in how to reach a student in order to strive for other goals; others view the ability to form a relationship to *be* the goal. These facets of relationship were gathered under the same theme, but they were examined separately.

Severe and profound disabilities are considered low-incidence student populations, and often they remain in a classroom for more than a single year. Ms. Duffy shared that she felt "pretty lucky" because she is typically able to keep the same students for two to three years. Because it may take time to attune to students with profound disabilities, several teacher responses indicated that their feelings of success came after they had been able to take the time to "follow the lead" of the students and find out what brought about positive results with each one.

Returning to Ms. Duffy's story cited earlier regarding the student who is able to vocalize her enjoyment of science experiments, an anecdote of success was shared that demonstrated the teacher's perceived benefit of having had three years to come to know this student. As a result of having spent a great deal of time with the student, the teacher was able to create a graphing lesson that utilized the student's favorite topics, and the young lady was able to vocalize her enjoyment.

Mr. Cox spoke of a small success within what felt like a failure. He had hoped to teach Braille to a young man with blindness, but as he came to know this young man's abilities, he realized that the goal was "just not in the cards" for him. Through the period of coming to know this student, he was able to discern what textures the student enjoyed and what sounds he could hear. He summarized the experience by saying, "I almost wish we could have taught him Braille or something. Right? [What we did], it's somehow a little bit."

The remainder of the responses under the theme of *relationship* suggested that these four teachers perceive the establishment of a positive relationship with a student with profound challenges to be a successful outcome, without any academic goal necessarily being derived from the interactions. The teacher responses in this area were succinct, and spoke to the power of typical human interactions of silliness, laughter, being included in a group, conversation, love, and quality of life. Each teacher who participated in the interview offered one of the statements below about relationship and meaning.

"Keep it fun…Like they probably think I'm crazy and I don't mind. I have these silly glasses…I put them on and they go all funny and just start cracking up." (Ms. Arnold)

"Just knowing they're included in whatever we're doing, whether it's something they can handle and participate [in] or not. Just making sure you're talking to them and interacting with them." (Ms. Brookes)

"I felt like I could give him a good experience. Um, you know, loving him, like giving him something to do and loving him." Ms. Duffy

"I sort of look at it, you know, what if I can make life happy for him and meaningful for their circumstances. I think I've done my job. And I think they deserve some kind of quality of life…" (Mr. Cox)

Peer Socialization

Successes were described in terms of peer socialization by 3 out of the 4 participants. Ms. Brookes, who did not mention peer interaction, is a participant who works in a separate school that does not include typically-developing peers. Responses under this theme represent 15% of the total category. Two separate contexts for inclusion were mentioned in these thematic responses.

The first was related to the goal and purpose of the practice of Universal Design for Learning (UDL), a model of inclusive practice that is designed to make learning in the general education classroom more accessible for all learners. This practice is one tenet of the ESSA mandate in U.S. public education, but is challenging for learners with profound disabilities. Mr. Cox saw the success of UDL embedded in the impact it had with peers:

> We see UDL mostly as a chance for [our students] to socialize and get to know peers. And just, I guess, more good for the other students, you know, like their peers. 'Oh, yeah, yeah, he's in our class'.

This vision of success is related to the challenges with socialization mentioned by participants in their responses regarding students with profound disabilities not being accepted in their community.

The second subset of responses within the idea of successes involving peer socialization introduce the topic of reverse mainstreaming, a practice that brings nondisabled peers to a self-contained classroom or separate school environment to provide opportunities for interaction. These success stories were shared by teachers in regular public schools as well as by a teacher who works with students in a separate, public school setting. Ms. Arnold shared the enjoyment of her students and their peers: "We cook…so they love that…and we invite friends, we have friends coming."
Ms. Duffy spoke at length:

> I do one of my favorite things, and we can't really do it any more [due to COVID-19 restrictions], but I loved when the different groups from the schools came into [our school] because a lot of them were unsure…some would even cry and we felt horrible for them. And obviously we didn't make them participate, but for the ones that, you know, you could just see them once they hung out for a little bit and got to know our kids, our kids loved it. And then they kinda got to know our students. And then you could just see the friendships and the attitudes…all the different schools would come out to us and we would have science fairs and

> holidays around the world type things…Every time the schools would come, we would have a disability awareness and then they would go around to our classrooms. So that was really nice.

Life Experiences

Ms. Arnold was one of the teachers who believes that some of her most important and successful work with her students comes in the form of the real, life experiences that she can offer within the realm of school. "I try to get as many real life experiences…we go on field trips, we go shopping." Mr. Cox also looks at his work as extending beyond the classroom and involving other professionals that can help his students. His is a perspective of facilitating future quality of life experiences.

> If I can get them enough where they can…even just answer simple questions…either feed themselves or [get] good health care. I'm happy with that. I guess. The one kiddo…she can listen. And she seems to know what's going on around her. I ask the PT (Physical Therapist), "Where are we going with this girl?" We keep her in gait trainers just to keep building up her leg muscles and keep her more mobile.

Ms. Duffy included an experience that went in the direction of facilitating meaningful life experiences for the siblings of her students, a tangent to the central topic, but important when students with PIMD are viewed within the context of their family system:

> My mom is a teacher…and she had a little girl and her brother [with profound disability] actually went to a school around us. She…didn't know how to express that she had a brother like this. So my mom asked me to come in and I did a disability awareness just on my students. And it was really neat to see how the kids reacted to that. So I didn't get to take anybody from my school, but just going into the school and talking about them was really neat.

Other

The 10% of responses in the final category, *other*, included just two additional comments. Ms. Duffy stated that her greatest successes come as she works in collaboration with other special education teachers:

> I do feel lucky because I can't imagine being in a typical school…I mean, I work with all intervention specialists there, so it makes a big difference. It's hard because there's not a lot out there for us, but some of the teachers have been teaching forever. They have lots of experience and then we all just kind of bounce ideas off of each other.

The final statement about perceived successes in teaching a student with the most severe manifestation of profound disability was a single word. "None." Upon further examination and probing, however, this was found to be a discrepant comment by a teacher who had already shared three instances of what she considered to be successes. This teacher felt that she, as the teacher, had felt successful when she used sensory input with her student, as well as when she included him in the classroom community by proximity and talking with him. Her final comment of "none" was her feeling that

nothing that she did as a teacher was making a change in the growth or success of her student. This single response bears weight in this discussion as it articulates the difference between successful teacher practices with students with PIMD and measurable, improved student outcomes.

Research Question 2: Curriculum, Activities, and Practices

The work that special education teachers do with students is built on a structure that includes curriculum (the subjects that comprise a course of study and academic content taught), activities that they use to engage students to teach this curriculum, and the practices they used regularly to serve their students. The second research question that I explored in the semistructured interviews related to these topics. In their discussion of *curriculum*, I probed teachers for the explicit or stated curriculum they use as public school teachers. Through these discussions, it became apparent that there was a mismatch between the explicit curriculum and students with profound manifestations of disability.

Of the four primary participants in this study, three mentioned that they use or have attempted to use a program known as *The Unique Learning System*, called simply "Unique" by teachers, which was briefly reviewed in Chapter 1. This special education program was designed to give students with complex, moderate to severe learning needs access to the general education curriculum. This program parallels the general education curriculum in states throughout the United States.

Two of the teachers in the study taught in schools where there was no specific program in place for students with severe challenges to access the curriculum of their particular state. Feeling at a loss for resources, these two teachers sought and discovered

Unique to help meet their needs as teachers as they in turn try to meet the needs of their students. Consider the following exchange with Ms. Arnold. My questions are italicized for clarity:

> I do use Unique Curriculum for ELA, Math, a lot of life skills, and then they have science and social studies extras…so, I mean, I use something, but that might be 25%. I supplement a lot, or I make things.
>
> *When you moved into [your current] job, is that what [the school] used or did you choose it?*
>
> I found it. They were kind of just throwing crap together and I'm like, 'I don't have time for this'. And I found that in looking more out, there is nothing. Like if I had the resources, I would make some kind of special needs, transitional, whole thing for people to do. You know, [now] it's just kind of looking at crap here and there thinking, 'Okay, what can I find for that?'

Mr. Cox articulated a similar experience with his use of curriculum:

> I do have one I found called Unique Learning, and we try to use that…the one kiddo, I mean, he does catch on to some things, and the same with [another female student]. I mean, usually when I'm doing the one group that's reading about a kindergarten level, I'll have her up there just so she can listen. And she seems to know what's going on around her…I'm not sure what she can learn. She's pretty much to the point where she's regressing now and that's just the nature of her disability…

Do you think Unique is a meaningful curriculum for her?

To be honest, probably not. And I don't really know what curriculum would be meaningful for her.

The third teacher, Ms. Brookes, who mentioned the Unique Learning System expressed the challenge that she encounters with the overall topic of curriculum in the following exchange, in which she was referring to one of the students she teaches who has profound disability:

What curriculum do you use with him?

Attainment Curriculum is what we're supposed to use, but I don't really use it.

Why don't you use it?

Because it doesn't work.

Would you say it's too high? Too low?

Too high. And the Extended Standards are too high. And the Unique Learning that's supposed to be appropriate for everyone is too high.

Acknowledging the teachers' comments pointing to a dearth of a standard, explicit curriculum, I probed to elicit responses regarding what other avenues these teachers pursue in creating curriculum for their students. Once again, the same three teachers, Ms. Arnold, Mr. Cox, and Ms. Brookes had similar responses, with each of them saying that it is their own responsibility to seek curriculum ideas to guide their

teaching. They all reported using internet searches and internet sources. Other responses included the use of an online resource called “Science A to Z” to print downloadable books that students can handle, color, and interact with; “scrounging around” for old materials that might be used with their students, “making things,” and the necessity of “thinking outside the box” to develop curriculum.

Activities

The activities that participants use to engage their students in learning experiences can be categorized under the two broad themes of sensory experiences and quality of life activities. All four teachers interviewed reported that activities that engage the sensory systems of their students are the ones that they return to the most often to create meaning for their students in an educational environment.

In sharing about her greatest success in teaching a student with profound disability, Ms. Arnold spoke at length about her creation of a simple sensory room out of a storage closet next to her room. That room included a bean bag for tactile input, a strobe light that provided visual input, music, and an iPad for both visual and auditory input. Ms. Duffy also mentioned the use of iPads to provide visual and auditory input for her students. Ms. Brookes spoke of her efforts with one of her young men with most profound disability, including blindness, who does not like touch. She focuses on auditory input, particularly “talking to him,” in an effort to provide him with “all the sensory input that [he] needs.”

Like Ms. Brookes’ student, many individuals with profound disability have blindness as one of their diagnoses. Both Mr. Cox and Ms. Duffy spoke of using sounds,

smells, and textures to engage their students. Mr. Cox discussed some of the challenges he has faced:

> What we worked on with him was just trying different textures, or trying to give him a couple of [sound] options and see if he heard something…We tried [using] a switch [referring to a Big Mac switch; a simple communication button on which speech, music, or any sound may be recorded for a user to play back] and that didn't really seem…every once in a while he'd hear something. He'd just keep repeating it then [by pressing the button].

Ms. Duffy, whose school places a strong emphasis on using the State Standards as the basis for student educational content speaks of embedding sensory experiences into academic instruction. During reading, when certain books or genre of books are the focus of a standard being taught, she prints material related to the book onto a transparency sheet and places it on a light box for visual input. She also creates tactile books: "I cut out felt and string and made the hat and the coat for a winter book [so she could] feel different textures. So I would just try to do different things for everybody, but still around the standard." Ms. Duffy also shared that she particularly finds success in the area of science:

> I really enjoy doing science with them. I do a lot of the experiments in the class and them seem to like that, especially my young lady who can vocalize.

> I'm trying to picture this, because I know you've got some kids that are more capable, and then you've got the really profound kids…How do you gauge their involvement?
>
> A little bit of everything. Some just, you know, if they're looking, if they're awake, if they seem to be paying attention, if it's something that has a smell or a texture to it, then we can go around and show everybody. Some can smell, some can feel, some can just look.

The final theme that emerged as participants spoke about the activities that they turn to most frequently in their daily work of teaching is that of quality of life activities. All four teachers spoke of the activities that they utilize to enhance the quality and richness of life for their students. As mentioned earlier in this chapter, Ms. Brookes spoke of the importance of talking to the students, and her planning of activities that purposefully provide a context for interaction. Ms. Arnold described cooking activities that culminate in bringing others in the school environment, known to her students as "friends" into the classroom, as well as facilitating the involvement of her students in a school walking program. In addition to the social aspect of the educational experience, Ms. Arnold also spoke of the importance of trying to teach one of her students to brush his teeth. Mr. Cox spoke of the importance that he and the therapists in his building place on helping the students learn to feed themselves, and utilizing physical therapy equipment to try to enhance strength and mobility.

Finally, Ms. Duffy focused on the students' educational experiences. She works on communication for her nonverbal students through practices of eye gaze and the use of

vocal output devices. “It’s using a vocal output device to request ‘more’ of an activity, or to communicate that they are ‘all done.’” Beyond the communicative function, these communication devices also require that a student gain skills using their arm or hand to touch the button, so motor learning is an important foundational ability that may increase opportunities for communication in the future. As Ms. Duffy described, teaching the students to activate communication switches is an embedded skill within the context of academic instruction. Mr. Cox summarized the ethical and moral importance of activities that are life-enhancing:

> I think they deserve the same thing what anybody else deserves. I mean, I think they deserve a decent quality of life. I’ve always looked at it, ‘You know what, as long as they’re happy’…It sounds bad, I mean, I hope they would catch on to something I teach them, but I sort of look at it, ‘You know what? If I can make life happy for them and meaningful for their circumstances, I think I’ve done my job’. And I think they deserve to have some quality of life that at least makes it meaningful for them.

Practices

In the interview discussions, I directed the topic of *practices* to go beyond isolated activities of teaching and probed toward those routines, habits, and mindsets that are ingrained into the long-term work of teaching students with profound disability. Like curriculum, practices can become a part of the framework on which teachers consciously or unconsciously build their planning and daily interactions with students. The comments

during the conversations about *practices* emerged into three thematic areas: collaboration, community, and relationship.

Collaboration. Observations on teacher demeanors and attitudes are discussed later in this study, but one note is included in the current analysis. Throughout the interview process, Ms. Brookes displayed a tone of resignation in her brief responses. As the theme of collaboration began to emerge from three of the participants, it was notable that Ms. Brookes practice does not include instances of collaboration with other professionals, a habit that is important to the work of the other teachers.

In discussing her belief that the setting of a separate school environment is a good fit for her students with profound disability, I asked Ms. Brookes if she has the opportunity to collaborate with others. “No. No, very rarely. I shouldn’t say never, but very rarely.” Conversely, Ms. Duffy spoke positively about being a part of a team, and the practice of calling in specialists to consult on more elusive aspects of a student’s disability. In the case of one of her students, a vision specialist was going to come to the school and offer mentorship as she worked with a student who is blind. Earlier in this chapter, it was noted that Ms. Duffy felt that the most successful aspects of her teaching occurs within the context of collaboration with other special education teachers. During this facet of the interview, she included therapists in this collaborative support team. “The therapists are from [our facility], so some of them have been there when I got there. So, throughout the years, I mean, we’ve worked really well together, coming up with goals.”

Ms. Arnold and Mr. Cox both spoke of the ongoing collaboration that occurs with their peers and the therapists in the building. Ms. Arnold did not elaborate, but

communicated her ongoing work with the therapists enthusiastically: “Physical therapy. I love them. Yep! Yep! Physical, occupational, speech, yes!”

Mr. Cox did not directly use the word *collaboration*, throughout the interview he consistently responded to questions using the pronoun “we” and spoke of his peer teacher, his classroom assistant, special education director, and two of the therapists repeatedly by name in his responses to questions. In 16 separate instances, Mr. Cox referenced specific conversations he had and ideas that were shared with other team members. In examining the content of his comments, it is apparent that he values collaboration with these individuals. A 17th comment concerning the work of an additional therapist was noted, as well, but was not included under the *collaboration* theme as the content of that comment referenced a positive, yet separate approach to their work rather than shared, collaborative teaming.

Community. Theorist Dewey wrote prolifically on the topic of community, and the importance of the placement of students with special educational needs within educational communities has been reiterated most recently by ESSA. Having their students acknowledged and accepted into their individual communities is a priority and part of their practice for all four of the participants interviewed.

Ms. Arnold’s classroom is located in the central portion of their school building. Her regular practice includes inclusion and reverse inclusion for her students. “For us, we’re part of the community…My kids eat with everybody. We cook…so they love that. And we invite friends, we have friends coming. We’re out a lot.”

Ms. Brookes has a similar desire for her students to be "part of the community," but because she teaches in a separate school, her regular practice includes taking her students out into the larger community, making them visible in the community. Her experiences have been troubling, as has been shared previously:

> What do you try to do? What do you think [is] meaningful for them?
>
> I think just knowing that they're included in whatever we're doing, whether it's something that they can handle and participate in or not.
>
> Do [others] treat them like they have value?
>
> In our building, yes. But when you're out in public, no…I was mad.

Like Ms. Brookes, Ms. Duffy's teaching position in a separate school for students with disabilities necessitates a definition of community that includes those outside of the school building. In Ms. Duffy's situation, however, reverse inclusion is the typical practice, with other school students coming to their site. Due to already-discussed limitations resulting from the COVID-19 pandemic, this practice has had to be discontinued for the present time. In her recollections of previous years, however, Ms. Duffy called these experiences "one of my favorite things."

> A lot of [the kids] were unsure. Some would even cry and we felt horrible for them. And obviously we didn't make them participate, but for the [other] ones that, you could just see them, once they hung out for a little bit and got to know

> our kids, our kids loved it. And then they kinda got to know our students. And that you could just see the friendships and the attitudes.

Mr. Cox included inclusion in his practice because he desires that his students be known and viewed as a normal part of the school community even though they are in a self-contained classroom setting:

> We do send some of them down [to general education classrooms]…for the most part we just sort of send them down to [garbled connection] so it's more socialization that they're around a little bit…And just, I guess just more good for the other students, like their peers. 'Oh, yeah, yeah, he's in our class.'

Relationships. The final set of responses to the question regarding the practices that help form their teaching centered around beliefs, attitudes, and practices that build relationships with students, and at the same time, impact relationships with students. Many of the comments refer to the time it takes to truly know students with profound disabilities. "I've been pretty lucky. I've been with [a particular student], I think this is our third year." Ms. Arnold discussed the necessity of trial and error in learning to teach individual students: "I kind of just follow his lead…sometimes it takes a while to figure that out. We tried different things and certain things don't work, but this happened to work." In addition, the use of humor and silliness to reach the students was mentioned, as well as the practice of, "Don't baby them. Push them and see what you can get out of them."

Communication challenges were one of the primary areas that elicited comments regarding what seems to be the unanimous importance of the practice of taking the time

to know their students. One primary characteristic of individuals with PIMD is the lack of clear communication. Present, instead, are idiosyncratic manifestations of communicative efforts, and each participant spoke of the importance of wanting to understand their students. Each teacher described building into their daily practice the goal of trying to find ways to understand.

Ms. Arnold has a student who is able to say one clear word. “This is my second year with him, and it’s very repetitive. It’s just ‘teacher’ and he’s monotone and I don’t think he could...[trails off]…yeah.” Ms. Brookes’ student does not have a reliable form of communication. “He has a deep grumbling sound if he’s upset.” She struggled to explain how she knows when he is happy or sad. “And he’s like…and then he’ll kind of…I don’t know. There’s just a difference in the tone so that, you know he’s happy or upset.”

Mr. Cox spoke of their efforts to help one of his students learn to answer a simple question using [switch technology]. “Every once in a while, he’d seem to hear something [when he hit the button]. He just kept repeating it then.” Ms. Duffy said that once she got to know one of her students, she came to know his communication. “Vocalizations, like when he was mad or upset. And so getting to know him, I could make him comfortable.” She spoke, also, of the challenge and the goal of trying to interpret a student’s communication who used eye-gaze to communicate. Even then, the level of comprehension was hard to discern. “I could kind of tell [what she was looking at],” Ms. Duffy explained, but had a level of uncertainty in her voice.

Research Question 3: Effectiveness of State Extended Academic Standards

The final research question that was addressed in the interview portion of data collection pertained to the applicability and use of state academic standards with students with profound manifestations of disability. As discussed at length in Chapter 2, ESSA states specifically that it is the responsibility of individual states and public school districts to ensure that *all* students are held to *the same* high academic standards. States have taken great strides to create extended standards, connectors, or access points to facilitate the ability of teachers to instruct exceptional learners in the required content. Asking the participants to discuss their use of academic content standards was a question that I deemed to have some risk involved, as it pertains to the implementation of an educational mandate, yet all participants were forthcoming in discussing this topic.

Participant responses were mixed regarding their use of the extended standards required by their state. Two participants reported a high level of implementation of the standards and the remaining two acknowledged little to no implementation. It would be expected that the teachers from the separate schools for students with severe disabilities would have comprised the half that does not utilize the standards, but the responses were actually mixed. Ms. Arnold and Ms. Duffy both use state academic standards as a basis for their instruction. Ms. Brookes and Mr. Cox rarely or never use the standards as a foundation for their instruction.

Acutely aware of the mandate to use the extended content standards as the foundation of her planning and teaching, Ms. Arnold began her response regarding standards indirectly:

> I feel like [I] get stuck when I know I have to teach something and I know that there is only so much my kids are going to understand…and it's, I just feel like it's useless. I'll cover it, and I'll go over it, and I'll read a simple book about it, and they're just looking at me and I'm like, 'Okay, I got rid of it'. So I think I definitely get stuck with stuff like that where I'm like, 'They're just not going to get this, but I gotta cover that one.'

She did not state that the content she had to cover was related to the state academic standards, so I probed:

> Do you use the extended standards?

> I do. I don't [use them] a ton, but I'll look at it. I'll get the main point. I've got seventh grade this year and I use that [the extended standards] and then my seventh grade science teacher, I'm like, what are the main points that I need to hit and then just broadly go over…so I just kinda look for stuff to pull from that.

> When you are actually teaching those standards, do you think it is really meaningful for your kids?

> No. no.

Ms. Duffy bases her planning and instruction directly on state academic content standards. She has a certain set of standards that she is required to address with her students, and she then has the freedom to organize those standards into the sequence that she feels would best fit her students. Her explanation of how she uses the standards

demonstrated her confidence in how those academic standards can be used with her exceptional learners. One example she offered was that she is currently teaching the standard that addresses the colonization and resources of North America. Part of the standard says that students will 'engage with maps of North America showing regions colonized'. This engagement may be attained through visual, auditory, olfactory, gustatory, or tactile means, and does not indicate the level of cognition that must be achieved by the student for success on the standard.

Ms. Duffy continued, "I always present the standards and I always try to come up with a way to make it different for all my learners." Earlier in this chapter, she was quoted on her strategies for using sensory input (in her example, visual and tactile) to "just try and do different things for everybody, but still around the standard." She added that the majority of her students' IEP goals are for life skills and sensory stimulation. The academic standards provide the topic or theme that guides the variety and type of stimulation that will presented. For Ms. Duffy, the academic standards provide the context for learning, not necessarily the content that will be learned.

The second pair of participants, those who do not feel compelled by internal or external pressure to teach their students in accordance with the state standards, tend to look at the academic rigor required to address the content of the standards and realize that the level of cognition and understanding that is intended in the standard is far beyond the reach of their students. When asked if he uses his state's content standards, Mr. Cox shared:

> I'm going to be honest. I don't. So, you know, I've got my fourth graders, and I looked at what they have for the extended standards for fourth grade. It's way, it's still way too hard for where they're at. I think they need to be scaled down…I don't see where there's a huge difference from the regular standards.

Ms. Brookes, in a succinct manner, stated, "The extended standards are too high." Later, she continued, "But there's more to life than academics. Sometimes I think I wasn't really cut out to be a teacher because that's, like, the least of my worries."

In summary, all four participants in this study were able to identify challenges and successes that they experience as teachers of students with profound disabilities. Each has found ways to provide student-centered experiences that they believe are meaningful to the individuals in their classrooms, but although the ESSA mandate for the education of all students is that of college and career readiness and the enactment of rigorous academic standards, the issues of academic attainment were not discussed by teachers in these interviews, except the one response that indicated that perhaps academics were not the biggest concern for students with PIMD. In the next section, document review findings are described to add objective, measurable data that may be compared and contrasted to this subjective interview data.

Document Review

Two sources of existing documentation were reviewed to offer information regarding how teachers of students with profound disabilities translate the characteristics and abilities of their students with PIMD into the required forms and educational goals and processes required by law for all students under IDEA. For a student with suspected

special educational needs, a multifactored, multidisciplinary evaluation team report (ETR) is completed by a team that must include parents or guardians, special education and general education teachers, and school district administration. Depending on the student and their needs, the team may also include a school psychologist, physical, occupational, and speech/language therapists, medical and mental health professionals, and others knowledgeable about the student.

The Individualized Educational Program (IEP) is the document that follows the ETR, and translates the information from the evaluation into a wholistic, actionable, measurable plan to address the daily implementation of the student's schooling. The IEP includes student goals, the specific locations education that will be provided and by whom, how growth will be evaluated, and how the student's legal rights to an appropriate education under IDEA will be met. The IEP is a legal document, and all members of the team who are included in the program are held accountable for its' execution.

For this study, the ETR and IEP were reviewed following the records review guide included in Appendix F. These record reviews were designed with several objectives. First, to verify that the demographic characteristics of the students being served by the teachers in this study matched the characteristics of PIMD delineated in prior chapters of this dissertation. Next, to give objective and multifactored data to support the subjective interviews with the teachers who work with these students. And primarily, to add to the complete picture of the work of teachers who engage with students with profound disability and the manner in which these teachers translate broad

federal and state mandates into daily practices that are appropriate and meaningful for their students.

Because these documents contain protected student information, and are maintained by both the parents or guardians of the students and the public school district attended by the student, permission was granted from the designated administrator in each participating school district, and in all cases, the Special Education Directors or Superintendents. These documents were obtained only under the provision that all information protected by the Family Educational Rights and Privacy Act (FERPA) was redacted.

To ensure consistency, all ETRs were evaluated first, and IEPs were evaluated next. The documents were coded with consecutive letters (e.g. ETR-A and IEP-A; ETR-B and IEP-B) so that after individual review, it would be possible to compare the two reports, if necessary. Tables 4 offers a side-by-side view of the ETR and IEP findings for each student so that the information can be easily corresponded. After examination of the IEPs, the Gross Motor findings of both the ETR and IEP were omitted, as these goals were under the scope of a Physical Therapist or Physical Therapy Assistant rather than direct or primary responsibilities of the special education teacher. In addition, during the interview portion of the data collection, none of the participants commented on gross motor issues as a factor in their teaching practice.

Finally, due to the complex nature of the needs of students with profound disability, academic and functional domains were often overlapping and integrated. Academic, speech/language, and occupational therapy disciplines can typically be clearly

divided in ETR and IEP documents. In the cases that I reviewed, however, functional areas were not clearly defined. In these cases, two areas were evaluated to determine inclusion in the document review, as the focus is on the practice of teachers: which team member had identified the student need in the ETR document, and what professionals were documented as providers of the service in the IEP.

Table 4

Document Data Analysis

Records Review Document: ETR/IEP-A		**Student Eligibility Category Under IDEA:** Multiple Disability	
Student Age: 12 (General Education Equivalency Grade 7)		**Extended Standards Listed as Modification?** Yes	
Academic/ developmental domain]	ETR findings	ETR student needs	Corresponding IEP goal
Adaptive behavior	Scaled score 23 (>-5 Standard Deviations) Oral fixation: hands in mouth Can crinkle and tear paper	Functional skills	Reduce oral fixation Reduce amount of time hands are in mouth
Communication	Uses gestures Understands some cause/effect Smiles and rocks body when happy Pushes undesired items away Vocalization limited to open vowel sounds	Use of assistive technology	Imitate actions of others Follow 1-step directions: go, stop, clap, wave Indicate "more" Reach toward [communication] device
Cognitive	"Very delayed" No score could be obtained through testing "No concrete idea of what student knows" Learning must be through concrete objects	Multisensory, hands-on functional learning opportunities Exposure to functional learning	Identify a requested color from a field of 2
Fine motor	Minimal functional grasp All activities require hand-over-hand assist Fingers in mouth 95% of time	Materials within reach Cues and prompts faded as level of need or dependency decreases	Reduce the time student has hands in mouth
Social-emotional	Requires constant attention from adult to avoid self-injury	Exposure to the community and real-life situations Increased independence	No goal in IEP

Records Review Document: ETR/IEP-B **Student Age:** 14 (General Education Equivalency Grade 9)		**Student Eligibility Category Under IDEA:** Other Health Impaired (Major) **Extended Standards Listed as Modification?** Yes	
Academic/ developmental domain	ETR findings	ETR student needs	Corresponding IEP goal
Adaptive behavior	None noted in ETR	None noted in ETR	None noted in IEP
Communication	Distinguishes voices of familiar people, particularly mother Communicates happiness or distress through vocalization and verbal "clicks" After priming is sometimes able to hit a "BigMac" switch to turn music on	Continue working on cause/effect	"Engagement and Access" Communicate consistent preferences and affective experiences Cooperate with shared exploration and supported participation
Cognitive	Could not be assessed by School Psychologist Alternate Assessment: Responded only to engagement tasks that allowed him to touch items or attend to voice of test administrator "Best reached through integration of smell, touch, and sound"	Engage in multi-sensory experiences Develop skills to allow him to communicate with his world Repeated opportunities to develop his understanding of cause/effect	Recognize familiar people, events, and objects Remember and perform learned responses Engage switches placed wheelchair tray Demonstrate awareness, attention, and interest in stories read aloud
Fine motor	Pulls away from scratchy textures Body calms when presented soft textures Could bring left hand to mouth and reach out after priming	Develop consistent motor responses to allow him to use augmentative communication devices Engage in a variety of sensory Experiences	No "stand alone" goal; integrated into goals for switch activation
Social/ Emotional	None noted in ETR	Develop skills to communicate with his world	Adequate exposure to human interaction and pleasurable activity

Records Review Document: ETR/IEP-C **Student Age:** 10 (General Education Equivalency Grade 5)		**Student Eligibility Category Under IDEA:** Multiple Disabilities **Extended Standards Listed as Modification?** Yes	
Academic/ developmental domain	ETR findings	ETR student needs	Corresponding IEP goal
Adaptive behavior	Frequent engagement in activities to provide self-stimulation and sensory input	Functional Skills needed for everyday life Improved attention Improved independence and self-help	"Functional behavior": engage in play by tapping another student or handing an object to a peer
Communication	Some use of picture cards and gestures Reaches for an adult to gain attention	Improvement of functional communication using AAC to effectively communicate wants and needs	Make eye contact with communication partner Wave "hello" or "good-bye" with hand-over hand assist Imitate a word approximation, sign, or give a picture to make a request
Cognitive	Cognitive and achievement tests could not be given due to student limitations	Multi-sensory activities Visual supports for activities	Use eye gaze or reach to identify animals when given choice of 2
Fine motor	Cuts using adapted platform scissors Can use a straw or sippy cup with assist; does not use eating utensils Uses an oral motor tool to decrease placement of fingers in mouth	Adapted feeding utensils Hand-over-hand assist for all fine-motor activities	Use adapted eating utensils Lift pre-loaded spoon to mouth
Social-emotional	Reaches toward peers in close proximity Smiles, laughs, rocks in wheelchair Can exchange a picture for a snack	To communicate her wants and needs to others	Integrated into "Functional Communication" Make eye contact with communication partner Wave "hello" or "good-bye" with hand-over hand assist

Records Review Document: ETR/IEP-D **Student Eligibility Category Under IDEA:** Traumatic Brain Injury **Student Age:** 15 (General Education Equivalency Grade 10) **Extended Standards Listed as Modification?** Yes			
Academic/ development domain	ETR findings	ETR student needs	Corresponding IEP goal
Adaptive behavior	Very low level of alertness Is aware of sound	Program for stimulation Focus on personal needs Increase levels of alertness	None
Communication	Does not appear to recognize his name Communicates through facial expressions and body tone Uses switch-adapted devices mounted by his head to communicate Cannot respond to visual stimuli Cannot communicate “yes” or “no”	Continue using technology with student Increased alertness Attend to multi-sensory materials	To protest unwanted interaction or activities using non-verbal means Activate a sequencer switch
Cognitive	Profound cognitive deficit Does not demonstrate sustained attention No cause/effect or object permanence Pre-academic level of understanding Can initiate a head-controlled switch	Program for sensory stimulation Opportunities to participate in multi-sensory activities Increase self-awareness Hand-over-hand assist. to explore his environment	None
Fine motor	Minimal arm movement, trace grasp Allows physical guidance to help him interact with sensory items	Needs to remain alert Needs to be attentive to multi-sensory materials	Once hands are placed in an activity, demonstrate sustained attention (eye gaze, blinking)
Social/ emotional	Seems unaware of the presence of others in the environment Comforted by being held and cared for by familiar people Responsive to touch; enjoys soft textures and vibration	Increase levels of alertness	None

Evidence of Trustworthiness

In an effort to ensure the trustworthiness of this study, I have referred to the work of Lincoln and Guba (1990) as well as to Shenton's (2004) amplification of Guba's four criteria that lead to a trustworthy study. The four facets of trustworthiness proposed by Guba include: credibility as related to internal validity; transferability as related to external validity; dependability as related to reliability; and confirmability as the counterpart to objectivity. Lincoln and Guba (1990) described trustworthiness as important not only to the process of case study, but also to the quality of the narrative and the story being told through the study. In addition, trustworthiness also has an impact on the power of a study to help stakeholders to find value in the work and to transfer the findings into their own contexts (Tracy, 2010).

Credibility

One of the criteria of credibility advised by Lincoln and Guba (1990) suggest that trust must be established between the researcher and participants, often emerging from prolonged engagement. To achieve trust with participants with whom I did not have the opportunity for prolonged engagement, I sought to communicate credibility and legitimacy through sharing my own background as an educator of students with profound disability. As a facet of credibility, I also used the strategy of triangulation by comparing the subjective, narrative experiences of teachers against the information contained in legal evaluation and educational planning documents to ensure congruence of student characteristics, educational plans, and teacher perceptions.

I attempted to maximize content validity of the interview data by having two participants serve in limited manner to check for data saturation. Data saturation was addressed by a purposeful plan to include participants from diverse teaching locations and experiences. In this study, participants included those working in typical public school settings, separate schools, and Educational Service Center models. When examining interview data, the additional interviews mirrored the content of the full interviews with no new themes emerging. One data saturation participant identified the most important aspect of her work as that of a *caretaker to service provider liaison*, a role that was also mentioned by only one full participant. This topic is addressed in Chapter 5.

Transferability

As an element of external validity, transferability may be challenging in qualitative study. I used the strategy of following a semistructured interview plan with each participant to facilitate a similar framework for interview content. I had planned to further increase transferability by including participants from a broad geographical and cultural area to allow for optimal variation of knowledge and experiences. As stated earlier in this chapter, contacts were sought from educational institutions in the western, southwestern, and midwestern United States. However, letters of cooperation were received only from administrative leaders in the midwestern United States, limiting the variation of contexts and perspectives of teacher participants.

Finally, throughout this study, and particularly through the examination of narrative interview data, I attempted to use thick description to convey actual

experiences, situations, perspectives, and contexts of the participants. Exact quotes were used in an attempt to communicate the words of the participants in their own voices.

Dependability

The most salient aspect of ensuring dependability in this research originated with one of the expert reviewers during the establishment of my interview guide. His explanation of the importance of using multiple coding-recoding iterations to ensure stability of themes and interpretations throughout the data analysis period of the study was a critical factor in my examination of the data. The process was used in the analysis of documents, as well. Transcripts, ETR, and IEP documents were revisited continually as analysis was performed, with recoding and side-by-side comparison strategies repeated continually.

Triangulation of the data sources was also an important factor in insuring that data being collected and analyzed were congruent with the specific parameters of this study, as well as comparing teacher perceptions with documentation of the phenomena of teaching students with profound disability. Finally, guides and protocols that guided the content of interview data and document examination and comparison are included in the appendices of this study to facilitate consistency in data collection and analysis, as well as replication of the study.

Confirmability

Confirmability is the qualitative equivalent to objectivity, dealing with issues of neutrality and reduction of bias (Gibbs, 2012a). Reflexivity, as a component of confirmability, was enhanced throughout interviews and examination of documents as I

was intentionally aware of my own experiences and beliefs about being a teacher of students with PIMD. As I spoke with participants about their experiences and read their descriptions of students, needs, and plans for meaningful education, I allowed myself to be surprised by their spoken and written words, and I recorded these unexpected surprises in log notes for further reference and examination.

Results

The results of the three research questions investigated through this study are addressed separately. These results are followed by some overarching themes that emerged, offering a global look into the central intent of this study, to increase awareness of the subgroup of students with PIMD whose needs, strengths, and educational goals fall outside of the range of traditional educational practice in the United States public school system through glimpses of the work of the teachers who engage with them.

Research Question 1

What are the lived experiences of teachers of students with profound intellectual disability who teach in public school districts in the United States regarding challenges and successes in their teaching practice?

The teachers' responses to probes regarding challenges and successes were examined separately, but in analysis of these two areas paradoxically reveals the they mirror one another. Although the responses regarding *challenges* of teaching student with PIMD could be clustered under six distinct themes, two of those themes were dominant: student-centered challenges and lack of resources.

All four of the participants in this study struggle to know what to do with the students they teach. Their comments included, “It was hard to know if I was reaching him or not.” “Could he see anything? Could he hear anything? We really didn’t know.” “What are the things where you can keep him focused for a few minutes?” and in a statement about a student’s chronic violent behavior, “I can’t do this for five years.” The other side of the discussion, however, all four respondents cited their greatest successes as the moments when they found a meaningful connection with those students whom they weren’t sure they were reaching, the students who made them wonder if they could keep “doing it.” Because clear communication and ability to respond meaningfully to the world around them are a part of the challenges inherent in individuals with PIMD, it is very difficult for teachers to know what their students know. When a teacher knew a student well enough to discover what they liked, when they could share normal human experiences of silliness and laughter, when they felt capable of demonstrating love and including them in the world of the classroom, the participants felt success. These relationships filled the challenges of *not knowing*.

A similar dynamic was found in the second and third most-mentioned themes of *lack of resources* and *curriculum not meaningful/applicable* as challenges. Two of the respondents spoke of lack of human resources and time. The final two teachers referred to their attempts to teach required academic skills in a meaningful way: “It’s really hard to find out there…different things we had to do that I didn’t feel were applicable,” and “[Academics] are the least of my worries.” In contrast, when teachers were able to work

with students on a variety of strategies for sensory input, a facet of cognition, communication, and quality of life, they believed that success was achieved.

Research Question 2

What kinds of curriculum, activities, and practices do teachers of students with PIMD utilize in their teaching to fulfill the federal mandate of meaningful education and from what sources are these tools (curriculum, activities, practices) obtained?

Curriculum to Fulfill Mandate of Meaningful Education

The Unique Learning System was mentioned by three of the four teachers in this study. Of these three, one reported that she had tried to use it, but even the entry level of the program was too "high," or difficult, for her students. A second teacher utilizes Unique "about 25%" of the time. The remainder of her curriculum is comprised of things that she makes and supplements:

> I mean, I guess I use *something* [from Unique]…I supplement a lot, or I make things.
>
> *When you moved into your job, is that what [the school] used or did you choose it?*
>
> I found it. They were kind of just throwing crap together and I'm like, 'Ahh! I don't have time for this!' And I found out, looking [for] more out there, there is nothing. If I had the resources, I would make some kind of special needs, transitional, like just, whole thing for people to do. You know, [right now] it's just kind of looking at crap here and there and thinking, 'Okay, what can I find for that?'

Mr. Cox remarked that he tries to use Unique, and that he feels the students may catch on to "some things." *Do you think Unique is a meaningful curriculum for [your student]?* "To be honest, probably not. And I really don't know what curriculum would be meaningful for her." Mr. Cox added that his district does not mandate a curriculum, but allows him to do what he feels is right for his students. His special education director is willing to purchase items that the teachers of students with severe to profound disability feel might work with their students.

One teacher also mentioned an additional specific curriculum, Attainment Curriculum, which has been created for students with severe disabilities. She found this curriculum to be too challenging to meet the needs of her students with profound disability.

During the discussion of curriculum, all four participants reported being aware of the extended academic standards for their state that are intended to guide the curriculum and allow students to have access, or entry points, into the general education curriculum. The topic of Extended Academic Content Standards is addressed fully in the discussion of Research Question 3, which pertains specifically to this topic.

Activities to Fulfill the Mandate of Meaningful Education

When asked about the activities that they use with their students, as well as what activities they feel are most meaningful, the four participants were unanimous in the importance of using multi-sensory strategies and materials that provide students with high levels of sensory input. The discussion of sensory-based activities included the topics of sensory rooms that are designed with materials that allow for input that engages

students with textures, varied surfaces for seating or lying down, music that is known to be a students' preference, and lighting that engages the students visually. In an effort to create meaningful engagement in the standards-based curriculum, Ms. Duffy spoke at length about her use of science experiments that allow for engaging visual stimulation for student observation, including smells to engage the olfactory sense, and items to touch. Mr. Cox described some of his most meaningful work with one of his students with profound disability as working with different textures. He also tried auditory stimulation: "just trying to give him a couple of options [of sounds] and see if he heard something. And usually he couldn't."

Although statements of specific curriculum were not mentioned in any of the students' ETR or IEP documents, all four multi-factored teams and all four teacher-written IEPs contained frequent references to the importance of utilizing multi-sensory strategies and experiences for the education of the students with PIMD. This information gleaned from document review offers information from various disciplines, and gives a glimpse of how teachers are integrating the student's sensory needs into their Individualized Educational Programs. The documents provided for the students corroborate the teacher narratives about sensory-based educational strategies.

The ETR of student A included references to the student's need for: sensory input, sensory breaks, tactile prompts, real-life objects to touch, his enjoyment of crinkling and tearing paper, playing in water, and items that make noise or light up" to fulfill sensory needs, as well as and rocking, flapping, and swinging to engage the proprioceptive system. These activities were also mentioned in the student's IEP goals: Demonstrating

cognitive understanding by touching specific objects to indicate color; offering various liquids as an acceptable replacement behavior for his sensory need of putting his hands in his mouth to experience the heightened amount of saliva. His specially-designed instruction includes statements of "sensory teaching," while his accommodations include sensory breaks.

The ETR of student B stated that, "[the student] is a young man who may best be reached through integration of the avenues of smell, touch, and sound." Three team members advocated for activities that engage the senses. His special education teacher recognized that the student is most cooperative and reacts positively with hand-over-hand activities that include "music, textures, smells, and motions." The description of his educational needs provided by the school psychologist was simply, "[The student] needs to continue to be provided multi-sensory activities." Finally, the Occupational Therapist recommended that the student should experience instruction using "a variety of sensory experiences in order to make sense of his world." In his IEP, the teacher responded to these recommendations by writing an engagement goal that included increasing the student's awareness and engagement when a book was read aloud by offering multisensory items that relate to the text. This student's specially-designed instruction included a focus on "integrated sensory and cognitive stimulation."

Student C has "tactile and sensory needs [that] appear to have increased and she often seeks out more tactile and oral input." Favored sensory activities include putting her fingers in her mouth and investigating the feeling of the saliva, rolling and tapping toilet-

paper tubes, and rocking in her wheelchair. Her IEP mentions the use of "sensory supports" as a facet of assistive technology.

Finally, Student D is reported in the ETR to be nonresponsive to light or sound, and his team felt that an implication for his education was to engage in sensory stimulation to increase environmental awareness. The student's needs are denoted as access to "soft textures and vibration," physical guidance to touch and interact with multi-sensory items and activities. These student needs are addressed in the educational goals as demonstrating sustained activity when his hands are placed in a sensory activity, as well as in his Specially Designed Instruction as "repeated practice with different sensory materials."

Additionally, under the theme of meaningful activities, interviews with all four teachers described their belief that it is critical to work with students on skills that could impact their quality of life. The teachers wanted to give their students experiences with peers and in the "real world," they worked with them to use vocal output switches, head control triggers, and eye gaze technology in an effort to help them communicate. They wanted them to gain skills to feed themselves, and they wanted to talk to their students, so they would learn to attune to the presence and language of others.

These beliefs were shown to be translated into educational goals in the IEPs. Goal statements include:

- Strengthening functional play
- Requesting "more" of an enjoyable activity
- Choosing between two options of activities,

- Recognizing basic colors to increase awareness of the environment
- Gaining greater control over their environment by using switch technology to turn on a fan, music, to gain attention, and provide information to others
- Increasing awareness, memory, enjoyment, boredom, and attention to books

Research Question 3

How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?

The Every Student Succeeds Act of 2015 was discussed previously. As I analyze the data pertaining to state academic standards, I reiterate that ESSA includes mandated academic indicators for all students. These indicators include "challenging" academic standards in reading, math, and science, and a curriculum that prepares students to succeed in college and in a career. These standards apply to all students, including those with disabilities, and states have been permitted to establish extended standards for students with severe disabilities. Per this mandate, it should be noted that all four Individualized Educational Programs includes in the area of modifications a note that the student's curriculum will be in accordance with the state's extended academic standards.

Mr. Cox stated that he has "looked at what they have for the extended standards," but they are still "way too hard for where [the students] are at." Ms. Brookes reported that the Standards are "too high." Ms. Arnold stated that she does use the extended standards as a basis to select what topics she exposes her students to. She tries to "pull stuff" that relates to the topic stated in the correct grade level standards. Ms. Duffy explained that

she presents the extended standards to her students, but that their function is exposure to academic content and to serve as the framework on which she designs sensory experiences for her students.

In ETR and IEP review, none of the documents for these students included academic achievement goals based on the symbolic understanding of letters and reading or numbers and math. The only goals from the IEPs that could be considered "academic" could be one goal for color recognition for an 11 year-old child and one goal addressing the identification of animals for a 10-year-old student.

Summary

Chapter 4 was concerned with the results of this multiple case study regarding how teachers of students with profound disabilities view various aspects of their teaching practice. Data were collected from interviews with six special education teachers from the Midwest region of the United States as they shared their successes, challenges, and strategies for teaching students in a manner that meaningful and appropriate. I also collected two documents from each teacher, a student's Evaluation Team Report and Individualized Educational Program both of which had all identifying information redacted. These documents were used to determine how a student's educational needs were reported and how their teachers interpreted these needs into daily educational practices.

I first conducted single case analysis for each interview by using open coding and then drew connections between the cases using axial coding to reveal themes that emerged from the participants' responses, organized by research question. Next, I

analyzed the information contained in the collected documents according to a predetermined plan, based on the research questions. The specific details that I drew from these documents had been selected to validate the study findings by comparing participants' voiced experiences with written documentation pertaining to the research questions.

Interview coding for the first research question revealed six overarching themes of challenges and 5 themes related to successes. The two themes that dominated each of these findings were further related as key findings in the review of results. The second research question elicited information about curriculum and revealed a theme challenge in this regard. Discussion surrounding research question 2 on the topic of *activities* used by teachers revealed the two major themes of sensory input and quality of life. The third facet of the question that asked teachers to consider their practices as special educators revealed three themes of collaboration, community, and relationships. Finally, analysis of interview data regarding use of state academic content standards demonstrated that teachers understand and utilize the standards in three major ways: not at all, through direct instruction, or as context for what are considered to be meaningful educational experiences for their students.

Document review revealed that student characteristics cited in student ETRs were the basis of student IEP goals and specially-designed services. Academic growth, while being the primary tenet of the state academic standards, was mentioned only twice in student IEPs.

In Chapter 5, I include further discussion and interpretation of these findings, limitations of this study, and recommendations and implications arising from this research.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this exploratory multiple case study was to investigate how special education teachers are providing appropriate and meaningful education to students with PIMD, profound manifestations of disability, with little guidance from state and federal educational standards. The intent was to increase awareness of the subgroup of students with PIMD whose needs, strengths, and educational goals fall outside of the range of traditional practice in the U.S. public school system. The interviews and documents reviewed revealed the work of public educators who engage with these students. To accomplish the study's purpose, I used an exploratory multiple case study design that included teacher interviews and reviews of legal educational documents related to the education of four students with PIMD. Four cases were presented, all from states in the midwestern section of the United States.

Key Findings

Key findings for this study indicated that students with PIMD are included in public education settings in the United States under a variety of broad categories of disability, and that the public school teachers who participated in this study do not feel that they were well prepared to address the challenging needs of these students in their classrooms. Three of the four teachers who were included as full participants in this study shared explicitly or implicitly that they felt that they should be doing better with their role in educating students with PIMD.

The challenges of this work stemmed from five major areas: categories of social challenges; lack of resources; curriculum that was not meaningful or applicable for the

students; lack of preparation; and difficulties that occurred due to the physical, emotional, and cognitive circumstances of their students. Although all students who were represented in this sample by their teachers are reported to receive education aligned with rigorous academic standards, there were no successes equated with the academic attainment of the students. The four major categories of successes reported by teachers were those that matched the sensorimotor developmental status of the students with PIMD: sensory experiences, relationships with others, peer socialization, and opportunities to have real-life experiences.

All of the participants in this study reported a lack of appropriate curriculum, and three discussed programs that had been developed for the larger population of students with cognitive disabilities as being too difficult for their students to access due to the presymbolic nature of PIMD communication. With a lack of published materials, teachers reported regularly using internet searches and sources to find ideas, scrounging for materials, and making items to facilitate the educational experiences of their students. The teachers spoke of the importance of collaboration with peers and acceptance in the community as adding value to their work as teachers of students with profound disability.

Although the use of extended academic standards by teachers was noted in legal documents for all four students, the degree to which these standards were found to be meaningful to students with PIMD was negligible. Document review of team reports prepared by professionals from a wide variety of disciplines who had knowledge of the student indicated academic standards only two times, and both of these instances were in regard to skills that would typically be attained by a child between 12 and 15 months of

age, but were cited as goals for teenage students. Goals developed by special education teachers based on student needs were centered on self-regulation, sensory input, alertness and awareness, developing means of simple communication of wants and needs, and tolerance and participation in activities with others.

Chapter 5 includes the interpretation of the findings in this study, as well as conclusions regarding the points of nexus between the literature review and theoretical basis described in Chapter 2 and the findings of the triangulated data collection tools presented in Chapter 4. I acknowledge the limitations of this study and suggest recommendations in regard to moving forward with the research and work of educating students with PIMD in the United States. Finally, I include implications for social change that may improve the work of teachers charged with educating students who fall outside of the traditional profile of students with disabilities in the public school system and may enrich the educational experiences of these students throughout their schooling.

Interpretation of Findings

The findings of this study are interpreted first in relation to the three central research questions that guided this study. Following this, findings are interpreted in the context of the theoretical and conceptual frameworks on which this study was positioned.

Knowledge of the Discipline

The impetus for this study was that the U.S. public school system includes a very small population of students with profound disabilities who have severe physical, developmental, and cognitive needs. Before I could learn about the work of the special education teachers who respond to these needs, the first challenge was to develop a

shared understanding of the unique characteristics of students with PIMD, as well as the tendency to group these students into broad categories of special education eligibility. Recognition of PIMD cannot be located within the confines of IDEA or ESSA mandates that guide educational practice in the United States. This key understanding of student characteristics was discussed at length in Chapters 1 and 2, and researchers Nakken and Vlaskamp (2002, 2007) and others wrote about the potential for students with PIMD to receive inappropriate instruction if their educational goals and quality of life issues are not understood by educators and policymakers. Within the realm of these considerations, two specific issues were addressed through document review and teacher interviews.

First, when reviewing the evaluation team documentation that indicates that a student is legally eligible to receive special education services and under what category of disability, I found that of the four students included in this review, two were eligible under the category of multiple disability, one under other health impaired, and the final student under traumatic brain injury. Under IDEA, the designation of multiple disability indicates that a child has more than one condition covered by IDEA law (Individuals with Disabilities Education Improvement Act, 2004). Other health impaired covers conditions that limit a child's strength, energy, or alertness, including attention deficit hyperactivity disorder. Traumatic brain injury is an injury caused by an accident or some kind of physical force. Severity of the disabling characteristics of the student are not factors in service category. Although this finding was not especially troubling because the remainder of the Evaluation Team Report described a child's strengths, needs, and medical conditions in depth, it was an indication that although there are specific criteria

for students with profound manifestations of disability, as described in Chapter 1, the unique combination of student characteristics of PIMD is not acknowledged in IDEA law or designation.

These findings from document review and interview data confirm that there is no recognized category of profound disability that suggests the level of disability that a student may present, which generally precludes the understanding that a different form, content, and practice may be necessary in providing for the educational experience of these students. Students in all categories of special education identification under IDEA are subject to the same mandates of college and career-based education. Nakken and Vlaskamp (2007) cautioned that students with PIMD could receive inappropriate education if educators and policymakers failed to recognize the unique nature of their disability, which was corroborated by the four current participants in their reports of receiving no specific instruction in meeting the needs of students with profound disability throughout their college degree programs.

Research Question 1

What are the lived experiences of teachers of students with profound intellectual disability regarding challenges and successes in their teaching practice?

Although all four participants in this study had bachelor's degrees in special education, with one having attained a master's degree, the lack of preparation and lack of access to knowledge, research, and evidenced-based practices for teaching students with PIMD were discussed as significant challenges by all participants. Two participants reported that they had no awareness of students with profound disabilities until those

students arrived in their classrooms. The two participants who had prior awareness of students with profound disabilities did not report any college preparation to work with these students. One was also a parent of a child with profound disabilities who attained a special education degree after her child was born; the other gained her understanding while working a summer job in high school.

As reported in Chapter 4, comments from the teachers included the following statements: “In college they never talked about kids like this,” “they went over different disabilities, I guess, but they never prepared you for what to expect,” “this is not what college made it sound like,” and “[In college], it’s always about the ones that need reading intervention.” Within the interview framework, when teachers were asked about the challenges they face in educating their students with profound disabilities, three out of four participants stated that there were few resources available to them, and that available curriculum did not reach an appropriate lower range of developmental levels to be applicable or meaningful to their students.

The reported challenge of too little preparation for teaching students with profound disabilities was foreshadowed in published literature, where nearly all research on PIMD was found to be undertaken outside of the United States where students are being treated in residential or day-treatment facilities (Bunning et al., 2013; deBoer & Munde, 2015; Griffiths & Smith, 2016; Hostyn & Maes, 2013; Jansen et al., 2012, 2016; Ten Brug et al., 2015) as opposed to public school settings.

Further, literature review found that articles published in the United States focus on medical and psychological implications of disability rather than educational

implications. Vorhaus (2016) also discussed the dilemma discussed by the teachers in this study in his observation that there are few books "devoted to exploring the lives of profoundly disabled people, and the experience of those who care for them and work with them" (p.1). Special education teachers who invest approximately 35 hours per week into the educational lives of these students often find themselves alone in the work, as evidenced by Ms. Brookes, who upon hearing about the research that she was being invited to participate in, expressed relief, "Oh, good! I'm not alone!" Her relief was shared by other participants who, in the face of little guidance and information, mentioned the importance of having a peer with whom to share experiences.

Evidence-based successes that participants described in their work of teaching students with PIMD included the practice of engaging the students in sensory experiences. These practices are validated in the research, as well. The Reinforcer Assessment for Individuals with Severe Disability (Fisher et al., 1996) that was designed to help educators utilize the knowledge of student care-givers to discover what sensory experiences are most pleasurable and beneficial for the students could be a resource for teachers who find meaning in their ability to match activities to the sensory preferences of their students. Ten Brug et al. (2015) linked the enjoyment of literature and stories to multisensory opportunities to experience and share the experience of storytelling. Giles and Fresne (2016) connected the practices and listening and making music to help activate with the formation connections along neural pathways of the brain.

The final area of successes described by participants was practices that focus on social relationship with teachers, peers, and others. Once again, these practical

experiences of teachers can be traced in the research, as well. Nijs et al. (2016) conducted research that revealed that being with typically-developing peers caused students with PIMD to be more awake, active, alert, and communicative than when they were at baseline. Blain-Moraes et al. (2013) shared findings that when the relationship that a teacher or caregiver has with a student with PIMD is described as "warm" and stemming from familiarity and time spent together, the understanding of human value and feelings of affection increase.

Research Question 2

What kinds of curriculum, activities, and practices do teachers of students with PIMD utilize in their teaching to fulfil the federal mandate of meaningful education and from what sources are these tools obtained?

Although some of the study findings pertaining to curriculum, activities, and practices are integrated into discussion about teaching successes and standards-based practices, one consistent response from participants is specific to this second research question. When speaking of activities and practices, as well as when writing yearly need and goal statements for students, study participants spoke frequently about the importance of working toward a positive quality of life for their students. For the participants in this study, quality of life evidences itself largely through heightened self-help and communication competencies including self-feeding, technology-assisted communication, and times of happiness.

Once again, literature supports the experiences and values of teachers of students with PIMD. Vygotsky (2011) and Vorhaus (2015) wrote extensively about how human

competencies may be expanded given the assistance of capable helpers. These theorists offer the idea that full independence and mastery of self-help skills are not the only goal of value, but rather, it is acceptable for individuals to work toward maximizing their own skills to extend the point at which their need for help meets capable assistance.

Participants mentioned the importance of time spent with their students in the facilitation of communication. One key characteristic of individuals with PIMD is idiosyncratic communication that is very difficult to interpret. Every participant in this study spoke of wanting to understand their students, and the importance of building time into their daily practice of finding ways to understand. One stated, “Sometimes it takes a while to figure things out.”; another mentioned that she was lucky to have had three years with a student to come to truly know him.

This belief in the value of time with a student to build communication and understanding is borne out in the research of Darling and Circo (2015), Griffiths and Smith (2016), and McFerran and Shoemark (2013), among others, all cited long-term relationships with students as a fundamental and requisite factor in knowing a student well. The participants’ feelings and beliefs about the importance and power of time and communication had been denoted by the United Nations Human Rights Office of the High Commissioner in 1966, when the Commission declared that all persons should have the right to freedom of expression to seek, receive, and impart information. Antaki et al. (2017) believed that one of the greatest risks for individuals with PIMD was that the inability to communicate clearly put their very personhood in jeopardy. Dewey (1916) challenged educators with his statement that being a recipient of communication enlarges

and changes the experience of students. The participants of this study stated that some of their most important practices include communicating with their students, talking to them, teasing them, and involving them in the life of the classroom. These teachers are practicing, through their own passion and intuition, a critical research finding.

Research Question 3

How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?

In the United States, all public schools are held accountable for how students learn and achieve. In light of this mandate, Every Student Succeeds Act (2015) also requires that all students are expected to learn challenging academic standards in reading, math, and science, thus preparing students to succeed in college or a career. ESSA law does not include any alternative educational routes for students with PIMD who operate at a sensorimotor level of functioning so these students must receive education based on the state-specified academic standards. Despite this mandate, a review of extended academic standards by state revealed that only Massachusetts, Ohio, and Wyoming included mention of the developmentally-attainable "tactile engagement," "grasp and release," and "active engagement" embedded within symbolically-based academic standards (see Appendix B). Legal documents provided by the teachers participating in this study indicated student characteristics that describe student levels at the sensorimotor stage of learning, where children learn through basic reflexes, sensory experiences, motor

responses, and emergence of cause and effect. For example, characteristics from the ETR documents include:

- Self-stimulation through oral fixation: hands in mouth, rocking body, movements that cause self-injury
- Communication through smiling or vocalization such as open vowels, clicks, and groaning
- No understanding of cause and effect/Emergent understanding of cause and effect
- Responds to texture, smell, and sound

Student goals documented in Individualized Educational Programs include:

- Reduction of self-stimulation activities
- Consistent communicate of preferences through movements, sounds, or assistive technology
- Demonstrating awareness and engagement in the world and people around them
- Assisted self-feeding
- Sustained attention
- Cognitive skills of color and animal recognition

Although these student developmental levels are not indicative of readiness for academic content, all four IEP documents contained the assurance that each student's curriculum would be provided in accordance with their state's extended academic standards. With the exception of the three states formerly mentioned, current state

academic standards do not extend to include student growth in sensorimotor and presymbolic levels of development.

Two of the four participants reported using the extended standards as the basis for their instruction, but both of these teachers reported that they did not believe that the standards were appropriate for their students. One uses the standards as a springboard for sensory stimulation and engagement and not for academic growth; the other admits to finding a book or video on the topic of the standard and going over it quickly to check off the standard as completed without the expectation of cognitive understanding. The final two teachers reported that they are not able to utilize the standards with their students.

All participants, however, articulated their conceptions of what educational experiences were appropriate and valuable for their students. These responses included making them happy, making them laugh, including them in the life of the classroom and community, talking to them, human interaction, loving them, giving them interesting sensory experiences, and facilitating quality of life indicators. As mentioned previously, these ideas, these beliefs echo the research on personhood, human value and moral rightness of Curtis and Vehmas (2016).

One somewhat subjective finding was that three of these teachers who are engaged in the work of caring for and attempting to meaningfully educate students with profound needs, communicate through voice and words a sense of chagrin and apology for their inability to utilize academic standards for their students. One of the teachers had a defensive tone: “I deal with *them* [my students], you know, the things that are really going to help them in life.” Another teacher whose class is comprised of only students

with PIMD stated, “I sometimes think I wasn’t really cut out to be a teacher because [academics] are the least of my worries. If I tell [my principal], she’ll probably think I need fired.” The third, apologized as he shared his vision for his students. “I think they deserve a decent quality of life. It sounds bad…I mean, I hope they would catch on to something I teach them, but if I can make life happy and meaningful for their circumstances, I think I’ve done my job.”

These comments and attitudes of participants confirmed Vorhaus’ (2016) concern that the prevalent message conveyed through mandated academic standards for all students may communicate the perception that other goals for students with profound disability are less desirable, and that they may unintentionally diminish the recognition of the personhood and value of individuals with PIMD, inhibiting appreciation for goals that foster student personal growth, quality of life, and dignity. In their descriptions of success, the four teachers participating in this research study described activities and practices that were based on student-centered needs and enrichment: sensory input, the building of relationships, peer socialization, real life experiences, and collaboration with other professionals to create ways to reach their students. None of the responses offered by the teachers mentioned academic successes for their students, and with the exception of sensory input, the topics of success related to relationships, socialization, real-life experiences, and professional collaboration for teachers are not indicated in these standards.

A second significant finding of this study was that the participants did not have access to curriculum that they felt was applicable to their students with PIMD. The

activities that they find to be most meaningful for their students are primarily sensory and relational, and are devised and created through collaboration with peers from other disciplines (particularly technology, occupational, and physical therapies). Overall quality of life (happiness, health, comfort) goals were also cited as priorities in their work with their students with PIMD.

Support of Theoretical and Conceptual Foundations

The theories of Dewey (1893, 1899, 1902, 1909, 1916) and Vygotsky (1978, 2011) were discussed as historical entry points into the education of students with disabilities beyond the confines of academic attainment and growth. These theorists championed child-centered instruction, educating for self-actualization, active and shared experiences, communication, and democratic principles. The work of both Dewey and Vygotsky emphasize education as a meaningful process, and not just a means to an end product.

The findings of this study validate the idea that the theories of Dewey, which date approximately from the late 19th to early 20th centuries, and Vygotsky in the late 20th century to early 21st centuries, may serve as frameworks on which to begin envisioning the work of educating students with PIMD in the current educational culture of technology and accountability. The theoretical base of this study focused on five features that were shared by Dewey and Vygotsky: child-centered instruction, educating for self-actualization, active and shared experiences, communication, and democratic principles.

Each of these features emerged from the interviews and were documented in evaluation team reports and IEP documents, as the phrases and ideas below indicate:

- Child (or student)-centered instruction: following the student's lead, taking time to figure out what works with a student, knowing him or her well enough to be able to fulfill a student's specific sensory needs, making the experiences different for every student according to their need while still basing instruction on the same standard, utilizing what is known about a student's preferences in planning instruction
- Self-actualization (the idea of maximizing a student's abilities and resources to fully realize their potential was embedded largely in ETR and IEP documents): learning functional skills, using assistive technology to gain some control over their environment, increased independence, gaining motor skills to allow reaching toward desired objects, increasing awareness, developing an understanding of cause and effect; self-feeding
- Active, shared experiences: being included in activities and conversations, laughing with a teacher, interacting and engaging in play with a peer, cooperating and tolerating shared exploration and participation in activities
- Communication: making wants, needs, and preferences known, protesting unwanted experiences, utilizing communication switches, electronic buttons, and eye-gaze technologies for communicative purposes, waving hello and goodbye
- Democratic principles (Equality, social justice, pursuit of happiness, acceptance of diversity): teachers report that they value educational experiences that, "make life happy and meaningful, good experiences, being

loved, being both known and accepted by peers and the community, enjoyable sensory experiences, having experiences in the community, having a decent quality of life.

To summarize, in the small scope of this study I found that students with profound disability are included on the caseloads of public school teachers in the United States, yet there is no acknowledgment of their unique and challenging developmental, cognitive, and physical needs in federal mandates and little acknowledgement in state academic standards. Teachers who have degrees in special education have not received information or education in how to serve these students, nor do they have the guidance of specific and appropriate curricula or resources to support their efforts for appropriate and meaningful educational experiences for these students. Ideas for engaging students are largely sought through internet searches and through collaboration with other professionals who work with the students. Finally, as teachers work with these students, often over the course of several years, they are able to develop knowledge of the personal and idiosyncratic facets of their students' personalities and preferences. Those relationships enable them to experience successes in their work, but often, those successes feel like they are insignificant or have little value in the light of state and federal expectations.

Limitations of Study

The primary limitation of this study was the small number of participants and their similar geographic location of the midwestern United States. Although the

participants were drawn from rural, suburban, and urban school districts, their geographical cluster impacts the transferability of the findings of this study.

Recommendations

Recommendations for future research are grounded in the strengths and limitations of this study as well as in the literature review. The first two recommendations are extensive, and would require the work of federal and state education departments to implement, an undertaking well beyond the reach of educators at the K-12 and university levels. On a broad, nationwide scale, study into the feasibility of adding an additional category to the 14 already-established *eligibility for special education services* qualifying conditions could be undertaken. This designation would provide educational teams with a way of describing students for whom traditional educational goals could be supplanted by goals reflecting presymbolic or asymbolic development. This recommendation has precedent in the 1990 decision of the U.S. Congress to add *autism* as a category of educational disability under IDEA law (Pennington et al., 2014), 10 years after first being included as a developmental disorder in the DSM-III. As discussed in Chapter 1, the DSM-5 includes specific identifiers of the profound severity level of intellectual impairment. The addition of PIMD to the IDEA qualification criteria could advance educational understanding on the impact of profound disability, thus opening the door for more widespread recognition of the unique needs and challenges presented by these students.

The second recommendation is related to the first. To better meet the need of teachers of students with PIMD for access to legally-acceptable, relevant, and meaningful

goals for their students, an additional set of extended state educational standards, similar to the P-Scale system used in European countries, could be adopted at the state level. A system such as this would give research and evidenced-based guidance to the hierarchy of skills that validate achievement for students with profound disability, thus offering teachers a framework on which to plan their instruction for their students.

The third recommendation deals with undergraduate and graduate preparation and professional development for special education teachers. The participants in this research indicated that they felt unprepared to understand and meet the needs of students with PIMD. The participants had not encountered any mention of these students in their college preparation. College and university special education departments should explore the possibility of introducing this level of disability to future special education teachers, along with ideas of how to access resources regarding the education of these students. The introduction of PIMD need not be extensive, due to the low incidence in student populations, but it should be included in any overview course of special education, and explored more fully in master's degree programs.

In response to the comments of participants that they struggle to know "what to do" with their students with PIMD and that they spend a great deal of time creating meaningful experiences for these students, it is further recommended that research be translated into professional development seminars for in-service teachers in an effort to provide both teachers and transdisciplinary team members with opportunities to deepen their understanding of developmental trajectories, meaningful goals, and daily activities

for the education of the student population with PIMD based on sensory experiences, relational attuning, and peer and community interactions.

Finally, administrative support for the work of educating students with needs that diverge so greatly from the general student population is critical to teacher and student success. Two of the participants directly spoke of how they perceived the support or lack of support of their administrators, and its impact on their work, while all four spoke of the use of sensory input strategies, adaptive technology, and flexibility in engaging their students in peer and community experiences. All of these activities require both administrative approval and financial support. It is recommended that administrators work in tandem with the teachers of students with PIMD to understand and offer various means of personal, educational, and financial support for their efforts to educate students who present with the complex and challenging manifestations of profound disability.

Implications

The focus of the United States educational system under ESSA law is to improve students' college and career readiness. For students with disabilities, states have the mandated responsibility to hold all students to high academic standards that will "equip students with knowledge and competencies needed to enter postsecondary education, join the workforce, and lead full and independent lives" (Tomasello & Brand, 2018, p. 1). In the light of this educational framework, this study may contribute to positive social change in several ways. First, this research may contribute to the ability of public school districts and teachers to consider and address the issues of the value, dignity, development, and the quality of life of students who are unable to access goals of

economic potential, independent living, and personal self-actualization that underlie the mandate of college and career readiness.

A second contribution of this study is that the awareness of special education teachers pertaining to the characteristics of students with PIMD may be increased, and understanding of their educational needs may be deepened. As teachers have a better understanding of their students, as well as access to collaboration and resources that guide them in preparing curriculum and activities that further cognitive, communicative, and social growth, the educational experience may become more meaningful for students with PIMD, as well as increasing their integration and acceptance into the life of schools and communities after they graduate.

Finally, individuals in the research, governance, administrative, and teaching disciplines of special education may gain a fuller understanding of the PIMD population and the role they play in our schools and communities. As research and policy begin to reflect the separate and valuable place that students with profound disability hold in the United States educational system, the importance of teacher training at the undergraduate, graduate, and in-service professional development levels specifically for teachers of students with profound disability may be realized and prioritized. Administrative support for these teachers may be provided, allowing them to serve their districts and their students in appropriate and supportive ways. When growth in knowledge and understanding occurs at each level of education, practices that further democratic, ethical, and educational experiences for individuals with profound disability may increase.

Conclusion

In defining the purpose of this study, I realized that I had two desired outcomes. First, I sought to provide understanding and insight into the educational world of students with profound learning challenges. Vorhaus (2016) would articulate this as "giving voice" to those students who have no voice of their own. The voice that I chose to use was that of their teachers, who outside of their families and caregivers, are often the closest people to these students. My second desired outcome, then, was to *share the voices* of the teachers whose work is determined not only by laws, mandates, and curriculum, but also by the desire to provide instruction that affirms the value, quality of life, and optimal growth of students with PIMD. As described throughout this study, the culture of outcome-based education and the mandate of college and career readiness are not appropriate for all students in the public school system, and these federal and state expectations fail to give meaningful guidance to the daily responsibility of creating and providing an appropriate education for students with profound disabilities.

The practice of educating students with disabilities in the United States has made exceptional legal, philosophical, and practical gains since the earliest days of Public Law 94-142 in 1975. The next step in supporting the education of all students, regardless of the severity of their disability, is for researchers, law-makers, and educators to work together to broaden the vision of appropriate education to specifically include those with PIMD, beginning with these students at the center. At the present time, teachers begin with the educational framework of academic standards and traditional teaching goals, and then find creative ways to fit the unique needs of their students onto that structure. As

PIMD becomes more widely recognized in the United States as a disability manifestation that is essentially different, requiring different knowledge and understandings by teachers, a model of practice may be developed that begins with a framework of student characteristics, to which standards, goals, activities, and outcomes are then added. When teachers are provided with the knowledge, resources, and support they need, they are then enabled to more effectively provide richness, meaning, and value to the education of students with Profound Multiple and Intellectual Disabilities who come into their classrooms and into the world of public school.

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Appendix A: Intellectual Disability Qualifying IQ by State

State	Intellectual Disability IQ (all states must include deficits in adaptive behavior in addition to IQ)	Documentation Links
Alabama	-2 Standard Deviations (70 and below)	http://adap.ua.edu/uploads/5/7/8/9/57892141/rnfcomplete_book.pdf
Alaska	-2 or more standard deviations	https://education.alaska.gov/tls/SPED/docs/SPEDGuidance.docx
Arizona	Mild: 55-70 Moderate: 55-40 Severe: 40 and below	http://toolbox1.s3-website-us-west-2.amazonaws.com/site_0419/EligibilityDefs_SpecEd_SCVUSD.pdf
Arkansas	70-75 or below	https://arksped.k12.ar.us/rules_regs_08/3.%20SPED%20ELIGIBILITY%20CRITERIA%20AND%20PROGRAM%20GUIDELINES%20FOR%20CHILDREN/PART%20I%20ELIGIBILITY%20CRITERIA%20AGES%205-21/E.%20MENTAL%20RETARDATION.pdf
California	At least -2 SD	https://www.scoe.net/selpa/resources/Documents/eligibility_critera_guidelines.pdf
Colorado	-2 Standard Deviations (70 and below)	https://www.cde.state.co.us/cdesped/guideliensfordeterminationeligibility_id_md
Connecticut	-2 standard Deviations	https://portal.ct.gov/-/media/SDE/Special-Education/ID_Elig_Worksheet.pdf?la=en
Delaware	Not Found	
Florida	-2 Standard Deviations (70 and below)	http://www.fldoe.org/academics/exceptional-student-edu/ese-eligibility/intellectual-disabilities-ind.stml
Georgia	70 and below	http://archives.gadoe.org/DMGetDocument.aspx/160-4-7-.05_ID_Eligibility_3-31-10.pdf?p=6CC6799F8C1371F60491518A7964E3637EAB863F5EFC1DEFA52C6DE25E2059CC&Type=D

Hawaii	-2 or more SD	https://www.hawaiipublicschools.org/DOE%20Forms/Special%20Education/Ch60Guidelines.pdf
Idaho	At or below 70	http://www.sde.idaho.gov/sped/files/shared/Idaho-Special-Education-Manual-2018-Final.pdf
Illinois	70	http://3qv5lo39ipx92v9slf1b221vdb4.wpengine.netdna-cdn.com/wp-content/uploads/2015/01/Intellectual_Disability.pdf
Indiana	Divides into mild (70), moderate (55), severe (40)	http://www.sped.sbcsc.k12.in.us/ppm/eligibility.html#cd
Iowa	No specific IQ	https://educateiowa.gov/sites/files/ed/documents/Special%20Education%20Eligibility%20and%20Evaluation%20Standards%2012_2015.pdf
Kansas	Significantly below…no stated IQ	https://www.ksde.org/Portals/0/SES/misc/iep/EligibilityIndicators.pdf
Kentucky	-3 Standard Deviations (55 and below)	https://education.ky.gov/specialed/excep/forms/Documents/Functional_Mental_Disability_Eligibility_Determination_Form.pdf
Louisiana	Varies by grade level: Grade 5 and below: -3SD (55) After Grade 5: -2.3 (below mean OR -2.0-2.29 SD w. addnl. Empirical evidence	http://louisianabelieves.com/docs/default-source/students-with-disabilities/swsds_eligibility-and-leap-connect-updates_october-webinar.pdf?sfvrsn=cef911f_4
Maine	Not Found	
Maryland	-2 standard	https://www.montgomeryschoolsmd.org/departments/specialed/OSSresources/Procedures%20for%20Confirming%20ID.pdf
Massachusetts	No IQ; uses “Mental Retardation” as qualifier	http://www.doe.mass.edu/sped/definitions.html
Michigan	-2 Standard Deviations (70 and below)	https://www.michigan.gov/documents/mde/MARSE_Supplemented_with_IDEA_Regs_379598_7.pdf
Minnesota	Not Found	
Mississippi	-2 SD (70)	https://www.mdek12.org/sites/default/files/documents/vol-i-cf-eval-elig-final-

		volume-09-22-2015_20160708142156_277140.pdf
Missouri	-2 SD (70)	https://dese.mo.gov/special-education/effective-practices/disability-resources-Intellectual-disability
Montana	-2 SD (70)	http://opi.mt.gov/Portals/182/Page%20Files/Special%20Education/Forms/Criteria%20Checklists%20-%208-31-17WITH%20watermark%20-%20no%20autism.pdf?ver=2017-09-05-123043-767
Nebraska	-2 SD	https://www.education.ne.gov/wp-content/uploads/2017/07/verificationguidelines.pdf
Nevada	Differentiates: Mild: -2 SD (70-56) Moderate: -3 SD (55-41) Severe: -4SD (40-26 Profound: -5 SD (25 and below)	http://www.doe.nv.gov/uploadedFiles/ndedoenvgov/content/Special_Education/IDEA_Forms_and_Docs/508_EligIntellectualDisaMultipleImpairment.pdf
New Hampshire	-2.5 to 3 SD (Below 62.5)	https://www.education.nh.gov/instruction/assessment/alt_assess/documents/decision_making_worksheet_2018-2019.pdf
New Jersey	Mild (-2 to -3 SD), Moderate (-3 SD), Severe: Student is incapable of giving evidence of understanding and responding; cannot express basic wants and needs	https://www.state.nj.us/education/code/current/title6a/chap14.pdf
New Mexico	-2 SD	https://tb2cdn.schoolwebmasters.com/accnt_67464/site_67465/Documents/RegionIX_IntellectDisabScript_073012.pdf
New York	Not Found	
North Carolina	Mild (-2SD Moderate (-3 SD) Severe (-4 SD)	https://ec.ncpublicschools.gov/policies/forms/state-forms-directions/english-forms/id-worksheet.pdf
North Dakota	IQ undefined	https://www.nd.gov/dpi/uploads/60/IDGuidelinesFinalVersionPosted.pdf
Ohio	70-75	http://education.ohio.gov/Topics/Special-Education/Students-with-Disabilities/Intellectual-Disability
Oklahoma	At/below 70	https://sde.ok.gov/sites/default/files/documents/files/Oklahoma%20Special%20

		Education%20Handbook%20%28live%29.pdf
Oregon	IQ -2 or more SD	https://secure.sos.state.or.us/oard/viewSingleRule.action?ruleVrsnRsn=259175
Pennsylvania	-2.5 to -3 SD (62.5 to 55)	https://www.education.pa.gov/Documents/K-12/Special%20Education/Assessment/PASA%20Getting%20Ready%202018%2019.pdf
Rhode Island	Not Found	
South Carolina	-2 SD	https://www.ed.sc.gov/scdoe/assets/file/programs-services/173/documents/43-243_1EligibilityCriteria.pdf
South Dakota	-2 Standard Deviations	https://doe.sd.gov/sped/IEP.aspx
Tennessee	-2 Standard Deviations	https://www.tn.gov/content/dam/tn/education/special-education/eligibility/se_eligibility_intellectual_dis.pdf
Texas	-2 Standard Deviations (70 and below)	https://www.esc14.net/upload/page/0170/docs/Quick%20Guide-ID.pdf
Utah	Not Found	
Vermont	-1.5 standard deviations (77.5)	https://education.vermont.gov/sites/aoe/files/documents/edu-series-2360-special-education-rules.pdf
Virginia	-3 Standard Deviations (55 and below)	http://www.doe.virginia.gov/special_ed/disabilities/intellectual_disability/index.shtml
Washington	-2 SD	https://www.k12.wa.us/sites/default/files/public/specialed/resourcelibrary/pubdocs/iep-team-guidelines-assess.pdf
West Virginia	73 and below	http://wvde.state.wv.us/osp/Fact_Sheet_Intellectual_Disability.pdf
Wisconsin	-2 SD	https://dpi.wi.gov/sites/default/files/imce/forms/pdf/podelg-id-001.pdf
Wyoming	-2 or more SD	https://1ddlxtt2jowkvs672myo6z14-wpengine.netdna-ssl.com/wp-content/uploads/2015/11/chapter_7_rules_march232010.pdf

Appendix B: Extended Academic Content Standards by State

State	Name of State Standards Utilized	Presymbolic Level in Kindergarten Reading Standards? Yes/No	Link
AL	Alabama Alternate Achievement Standards	No	https://www.alsde.edu/sec/ses/Assessment/ELA%20Final%20-AAS.pdf
AK	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
AZ	Core Content Connectors	No	https://cms.azed.gov/home/GetDocumentFile?id=586fcb9faadebe04385092a2
AR	Dynamic Learning Maps Essential Elements	No	http://dese.ade.arkansas.gov/divisions/learning-services/assessment/assessments-for-students-with-disabilities
CA	Core Content Connectors	No	https://www.cde.ca.gov/ta/tg/ca/altassessment.asp
CO	Extended Evidence Outcomes	No	https://www.cde.state.co.us/sites/default/files/documents/coextendedeo/documents/rwc_with_eeos.pdf
CT	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_St

			andards_for_Foundational_Skills_Grades_K-2
DE	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
FL	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
GA	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
HI	Range Performance Level Descriptors	Not located for Kindergarten	https://hsa-alt.alohahsap.org/core/fileparse.php/3344/urlt/HSA-Alt-Spring-2019-TAM.pdf
ID	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-

			Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
IL	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
IN	Indiana's Alternate Standards (Content Connectors)	No	https://www.doe.in.gov/sites/default/files/standards/ela-kindergarten.pdf
IA	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
KS	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
KY	K-PREP	Grade 3 and above only; no presymbolic level	https://education.ky.gov/AA/Assessments/kprep/Pages/AltStd.aspx
LA	Louisiana Connectors	No	https://www.louisianabelieves.com/docs/default-source/students-with-disabilities/k-12-louisiana-connectors-for-students-with-significant-disabilities.pdf?sfvrsn=10
ME	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_

			Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
MD	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
MA	Massachusetts Curriculum Frameworks for Students with Disabilities	Some: "grasp and release "	https://www.mcas-alt.org/materials/Files/2018/ELA_2018.pdf
MI	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
MN	"modified achievement standards" mentioned in testing data, but not found	Unknown	file:///C:/Users/tamih/Downloads/MCA-Modified%20ParentFactSheet%202013-14%20English.pdf
MS	Mississippi Extended Curriculum Frameworks	Grade 3 and above only; no presymbolic level	http://www.sos.ms.gov/ACCode/00000428c.pdf
MO	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
MT	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_b

			y_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
NE	Nebraska Standards with Extended Indicators	Grade 3 and above only; no presymbolic level	https://cdn.education.ne.gov/wp-content/uploads/2017/07/ELA_Extended_Indicators_Final.pdf
NV	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
NH	Dynamic Learning Maps: Essential Elements	No	https://dynamiclearningmaps.org/newhampshire
NJ	Dynamic Learning Maps: Essential Elements	No	https://www.nj.gov/education/specialed/learning.shtml
NM	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
NY	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-

			Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
NC	North Carolina Extended Content Standards	No	https://ec.ncpublicschools.gov/disability-resources/significant-cognitive-disabilities/nc-extended-content-standards/ecselak12final.pdf
ND	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
OH	Ohio Learning Standards-Extended with Learning Progressions	Some: "Active Engagement" Requirement-ELA Yes: In Life Skills Curriculum	https://www.ocali.org/up_doc/ELAExtendedStandards.pdf https://www.ocali.org/up_doc/Life-Skills-Curriculum_Guide.pdf
OK	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
OR	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
PA	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_b

			y_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
RI	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
SC	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
SD	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_Standards_for_Foundational_Skills_Grades_K-2
TN	Core Content Connectors	No	https://wiki.ncscpartners.org/index.php/Core_Content_Connectors_by_Common_Core_State_Standards:_English_Language_Arts-Language_Reading_St

			andards_for_Foundational_Skills_Grades_K-2
TX	Texas Essential Knowledge and Skills (TEKS) with Essence Statements	No	https://www.esc11.net/cms/lib3/TX21000259/Centricity/Domain/536/TEKS%20Aligned%20Curriculum%20Tools.pdf
UT	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
VT	CCSS: Dynamic Learning Maps Essential Elements	No	https://education.vermont.gov/student-learning/content-areas
VA	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
WA	Common Core State Standards for students with significant cognitive disabilities	None found	http://www.corestandards.org/assets/application-to-students-with-disabilities.pdf
WV	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf
WI	Dynamic Learning Maps Essential Elements	No	https://dynamiclearningmaps.org/sites/default/files/documents/ELA_EEs/DLM_Essential_Elements_ELA_%282013%29_v4.pdf

WY	The Extended Wyoming Content and Performance Standards	Yes (tactile engagement)	https://1ddlxtt2jowkvs672myo6z14-wpengine.netdna-ssl.com/wp-content/uploads/2016/11/2014-16-FINAL-RECOMMENDED-ELA-EXTENDED-STANDARDS-K-12_November-2016.pdf

Appendix C: Dialogue Prompt for Partner Organization

Hello.

My name is Tami Jaynes and I am a PhD student in Walden University's Special Education program. I am also a special education teacher who works with students who have intellectual and multiple disabilities. My dissertation study focuses on the educational practices, challenges, and experiences of teachers who work with the population of students on the most profound level of the disability spectrum.

For my research, I hope to interview special education teachers on their challenges, successes, curriculum and material choices, and teaching strategies as they work with students who have profound disabilities. I am seeking a teacher or teachers on your staff who might fall into this category of educator.

The interview would not take place on school or work time, and would be conducted over the phone or over a computer-facilitated program such as Zoom. I would ask to see a copy of an ETR/IEP with all identifying information omitted (usually this information is located on the cover page and signature page) so no student, teacher, or district could be linked to the documents. I would be looking primarily at the type of goals the student is working on and the adaptations being utilized.

Proper, required precautions are being taken to protect the identity of the teacher and students, school district, and state of residence. Walden University's approval number for this study is 08-07-20-0248531 and it expires on August 6th, 2021

Thank you for your help!

*Request an email address where the following document of study approval may be sent.

Appendix D: Letter of Informed Consent

(Date to be Inserted)

Dear (Insert Potential Research Participant's Name):

You are being invited to take part in a study on your experiences as a teacher of students with profound intellectual and multiple disability in a public school district in the United States. Teachers who have special education certification and work with students on the most profound end of the disability spectrum are a very specific (and small) group. In particular, I am interested in the challenges and successes you have experienced, the curriculum and activities you utilize as you work with your student(s), and how state academic standards impact your planning for these students. I am undertaking this research because I believe the voices of the teachers who work directly with these students need to be heard if knowledge and understanding about profound disability in education is to grow.

To Share in this Research:

- We will begin with an interview of approximately 1 hour in length. The interview will be held on the telephone or through computer facilitation (such as Zoom meetings), and will be audio recorded to help with accuracy. We will talk about the experience of teaching a student with profound disabilities in a public school setting. Some questions we may discuss include how you first became aware of students with profound disability, the most difficult and most satisfying parts of your work, curriculum and guides you use to set and work on goals.
- I will ask to see a copy of a student's IEP and ETR with all identifying information related to student, teacher, or school district removed. I am interested in the goals that have been established for the student.

The risks to this study are minimal, and are not anticipated to exceed what might be experienced as part of a conversation with a colleague who has had similar experiences with this population. Any information that you share or that is observed will be kept confidential. Our interview will be recorded so that I can type the dialog. The interviews will NOT contain any mention of your name, any student's name, or any identifying information about your school, district, or location. The interviews data will be kept on a password protected thumb drive in a locked box in my home and will be destroyed after five years. If child abuse is disclosed, I am a mandated reporter, and must follow the procedures set forth by your school district and state for teachers as mandated reporters.

It is my hope that you will find the experience to be enjoyable and rewarding, as you have an opportunity to share your knowledge, unique viewpoint, and professional experiences as a teacher of students with the most profound disabilities. You will be able to share

your professional work with others who are interested in the education of our students. The population of students with profound disability is largely unknown in public education, and it is my hope that you can provide a teacher's perspective to this unique educational situation. There is no financial compensation for your participation, but you will be provided with findings of the study and ideas shared by other research participants, although their identities will not be provided.

Your participation in this study is voluntary. Reports coming out of this study will not share your identity, nor that of your state, school district, school, or students. No one at your school or school district will be made aware of your participation. If you feel stressed at any time, or would prefer not to answer some interview questions, you may skip any questions that make you uncomfortable. Again, at no time will your name, location, or identifying information be revealed. This data will not be used for any purpose other than researching the work of teachers of students with profound disabilities in the U.S.

My name is Tami Hardesty-Jaynes. This study is being conducted as part of a doctoral dissertation through Walden University. In addition to my role as a doctoral student, I am also a special education teacher in the U.S. You may ask me any questions that you may have concerning this study by contacting me through text, e-mail or phone call (this information will be inserted). If you want to talk privately about your rights as a participant, you can call Walden University's Research Participant Advocate at (612) 312-1210. Walden University's approval number for this study is 08-07-20-0248531 and it expires on August 6th, 2021.

Statement of Consent:

If you feel you understand the study well enough to make a decision about it, please indicate your consent by replying to this email with the words, "I consent." This will indicate your consent to for me to contact you to arrange the details of your participation in the study.

Please print or save this consent form for your personal records.

Appendix E: Interview Protocol and Research Question Alignment

Interview Protocol Form

Special Education Teacher Interview Protocol
Date: _____
Designated Interviewee Number: _____
Designated Interviewee Pseudonym: _____
E-mail address to be deleted after member check: _____

Introductory Protocol

To facilitate my note-taking, I would like to use an audio voice recorder for our conversation today. Please sign the release form. I would like you to read this release, but for your information, I am the only person who will have access to the recording. Once it is transcribed and you have had the opportunity to review the transcript, the recording will be destroyed, and your e-mail contact will be deleted. In addition, you will be asked sign a form to meet our human subject requirements. Essentially, this document states that: (1) all information you share will be kept confidential. I will not share your thoughts or experiences in any manner that can be connected to your name or position. (2) your participation is voluntary and you may stop the interview at any time if you feel uncomfortable, and (3) I do not intend to inflict any harm. Thank you for your agreeing to participate.

Introduction

I have asked you to be part of this interview because you are a teacher in a public school district who has experience working with a student or students who have profound levels of disability. This research project focuses on the work you do with these students, with particular interest in your experiences, the curriculum and activities that you use in working with these students, and what impact federal and state rules governing special education have on your work. This study is not for the purpose of evaluating your techniques or experiences. The goal is to learn more about the way you teach students with profound disabilities; challenges and successes you have experienced, and hopefully gain knowledge that can provide a picture of the work that is being done with this small subgroup of students.

Interviewee Background Questions

How many years have you been working in the field of special education?

What is your degree and field of study?

Can you remember the time that you first became aware that there were students with this very profound level of disability?

Probe:

- *Please share that experience.*

Tell me about one of the students you worked with who had the characteristics of profound disability.

Probes:

- *In what setting do you work with this student?*
- *Physical health challenges (sensory impairment, epilepsy, etc.)*
- *Mobility*
- *Developmental age (symbolic language, communication)*
- *Reaction to people and activities around him/her*

Lived Experiences, Challenges, & Successes

What has been the most difficult aspect of your experience working with a student/students with profound disability?

Probes:

- *Impact of location*
- *Opportunities for collaboration/teaming*
- *Communication*
- *Self-efficacy*

Tell me about a rewarding aspect of this experience.

Probes:

- *Communication with student*
- *Glimpses of "personhood"*
- *With whom could you share this success?*

Curriculum, Activities, and Practices

In regard to the curriculum that you use with your student(s) with profound disabilities, how was the curriculum chosen?

Probes:

- *Was it mandated by the school district*
- *Recommended by other educators*
- *Self-selected*

What resources do you use to help you plan your curriculum for your student/students?

Probes:

- *Internet*
- *Workshops*
- *Purchased Curriculum*
- *Team Members?*

Do you ever "get stuck" when planning for your time with your student/students?
Probe:

- *What causes you to feel "stuck"?*
- *What do you do about it?*

Tell me about some of your favorite activities to do with your student/students with profound disability.
Do you feel that the activities that you share with your students are meaningful for their own lives right now or in the future?

Impact of Federal and State Laws and Mandates

How do you utilize the State Extended Academic Standards (Name of Standards will be inserted to correlate with the appropriate state) for you student(s) with profound disabilities?

Probes:

- *Restate confidentiality*
- *If answer is yes, probe for how an example of how it has been used*
- *If answer is no, probe for why they are not being utilized*

How do you develop meaningful goals for your student(s)?
Probe:
Family, student, or standard centered?
Universal Design for Learning is now the ideal for students with disabilities. How do you feel about the idea of Universal Design for Learning as applied to your student(s)?

Closure to Interview

Have your feelings changed over the time that you have worked with these students?

What would be the most helpful thing for new teachers of students with profound disabilities to know?

Closing Script

Thank you so much for sharing your time and experiences with me. In addition to what you've added to the research, as a teacher of several students with profound disabilities, it is good for me to be able to hear from someone else who is doing similar work. I will e-mail you a transcription of our

interview in the next few days. Read over it, and if there's anything you would like to clarify, please let me know. You can call or e-mail me.

Interview Research Question Alignment

Research Question	Interview Question	Type of Question
Introductory/Demographic Questions	How many years have you been working in the field of special education?	Low risk Sets Context
	What was is your degree and field of study?	Low risk Sets Context
	Can you remember the time that you first became aware that there were students with this very profound level of disability?	Low risk Evokes stories
	Tell me about one of the students you worked with who had the characteristics of profound disability.	Seeks understanding of population
1: What are the lived experiences of teachers of students with PIMD in public school districts in the U.S. regarding challenges and successes in their teaching practice?	What has been the most difficult aspect of your experience working with a student/students with profound disability?	Higher risk/greater transparency Explore emotions Probes are grounded in the research
	Tell me about a rewarding aspect of this experience?	Lower risk Evokes stories Explore emotions Probes are grounded in the research
2: What kinds of curriculum, activities and practices do teachers of students with PIMD utilize in their teaching to fulfill the federal	What resources do you have to help you plan your curriculum for your student(s) with PIMD?	Factual Low risk

mandate of meaningful education and from what sources are these tools (curriculum, activities, practices) obtained?	Do you ever "get stuck" when planning for your time with this/these student(s)? What are some of your favorite activities to do with your students with PIMD? Do you feel that the activities that you share with your students are meaningful for their own lives right now or in the future?	Higher risk Factual Low risk Evoke stories Explore emotions High risk Probe for the teacher's ideas of meaningfulness (probe based on Federal law)
3: How do teachers view the effectiveness of state extended academic standards and selected curricula as meeting the mandate of a meaningful education for students with PIMD?	How do you utilize the State Extended Content Standards for your students with profound disabilities? How did you determine the goals you would include on the student's IEP?	Medium risk: teachers may or may not be using these standards for their students Low risk

Appendix F: Records Review Documents

Records Review:
Evaluation Team Report

Teacher of Record Code: _____
Date of Retrieval: _____

ETR:
Team Members by Title:

_____ _____

_____ _____

_____ _____

Eligibility Category:

_____

Testing and Result Summary:

_____

_____

Student Educational Needs:

_____

IEP:
Least Restrictive Environment:

Inclusion with Typically-Developing Peers:

Parent Goal Statement:

Goal Area 1:

Goal and Objectives:

Goal Area 2:

Goal and Objectives:

Goal Area 3:

Goal and Objectives:

Goal Area 4:

Goal and Objectives: