PERCEPTIONS OF IMMEDIATE FAMILY MEMBERS ON CURRENT CURRICULAR EXPECTATIONS FOR INDIVIDUALS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITIES

by

MEGHAN DIANNE LOWE WINDHAM

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MEGHAN DIANNE LOWE WINDHAM

Approved:

Kelly Reffitt, Ph.D.  Date
Dissertation Committee Chair
Associate Dean, Tift College of Education

Sharon M. Augustine, Ph.D.  Date
Dissertation Committee Member
Department Chair, Teacher Education

Sybil A. Keesbury, Ed.D.  Date
Dissertation Committee Member

Jane West, Ed.D.  Date
Director of Doctoral Studies, Curriculum and Instruction Program

D. Scott Davis, Ph.D.  Date
Acting Dean and Provost, Tift College of Education
DEDICATION

for Hank, my greatest accomplishment
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First and foremost, I would like to give all honor, glory and praise to my merciful Lord and Savior Jesus Christ, the Author and Finisher of my faith. I am confident of this very thing—that He which began a good work in me continues to perform it until this day (Philippians 1:6). Amen.

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ABSTRACT

MEGHAN DIANNE LOWE WINDHAM
PERCEPTIONS OF IMMEDIATE FAMILY MEMBERS ON CURRENT CURRICULAR EXPECTATIONS FOR INDIVIDUALS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITIES
Under the direction of KELLY REFFITT, Ph.D.

With consideration of current mandated standards-based curricular requirements for students with Intellectual Disabilities, this dissertation sought to examine the perceptions of students and their immediate family on how this curriculum supports students with Severe and Profound Intellectual Disabilities (SID/PID) to realize their post-secondary goals and aspirations. This qualitative case study considered the implementation of a standards-based curriculum versus a life-skills curriculum on the achievement post-secondary goals from the Transition Plans of four individuals with SID/PID.

Pre-interview questionnaires, document analysis, semi-structured interviews, and journaling methods were used to answer the research questions. The researcher transcribed each interview utilizing the online software Sonix. Once transcribed, interviews were uploaded to QDA Miner, an online qualitative data analysis software that assists in coding and retrieval. The researcher coded the interviews, creating categories and subcategories.

Themes that emerged from the data addressed the following: 1) how standards-based and life-skills curriculum each prepare individuals with SID/PID for post-
graduation, and 2) perceptions of immediate family members on the impact of these curriculums post-secondaryly. Data showed that all four students passed every part of the Georgia Alternate Assessment (GAA), but none of the former students met 100% of their post-secondary goals.

Four themes emerged from the data: 1) these families favored the development of independent life-skills prior to graduation for their loved one with SID/PID, 2) the families did not feel that academic curriculum fostered post-graduation attainment of Transition Plan goals, 3) the families believe that additional teacher training is needed to increase awareness of parents’ rights and options, and 4) the families believe there is a need for a family-centered curriculum. Recommendations for further study include conducting a longitudinal study of families of students with SID/PID from 9th grade to age 25. This type of study could explore the path that families must take and the experience of making life-altering decisions at the beginning of the transition process, the transition immediately following graduation, and for life beyond.
CHAPTER 1
INTRODUCTION

The federal Individuals with Disabilities Education Act (IDEA) and the Elementary and Secondary Education Act (ESEA) (reauthorized as No Child Left Behind (NCLB) mandate that all students, including students with disabilities, must have access to and be assessed on grade-level content standards. This mandate is inclusive of students with severe and profound intellectual disabilities. A student in the United States with a chronological age (CA) between thirteen and fourteen is typically in the eighth grade. A typical eighth-grade math student is expected to demonstrate knowledge of number sense, addition and subtraction, multiplication and division, and have a general mastery of ratios and proportions. Algebraic and geometric explorations are the theme in eighth grade classrooms across the state of Georgia. Knowledge and understanding of square and cubed roots, real-life scenarios within equalities, and demonstration of mastery of representative samples in a survey are current expectations of eighth-grade students. These expectations also apply to students in the Severe/Profound Intellectual Disabilities Self-Contained classroom.

Within this classroom there may be another eighth grader—a thirteen-year-old student who is unable to speak, inconsistently responds to touch with eye gaze, depends on her family, caregivers, and educators to assist with her daily personal needs and who is ambulatory only with the support of a wheelchair. According to IDEA and ESEA, this eighth-grade student is also expected to demonstrate knowledge of square and cubed
roots and real-life scenarios of equalities and representative samples within surveys. This student, not unlike the rest of the eighth-grade population within the school, is also expected to show understanding and progress within English/Language Arts, Science and Social Studies—the ‘core’ content areas.

All students are not only entitled to a free public education, but a free, appropriate public education. Today, there is a ravine of differing opinions of the applicability of curricular expectations for some of the cognitively lowest functioning students within the school system. The argument of many teachers, administrators, and policy-makers rage on, but the perceptions of students and their families are often overlooked.

What do students with Severe/Profound Intellectual Disabilities (SID/PID) and their families think about curriculum policies that impact them so deeply? Are these curricular requirements appropriate? Do these requirements allow students with SID/PID to meet their post-secondary aspirations? Documentation of teachers’ perceptions of this conundrum can be found (Alwell & Cobb, 2009; Ayers, Lowery, Douglas, & Sievers, 2011; Courtade, Spooner, Browder, & Jimenez, 2012), but the opinion of students with Severe/Profound Intellectual Disabilities and their families is not found in published research literature.

The aim of this study is to add to the body of existing literature concerning the curricular requirements of students with Intellectual Disabilities, specifically within the Severe/Profound range of functioning, and the functionality and appropriateness of those requirements, based on the perceptions of the families to whom they matter most.
Statement of the Problem

Among many other purposes, compulsory education in the United States focuses on making students successful, productive members of society or ready for entry into a post-secondary institution upon graduation (Courtade et al., 2012). Federal law (20 USC § 1400 et seq.) outlines that every student is entitled to a free, appropriate, public education (Individuals with Disabilities Education Improvement Act (IDEiA), 2004). The focus of this study centered on the appropriateness of the mandated curriculum for students with severe and profound intellectual disabilities, and the purpose of this study was to add to the body of literature concerning students with the most significant disabilities and their families’ opinions of whether or not the curricular expectations are appropriate for their personal post-secondary goals. Is the expectation that students with SID/PID prove access and progress in biology and physical science or in US History? Consider the necessity of analytic geometry for a student with a Profound Intellectual Disability. Is progress within this portion of the curriculum necessary in propelling this student in reaching his/her post-secondary goals?

Teachers, administrators, stake holders, and policy makers cannot agree (Alwell & Cobb, 2009; Ayers et al., 2011; Courtade et al., 2012; Ryndak, Jackson, & White, 2013), and the opinion of students with disabilities and their families is often unsolicited, hence the gap in existing bodies of literature within this area. Speculations for neglecting the opinion of this population vary; however, two primary reasons can be determined: the level of communicative abilities possible by students functioning within the SID/PID range (Sigafoos, Arthur-Kelly, & Butterfield, 2006) and because the opinion of students
are not often considered by stakeholders when determining mandates (Sigafoos et al., 2006; Biklen & Moseley, 1988). These reasons are considered with more depth in this study’s review of the literature.

The needs of individuals functioning within the SID/PID range vary greatly from the needs of those that are not Intellectually Disabled, and even those with a milder case of Intellectual Disability (Biklen & Moseley, 1998; Bouck, 2012). Given the diverse needs of this population, should curricular expectations really be the same? Certainly, the IDEA and ESEA were implemented to ensure an enhanced educational experience for students who have historically gone unconsidered in many facets of life, the least of those not being education (IDEiA, 2004). However, has the educational pendulum now been positioned so far opposite historical treatment that educational success is still unattainable for students functioning within the SID/PID range? While pioneers such as Lou Brown (1973) established strategies for encouraging chronological-age-appropriate and functional curriculum for students with significant, low-incidence disabilities, more recent longitudinal studies revealed that exposure and access to general education classes and same-age peers led to the student demonstrating more independence and involvement in contexts not only in school, but in postsecondary environments as well (Ryndak et al., 2013).

One longitudinal study posited that post-secondary success for students with severe disabilities was marked with entry to the “world of work,” and within their study found that 26% of young adults functioning within the SID/PID range of intellect were working within two years after graduation from high school (Carter, Austin, & Trainor,
This study cited an increase in the odds of post-secondary employment (the study’s characterization of “success”) could be associated with having vocational goals in their IEP, job instruction, and coaching and with spending more than 25% of the day in outside school work-study (Carter et al., 2012). This dissertation study sought to define how the students and their families within this case study defined “success,” and whether or not they perceived that the academic focus of the mandated curriculum aligned with what research outlines as effective means of attaining “success.”

Within the longitudinal study conducted by Carter et al. (2012), another facet of student success was uncovered: the role of the parent. Parental involvement was critical to post-secondary success in that expectations held by parents was strongly associated with whether their student with significant cognitive impairments was working after high school graduation (Carter et al., 2012). Consider the plight of the student functioning within the severe or profound range of cognitive functioning and that of their parent: decisions during the transition meeting portion of the Individualized Education Program (IEP) meeting focus on where the student will live after graduation; how the student will be protected even if they are functionally non-verbal; how the student will provide for themselves after graduation; how the student will manage after the death of their parent(s)…parental involvement is critical and within transparent consideration by parents and caregivers serving this population of individuals (Carter et al., 2012; GADOE, 2015a).

Within this dissertation study, the purpose of education in the United States (specifically students within the metro Atlanta area within the state of Georgia) was taken
into consideration. Former students in this study were exposed to a significantly modified scope and sequence of the Georgia Standards of Excellence as compelled by the IDEA and NCLB/ESEA. Due to deficits in abilities, some functional life skills were addressed through their IEPs. However, research was deemed necessary to determine if “success” was achieved for these individual students with SID/PID. This case study included four individuals with SID/PID. Data were collected through pre-interview questionnaires and semi-structured interviews with students’ families and document analyses of the students’ IEPs, Transition Plans, Psychoeducational Reports, and Georgia Alternate Assessment reports.

Research Questions

1. How does the current mandated standards-based curricular requirements and functional, life-skills curriculum allow individuals with Severe/Profound Intellectual Disabilities to realize their post-graduation goals?

2. What are the perceptions of family members of students with Severe/Profound Intellectual Disabilities on how the current mandated standards-based curricular requirements and functional, life-skills curriculum allow their child to realize their post-graduation goals?

Theoretical Framework

According to Mertens (2009), transformation may be achieved when historically marginalized individuals are able to make a shift from allowing life to simply happen to them or decisions to be made for them to becoming active participants in their own lives (p. 296). The transformative paradigm is a broad lens that encompasses a variety of
perspectives (Sweetman, Badiee, & Cresswell, 2010). For the purposes of this study, an advocacy perspective was utilized. Sweetman et al. (2010) purport the necessity of the Transformative Framework in research to bring “an advocacy perspective” (p. 442) to studies that focus on historically marginalized individuals with special needs.

The voices of individuals functioning within the Severe/Profound range of intellectual functioning are noticeably absent from not only scholarly literature (Sweetman et al., 2010, p. 298), but also absent from the legislative decisions made regarding their education and futures beyond. This notion of including the voices of the oppressed is central to the transformative paradigm, as “The inclusion of diverse voices, particularly the voices of people who have been pushed to the margins, is a core issue for transformative research and evaluation” (Sweetman et al., 2010, p. 298). Research within the framework of Disability Theory gives the “power of using the perspective of people with disabilities as a socio-cultural group as [a lens] for research with people who have disabilities,” while also allowing the opportunity for a “transformative experience for the researchers” themselves (Mertens, 2009, p. 289). By nature, the Transformative, or Emancipatory, Framework challenges the status quo, along with the assumptions and influence that often accompany such normalcies and seeks to positively affect change in not only individual mindsets, but in cultural standards as well (Trede, Higgs, & Rothwell, 2009). Transformative refers to a population being studied that is no longer an “exotic” phenomena, but rather a cultural group with acceptable values, beliefs, and traditions unique to them as a means to fully participate in society (Mertens, 2009). The purpose of this study was to reveal that, indeed, every child has the right to a free, appropriate public
education, but at what point do students and parents have the right to define the appropriateness of an education with consideration to an individual student’s needs within a given school system? Boards of Education, stakeholders, teachers, administrators and parents are all valued members of the committee to determine appropriate standards and skills with which students should graduate. Even students themselves are entitled to stand and deliver at board meetings when decisions are being made. However, students functioning within the Severe or Profound range of intellectual functioning are typically not those individuals standing and defining their own paths—those decisions are made for them.

At the federal level with new mandates and reauthorizations, within local boards of education legislations, at IEP meetings, and on curriculum nights at the local school—decisions for students functioning within the Severe or Profound range of intellectual functioning are happening to them, not in collaboration with them. Disability Theory within the Transformational framework allows for all individuals—regardless of eligibilities, labels, or verbal ability to give voice to students that have been historically marginalized (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005; Mertens, 2009).

Significance of the Study

The United States mandates that all students access general curricular standards. All students, including students with SID/PID, are required to be exposed to, be assessed on and show progress within the documented standards for each specific state (Salend & Garrick Duhaney, 2011). This study sought to understand the lasting impact that these
mandates had on students with SID/PID, specifically the attainment of post-secondary goals held by the student and his/her family. Contention exists between two schools of thought within the realm of Intellectual Disability and educational expectations: Academic standards centered curriculum or a functional, life-skills centric curriculum (Ayers et al., 2011; Ayres, Lowrey, Douglas, & Sievers, 2012; Courtade et al., 2012).

Activists, lawmakers, care-givers, educators, and parents continue to argue who is entitled to special education services and what goals service providers and politicians should implement for these students. They struggle with the best way to implement an appropriate, research-based pedagogy for students with disabilities and what the focus of this pedagogy should be: academic or functional life-skills. This contention is derived from emotions and opinions of families and care-givers of individuals functioning within the SID/PID range questioning the lasting purpose of academic strides made in school when their children/clients do not possess the basic skills to protect and provide for themselves (Ayers et al., 2011; Ayers et al., 2012).

On the other side of the argument, academic proponents cannot fathom a world in which any student attends school during which they have not been exposed to curricular content deemed necessary to enter adulthood (Courtade et al., 2012). Researchers argue that job opportunities are increased as a result of having participated and progressed within an academically competent program for individuals with severe intellectual disabilities and that learning “general curriculum content is a right of every child who attends school (Courtade et al., 2012, p. 5).
Rationale

The goal of this study was to support and help individuals with Intellectual Disabilities. Many individuals within this population are unable to speak for themselves; it is the calling and passion of this researcher to give these souls a voice. It is their right to speak on their own behalf to lawmakers, caretakers and stakeholders regarding their personal goals and what education is needed to reach these goals. When they are unable to speak for themselves, their families need support in communicating the needs and goals of these students. With replication and further studies including this one as a stepping stone within the continuing body of literature, this researcher hopes to one day influence federal-level curriculum polices as well.

Methodology Overview

Qualitative research “assumes that there are multiple realities” and that rather than being objective, the world is perceived and experienced through personal interactions (Merriam, 1988, p. 17). The inductive nature of the qualitative approach allowed for the researcher to understand, discover, and describe cultural and personal narratives while generating findings through meaningful, comprehensive, and holistic experiences (Merriam, 1988). A qualitative research approach provided “a systematic approach to understanding qualities, or the essential nature, or a phenomenon” within the context of individuals with Intellectual Disabilities (Brantlinger et al., 2005, p. 195). This systematic approach allows for the researcher to revisit portions of the data to bolster and bring understanding to other portions of the data (Stake, 2005; Mertens, 2010).
Seidman (2006) indicates that selection of the research paradigm and method should be determined by the research question and what the researcher wants to know; Mertens (2010) asserts that the researcher’s personal experiences and worldview influences the research questions, thereby driving the proposed methodology and its’ situation within one of the key research paradigms. Due to the nature of the research questions of this study, qualitative methodology was most appropriate. There are many paradigms within qualitative research; consequently, it was important that the researcher explicitly defined which paradigm was employed within the study and why (Maxwell, 2012). It is also acceptable that the research combines various schools of thought, traditions, and paradigms given that each aspect contributes to the study in a compatible manner (Maxwell, 2012).

This study sought to understand the lasting impact that current curricular mandates had on four students that graduated from a public school system within the state of Georgia in the last five years, some with Severe ID and some with Profound ID, specifically on the attainment of post-secondary goals held by the students and their families. Drawing from the context of this study and the focus of the research questions, the assertion of qualitative studies within special education was to “produce science-based evidence that can inform policy and practice in special education” (Brantlinger et al., 2005, p. 195). As this study focused on ‘personal meanings’ within special education curriculum, historically marginalized members of society were given a platform from which to express their once-silenced point of view (Brantlinger et al., 2005).
Data for this study were gathered through a case study and narrative methodology. The primary focus of this study, as outlined through the research questions, required in-depth exploration of specific, complex personal accounts of living with and making decisions for a family member with intellectual disabilities; therefore, a case study approach best represented the unique stories of the families (Brantlinger et al., 2005; Mertens, 2010; Stake, 2005). Yin (1984) qualifies that non-experimental research questions that seek to find ‘how’ and ‘why’ are best answered through a case study approach. In this study, the researcher gathered historical data regarding parental opinions and the motivations and extent of said opinions without employing manipulated or controlled means (Merriam, 1988).

The analysis, based on the nature of the research questions that ask ‘how’ and ‘why,’ resulted in a holistic, richly-descriptive interpretation of a “contemporary phenomenon” with participants bound together in a case by a very specific common denominator: planning post-secondarily for an individual with severe or profound intellectual disabilities (Merriam, 1988; Smith, 1978).

The purpose of this study was to concentrate on four family units to reveal specific and significant factors that characterized this phenomenon of personal and familial expectations for four young adults with severe and profound intellectual disabilities (Merriam, 1988).

Data Collection Procedures

Because the design of this study was descriptive in nature and non-experimental, a case study approach to the collection of data was chosen (Merriam, 1988). A holistic
view of family dynamics (i.e. expectations for other siblings, internal struggles of the family caused by the disability of the loved one, and goals of the families and the students) worked in tandem to descriptively answer the questions set forth by this study through open-ended, semi-structured interviews (Merriam, 1988; Seidman, 2006; Mertens, 2010).

The researcher began with broad questions that covered the specific requirements of the research questions within the interview protocol but allowed the interview to occur as naturally as possible; seeking to question the participant as points of interest of the study occurred within the conversation, and then used the protocol to gently guide the conversation back to the task at hand (Mertens, 2010). The narrative aspect, specifically through the psychological lens, allowed personal reflections, motivations, and responses to paint the picture of the student and familial goals while bounding the study with specific limitations and delimitations (Merriam, 2009).

The researcher also conducted a document collection and analysis of individual Transition Plans, IEPs, Psychoeducational Reports, and Georgia Alternate Assessment scores. According to Bowen (2009), the use of document analysis is “a case of text providing context” that gives historical background to the case and contributes to the trustworthiness of the study (p. 29). The triangulation of the four datasets, in addition to thick, rich descriptions emerging from each interaction, created as complete a portrait of each case as possible in a shortly defined amount of time (Geertz, 1973; Janesick, 1999; Mertens, 2010; Stake, 1995).
Participants

Participants in this study consisted of the immediate family members of four individuals functioning within the Severe and Profound Intellectual Disabilities range who graduated from a metro-Atlanta public school system within the state of Georgia within the past five years.

Individuals functioning within the Severe/Profound Intellectual Disabilities range are often marginalized because of their inability to communicate effectively, consistently, and in the manner in which most individuals are comfortable exchanging ideas and opinions (Mertens, 2011; Sigafoos et al., 2006). Individuals functioning within SID/PID range have severe communication deficits, both receptively and expressively (Biklen & Moseley, 1988; Brantlinger, 2005; Sigafoos et al., 2006); this aspect of the disability quite often results in their opinions and desires being guessed, assumed, or sometimes overlooked (Biklen & Moseley, 1988).

One aim of this study was to explicitly elicit the opinion and input of these individuals regarding personal post-graduation goals. As immediate families of students with significant intellectual disabilities are often “given little support concerning their dreams for their child” (Grigal & Hart, 2010, p. 231), this study also aimed to gather and understand family members’ opinions regarding the curriculum and the role said curriculum serves in the realization of post-graduation goals. Such lack of support is evidenced by inadequacies in appropriate services and supports, exclusion of family members as team members, and “unsatisfactory quality” of programs, supports and educators (Mueller, Singer, & Draper, 2008, p. 193).
Marginalized and excluded as they may be, this study sought to include the voice of the individuals with significant intellectual disabilities through their immediate families, as authorized by Brantlinger et al. (2005). The researcher hoped to solicit the opinion of individuals with Severe/Profound Intellectual Disabilities; however, the intellectual functioning of students with SID/PID is such that most individuals within this population are nonverbal and have significant communication deficits (Biklen & Moseley, 1988; Brantlinger et al., 2005; Sigafoos et al., 2006). Due to the students’ inability to communicate, the researcher sought the perspectives of the students’ families.

There is precedent for families completing interviews if the student was unable to do so (Bouck, 2012; Brantlinger et al., 2005; Carter et al., 2012). This study explored the perspectives of students with significant intellectual disabilities through their immediate families regarding the functionality of standards-based curriculum compared to that of a functional, life-skills curriculum in the success of meeting post-secondary goals.

The participants within this study were the immediate family members of individuals with Severe/Profound ID. The participants all currently reside in metro-Atlanta, Georgia communities, and each have a relative that graduated from a public school system in Georgia within the last five years. Each of the participants have a family member who was served through the Severe/Profound Intellectual Disabilities Self-Contained Program, which is their binding characteristic. The immediate family participants were each related to an individual that was eligible for special education services through the Severe/Profound ID category, and who participated in the high
school administration of the Georgia Alternate Assessment, and who had an IEP and Transition Plan.

Researcher Positionality

Within this section the researcher will break protocol of writing in third person to give a first-person, personal narrative of her positionality. The purpose of the positionality component within a qualitative research project is to share variables such as beliefs, political stance, gender, personal beliefs, socioeconomic class, cultural background, and race of the researcher with the reader (Bourke, 2014). Because the researcher serves as the instrument of data collection within qualitative research, these variables may then “affect the research process” (Bourke, 2014, p. 2).

Within this portion of my study, I will share my positionality with you, the reader, so that you may discern my personal threads throughout this study in contrast to existing literature and within the data collection and analysis.

I went to college right after high school and graduated with a degree in Special Education: Mental Retardation and Autism. At the time of this writing, I have taught for fifteen years within the community in which I grew up.

My parents are east Tennessee, proud Appalachian hillbillies. Unless you are from this region of the United States, this characterization may sound derogatory and insulting; but, quite the opposite—this label is a source of pride for my family and me. Growing up in Appalachia can be a hard-scrabble affair where life does not come easy. To this present day, there are homes without electricity and with dirt floors. Parts of Appalachia are some of the poorest socioeconomically in the nation, and it is from this
region that my parents emerged. My Daddy has worked a full-time job since he was 14 years old. This did not leave much time for school, but he is the most hard-working, business savvy, and industrious man I know.

My Mama’s side of the family was much poorer than Daddy’s. Education was valued in their home, and eventually a doctor, a registered nurse, a certified teacher, a master welder, and a long-haul trucker were produced from a home where neither parent graduated from high school. My Mama has pushed and encouraged me throughout my life in all areas, but especially in education. It is in honor of her tenacity that I am going through this dissertation process.

My familial history has shaped who I am and how I view the world; this being said, it also shaped how I view the literature and what I believed to be important within the lives of my students in this study. I grew up with stories about how teachers were mean to my Mama because she was so poor, and with stories of how my Daddy didn’t have enough clothes to make it through a week at school. The perseverance engrained within my people is also woven into my spirit. I fight for those that cannot fight for themselves. My students have me as their teacher, but they also have me as their advocate. I work doggedly to make sure that my students have every advantage and experience every benefit that those without cognitive impairment enjoy.

I strongly support that all students are entitled to a free, appropriate education, no matter the cost or effort required to ensure they receive it. When the Georgia Alternate Assessment was re-structured, and we began accessing grade-level standards, I was a skeptic. However, implementing the tenants and administering the alternate assessment
made me a better teacher; my students were being exposed to so many new ideas and concepts that they, otherwise, would not have seen had I, their teacher, not been forced to do so.

Given that my worldview on knowledge and education is not necessarily gained through progression through the standards, it is the experiences that the application of the standards foster that I value. In spite of all of the rhetoric and debate, I must consider the core question: would my students truly need to know how to identify the main ideas and supporting details of a literary passage to reach their goals in life? No, in all probability they would not.

But my worldview pushes me to identify that it is not just the implementation of the standard, but the experience that goes along with that implementation that matters. It is the one-on-one attention that the teacher gives to the student to help find that main idea that helps student learn. It is the language-rich interaction that the student receives that most helps the student. The hand-over-hand assistance and physical contact that the student experiences matter to my students. The praise and reinforcement for participating in a novel activity outside of their normal existence aids their confidence.

The implementation of grade-level standards is about so much more than implementation of grade-level standards. Through these experiences the parent and the teacher observe the student’s interests and strengths that may lead to a vocational trade, but these revelations are rarely about the standards themselves.

However, I do not have a child with a significant cognitive disability nor the daunting undertaking of preparing that child for life beyond school. When the doors of
the school clank shut for that last time, and the bus pulls away from the curb at home for that last time, what experiences within that student’s educational history will truly impact their life beyond school? It is for these reasons, and to seek answers to those questions, that I conducted this study.

Limitations

Possible limitations of this study were identified by the researcher and included within this section. A limitation is a boundary of a study outside of the researcher’s control.

Researcher Bias

The researcher within this study is a public school system educator for students with Severe/Profound Intellectual Disabilities and Autism. The researcher’s Bachelor of Science teaching degree has a focus of Mental Retardation and Autism; this researcher has never taught in a general education setting, but always in that of a self-contained special education setting for students with Moderate, Severe and Profound Intellectual Disabilities. The posture of this researcher is deeply rooted in advocacy and transformation. Given this bias, the researcher expects to cause transformation for individuals with Intellectual Disabilities in the type of curriculum required for graduation.

Characteristics of Individuals with Severe/Profound Intellectual Disability

The graduated students at the focus of this study were identified as functioning within the Severe/Profound range of Intellectual Functioning. Identification as a person functioning within the SID/PID range denotes specific limitations in cognition, receptive and expressive communication and adaptive functioning (Taylor, Richards, & Brady,
Alternate methods of communication are many times necessary when attempting to evoke communication from an individual within the SID/PID range; these types of communication are dependent upon the interpersonal intelligence of the person developing the method of communication and may not at all reflect what the individual with SID/PID wishes to convey (Brantlinger, et al., 2005; Sigafoos, 2006).

Due to limited cognition, the consistency of communication is often compromised; many individuals with SID/PID do not know the difference between ‘yes’ and ‘no,’ and this can complicate answers to specific questions relating to preference and opinion, therefore the input of the case study students’ immediate families was required (Brantlinger, et al., 2005; Sigafoos, 2006).

Participant Emotionality

The graduated students and immediate families involved in this study love each other; they want the best for each other. Concerns about the future care and provision of a family member with an Intellectual Disability can consume families. Fear, anxiety, anger, regret, and hopelessness characterized some of the experiences for the families in this study while hope, trust, excitement and encouragement characterized others. There were emotions involved with every participant involved that in some ways fortified, and in some ways discouraged the families who participated in this study.

Delimitation: Case Study Methodology

The researcher selected a case study methodology for several reasons. A case study methodology bounds the number of cases involved in the study and the researcher had a limited amount of time and resources to complete this study. The number of cases
must be bound to a smaller number for management, monetary and time factors (Yin, 2003).

A case study methodology allowed for a narrative experience to be shared. The researcher elicited thick, rich description and raw, honest opinions regarding this study. This case study methodology allowed for a small percentage of the population to be highlighted in a way that shared personal stories while also reporting phenomena specific to the participant group.

Definition of Terms

For the purpose of this study, several terms related to special education are defined as follows:

Curriculum, Required Curriculum, Standards, Standards-Based Curriculum, Academic Standards-Based Curriculum: “A curriculum that is developed by looking at the standards (district, state or national); identifying the skills knowledge and dispositions that students should demonstrate to meet these standards; and identifying activities that will allow students to reach the goals stated in the standards” (Lund & Tannehill, 2014, p. 7).

Functional Life-Skills Curriculum, Functional Curriculum, Life-Skills Curriculum: “A functional curriculum approach is a way of delivering instructional content that focuses on the concepts and skills needed by all students with disabilities in the areas of personal, social, daily living, and occupational adjustment. What is considered a functional curriculum for any one student would be the content (concepts and skills) included in that student’s curriculum or course of study that targets his or her
current and future needs. These needs are based on a nondiscriminatory, functional assessment approach” (Clark, 1995).

*Georgia Alternate Assessment (GAA):* “The GAA is a portfolio of student work that enables the demonstration of achievement and progress relative to selected skills that are aligned to the Georgia curriculum. The portfolio is used to capture student learning and achievement/progress in four content areas: English/Language Arts, Mathematics, Science, and Social Studies. This assessment program promotes a vision of enhancing capacities and integrated life opportunities for students who experience significant cognitive disabilities” (GADOE, 2016).

*Intellectual Disability (ID):* Refers to significantly sub-average general intellectual functioning which exists concurrently with deficits in adaptive behavior that adversely affects educational performance and originates before age 18 (§ 300.8 Child with a disability, 2017).

*Severe Intellectual Disability (SID), Functioning within SID Range:* Given the understanding of the definition of Intellectual Disability, Severe Intellectual Disability is characterized as:

1. Intellectual functioning ranging from an upper limit of approximately 40 to a lower limit of approximately 25; and
2. Deficits in adaptive behavior that significantly limit a child’s effectiveness in meeting the standards of maturation, learning, personal independence or social responsibility and especially school performance that is expected of the individual’s age-level and cultural group as determined by clinical

_Profound Intellectual Disability (PID), functioning within PID Range:_ Given the understanding of the definition of Intellectual Disability, Profound Intellectual Disability is characterized as:

1. Intellectual functioning below approximately 25; and
2. Deficits in adaptive behavior that significantly limit a child’s effectiveness in meeting the standards of maturation, learning, personal independence or social responsibility and especially school performance that is expected of the child's age-level and cultural group, as determined by clinical judgment (APA (DSM-5), 2014; § 300.8 Child with a disability, 2017).

_Severe/Profound Intellectual Disability (SID/PID), Functioning within SID/PID Range:_ Given the understanding of the characteristics of Severe Intellectual Disability and Profound Intellectual Disability, Severe/Profound Intellectual Disability is characterized as:

1. Intellectual functioning from IQ of 40 and below; and
2. Deficits in adaptive behavior that significantly limit a child’s effectiveness in meeting the standards of maturation, learning, personal independence or social responsibility and especially school performance that is expected of the child's age-level and cultural group, as determined by clinical judgment (APA (DSM-5), 2015; § 300.8 Child with a disability, 2017).
Transition Plan, Transition Service Plan: “The successful transition of students with disabilities from school to post-school environments should be a priority of every IEP team. The purpose of a Transition Service Plan is to assist students in building the skills and supports they need to reach their post-school goals. Transition requires support from multiple sources so the student and his or her family can make choices, develop connections, and access services. Beginning not later than the IEP to be in effect when the student begins 9th grade or turns 16, or younger if determined appropriate by the IEP team, and updated annually thereafter, the IEP must include:

1. appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills; and
2. the transition services (including courses of study) needed to assist the child in reaching those goals. A course of study should focus on instructional and educational classes and experiences that will assist the student in preparing for transition from secondary education to postsecondary life. This should relate directly to the student’s postsecondary outcome goals and should show how a planned course of study is linked to these goals. The course of study should be meaningful to the student’s future and should motivate the student to reach successful post-school outcomes” (GADOE, 2012, pp. 73-75).

Summary

The purpose of this study was to add to the body of existing literature concerning the perceptions of immediate families of curricular requirements for individuals with
Intellectual Disabilities, specifically within the Severe and Profound ranges of intellectual functioning. These perceptions were in regard to the functionality and appropriateness of the mandated academic curriculum for their loved ones functioning in the SID/PID range. The researcher also wanted this study to serve as a transformative piece for these students and their families. This study sought to understand the lasting impact that these curricular mandates have on individuals functioning within the SID/PID range, specifically the attainment of post-secondary goals held by the student and their family. The researcher used a qualitative case study approach to determine whether the purpose of education in the United States, specifically within a county located in the state of Georgia, was achieved for individuals functioning within the SID/PID range, and to illustrate the perspective of these individuals’ family members.

This chapter included the study’s background, purpose, rationale, significance, methodology overview, researcher positionality, limitations, delimitations, and definition of terms. Chapter Two includes the review of related literature. Chapter Three describes the study’s qualitative case study methodology. Chapter Four describes the data analysis and findings. Finally, Chapter Five presents final discussion, implications, and recommendations for further research.
CHAPTER 2

REVIEW OF THE LITERATURE

Education of students with intellectual disabilities was first documented around the year 1801 by Dr. Jean-Marc Gaspard Itard through his work with the Wild Boy of Aveyron. Dr. Itard worked with the young boy he named “Victor” after he was discovered and captured nude, dirty, scared and alone in a thicket of woods in southern France. After observation, psychiatrist Philippe Pinel reported that Victor was "an incurable idiot" (Gaynor, 1973). Dr. Itard ultimately disagreed and devoted the next five years to implementing what is now known to be the first Individualized Education Program (IEP). Although Victor showed progress during those five years, he did not reach Dr. Itard’s ultimate goal of “normalcy.” The importance of this story is not that Dr. Itard failed to reach his goal, but that he tried to initiate success with a child who demonstrated deficient cognitive processes or an intellectual disability—commonly known as “incurable idiocy” at the time (Gaynor, 1977)—a task which previously had been considered unnecessary.

Inspired by his mentor Itard, Dr. Eduard Seguin carried the torch of educating students with “sensory idiocy” through the education of another young man demonstrating characteristics similar to what educators and doctors now characterize as Autism Spectrum Disorder (ASD). Dr. Seguin documented his work with Boston, MA teenager “Geo. C.P.” in 1843 in the British Medical Journal released in 1877. He, like
his mentor, argued that students with intellectual disabilities, like Geo, *could* make progress in areas of education if allowed to do so (Seguin, 1877).

Even with the contributions of these forerunners of special education, intentional instruction of students with significant intellectual disabilities really did not gain a foothold until the implementation of the *Education for All Handicapped Children Act* (Public Law 94-142) of 1975. This law was enacted in 1990 under the official name most are familiar with today, the *Individuals with Disabilities Education Act* (IDEA). The IDEA was reauthorized and expanded to meet growing expectations for students with special needs in 1997 and again in 2004. The 1997 amendments to the IDEA mandated that all Individual Education Programs (IEPs) of students with disabilities should include how they will participate and make progress in the general academic curriculum. Agran, Alper and Wehmeyer (2002) found indications within the literature that the changes in the IDEA were to ensure the inclusion and academic challenge of students with intellectual disabilities.

**Context and Background**

The federal *Individuals with Disabilities Education Act* (IDEA) and the *Elementary and Secondary Education Act* (ESEA) (reauthorized in 2001 as *No Child Left Behind* (NCLB), and again in 2015 as *Every Student Succeeds Act* (ESSA)) mandate that all students, including students with disabilities, must have access to and be assessed on grade-level content standards. This mandate is inclusive of students with severe and profound intellectual disabilities. Compulsory education in the United States focuses on developing and preparing students to be a successful, productive member of society or
ready for entry into a post-secondary institution upon graduation (Courtade, Spooner, Browder and Jimenez, 2012; GADOE Graduation Requirements, 2011). Federal law outlines that every student is entitled to a free, *appropriate*, public education that purports this same goal: success subsequent to graduation (20 USC §1400 et seq.; GADOE, 2011). Success subsequent to graduation, according to Sloan (2012), is to prepare individuals in “developing the skills, the knowledge, and the dispositions that will allow them to be responsible, contributing members of their community” (p. 2). Sloan (2012) further characterizes this preparation as becoming “a good friend, to be a good mate, to be able to work, and to contribute to the well-being of the community” (p. 2).

Peifer (2014) documented additional illustrations of “success” subsequent to graduation in the 2010 report on *Governance in the Accountability Era*, a joint effort of the National School Boards Association, the Iowa School Boards Association, and the Thomas B. Fordham Institute. This report examined the rank of importance of six goals for education as determined through a survey answered by 875 respondents (Peifer, 2014). The percentages per goal for the 875 respondents are outlined in Table 1.
Table 1

*School Boards Circa 2010: Governance in the Accountability Era Report*

<table>
<thead>
<tr>
<th>Goals for Education</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help students fulfill their potential</td>
<td>42.6%</td>
</tr>
<tr>
<td>Prepare students for satisfying, productive life</td>
<td>31.7%</td>
</tr>
<tr>
<td>Prepare students for the workforce</td>
<td>8.1%</td>
</tr>
<tr>
<td>Prepare students for college</td>
<td>8.1%</td>
</tr>
<tr>
<td>Help students become well-rounded</td>
<td>6.5%</td>
</tr>
<tr>
<td>Prepare students for civic life</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

*Note:* One of the questions in the 2010 (a joint effort of the National School Boards Association, the Iowa School Boards Association, and the Thomas B. Fordham Institute) asked board members to rank the importance of six goals for education.

Operating within the understanding that a suitable education results in the “success” of each student that graduates, the focus of this study centered on the appropriateness of the mandated curriculum for students cognitively operating within the severe or profound range of intellectual disabilities to enable the realization of goals after graduation.

**Cognitive and Educational Characteristics of Students Functioning within the Severe/Profound Range**

An individual functioning within the Severe or Profound range of intellectual functioning typically demonstrates an Intelligence Quotient (IQ) of 40 or below (APA (DSM-5), 2013). Individuals functioning within this range typically exhibit similar social, academic, behavior and communicative characteristics (Taylor, Richards, & Brady, 2005). According to the Georgia Department of Education (2016), students functioning within the SID/PID range show significant deficits in adaptive behavior.
Limitations in adapted behavior results in significant confines in “meeting the standards of maturation, learning, personal independence or social responsibility and especially school performance that is expected of the child's age-level and cultural group, is determined by clinical judgment” (2016). Specifically, “the absence of appropriate communication skills could negatively affect a child’s overall quality of life” (Sigafoos et al., 2006, p. 2). Interaction with loved ones and school staff is limited when a student is nonverbal; this lack of interaction extends into critical settings in which individuals typically participate, such as “home, school, vocational, and community-based activities” (Sigafoos et al., 2006, p. 3). State of Georgia regulations of Speech Impairments for students with SID/PID outline that individuals with “autism and/or significant intellectual, sensory, or physical disabilities” may present as nonverbal and verbally limited (GADOE, 2018b). For these individuals, a multidisciplinary team will determine if speech/language services are appropriate as related to the individual’s area of disability. This aspect of functioning becomes critical as this study seeks to elicit student perceptions of current curricular requirements.

Educational Legislation for Students with Severe/Profound Intellectual Disabilities

All students have the right to have access to and be assessed on grade-level content standards (20 USC §§ 1400). This mandate is inclusive of students with severe and profound intellectual disabilities through the federal Individuals with Disabilities Education Act (IDEA) and the Elementary and Secondary Education Act (ESEA) (reauthorized as No Child Left Behind (NCLB) in 2001 and reauthorized again in 2015 as Every Student Succeeds Act (ESSA)) laws. This section of the literature review will
examine what each law mandated and the cultural reasons why those expectations were put into place.

Individuals with Disabilities Education Act (IDEA)

The IDEA “was originally enacted in 1975 [as Education for All Handicapped Children] because children with disabilities often failed to receive an education or received an inappropriate education” (Apling & Jones, 2002, p. CRS 4; Office of Special Education and Rehabilitative Services (OSERS), 2019). This “lack of education” led to multiple court rulings that found “constitutional infirmities with the lack of education for children with disabilities” when compared to the education provided for students without disabilities (Apling & Jones, 2002, p. CRS 4). Two examples of such inconsistencies in education for students with Intellectual Disabilities can be found in the rulings of Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania and Mills v. Board of Education of the District of Columbia.


Prior to 1971, Pennsylvania law enabled public schools to deny education to children who had not yet “attained a mental age of five years by the start of first grade” (Blankenship, Boon, & Fore, 2007). This was the first ‘right-to-education’ suit in the United States. The US District Court ruled through a consent decree that students with Intellectual Disabilities were entitled to a free public education (Li, 2013). This forerunner to the IDEA, and the induction of the FAPE expectation for the entire nation, overturned this seclusionary law in Pennsylvania (Li, 2013). Soon after PARC v. PA was settled, another defining court case topped the horizon.
1972: *Mills v. Board of Education of the District of Columbia*

In 1972, a class-action lawsuit on behalf of seven children with disabilities ranging from Intellectual Disabilities to emotional and behavioral concerns were denied the right to a public education in the District of Columbia because the cost of accommodating these students would be too much of a burden on the school system (Mead, 2019). The Federal District Court ruled that the “deprivation suffered by the children clearly violated their right to a public school education under the laws of the District of Columbia” (Mead, 2019). The court based this ruling by relying on precedent set forth in *Brown v. Board of Education in Topeka*, a 1954 determination that separate schools for white and black students was unconstitutional. This, the *Mill* court reasoned, “likened the treatment of the plaintiff students to the segregation outlawed by the Supreme Court” in *Brown* (Mead, 2019). The court ruled that because every child, including those with disabilities, had the right to attend free public schools, as “each child had a right to such an education” (Algozzine & Ysseldyke, 2006; Mead, 2019).

As a result of court rulings like *PARC* and *Mills*, “states were under considerable pressure to provide such services and they lobbied Congress to assist them” (Apling & Jones, 2002, p. CRS 4). Congress responded with the passage of the Education for All Handicapped Children Act of 1975 (renamed IDEA in 1990) that “delineated specific requirements that the states must follow in order to receive federal funds” to support the free, appropriate education of every student, regardless of ability or disability (Apling & Jones, 2002, p. CRS 4). In the 1997 reauthorization of IDEA, states were required to
develop guidelines for students that could not participate in conventional district- and state-wide assessments to ensure that all students have comparable and fair access to general education standards (Kohl, McLaughlin, & Nagle, 2006). Herein lies a crucial tenet of this study: “Because functional skills are not identified as priority skills under NCLB, they are not assessed… [and] may potentially be moved to lower instructional priority even if a teacher acknowledges the need for instruction in a functional area” (Ayers et al., 2011, p. 13).

ESEA, NCLB, and ESSA

The initial ESEA was passed in 1965 with the intent of providing additional supports for students that are vulnerable. Many of these supports were fiscal so that additional books, brick-and-mortar centers and specialized post-secondary instruction could be provided for these students. This law also included a provision for scholarships for students coming from low income areas (Brenchley, 2015). The overall purpose of this act was to improve the quality of the public school system. The ESEA was reauthorized several times throughout the past 50+ years, invoking change as outlined in Figure 1.

Figure 1. Historical Progress of the Elementary and Secondary Education Act (ESEA)
Following the passage of the NCLB in 2001, state education agencies began to interpret and react to stipulations that each student’s—including those with severe cognitive disabilities—educational program be tied to grade level standards (Ayers et al., 2011; Kohl et al., 2006). The NCLB not only requires that students with low-incidence disabilities have access to general education standards but also that they actively participate in the systemic accountability measures required by the Act; No Child Left Behind 2001 states that “all students with disabilities should have access to, participate in, and make progress in, the general curriculum. Thus, all students with disabilities must be included in the measurement of AYP toward meeting the State’s standards” (p. 68698). What the NCLB does not delineate is the scope or sequence that students with significant cognitive impairments must adhere to—this facet is left to state educational agencies to determine; the requirement of the NCLB is only that “it be linked to the standards in order for students to participate and progress” (Ayers et al., 2011, p.13). The State of Georgia interprets IDEA and NCLB and implements the regulation as:

“Every student with a significant intellectual disability deserves the opportunity to learn and be exposed to the same educational opportunities as his or her non-disabled peers through access to the same curriculum, the Georgia Performance Standards. Regardless of the severity of their intellectual disabilities, students must be provided access to the GPS [Georgia Performance Standards] through relevant skills and activities that are meaningful to them” (GADOE, 2018c).
In December 2015, President Barack Obama signed the first reauthorization of the ESEA since the 2001 inception of the NCLB Act. This new reauthorization is named Every Student Succeeds Act, or ESSA. At the time of the development of this literature review federal regulations have not yet been released for the 2015 ESSA, so the 2001 NCLB Act will continue to be used as an underpinning for this study. Upon review of the 2015 ESSA guidelines, there were no major changes in the portions of the law that impact this study: access to and assessment on the general curriculum standards for students with significant cognitive abilities.

Tracing Forward: The Elementary and Secondary Education Act & The Education for All Handicapped Children Act

In Table 2, the Elementary and Secondary Education Act of 1965 and the Education for All Handicapped Children Act of 1975 are traced through the years to the most recent legislation and reauthorization of each. Within the information contained within Table 2 the reader will find how each reauthorization and amendment impacts students with disabilities, and ultimately leads to the concerns that are addressed within this study.
Table 2

*Tracing the ESEA of 1965 Forward to 2015, and EAHC of 1975 to IDEIA of 2004*

<table>
<thead>
<tr>
<th>Public Law 89-10</th>
<th>President Johnson signed P.L. 89-10 into law on April 11, 1965 to “equalize educational opportunities” and to ensure that each student access their “inherent mental capacity” (Alford, 1965). ESEA provided funds that support primary and secondary education with aim to create fair access for all students, including those with disabilities. ESEA attempted to create this fair access through funding for teacher professional development, instructional materials and for additional educational programs. Major amendments of ESEA of 1965 occur as the Bilingual Education Act (P.L. 90-247), the Equal Educational Opportunities Act of 1974 (P.L. 93-380) and Improving America’s Schools Act of 1994 (P.L. 103-382). Two additional amendments that will be addressed within this review are the No Child Left Behind Act of 2001 (P.L. 107-110) and the Every Student Succeeds Act of 2015 (P.L. 114-95). (ESEA, 1965)</th>
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<tr>
<td>Public Law 93-112</td>
<td>P.L. 93-112, the Rehabilitation Act of 1973, guaranteed and protected the civil rights of individuals with disabilities by preventing discrimination within public settings, including educational settings. This law’s protection extended past the physical layout and access to buildings (and the funding allotted for that accessibility) to the right for individuals to participate and benefit from public programs. This Act includes Section 504 entitlements as well as served as the pre-cursor to the Free Appropriate Public Education language. (Rehabilitation Act, 1973)</td>
</tr>
<tr>
<td>Public Law 94-142</td>
<td>P.L. 94-142, or the Education for All Handicapped Children Act of 1975, ensured a free, appropriate public education (commonly accessed through the acronym of FAPE) for students ages 3-21 with disabilities. P.L. 94-142 was in response to growing concern for two groups of students: Group 1 were totally excluded from the education system due to the severity of their disabilities (i.e. Severe/Profound Intellectually Disabled), and Group 2 had only limited access to the educational system due to the nature(s) of their disabilities. There were four major purposes of this law: a.) to assure and ensure that all children with disabilities receive FAPE, including related services</td>
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Table 2 (continued)

Occupational Therapy, Physical Therapy, etc.) and instruction to meet their individual needs; b.) provide protection of the rights of students with disabilities and their parents; c.) monetarily support States and local educational agencies provide FAPE for students with disabilities; and d.) assess and evaluate the effectiveness of the local educational agencies in educating students with disabilities. In 1983, this Act was amended in P.L. 98-199 to include incentives to local educational agencies to also provide support to individuals through preschool special education programs, early intervention opportunities and secondary- and post-secondary transition programs. This Act was amended in 1983 under P.L. 98-199. (Teachnology, n.d.; USDOE, 2010; Olguin, 2005; EAHC, 1975).

Public Law 98-199
1983 Education for All Handicapped Children Act Amendments

The 1983 amendments to the EHA provided additional funding for Early Intervention research endeavors. Emphasis was placed on parent education in this amendment as well. Directly impactful to this study, school to work transition requirements were mandated. Specifically, monetary grants were issued for transitional supports (planning, training and supports) provided by State and local educational agencies as well as provision of parental training on services and supports available for their child with disabilities. This Act was further amended in 1990 in P.L. 101-476 and was renamed the Individuals with Disabilities Education Act. (EAHCA, 1983)

Public Law 98-524
The Vocational Educational Act of 1984

P.L. 98-524, commonly referred to as the Perkins Act (after Carl D. Perkins, a congressman from Kentucky that worked tirelessly in support of education for individuals that were disadvantaged, under-privileged and disabled), required that vocational education be provided to students with “greater-than-average” educational needs. P.L. 98-524 was reauthorized in 1990 as P.L. 101-392, or the Carl D. Perkins Vocational and Applied Technology Act, and then again in 2006 and 2018 as the Carl D. Perkins Career and Technical Education Improvement Act. (Olguin, 2005; VEA, 1984).
Table 2 (continued)

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<td>In response to growing concern, both nationally and congresionally, for children younger than 3 years of age with delays and deficits, P.L. 99-457, or the Education for the Handicapped Act of 1986, mandated that children with delays and disabilities beginning at birth are entitled to receive programming and services for said disabilities. (USDOE, 2010; EHA, 1996)</td>
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<thead>
<tr>
<th>Public Law 101-476</th>
<th>The Individuals with Disabilities Education Act of 1990</th>
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<tr>
<td>The Education of the Handicapped was reauthorized and renamed within P.L. 101-476 to the Individuals with Disabilities Education Act of 1990. The major changes made to the law in this reauthorization were the addition of Traumatic Brain Injury (TBI) and Autism (AUT) to the list of eligibilities that students can be identified as having special needs and receive special education services and supports under. An additional change that occurred was to include a student’s Transition Plan within the IEP at a specified age to assist students with special needs to transition to post-graduation life and endeavors. This Act was amended in 1997 within P.L. 105-17. (USDOE, 2010; IDEA, 1990)</td>
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<tr>
<th>Public Law 105-17</th>
<th>The Individuals with Disabilities Education Act of 1997</th>
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<tr>
<td>P.L. 105-17, the IDEA, continued the rights afforded to individuals with disabilities while also expanding some of those rights and entitlements. One of the amendments included extended the ages of young children served through the Significant Developmental Delay (SDD) eligibility to age nine. The original age range was birth to five years. However, the amendment that directly relates to this study includes President Clinton’s insistence that all students, regardless of disability or ability, should access the same curriculum as their non-disabled peers. This will lay foundation for language used in the 2001 NCLB act signed just a few years later. This Act was amended in 2004 within P.L. 108-446. (USDOE, 2010; IDEA, 1997)</td>
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<tr>
<th>Public Law 107-110</th>
<th>No Child Left Behind Act of 2002</th>
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<td>P.L. 107-110 served as an amendment of the Elementary and Secondary Education Act, and was reauthorized and renamed the No Child Left Behind Act of 2002 under the George W. Bush Administration. NCLB required that under-performing schools increase rigor as well as performance (as evidenced through test scores) for at-risk populations, including the population of students with disabilities. This Act was reauthorized in 2015 within P.L. as the Every Student Succeeds Act. (Wright &amp; Wright, n.d.; USDOE, 2010; NCLB 2002)</td>
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<tr>
<th>Public Law 108-446</th>
<th>P.L. 108-446, or IDEiA, focused on improving and increasing the standards by which students with disabilities are educated across the age spectrum. Early intervention is mandated within this P.L., and the standards for the certification for instructors that teach special education segments were defined and raised. Allotment of funding was also defined so that local educational agencies would truly consider the continuum of services and promote the inclusion of students with special needs in the general education setting if appropriate. This push was an attempt to correct the disproportionality of individuals belonging to minority groups being served in all special education small group classes for reasons other than their eligibility parameters. This is the most recent form of the IDEA law. Although the actual acronym is IDEiA (to include the “Improvement” word within the name), IDEA is still the acceptable and most widely used terminology within the educational and legal community (IDEiA, 2004).</th>
</tr>
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<tr>
<td>Public Law 111-5</td>
<td>A fulfillment to a campaign promise, the Obama administration allotted additional funding to the IDEA through P.L. 111-5, the American Recovery and Reinvestment Act of 2009. This Act was signed into law and budgeted $12.2 billion in additional funding for the tenants and programs afforded to individuals with disabilities within the educational system. (ARRA, 2009)</td>
</tr>
<tr>
<td>Public Law 114-95</td>
<td>P.L. 114-95, the Every Student Succeeds Act of 2015, is the most recent reauthorization to the NCLB of 2002. The ESSA of 2015 continues to ensure success for all students by implementing “critical protections” for America’s most disadvantaged and high-need students, including those with special needs. Specifically correlational to this study, the ESSA of 2015 requires that ALL students engage with and be taught academic standards that prepare them for post-secondary endeavors, including both college and career paths. (ESSA, 2015)</td>
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High School Diploma Requirements

Georgia graduation requirements for students that enrolled in ninth grade for the first time in the 2008-2009 school year and subsequent years for students with significant cognitive disabilities allow for students to obtain one type of diploma—a regular high school diploma—when three specific criteria are met. First, students are required to achieve twenty-three Carnegie units that include “an integrated curriculum based on the GPS” that includes instruction in English/Language Arts, Mathematics, Science, Social Studies, Physical Education/Health as well as career preparation, self-determination, independent living and personal care (Macdonald, Zinth, & Pompelia, 2019). The requirement for the diploma requires that all of these courses combined should “equal a minimum of 23 units of instruction,” meaning that for that student’s cognition, the access to the GPS was appropriate for their needs. Within the state of Georgia, these courses are referred to as “access courses” (GADOE, 2018c: GA Reg 160-4-2-.48; GADOE, 2017: GA Reg 160-4-2-.20). Access courses are specifically coded for students with significant cognitive disabilities that participate in the Georgia Alternate Assessment (GAA). The instruction within an access course will “align to the standards for that course and provide access to those standards; instruction must embed IEP objectives but will not necessarily address all the standards for the course or cover the same depth and breadth” (GADOE, 2017: GA Reg 160-4-2-.20). The second requirement for obtaining a diploma is that students must have participated in the GAA during middle school and high school. The third condition for graduation requirements for students with significant cognitive disabilities is that the student has either reached his/her twenty-second birthday or has
transitioned to employment, education or a training setting “by an entity other than the local school system” (GADOE, 2018c: GA Reg 160-4-2-.48).

Documents Critical to the Education of Students with Severe/Profound Intellectual Disabilities

The expectations set forth within the law to protect individuals with disabilities are to be carried out within the procedural safeguards in place by the local educational agency (GADOE, 2015a). For example, the IDEA requires that a Transition Plan and Goals must be implemented by age sixteen; Least Restrictive Environment (LRE) must be considered for each student when determining services, supports and placements; consideration of assessments must include identifying in which state assessment they should be given (GADOE, 2015a). To accomplish the requirements set forth by the legal mandates, school systems develop systematic paperwork procedures to make sure that every aspect of the IDEA and the NCLB act are carried out for each student (GADOE, 2015a).

The IDEA and NCLB require access to “appropriate grade-level educational standards developed by the state be provided for students with significant cognitive impairments” (GADOE, 2015c). Access to Georgia content standards can take several forms. The IEP may contain objectives that align with Georgia Standards of Excellence that would ensure consistent exposure to these standards. Teachers may also present materials “in the form of grade-level activities in which the student will practice and use skills and knowledge” (GADOE, 2015c). Students will then be assessed on their mastery
of these skills “as part of their educational program through the GAA in grades third through eighth and eleventh (high school)” (GADOE, 2015c).

Access to grade-level content standards look different for individual students. Access to the general curriculum standards are based upon individual strengths and deficits (elements that are easily accessible as they are required components within the Present Levels of Functioning in each student’s IEP). Teachers are encouraged to use a plethora or instructional materials and supports, including “pictures, symbols, tactile objects, adapted books, and assistive technology (GADOE, 2015c). And as diverse as each student’s needs are, so are the methods for demonstrating understanding of content standards including “including using Augmentative/Alternative Communication (AAC) devices to answer questions, matching symbols or tactile objects, using switches to make choices” (GADOE, 2015c). In addition to addressing content standards, the Georgia Department of Education also indicates the importance of addressing other skills such as “adapted behavior, self-help, communication and motor” within their IEP and instructional day (GADOE, 2015c). Particular portions of the law are fundamentally critical to this study, and will be discussed in detail below.

Individualized Education Plan (IEP)

Each student identified as having special needs and receives services through the IDEA must have an Individualized Education Program, or an IEP (U.S. Department of Education, 2010). The IEP “serves as the framework for determining the meaning of the term “free appropriate public education” in the least restrictive environment” for each student receiving services through the IDEA (GADOE, 2016). Contained within the IEP
are statements of the student’s present levels of performance, including strengths and weaknesses. These present levels are based on recent testing results found within each student’s psycho-educational evaluation, current classroom-, district-, and state-level testing as well as through progress monitoring data collected on the student’s IEP goals by the classroom teacher (present levels hereafter referred to as the PLAAFP, or the Present Level of Academic Achievement and Functional Performance) (U.S. Department of Education, 2010).

After a review of all present levels of performance and testing information, the IEP team will develop annual goals and short-term objectives (more discussion on the development of goals and objectives later in this literature review) for the student to meet over the following 365 days as well as service hours and settings that are based on the weaknesses identified through the PLAAFP (GADOE, 2016). The IEP team also discusses and implements supplementary aids and services (known as accommodations) for classroom instruction and for testing administration. It is during this portion of the meeting that depth and breadth of the curriculum that will be accessed is determined. If a student is accessing the full scope and sequence of the state standards, the team will explicitly state accommodations for each subject of state-mandated assessments (i.e. Georgia Milestones EOG or EOC). If a student is only accessing a modified scope of the state standards (see Appendix H) due to limited cognition, then the team will indicate that the student will show achievement in the standards through the Georgia Alternate Assessment (GADOE, 2016). The type of curriculum—functional or standards-based—
will also be reflected within the development of the goals and objectives (GADOE, 2016).

Goals for students that access the full scope of the curriculum will focus on weaknesses in the student’s profile that, if mastered, will lead to mastery of the curriculum (GADOE, 2016; U. S. Department of Education, 2010). Students whose cognition leads the education team to elect an alternate, functional curriculum that contains both goals and objectives (GADOE, 2016). Goals are written within overarching domains such as academic, communication, personal management, self-help, behavioral, etc. Objectives beneath each goal domain then address weaknesses documented within the PLAAFP. Goals for students accessing a modified scope of the standards through a functional curriculum address both academics as well as take the form of “grade-level activities in which the student will practice and use skills and knowledge;” skills can range from communication and self-help to behavioral management (GADOE, 2015c). Parent concerns and documentation of parent involvement are explicitly stated within the IEP as well; assurance of parent involvement was a major component of the 2004 reauthorization of the IDEA (Family Empowerment ad Disability Council (FEDC), 2012). The IEP also contains a Transition Plan and transition goals for students sixteen years and older that will be discussed in another section of this review. “Transition is the movement from school to post school environments. It should include the skills necessary for the student to be successful in education, employment, and independent living after completion of high school” (GADOE, 2015a). Ultimately, each student’s IEP, ergo the Transition Plan as a major
component of the IEP, must also be developed and reviewed on an annual basis unless a parent requests a review more frequently than that (GADOE, 2016).

Transition Plan

The transition plan is a critical component of the IEP. The implementation of the Transition Plan should be in effect when the child turns sixteen, or before if deemed appropriate by the IEP team. As a required component of the IEP, the Transition Plan and transition goals must be updated annually as well (e-CFR, 2007: §300.320-300.328). Like the IEP, parents are entitled to be involved in the development of this document. Federal and state parental rights and safeguards ensure and protect the participation of parents in the development of their child’s Transition Plan. Part B of the IDEA specifically requires the following of Transition Plans within the IEP:

- “Appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills. (e-CFR, 2007: §300.320(b)(1)).

- “The transition services (including courses of study) needed to assist the child in reaching those goals” (e-CFR, 2007: §300.320(b)(2)).

- “Transition requires support from multiple sources for the student and his/her family to make choices, develop connections, and access services (GADOE, 2015a).

Within the Transition Plan, the IEP team will include appropriate measurable postsecondary goals that are age appropriate and “related to training, education, employment, and where appropriate, independent living skills” for the student (GADOE, 2015a). The transition services must also document what services and individuals are
needed to assist the student in reaching those goals (GADOE, 2015a). The student’s course of study should prioritize and focus upon classes and experiences that prepare the student for transition from high school secondary education to post-secondary opportunities. Goals within the IEP and the Transition Plan should align with the student’s planned course of study and should “be meaningful to the student’s future and motivate the student to reach successful post-school outcomes” (GADOE, 2015a).

At all costs, the student should be involved in the development of the IEP and Transition Plan—this can be accomplished through preference assessments, student inventories, data collection, interviews with the student and with the parent(s) and classroom observations. The student should also be encouraged to attend the IEP meeting; however, if the student is unable to attend or participate, “the school system must take other steps including verbal and written input to ensure that the student’s preferences and interests are considered before developing the transition aspects of the IEP” (GADOE, 2015a).

The Transition Plan and transition goals component of each of the participants’ IEPs were of critical importance to this study. The goals set forth should outline and prioritize skills necessary for “the student to be successful in education, employment, and independent living after completion of high school” (GADOE, 2015a). The researcher examined components of these documents and compared them with the results of GAA testing and family goals for each student post-secondarily. These comparisons are described in Chapter 4.

Georgia Alternate Assessment
Due to mandates within the IDEA and the ESEA, states are tasked with ensuring that all students, including those with Severe and Profound Intellectual Disabilities, must have access to not only the general curriculum, but all that “encompasses challenging academic standards” (GADOE, 2016). The state is also required to ensure that all students are “assessed for their progress toward meeting academic standards” (GADOE, 2016). For students across the state of Georgia that access the full scope and sequence of the state standards, progress is monitored through the Georgia Milestones End of Grade (EOG) (for grades three through eight) and the Georgia Milestones End of Course (EOC) (at the completion of specific courses at the high school level) tests. Each of these sets of tests cover the academic areas of English/Language Arts, Mathematics, Science and Social Studies.

The GA Milestones are multiple-choice tests that the student completes on paper or online and include some constructed-response (writing) components (GADOE, 2019). The IDEA and the ESEA require that because these measures of progress are required of students, that students with significant cognitive impairments must have a comparable assessment that will fairly measure the modified scope and sequence of state standards that they access during the year. The state of Georgia only requires GA Milestones EOGs for grades three through eight; therefore, GAA is only required for those students as well.

All Kindergarten students, including those with significant cognitive impairments, are assessed using a different state-developed measure, the Georgia Kindergarten Inventory of Developing Skills (GKIDS). First and second grades do not have a
standardized measure of progress, so students with significant cognitive impairments that are in the first and second grades are not required to submit a GAA portfolio.

Over the past few years, the state of Georgia moved away from administering one encompassing graduation test that takes place during a student’s eleventh grade year during his or her high school career to the GA Milestone EOC tests. School systems within the state of Georgia can decide the sequence of required courses so that EOC tests can be taken over the four years of high school instead of all at once during what was formerly known as the GHSGT, or the Georgia High School Graduation Test (GADOE, 2011). However, the GAA is still required on the former GHSGT schedule, to be submitted during the spring of their eleventh grade year. High School GAA requirements for the modified scope of eligible standards are displayed in Appendix H.

The Georgia Alternate Assessment is a portfolio-based assessment through which Georgia educators of students with significant, low-incidence cognitive impairments access a modified scope of state standards to expose their students to, instruct their students on, and submit an assessment for (GADOE, 2016). The GAA “capture[s] student learning and achievement/progress” through submission of work samples, series of captioned photos, audio or video recordings, observation forms, interviews or through series of captioned photos (GADOE, 2016). This assessment program “promotes a vision of enhancing capacities and integrated life opportunities for students who experience significant cognitive disabilities” (GADOE, 2016). Evidence is gathered over two collection periods: Collection Period 1: Initial Performance of the Skill, and Collection
Period 2: Achievement/Progress. *Figure 2* displays the ‘autopsy’ of each portfolio entry, and *Figure 3* displays the scoring rubric used for each entry (subject) of the portfolio.

**COMPILING PORTFOLIOS**

**COMPONENTS OF A GAA PORTFOLIO ENTRY**

The following graphic illustrates the required components for a GAA portfolio entry:

![Diagram of portfolio entry components]

*Figure 2.* 2016-2017 Georgia Alternate Assessment: Basic Outline of the Organization of a Portfolio Entry

**GEORGIA ALTERNATE ASSESSMENT SCORING RUBRIC**

<table>
<thead>
<tr>
<th>Dimension</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tbody>
<tr>
<td><strong>Fidelity to Standard</strong></td>
<td>The instructional activity is aligned to and exposes the student to a content standard, but the student's work does not address academic content.</td>
<td>The instructional activity is aligned to a content standard; the student's work addresses academic content but at an access or entry level.</td>
<td>The instructional activity is aligned to a content standard; all aspects of the element selected are addressed, and the student's work addresses academic content at or approaching basic grade-level expectations.</td>
</tr>
<tr>
<td>(scored for each entry)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Context</strong></td>
<td>Materials are not grade appropriate.</td>
<td>Materials are grade appropriate, but the student's work does not reflect a purposeful application.</td>
<td>Materials are grade appropriate, and the student's work reflects a purposeful simulated application.</td>
</tr>
<tr>
<td>(scored for each entry)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Achievement/ Progress</strong></td>
<td>Student demonstrates little achievement/progress in targeted instructional activity.</td>
<td>Student demonstrates some achievement/progress in targeted instructional activity.</td>
<td>Student demonstrates reasonable achievement/progress in targeted instructional activity.</td>
</tr>
<tr>
<td>(scored for each entry)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Generalization</strong></td>
<td>Student performs tasks in one or more settings with no evidence of interaction(s) beyond those with the primary instructional provider.</td>
<td>Student performs tasks in one or more settings with evidence of interaction(s) with other instructional providers and/or disabled classmates.</td>
<td>Student performs tasks in two or more different settings with evidence of interaction(s) with non-disabled peers and/or community members.</td>
</tr>
<tr>
<td>(scored once across all entries in portfolio)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 3.** Georgia Alternate Assessment Scoring Rubric


The purpose of the GAA is to mark progress by students with significant cognitive impairments in their access of the general academic standards put forth by the state of Georgia. This assessment is the equivalent of the GA Milestones EOC tests for students that access the full scope of the academic standards. The purpose of the GA Milestones is to count toward the total acknowledgement that a student has engaged in
and made progress in within the entire set of standards set forth by that specific course. The GAA also shows that the student with significant cognitive impairment has made progress in the modified scope of standards to which they were exposed. GAA also shows that, in accordance with the IDEA and the ESEA, students with special needs have access and show achievement with general curriculum standards like their non-disabled counterparts.

Standards-Based Curriculum v. Functional Curriculum

The history of special education has been beset with uphill battles, victories, setbacks and heated debates (Salend & Garrick Duhaney, 2011; Bouck, 2012). Much of the debate swirls around recurring issues that cannot be settled because of polarized opinions surrounding the notion that Alexander Graham Bell coined during a presentation at a meeting of the National Education Association in 1884: “special education” (Winzer, 1998 as cited by Salend & Garrick Duhaney, 2011). Activists and lawmakers continue to argue over who is entitled to special education services and what goals service providers and politicians should implement for these students. The struggle is a tug-of-war between the best way to implement an appropriate, research-based pedagogy for students with disabilities and where the best placement for instruction to take place for these students (Salend & Garrick Duhaney, 2011).

From 1801 with Dr. Jean-Marc Gaspard Itard’s work with Victor, educational expectations have now progressed to a point at which grade-level assessments must be used to measure progress in addition to progress monitoring through students’ IEPs. Students with severe and profound intellectual disabilities must be assessed on grade-
level standards because of the IDEA and the ESEA (Bouck, 2012). The IDEA mandated that all Individual Education Programs (IEPs) of students with disabilities should include to what extent they will participate and make progress in the general academic curriculum. Agran, Alper, and Wehmeyer (2002) found indications within the literature that the changes in the IDEA were to ensure the inclusion and academic challenge of students with intellectual disabilities.

Situated within this educational conundrum, however, data do not reflect how parents of students with severe and profound intellectual disabilities perceive the implementation of academic curriculum within the self-contained classroom nor to what extent these parents believe the academic curriculum should be blended with the functional curriculum. Academic and functional curricular approaches are “not and should not be exclusive, however, current prioritizing of standards-based curricula seems to set them up as such” (Ayers et al., 2011). Therein lies the focus of this study: Do current curricular expectations set students with disabilities up for postsecondary success?

Ayers et al. (2011) observe, “Currently, a focus on functional curriculum for students with severe disabilities is being reexamined and to a large extent altered if not abandoned in favor of a more general education or standards-based curriculum” (p.16). This article further posits that “standards-based curriculum has an outcome of grade-level achievement that may or may not lead to more independent functioning while functional curriculum has outcomes of improving a student’s independent functioning in their current and future environments” (Ayers et al., 2011, p. 16).
There is no question that students with severe and profound intellectual disabilities can learn academic standards (Ayers et al., 2011; Browder & Spooner, 2011). This is evidenced through performance on the Georgia Alternate Assessment (GAA), a state assessment for low-incidence students that ensure not only that students have accessed the general curriculum, but also that “all students are assessed for their progress toward meeting academic standards” (GADOE, 2016). Ayers et al. (2011) raise serious questions for consideration, “At what cost do they learn these standards? Will these skills help the students get a job? Choose where to live? Actively participate in their community?” (p. 14). Just as the discussion between proponents of standards-based curriculum and of functional, life-skills curriculum is heated, so are the parameters of each type of curricular path as evidenced in the display of the following research. The primary focus of a functional curriculum is to meet the learner where they are and bring them to a functional capacity in their skill level that allows access and success within their society (Browder, Flowers, Ahlgrim-Delzell, Karvonen, Spooner, & Algozzine, 2004; Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1979; Brown, Nietupski, & Hamre-Nietupski, 1976). To proponents of the results of exposure to functional curriculum, a student’s independent functioning within not only their present environments, but future endeavors is improved (Ayers et al., 2011; Snell & Brown, 2006; Westling & Fox, 2004).

Clark (1995) further clarifies what is considered a functional curriculum for a student by explaining that the functional skills a student is taught should target that student in their present environment and related to future goals and aspirations.
Proponents of standards-based curriculum, a curriculum in which the standard being taught is of primary focus, argue that all students have the right to access standards-based curriculum; the primary concern of these researchers about teaching primarily within the functional curriculum is that the full potential of the student with intellectual disability may never truly realize his or her full potential or capability (Courtade, Spooner, Browder, & Jimenez, 2012).

Standards-Based Curriculum

Standards-based curriculum, also referred to in this study as an “academic curriculum,” is a curriculum designed by identifying the specific skills, knowledge, and dispositions that students need in order to meet district, state, or nationally-adopted academic content standards (Bouck, 2012; Lund & Tannehill, 2014). The purpose of this type of curriculum is to prepare all students to function as productive adults in the community as well as to prepare them to pursue higher education if they so choose (Courtade et al., 2012). The Georgia Standards of Excellence (GSE) require students to acquire, examine, and demonstrate knowledge of information and ideas that continually increase in complexity and that help prepare them for future life experiences in higher education and 21st century careers (GADOE, 2017). For instance, students are expected to learn information through non-fiction reading; examine and utilize evidence from literary and informational texts when reading, writing, and speaking; and to regularly engage with complex texts and academically-grounded language (GADOE, 2017).

Some curricularists posit that not only is it the right of every student to have access to general curriculum, but also that increased academic skills may provide
students with severe intellectual disabilities additional options for the future such as employment requiring basic math skills, an ability to engage in leisure activities (e.g., reading or hobbies involving science knowledge), and the ability to function more independently by reading their own mail or voting (Courtade et al., 2012). However, pro-functional academic curriculum authors argue that making progress on grade-level standards accessed with a modified scope and sequence may not lead to more independent functioning for those students with severe intellectual disabilities (Ayers et al., 2011). Additionally, while standards-based curriculum may provide guidance for educators as to what skills and knowledge should be taught in order for students with disabilities to progress with their typical peers, a curriculum focused on academic content standards does not clearly align with post-secondary outcomes for these students (Ayers et al., 2012).

Functional Curriculum

Functional curriculum, also referred to in this study as a “life skills curriculum,” is broadly defined as a curriculum that has “outcomes of improving a student’s independent functioning in their current and future environments” (Ayers et al., 2011, p. 11). Brown et al. (1979) argue that functional curriculum enables students to develop skills that are typically considered beyond their developmental capabilities, but that will enable students to function within the world (i.e. communication skills, community functioning, etc.) Brown et al. (1979) addressed the type of instruction being offered to individuals with significant cognitive disabilities during the 1970s and argued that student should work on “the variety of skills that are frequently demanded in natural
domestic, vocational, and community environments” (p. 127). Brown et al. (1979) further defined that “nonfunctional skills, by contrast, are those that have an extremely low probability of being required in daily activities” (p.127).

Other researchers agree that within the scope of a functional (or life skills) curriculum, the needs of the student to be age-appropriate and able to navigate daily life in their community are addressed (Bouck 2012; Brown et al., 1979; Ford, Schnorr, & Black, 2001). Given that a functional curriculum focuses on the explicit implementation of age-appropriate skills to successfully engage in daily life within their specific society, this program of study generally includes instruction within several widely-accepted domains among scholars; domains that typically include community living, functional academics and embedded skills (Ford et al., 1989). Community living skills include the introduction and instruction of vocational education such as specific job skills, following instructions, sharing information and communicating effectively for the needs of the job (Bouck, 2013; Chadsey-Rusch & Gonzalez, 1988; Ford et al., 1989). Functional academics include explicit teaching of daily-applicable academic concepts. For example, in math, the student learns to tell time and count money, and in English/language arts the student would be taught to read a bill that comes in the mail or to write a grocery list. Embedded skills include (but are not limited at) social and communication skills, daily living skills, fine motor skills and large motor skills in real-world settings. Communication skills, discussed earlier in this paper, include expression of wants and needs by the student as well as receptive language development (Ford et al., 1989;
Sigafous et al., 2006). Daily living includes dressing, eating, self-care, hygiene and personal safety skills (Ayres et al., 2011; Bouck, 2013; Ford et al., 1989).

Brown et al. (1979), however, contend that any single skill can be considered functional or non-functional “depending on the materials [and] teaching context” (p. 126). Brown et al. (1979) argue that students with severely and profoundly impacted cognition should not only be exposed to activities that are developmental age of the student, but rather “chronological-age-appropriate functional skills in natural environments” (p.126). The argument set forth by this seminal author is one that battled students sitting in a room in a school placing pegs in holes to develop pincer grasp motor-planning skills that will “someday” enable them to place a coin in a vending machine for a drink. However, his views still stand today, even when compared to the total opposite swing of the pendulum—the skills that should be taught should pass the litmus that Brown et al. (1979) posit: “Given a limited number of years remaining in school programs, can the student possibly progress fast enough or far enough to acquire the skills needed for the most independent functioning possible in complex, heterogeneous post-school environments” (p.126).

NLTS-2 published in 2012 sought to understand curriculum, both functional and standards-based, for students with significant cognitive impairments, and how this curriculum impacted post-secondary outcomes for these students (Bouck, 2012). Simply stated, a minimal outcome of a student’s academic program should be the achievement of useful skills—skills that will allow the student to enjoy a greater degree of participation in an enjoyable life-style” (Ford et al., p. 90).
Student and Parent Perspectives

The purpose of this study was to explore the perspectives of students with significant intellectual disabilities and those of their parents regarding the functionality of standards-based curriculum compared to that of a functional, life-skills curriculum in the success of meeting post-secondary goals. It is critical that the reader understand that the intellectual functioning of students with Severe/Profound Intellectual Disabilities is such that most individuals within this population are nonverbal and have significant communication deficits (Sigafoos et al., 2006; Biklen and Moseley, 1988; Brantlinger, 2005).

It is because of this fact that the perspective of the student’s parent was sought. There is precedent for parents completing interviews if the student was unable to do so (Bouck, 2012; Brantlinger, 2005; Carter et al., 2012). Although relatively little research has been conducted in how families impact any hope for a career past high school graduation, evidence from the NLTS-2 detected that it is likely that family factors do impact the success of students with severe intellectual disabilities, with success being identified as holding down a paying job (Carter et al., 2012; Lindstrom, Doren, Metheny, Johnson & Zane, 2007).

Brantlinger et al. (2005) explain how family members often tell “their versions of special education and/or living with someone with disabilities” and that “these personalized accounts provide insight into how classification and treatment are perceived by people with disabilities and their families” (p. 199). This emic, or insider to phenomenon, perspective allows for family members of individuals with Severe and
Profound Intellectual Disabilities to ‘give voice’ “to people who have been historically silenced or marginalized” (Brantlinger et al., 2005, p. 199).

Further bolstering the role of the parent in this study, results of the NLTS-2 found that while the data indicated that the curriculum that the student was exposed to (academic or functional) appeared to have “no bearing on the post-school outcomes evaluated in [the] study,” (Bouck, 2012, p. 1182), other studies, with confidence, found that “parental expectations at baseline were very strong predictors of student employment” after graduation from high school (Carter et al., 2012, pp. 57-58).

Summary

Education of students with intellectual disabilities has been documented since the early nineteenth century with Dr. Itard with his work with ‘Victor.’ This torch was picked up by predecessors such as Dr. Seguin with his work with Geo. C.P., and on down through the years; however a foothold was not gained for the purposeful, consistent and meaningful education of members of our society with disabilities until the implementation of the Education for All Handicapped Children Act (PL 94-142) in 1975. Educators today are more familiar with the reauthorization title of the Individuals with Disabilities Education Act. Through lawsuits (i.e. PARC v. State of Pennsylvania, Mills v. Board of Education of the District of Columbia) that shaped the IDEA, students with significant cognitive impairments are entitled to access the general curriculum at an access level. The IDEA and ESEA/NCLB/ESSA require that all students participate in the general curriculum to an appropriate degree.
The history of special education has been a dark and brutal one, with victories coming sometimes in small smatterings and at other times in swift pendulum swings. With such change came discussions—and certainly disagreements—on the type, frequency, sequence and scope of curriculum that our students with the most significant disabilities should be exposed to.

Two camps have emerged: Standards-Based Curriculum, and Functional Curriculum. Standards-Based Curriculum (SBC) is exactly that—a curriculum based on the rigorous, academic curriculum that all students are held to. Proponents of SBC acknowledge that there is a difference in scope, but firmly stand on the opinion that all students are entitled to work within the Common Core Standards. Functional, Life-Skills Curriculum focuses on self-help and independence skills rooted in the areas of personal, social, daily living and vocational skills; academics are taught only when directly linked to a life skill that is being taught to endorse independence and self-sufficiency.

The overall purpose of this study is to consider the perceptions of students with SID/PID and the perceptions of their parents on current curricular expectations and the impact these expectations have on post-secondary goals. Students functioning within the SID/PID range of functioning demonstrate an IQ of 40 or below, and also demonstrate significant deficits in adaptive behavioral skills (APA (DSM-5), 2014). In addition, many of these students are nonverbal or are significantly limited verbally. Previous special education studies have paved the way for family members to speak on behalf of disabled loved ones so that their voice can be heard; this enables that avenue for
gathering data to represent the thoughts and feelings of these students (Brantlinger et al., 2005).
CHAPTER 3

METHODOLOGY

Historically, students in the United States functioning within the severe range of cognitive functioning have participated in a functional life-skills curriculum across all grade levels (Bouck, 2012). However, a shift and reconceptualization of appropriate curriculum for students with significant cognitive impairments has been released; educational expectations are increasing (Bouck, 2012; Ryndak et al., 2013). These shifts coincided with the 2004 reauthorization the IDEA, in which it is mandated that all students must not only have access to general curriculum standards, but to make progress in these standards—regardless of cognitive functioning (Roach & Elliott, 2006; Bouck, 2012). The argument of which type of curriculum—academic or functional—to teach students with intellectual disabilities then became the debate. Regardless of the philosophical ideology one subscribes to, ultimately everyone from policy makers to educators to parents “want what is best for students with…severe ID in school and for post-school success” (Bouck, 2012, p. 1176). A survey conducted by Agran et al. (2002) revealed that teachers of students with severe cognitive impairments felt that progress in the general curriculum standards was less valuable than exposure to functional skills. However, Alwell and Cobb (2009), found that “in recent years the national curricular focus for all students in secondary education has shifted almost exclusively toward academic achievement and college preparation” (p. 91). The field is in conflict.
This study examines issues related to this conflict and the ways in which those issues were perceived and experienced by four family members of young adults with intellectual disabilities. The following sections of this chapter outline the purpose, research questions, theoretical framework, research design, participants and setting, and the methods of data collection for this study.

Purpose

It was the purpose of this study to add to the body of existing literature concerning the curricular requirements of students with intellectual disabilities, specifically within the Severe and Profound range of intellectual functioning, and the functionality and appropriateness of those curricular requirements, according to the families of these individuals. It was the researcher’s hope that this study would serve as a transformative experience for these students and their families, as well as to future graduates with intellectual disabilities.

This study provided clarity within the standards-based versus functional curriculum controversy by painting a picture of the perceptions and experiences of families of individuals functioning within the SID/PID IQ range who have graduated from high school and who participated in both standards-based curriculum and a functional, life-skills curriculum. The researcher explored these stories for evidence of “success” of each individual as measured by progress within their post-secondary goals. This study sought to understand the impact that these mandates had on students functioning within the SID/PID range, specifically the attainment of post-secondary goals held by the student and their family.
Research Questions

The following research questions framed this study:

1. How does the current mandated standards-based curricular requirements and functional, life-skills curriculum prepare individuals with Severe/Profound Intellectual Disabilities to achieve their post-graduation goals as identified within the individual Transition Plan?

2. What are the perceptions of immediate family members of individuals with Severe/Profound Intellectual Disabilities on how the current mandated standards-based curricular requirements and functional, life-skills curriculum prepare their children to achieve their post-graduation goals?

The researcher answered the research questions through analysis of the following data: (1) semi-structured interviews, (2) educational documents, (3) parent/family questionnaire, and (4) personal journaling.

Appropriateness of the Research Design

The designated approach of answering the research questions within this study was through a non-experimental qualitative design. Seidman (2006) indicates that selection of the research paradigm and method should be determined by the research question and what the researcher wants to know; because the research questions within this study seek to answer “how” current laws affect the lives of families living with cognitive impairments, the inductive nature of a qualitative research approach would best elicit the information being sought by the researcher. Merriam (1988) states that results from qualitative research provoke descriptive discoveries of culture and personal
narratives of the participants. The inspiration for the structure of this study came from an article by Brantlinger, et al. (2005) that outlined the need for creative research when focusing on individuals with cognitive, behavioral, and communicative deficits. Specifically, Dr. Brantlinger and her colleagues (2005) cited studies that explored individuals with disabilities have been completed by “loved ones,” thereby providing an “emic,” or “insider to phenomenon” perspective (p. 199) as a source to answer the research questions for this study.

Research Method

The primary focus of this study, as outlined through the research questions, required in-depth exploration of specific, complex personal accounts of living with and making decisions for family members with intellectual disabilities; consequently, a narrative case study was most appropriate in representing these unique stories (Stake, 2005; Mertens, 2010; Brantlinger et al., 2005). Yin (1984), as cited in Merriam (1988) and Mertens (2010), confirms that non-experimental research questions that seek to find ‘how’ are best answered through a case study approach. The desired outcome of this study, based on the very nature of the research questions that seek to know ‘how’ current mandates have impacted life outcomes of individuals with cognitive impairments will is a holistic, richly-descriptive interpretation of a ‘contemporary phenomenon,’ with cases bounded together by a very specific common denominator: planning post-secondarily for a child with severe and profound intellectual disabilities (Merriam, 1988; Smith, 1978 as cited by Merriam, 1988). The focus of this study was concentrated on individual, bounded cases to reveal specific and significant factors that characterize this phenomenon.
of personal and familial expectations for individuals and young adults with severe and profound intellectual disabilities (Merriam, 1988).

Examination of the Data Collection Methods and Triangulation

The purpose of this dissertation was to document and analyze the perceptions and experiences of families and individuals functioning within the SID/PID IQ range who have graduated from high school and who were exposed to academic, standards-based curriculum as well as to functional, life-skills curriculum on the success of their individual post-secondary goals. The researcher accomplished this through: (1) immediate family pre-interview questionnaire, (2) document analysis, (3) semi-structured interviews and (4) personal journaling. This qualitative study explored the impact of current curricular mandates on a bounded case of families with students with disabilities; therefore, triangulation was an acceptable method through which the results of this study are bolstered. The process of triangulation of data created the opportunity for the researcher (as well as the reader) to view a fixed point of origin (for this study, the opinions and experiences of the families in the framework of the research questions) from different angles, perspectives, and dimensions (Bowen, 2009; Creswell, 2009; Creswell, 2012; Mertens, 2010).

Barbour (2001) clarified that “different methods used in qualitative research furnish parallel datasets, each affording only a partial view of the whole picture” (p. 1117). Each of the data collection methods utilized (Pre-Interview Immediate Family Questionnaire, Document Analysis, Semi-Structured Interviews, and Personal Journaling) in this study were to collect data on the same topic, but also provided illumination from
different perspectives. These perspectives provided insight for the researcher as the process of data analysis took place (discussed later in this chapter). The methods employed in this study worked as cogs in a machine work: in synch, and collaboratively (see Figure 4).

*Figure 4. Impact of Methods on this Study*
For example, the questionnaire gives context to the documents and background within the interviews. While reviewing the documents, the codes from the interview began illuminating information that would not have been noticed without the impact of the other data collection methods. The ultimate purpose of this philosophical ‘machine’ was to give voice to families and individuals impacted by significant Intellectual Disability and to cause reconsideration and change in policy.

Pre-Interview Questionnaire

For this study, the immediate family pre-interview questionnaire (hereafter, ‘questionnaire’) was an inventory of questions presented to the participants in the study to gain demographic and edu-psychological information about the individuals with disabilities being studied. Birmingham and Wilkinson (2003) posit that an effective questionnaire can be used to gather information from multiple respondents, and that this information can be quickly and accurately analyzed by the researcher after submission. The questionnaire used in this study was used with a citation crediting the authors, and can be found in Appendix A. Seventeen of the questions within the questionnaire were closed, multiple-choice inquiries; the final question was open-ended, and invited the family to add any information they wished to share (Birmingham & Wilkinson, 2003).

The function of the questionnaire in this study was to engage the family members in a process through which they had to recall specific educational characteristics about their loved one with cognitive impairment, as well as to provide families with the opportunity to include any information about their loved one that they felt was relevant and necessary for the researcher to know. The questionnaire served as the initial
submission of information by the families to this study, and the first glimpse that the researcher had on the familial perceptions of their former students.

Document Analysis

Analysis of pertinent documents served as another lens through which the researcher analyzed and viewed the data. Bowen (2009) states that a researcher can systematically review documents to discover new information on a topic or to bolster the existing body of knowledge on a topic. In this study, documents contained words, graphics, and tables that were recorded/collected independent of the researcher’s intervention (Bowen, 2009). For the purpose of this study, Individual Education Plans, transition plans, psycho-educational reports and Georgia Alternate Assessment score sheets were analyzed and incorporated to paint a detailed picture of each participant.

Semi-Structured Interviews

Interviewing is “the most common format of data collection in qualitative research” because of the in-depth and extensive understanding of the subject at hand that the results can provide (Jamshed, 2014, p.87). Semi-structured interviews were employed in this study. A semi-structured interview is generally understood to be an interview in which the participant will answer “pre-set, open-ended questions,” (Jamshed, 2014, p. 87) with the opportunity for the researcher to follow-up to the responses of these pre-set questions with clarifying questions that will reveal, in this case, deeper opinions and perspectives on the impact of curricular mandates on the success of their loved one with cognitive impairment (Seidman, 2006).
The researcher relied on the research questions to develop the interview protocol (see Appendix B). The first research question asks how each curriculum prepared the former students for post-graduation aspirations. The researcher relied on the interviews to gauge the attitude of the families about the impact of each curriculum on post-secondary outcomes for their loved ones with SID/PID. The essence and emotionality that inevitably comes with a topic like this one cannot be captured as poignantly as when the respondent uses his and her own words freely (Holton, Strandbu, & Eriksen, 2014). The discretion afforded to the researcher through the semi-structured interview process allows the interview to progress in a meaningful, yet respectful method (Seidman, 2006; Holton et al., 2014). The second research question implored the perceptions of the immediate family members on the impact of both curriculums. The semi-structured interview process was not only utilized in directly answering the question “What do you think?,” but also allowed for follow-up and clarifying questions to ensure that the families’ perceptions was accurately encapsulated (Newcomer, Hatry, & Wholey, 2015).

Personal Journaling

Personal journaling was employed throughout this study to allow for personal reflection by the researcher to record assumptions, impressions, observations, and emotions related to the researcher’s own history and world view (Beale, Cole, Hillege, McMaster, & Nagy, 2004). For this study, ‘personal journaling’ was akin to keeping a diary in which the researcher recorded personal perceptions, observations, and impressions that arose within the mind and/or emotionality of the researcher during the semi-structured interviews. The researcher also journaled her personal reflections.
throughout the review of the questionnaire and document analysis. These notes were used to understand how personal feelings may influence this study, and were addressed within the analysis portion of this dissertation (Beale et al., 2004).

The next section of this chapter examines the methodological process of the data collection used in this study.

Participants

Participants in this study were the immediate families of four individuals with Severe or Profound Intellectual Disabilities who graduated from a public school system within the state of Georgia within the last five years. The participants were selected through convenience sampling. The researcher knew the families of some through private friendships, and others were known by the researcher because she taught the students in middle school.

A purposeful participant sample was used for this study. The immediate families of four graduated students who function in the Severe/Profound range of Intellectual Disabilities were studied; however, the parameters also allowed for convenience sampling because the researcher knew the families prior to this study. For the purpose of this study, “immediate families” were defined as guardians, parents, step-parents, grandparents, adult siblings, and adult step-siblings of the individual with cognitive impairment. “Guardians” were defined as adult individuals who had an active, daily role in the rearing of the graduated individual (could include aunts, uncles, etc. that lived within the home and provided support to the individual functioning within the Severe/Profound Range of Intellectual functioning). At the time of data collection, the
population of participants all lived in metro-Atlanta, Georgia communities, and each had a relative who graduated from a public school system within the state. In addition, each of the participants had a family member who was served through the Severe/Profound Intellectual Disabilities Self-Contained Program, which was their binding characteristic. Intelligence Quotient (IQ) score percentages of the population that functions within the SID/PID range of functioning are illustrated in Figure 5. Additionally, Figure 5 reveals the IQ score range in which the individuals function in relation to the mean, or average IQ scores.

![IQ Score Distribution](image)

*Figure 5. IQ Score Distribution Across the Population*

**Recruitment of Participants**

The researcher was already acquainted with and had a contact phone number for each of the families within the study. The researcher made initial contact with the parents of the former students through a text message. After ensuring that each of the phone
numbers were still valid phone numbers, the researcher made a voice call to each family. During the phone conversation the researcher shared that she was completing a study in fulfilment of requirements for her dissertation and asked if they would be interested in participating. After receiving an affirmative response from the family, the researcher sent an informative email to the email address provided by each family and included a request for informative documents to be analyzed for this study (see Appendix E). Initially, five participants were secured, so five informative emails were sent. However, after multiple attempts via email and text messages, one family decided not to participate, citing that management of their loved one’s unsafe and erratic behaviors was so time-consuming that they were unable to commit to anything else at that time.

Student Demographics and Descriptions

Four participants responded to the online pre-interview questionnaire entitled “Learner Characteristics Inventory” developed by Kearns, Kleinert, Kleinert, & Towles-Reeves (2006) in which immediate family members considered the functioning and characteristics of their loved one with SID/PID and answered seventeen questions as well as the option of giving additional information. Initially five families were given the link to participate, but only four responded, even after multiple attempts to contact the fifth prospective participant. Responders all resided in metro-Atlanta location, and all have a loved one that attended a local public school system in middle Georgia, United States of America. All four respondents were the female mother of an individual with SID or PID. All four families reported on their family member with SID/PID that graduated with a high school diploma in accordance with federal and state mandates and guidelines. Table
3 presents a brief demographic summary of the students represented by these participants.

Respondents’ responses to the pre-interview questionnaire are included in Appendix F and the following sections provide narrative description of data collected through the pre-interview questionnaires.

Table 3

Student Summary

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Woody</th>
<th>Esther</th>
<th>Luke</th>
<th>Mark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>25</td>
<td>24</td>
<td>21</td>
<td>26</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>Black</td>
<td>White</td>
<td>Black</td>
</tr>
<tr>
<td>Motor Skills</td>
<td>Ambulatory, but needs help with stairs and independent in most tasks</td>
<td>Ambulatory and requires some assistance in fine motor tasks</td>
<td>Ambulatory, but requires some assistance and dependent on others for fine motor tasks</td>
<td>Ambulatory and requires some assistance in fine motor tasks</td>
</tr>
<tr>
<td>Expressive Communication</td>
<td>Functionally non-verbal, but can communicate some words to people familiar to/with him, but primarily communicates through body language.</td>
<td>Functionally non-verbal, can communicate some words to people familiar to/with her, but primarily communicates through body language and eye gaze.</td>
<td>Totally non-verbal, but communicates through body language and some limited gesturing.</td>
<td>Totally non-verbal, but communicates through body language, eye gaze and some limited prompting.</td>
</tr>
<tr>
<td>Reading and Math Skills</td>
<td>Does not recognize text or numbers</td>
<td>Does not recognize text or numbers</td>
<td>Does not recognize text or numbers</td>
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</tr>
<tr>
<td>Family Member Participant</td>
<td>Mother</td>
<td>Mother &amp; Father</td>
<td>Mother</td>
<td>Mother, Father, Sister, &amp; Brother</td>
</tr>
</tbody>
</table>
All of the respondents indicated that the individuals with SID/PID at the focus of this study were in twelfth grade when they graduated. The average age of the individual with SID/PID being considered within this study is twenty-four years old, with a range of twenty-one years to twenty-six years of age. All of the respondents indicated that their loved one has an eligibility category of Intellectual Disability; the format of this questionnaire grouped all ID eligibility categories of Mild, Moderate, Severe and Profound into one set of “ID”. All of the participants within this study indicated that English is the primary language spoken within the home. Three of the four participants specified that their loved ones with disabilities attended a regular public school with a Federal Time Equivalent (FTE) spent in the special education setting greater than 80% of the time (also referred to as a ‘self-contained’ special education classroom), but that some time may have been spent in the general education setting, not to exceed 20% a day, at some point of the school day. The fourth respondent indicated that her loved one attended a special school; however, upon investigation of the IEP document and in speaking with the parent, it was discovered that this was mistakenly selected, and that this former student also attended a regular public school in a self-contained setting. Therefore, 100% of the participants being focused on were in a regular public school, served through a self-contained setting.

Expressive Communication

Two of the individuals use intentional expressive communication, while one participant communicates with primal methods (crying, facial expressions), and one uses symbolic language to communicate. The American Speech-Language-Hearing
Association (AHSA) (2019) explains that expressive communication includes the ability to share thoughts, feelings and ideas. Humans begin expressive language at birth by crying when hungry, wet, or in pain, and continue the progression of developing effective expressive communication throughout life (Encyclopedia of Children’s Health, 2019).

According to family observations recorded in the questionnaire, a quarter of the sample uses communication in a very basic form (crying, muscle tensing, etc.), another quarter of the sample uses verbal or written words, signs, Braille, or an Augmentative and Alternative Communication (hereafter, AAC) device to make requests or make their feelings known. Half of the sample communicates, but not symbolically. These two individuals use gestures, picture exchange systems (or variants of it), and familiar objects or textures.

Use of Augmentative and Alternative Communication Devices

Half of the Respondents indicated that their loved one utilizes an AAC (Augmentative and Alternative Communication Device) to assist with communication. AAC devices can range from low-tech devices (such as a picture exchange system) to a computer, voice-generating output system. Two of the four individuals being focused on in this study engage with AAC devices to promote their expressive language skills. This enables them to make choices and opinions known and promotes independence.

Receptive Language

Half of the individuals at the focus of this study receptively communicate by alerting to sensory input from another person, but do require some physical guidance to complete the request made. One of the individuals requires multiple cues in addition to
full physical guidance to fulfil a request, and one of the individuals can independently carry out one-to-two step directives with no additional supports. According to ASHA (2019), receptive language is communication that allows a person to understand the words and meaning of what others say. This includes understanding the feelings and point of view of others, but it also includes following directions. For the purpose of this questionnaire, family members were asked to consider the ability of their loved one to follow one-to-two step directions. One family reported that their loved one can independently follow one-to-two step directions with no cues or supports to do so. Another family revealed that their loved one, because of their low cognition (not because of choice), can only follow one-to-two step directions with multiple gestural, verbal, and full physical prompts. The other two individuals can understand what is being said, but sometimes need a moderate amount of cueing and guidance for carrying out a task.

Vision and Hearing

All of the respondents indicated that their loved one had hearing and vision within normal limits, with one individual requiring corrective lenses for their vision to be within the normal limits.

Motor Skills

Respondents were asked to consider both the gross (large motor movement like walking) and fine (small motor movement like dexterity, holding eating utensils, etc.) motor skills of their loved one. Three of the four respondents reported that their loved one with ID are motorically independent, and one participant answered that personal assistance is required for her son to engage in motor activities. The one individual who is
not independent does not require a wheelchair or walker but does require the assistance of a caregiver or partner when performing fine motor tasks (using eating utensils, brushing teeth, etc.) and gross motor tasks in some situations (i.e. taking stairs, getting in and out of a vehicle).

Social Engagement

Family respondents reported that none of the individuals are functionally verbal, they are social, and enjoy interaction with others to a degree. Two of the former students respond to social interaction but do not initiate nor sustain it, while two initiate and sustain social interactions.

Health Issues and Attendance

All of the participants’ loved ones were in good enough health to attend school (and now daycare and day-habilitation centers) 90% of the time that the institution was open.

Reading and Mathematics

Academically, all of the respondents indicated that their loved ones had no observable awareness of print, Braille, or use of numbers within the area of Reading and Mathematics. This is characteristic of individuals with Severe and Profound Intellectual Disabilities—most are unable to read for understanding or complete mathematical computation in any meaningful, real-world application. Herein lies a critical component of this study—has the school system provided these former students the ability to read for information and compute numbers in real-world applications such that they have a marketable skill for post-secondary options? For individuals with ID the inability to read
or compute numbers does automatically indicate a lack of strengths or skills, but it is a lack of the very basic academic components required by the federal and state governments.

Individual Vignettes

The following section includes an introduction to the four students and their immediate family members who participated in this study. Each student was assigned a pseudonym to protect his or her privacy. As with the Researcher Positionality section in Chapter 1, first person narrative is included in this section to describe the researcher’s relationship with the study’s participants.

Participant #1: Woody and His Family

“When it comes to people, it doesn’t matter! If you are a human being, he will acknowledge you...he respects you enough to let you know that he sees the difference.”

—Woody’s Mother

Woody is a 25-year-old white male who graduated from a public high school in middle Georgia with a general diploma. He currently resides with his family, and reports to a day program for adults with developmental disabilities in a county neighboring the county where he graduated. I attended college with Woody’s mother during our undergraduate studies, and we have maintained a friendship since that time. Woody’s mother is viewed as the glue that holds her family together, and she along with her husband care for Woody and his sister. Woody’s favorite movies are Toy Story and Frozen, and he especially enjoys organizing his movie collection within the binder that hold the DVDs. If one of his DVDs is out of place, he immediately takes action to locate
and replace it. Woody is a cancer survivor. He (with his family close by his side) battled cancer when he was only two years old. This illness has impacted him to this day causing intestinal issues and the inability to gain weight. Woody also lives with a seizure disorder. Woody’s family finds joy in simple, everyday occurrences, and are happy together.

Participant #2: Esther and Her Family

“She’s a happy individual…she knows when you’re down because you get your hug…she can feel your spirit…and she will come to your rescue even though you may not be feeling your best. Esther was always there with hugs and a smile.” – Esther’s Mother

Esther is a 24-year-old Black female who graduated from a public high school in middle Georgia with a general diploma. She currently resides with her family, and reports to a daycare facility for adults with developmental disabilities in a county neighboring the county where she graduated. I taught Esther in middle school. I watched her develop from a little girl into a young woman. Esther is precocious and mischievous. She is the only child of her mother and father and has earned the nickname “Queen” around her house.

Esther’s mother and father are kind and generous, and have devoted their lives to Esther’s happiness and care. Esther loves to people watch, and although functionally non-verbal, will articulate when she feels that she is either no longer the center of attention or not getting something that she wants. She quite often tells others that she is a “goo gul” (translation: “good girl”), even when she is doing something that she shouldn’t do. She is one of the sweetest souls I have ever met.
Participant #3: Luke and His Family

“He has a really full life! And he loves it! That’s what's incredible. Did I see him progress? Absolutely!! He’s Mr. Social Butterfly...instead of when he first started out in life in that wheelchair not able to move.” –Luke’s Mother

Luke is a 22-year-old White male who graduated from a public high school in middle Georgia with a general diploma. He currently resides in a group home and attends a day care facility for adults with developmental disabilities. I taught Luke for four years in middle school. I also watched Luke develop from a child to a young man. Luke is tall and handsome and loves his mother. I remember a time when I was on my way home from work, and I stopped by the stop sign arm on the bus dropping Luke at his home. I watched as his mother waited expectantly at the bottom of the bus stairs and watched as her only son (at that time) disembarked from the bus. Her face filled with love, she spoke a greeting to him that I could not hear (but did not need to in order to understand what was taking place), and then, with Luke towering in height over his mother, they made their way up the driveway, hand-in-hand, towards the house. Luke’s mother talked to him the whole way up, and a smile that I rarely saw at school remained on his face as long as he was in my sight.

I’ve never forgotten that exchange, and it transformed me. As an educator, I was often very clinical with my students—kind and loving, but clinical. After that day, I attempted to elicit the kind of smile I saw on Luke’s face that day, each and every day while my students are with me.
Participant #4: Mark and His Family

“Just knowing Mark...he is very smart, and he can do things that we don’t even think he can do.”—Mark’s Mother

Mark is a 26-year-old Black male who graduated from a public high school in middle Georgia with a general diploma. He currently resides in a group home and attends a day habilitation facility for adults with developmental disabilities. I did not have the pleasure of having Mark in my class, but I had occasion to interact with him at different county-wide events. He is part of a very loving family of all adult siblings (including Mark, two sons and one daughter). During the interview process, I was struck by the ownership of each member of the family in Mark’s well-being. Although Mark’s mother had the greatest frequency of response during the interview, I gathered from the body language of his siblings that Mark’s sister was a second mother-figure to him, and his brother thought of him as a typical brother would think of their brother. The love and respect that Mark’s mother and father have instilled in their children could be felt not only by me during the interview process, but also through the way they communicated about their older brother. Mark is a jovial, handsome, and loving person who always has a contagious smile on his face. One cannot help but be happy when in his purlieu.

Methodological Processes

To support the credibility of the study, multiple forms of data were collected and triangulated to support credibility (Bowen, 2009; Maxwell, 2005). To increase trustworthiness and decrease the chance of bias, data were triangulated through the findings from a pre-interview questionnaire, semi-structured interviews, document
analysis, and personal journaling (Creswell, 2009; Bowen, 2009; Mertens, 2010). The sequential nature to the collection of the data ensured that the participants’ emic point-of-view was heard with no outside influences.

After initial contact was made, an informative email with the link to the pre-interview questionnaire was sent to the contact person for each family. The questionnaire provided the researcher with a basic understanding of each of the family’s understanding of the functioning of their child with Severe/Profound Intellectual Disability. After the completion of the questionnaire, the interviews were scheduled. A holistic view of family dynamics (i.e. expectations for other siblings, internal struggles of the family caused by the disability of the loved one, and goals of the family and the child with SID/PID) worked in tandem to descriptively answer the questions set forth by this study through open-ended, semi-structured interviews (Merriam, 1988; Mertens, 2010; Seidman, 2006). The families submitted the requested documents to the researcher after their interviews. The researcher journaled while examining the collected data, and all data were coded and analyzed thematically. The pre-interview questionnaire was discussed above; the semi-structured interviews and document analysis are described in the following sections.

Semi-Structured Interviews

After receiving the pre-interview questionnaire from each family, the researcher contacted each participant via text message and email to set up a date, time, and location convenient for each of the families to conduct the semi-structured interview and to collect the requested documents. Three of the families elected to participate in the interviews
within their homes, and one family member asked to meet at her place of work after business hours to converse. The researcher accommodated each of these requests and travelled to each location at the time determined by each family. Because the researcher has previous relationships with each of the families, pleasantries, small talk, and “catching up” occurred upon initial arrival. Then, the researcher asked permission of each of the families to record the interview, and verbal consent was granted. The researcher asked about the requested documents, and two of the four families (Esther and Luke) provided the researcher with the documents at the time of the interview. Woody’s family mailed his documents to the researcher after the interview, and the researcher re-visited Mark’s home to pick the documents up at a later date.

Before each interview began, the researcher gave an explanation to the participants before implementing the interview protocol about the purpose of the study, and how they would each play a role in the completion of the study. The explanation was not scripted, but the researcher included the following elements and explanations to each of the families: the purpose of the study, a description of functional life-skills curriculum, a description of functional academic curriculum, and the current curricular requirements of the government for students with SID and PID. After this explanation, the semi-structured interview protocol was implemented (see Appendix B).

During the interviews, the researcher began with broad questions that covered the specific requirements of the research questions within the interview protocol, but allowed the interview to occur as naturally as possible while also allowing the opportunity to question the participant as points of interest of the study arise within the conversation,
and then using the protocol to guide the conversation back to the task at hand (Mertens, 2010). Some of the extended questions arose from the review of the pre-interview questionnaire. A generic interview protocol was used when conducting the interview as a starting place; the semi-structured manner in which this methodology was implemented allowed for the family members to move in directions that the researcher might not initially consider as appropriate or telling (Creswell, 2009; Merriam, 1988; Mertens, 2010; Seidman, 2009). The researcher audio-recorded the interviews in their entirety, and saved these audio recordings under coded names to ensure the confidentiality of the participants (Seidman, 2009). The researcher journaled throughout the interview sessions, using time markers from the audio-recording to bring attention to those points the analysis of the data took place (Seidman, 2009; Creswell, 2012). The researcher documented descriptive data of interactions or exchanges within the setting or between family members throughout the interview session (Mertens, 2012; Geertz, 1973).

At the conclusion of each of the interviews, the researcher offered gratitude to each of the families for their time and participation. The researcher then transcribed each of the interviews from audio to text utilizing an artificial intelligence online software called Sonix. After the transcription, the researcher then used Sonix to listen, review, and correct the transcription. Once the transcription was accurate, the researcher exported each one into a Word Document. The researcher then uploaded each interview into Qualitative Data Analysis (hereafter, QDA) Miner, an online data analysis program. QDA Miner is a qualitative data analysis software that assists in coding, analyzing, and retrieving data. The researcher entered codes with notes and subcategories, and then
using the program, identified and highlighted portions of the data that align with themes determined by the researcher.

Document Analysis

The purpose of the document analysis was to ascertain memorialized documentation of the present levels of functional academic and achievement performance through mandated reports by the local public school system, and to consider, compare and contrast this information with the other methods of data collection within this study. Each of the four participants elected to provide the researcher with paperwork that they currently had in their possession. Each family provided different elements that the researcher requested, but any and all documents submitted were helpful to this study.

In qualitative methodology procedure, “Document analysis is a systematic procedure for reviewing or evaluating documents” (Bowen, 2009, p.27). Bowen (2009) explains the use of document analysis in the trustworthiness in a study: document analysis is “a case of text providing context” and giving historical background to the case (p. 29). Documents provided by the participants served to establish the level of functioning of each student when they were in school and to determine what baseline transition goals the school and the families collaboratively determined. The document analysis occurred after all of the interviews were conducted, and were combed through for several items: a) documentation of the present level of functioning of the student, b) baseline documentation of the transition goals for the student (located within the Transition Plan), c) comparison of the annual goals and objectives to the present levels of performance documented in the psychoeducational report, d) documentation of each
student’s participation in and access to the general curriculum standards through the Georgia Alternate Assessment, and e) to triangulate the data by bolstering the interviews and questionnaire from documentation within formerly legally binding documents specific to each individual student.

Interview Transcription

After the interview sessions were complete, the researcher used an online program called Sonix to transcribe the interview from audio to text (Mertens, 2012; Seidman, 2009). The transcription process provided the researcher the opportunity to read the interviews multiple times for accuracy of transcription. This constant review of the interviews allowed for similarities and contrasts among the interviews to present themselves. The researcher uploaded the documents into Sonix, and approximately fifteen minutes later a text version was ready for review. The researcher cued the audio file, read along with the transcription, and made changes as necessary. The artificial intelligence software employed by Sonix correctly transcribed approximately half of each of the interviews. However, the helpful part of the program comes within the interactive formatting of the text version; time markers are included within the Sonix text document on which the researcher can click. When clicked, the audio version of the interview will play from that specific point. This was very helpful in several ways. It allowed the researcher to easily cue up and play specific parts of the interview without searching on the play bar that accompanies an audio-only form of the recorded material. Another benefit of the time stamps was the ability to click that link multiple times while correcting that portion of the transcription. As the researcher made corrections, she
would then go back and hit the timestamp and read along as the audio played to ensure accuracy of transcription. A third benefit of the Sonix program was the highlighted reading component; as the uploaded audio file played, the text transcription completed by Sonix would highlight in a scanning fashion to aid the reader in orienting within the document. As changes were made by the researcher, that highlighting feature did not transfer to the corrections she entered but would pick back up on portions that were originally created by Sonix. Again, this assisted the researcher in orientation not only within the written text, but within the interview in its entirety. The researcher would sometimes listen to one passage of an interview up to 20 times before being satisfied with the accuracy of the transcription.

Upon reflection of this process, the researcher credits the process of hearing the interviews so many times while also viewing the written text format with providing her with the most clarity in identifying the codes that emerged. For example, the researcher noted that all four participants spoke of self-management of personal hygiene as a critical skill needed for their loved ones with SID/PID. Their concerns varied from brushing teeth to showering to independence in toileting. The researcher documented this in her journal to focus on during the coding process. Another benefit of listening to the audio version multiple times was eliciting the memory and emotionality of the researcher herself. The researcher was emotionally and auditorily present during the actual interviews; however, reliving those interviews over and over allowed for reflection and introspection that could not occur during the face-to-face time with the families. The researcher was preoccupied with ensuring that every aspect of the interview protocol was
answered and with being an active and considerate listener that time did not permit for the type of reflection critical in really hearing what the families had to say.

This process of truly hearing began with the transcription process, and continued as this data was compared, contrasted and analyzed. It was during this time of hearing that the codes truly emerged, and that the tone of the interviews settled within the soul of the researcher. For example, a hefty portion of the conversation with Esther’s family was clouded with frustration and sometimes anger, specifically, anger and frustration of the perceived lack of concern school staff had for Esther’s progress; anger and frustration over not being heard as parents; anger and frustration over time and skill lost in Esther’s development. A confession never spoken by Woody’s Mother brought a feeling of despair and fear that resonated even through the recording of the interview. The tone of each of the interviews was re-lived and re-experienced by the researcher. This experience was transformative in her understanding of the research questions she posed so early in her study—perhaps the concepts set forth in those questions had everything to do with the success of these students, or perhaps had nothing to do with their success. Contemplation and data analysis would eventually be exposed and begin to reveal the answers to the research questions.

Data Coding

After the researcher was satisfied that the raw content of the text form of the interviews were accurate, each was downloaded as a Word document and saved under the pseudonyms assigned. The researcher then uploaded each of the interview texts into QDA Miner Lite, an online software used to aid in the coding and recall of qualitative
and mixed methods data. After uploading each of the interviews, the researcher began coding each of the interviews with primary categories that were then refined by specific concepts and subcategories documented within the program (Mertens, 2012; Seidman, 2009; Wolcott, 1994). The researcher began coding based on the concepts that emerged within the transcription process. The research journal entry from the transcription process listed “independence, daily living, residential, vocational skill development” as major themes to be considered when coding. The research journal also recorded the phrases “not a rocket scientist” and “never amount to anything” to reflect on during the coding process.

While coding within QDA Miner Lite, the researcher made “notes, comments, observations, and queries” using the “notes” application defined highlighted information for review and reference during analysis (Merriam, 2009). Because the researcher was open to all different types of themes that may continue to emerge, the researcher conducted open coding on the transcript of the interview, which highlighted everything that drew the interest of the researcher that was then assigned a category and subcategory in subsequent, refining reviews of the data (Merriam, 2009). As explained, this process took place with each of the transcripts from the interviews from the other participants but began to take shape long before uploaded into QDA Miner Lite.

The researcher elected to use two pre-determined, a priori codes to create categories and subcategories that directly answered the two types of curriculum addressed through the research questions: Academic Curriculum code and Functional Curriculum code. Creswell (2013) posits that the use of pre-determined, a priori coding
serves to “limit the analysis to the “prefigured” codes” (p.185). This pre-determined, focused analysis was the intentional to provide clarity when answering the research questions.

The remainder of the codes emerged from the multiple reviews of the data by the researcher. Glense (2011) supports this type of line-by-line coding to “immerse [the researcher] in the data” as opposed to a priori coding (p. 198). “Coding that comes from interpretation and reflection on meaning” (Richards, 2005, p. 94) was achieved by keeping a running list of overarching categories with specific subcategories with descriptive notes (Merriam, 2009; Strauss & Corbin, 1990). This process began in the transcription process and continued throughout the analysis phase. Through the categories and subcategories, the researcher then identified themes interwoven between each of the families’ experiences. The themes, in the form of stories, examples, anecdotes and tables and images (Creswell, 2012; Wolcott, 1994) are documented in the data analysis chapter of this study. The narrative aspect, specifically through the transformative psychological lens, allowed for personal reflections, motivations and responses to paint the picture of the participant and familial goals while bounding the study with specific limitations and delimitations (Merriam, 2009). The coding and triangulation of the data (questionnaire, interviews, documents, and journaling), in addition to thick, rich descriptions emerging from each interaction, allowed the researcher to create as complete a portrait of each family as possible in a shortly defined amount of time (Bowen, 2009; Geertz, 1973; Janesick, 1999; Mertens, 2010; Stake, 1995).
Data Analysis and Data Reporting

The procedure of this study operated within the understanding that individuals are entitled to specifically designed instruction that addresses in any setting and through multiple modalities, settings and support services such as speech therapy, travel training, vocational education, physical education, motor skill education/therapy, provision of skills in aquatics, dance, games and sports, environmental skills and, the area that this study is concerned with, academic education (IDEiA, 2004). Given these requirements, this study collected and analyzed data to determine the graduated student and parental perceptions of these expectations through the research questions posited, and were analyzed using an a priori, constant comparative method (hereafter, CCM).

Constant comparative analysis is a qualitative data analysis method by which data are coded in order to identify emergent themes (Boeije, 2002; Glaser, 1964; Hewitt-Taylor, 2001). This method provides a systematic way in which a researcher can order and manage a variety of data, identify themes, and it provides a logical and sequential relationship between data and the study’s research questions (Hewitt-Taylor, 2001). In this study, codes were first developed by identifying the topics and phrases that appeared most frequently and began emerging during interview transcription. Most of the codes were not predetermined but inductive and sought to tell a story and develop a better understanding of a phenomenon (Hewitt-Taylor, 2001). The less ‘personal’ codes were determined at the beginning of this step—less ‘personal,’ meaning codes specifically sought out to answer the concrete components of the research questions. The researcher
named these less ‘personal’ categories “Academic Curriculum” and “Functional Curriculum.”

The more ‘personal’ and meaningful impact of these codes were defined through the subcategories for each of these codes: “academic/functional curriculum helped” and “academic/functional curriculum did NOT help.” These categories and subcategories provided a basis for the researcher to elicit a concrete answer to the components of the research questions that addressed “mandated academic curriculum” and “functional, life-skills curriculum.” The concept of the category “Independence” emerged and became more defined as the highlighting and notation portion of the coding process continued. Initially the researcher included “independence, daily living, residential, vocational skill development” as major categories (prompted by the research journal from the transcription process). During the initial stages of coding “communication” and “social life” also emerged as categories. However, the researcher began noticing the context in which each of these elements were discussed by the families. The context in which daily living skills, residential options, vocational and work skills, communication and social opportunities were discussed was in reference to the level of independence needed to successfully carry these life skills out. Consequently, the researcher left Independence as a major category, and shifted daily living skills, residential options, vocational and work skills, communication and social opportunities to subcategories of Independence.

As coding continued, the researcher determined that the context of the subcategory ‘vocational and work skills’ was mentioned in reference to financial prowess, so this subcategory was renamed ‘vocational and financial’ and the codes were
re-organized to include the idea of holding a job, bringing in income and financial concepts within this subcategory. The original note within the researcher’s journal of the concept of ‘vocational and work skills’ was teased out of what was then the ‘vocational and financial’ category and renamed ‘further education/training’ to provide clarity for the researcher during the analysis of the data. The subtle difference between ‘vocational and financial’ and ‘further education/training’ is the concept of the attainment of funding (‘vocational and financial’ subcategory) and the attainment and mastery of a marketable skill that was typically included in the IEP in the Transition Plan (‘further education/training’ subcategory). This new subcategory allowed a clear connection between that code with the training/education Transition Plan goal from the IEP. When this clarification occurred, the researcher then reviewed the other codes to make sure that every aspect of the research questions was addressed.

At that point, every component of each of the research questions were addressed, but it was at this time that the researcher included an entry in her journal that assigned certain categories and subcategories to address one of the research questions. See Figure 6 for an excerpt from the researcher’s journal.
Figure 6. Journal Entry: Codes Assigned to Research Questions
The coding process was repeated until no new codes were identified and all categories. Subcategories and themes were gleaned and provided an answer to the research questions (Boeije, 2002; Glaser, 1964; Hewitt-Taylor, 2001). The categories and subcategories identified within the interviews were then used as a lens through which to analyze the documents; themes that emerged within the interviews were then supported or refuted through the information contained within the documents and questionnaire.

Researcher Emotionality and Advocacy

Advocacy and emotionality are seemingly derived from the same deep well. The passion and emotionality that someone holds on a subject can be transformative, and cause ‘advocacy,’ the verb form of ‘passion.’ A study like this one elicits emotion. When seeking approval for this study from the Office of Compliance through the IRB, the researcher anticipated that a possible risk for the participants in this study could include emotional discomfort. The same was a risk for the researcher that was realized. The position of this researcher is that of transformation and advocacy. The goal of this study was to impact policy. However, the weight of speaking on behalf of others is quite the charge to take on. In this section, first person narrative is used to convey the researcher’s emotionality and advocacy as they relate to data collection and analysis.

Within this study, I struggled with what information to share. Specifically, I will always preserve the dignity of individuals that cannot advocate for themselves, just as the former students in this study. My staunch position of protection and preservation of dignity prevented me from sharing some of the discussions from the interviews and some of the present levels of performance from the document analysis. The cognition of the
former students within this study would inhibit the comprehension that I violated this unspoken code that I have, but I would know. And their families would know. And the families and support circles of other individuals functioning within the SID/PID range would know. My sincere goal was to present the data in the purest, most un-biased position possible. However, there were times that I did exclude information to protect the integrity of the individuals at the crux of this study. For example, I did not include explicit discussions conducted about some personal hygiene deficits in this work.

Additionally, I struggled with sharing aspects of my research journal within the pages of this study. My desire to protect the families’ confidence and personal testimonies wrestles with my position as a researcher and my desire to advocate for the families and their loved one with SID/PID using the information that I have been gifted. After lengthy discourse with my dissertation committee, we agreed that explicit discussion addressing these would benefit the study, and to include them. An example of this struggle was reporting the tone of the interviews. There were instances within the interviews when the anger and frustration of the families was so overpowering that it felt irreverent to continue with the line of questioning until the family felt that they had been heard. So, I did not continue immediately.

I allowed the families the opportunity to vent their frustrations. The overall tone of two of the interviews was positive and light. However, the heartbreaking tone of the other two interviews was beleaguered with desperation and insecurity. The benefit of sharing these examples is rooted within the transformative nature of advocacy. Those varying tones within the interviews propels this researcher forward in a spirit of
advocacy—to fight for the happiness that can be achieved, and to fight against the desperation that so many feel when living with the harsh realities of SID/PID.

Summary

The purpose of this study was to understand the impact that federal curricular mandates had on graduated individuals with SID/PID, specifically with the attainment of post-secondary goals held by immediate family on behalf of the individual with SID/PID. All individuals are not only entitled to a free public education, but an appropriate public education. IDEiA (2004) defines special education and curricular expectations: IDEA, Section 300.39 (a) General “(1) Special education means specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including…(3) Specially designed instruction [and] (ii) To ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agency that apply to all children.” IDEA defines that ‘Specially designed instruction’ as “means of adapting, as appropriate to the needs of an eligible child under this part, the content, methodology, or delivery of instruction…” (IDEiA, 2004).

The population for this study consisted of four individuals with Severe or Profound Intellectual Disabilities who graduated from a public school system in Georgia and their parent(s)/guardian(s). From these participants, data were collected through the following methodologies: (1) pre-interview questionnaire, (2) document analysis, (3) semi-structured interviews, and (4) researcher journaling. Thick rich descriptions coupled with heart-felt interviews and communication and historical triangulation
provided through the document analysis provided the information needed to fully explore and answer the driving questions of this study. The following chapters document the results of the methodologies and analysis described in this chapter. Chapter Four outlines the results of the interviews and document analysis through anecdotes, quotes, and ideas of the participants as well as through tables and images (Bower, 2009; Mertens, 2010). Chapter Five then summarizes and discusses the results of the study and frames the conclusion and implications of the study within recommendations for further research and investigation.
CHAPTER 4

DATA ANALYSIS AND FINDINGS

This qualitative study focused on the perceptions of family members on the current curricular requirements for individuals with Severe and Profound Intellectual Disability. The purpose of this study was to describe the understanding of family members on curricular requirements and how these mandates provided a basis to meet post-secondary goals as outlined in high school IEPs as well as how the outcomes measured up in the opinion of said family members. The study took place in a suburban county in central Georgia. Participants included four family units that raised and graduated an individual with Severe or Profound Intellectual Disabilities. Two of the families were White, and two of the families were Black. The former student of one of the families was female while the other three former students were male. Pseudonyms were assigned to each family unit (primarily to the individual with ID, and the family was then identified as the family of ‘pseudonym’) to maintain confidentiality and to protect the privacy of the family and the privacy and integrity of the individual with ID. A pre-interview questionnaire was completed by each of the family units prior to scheduling a semi-structured interview with each family. Each family also provided documents to the researcher to serve within a document analysis for this study. The researcher also made notes during her interactions with the family to document unspoken actions and the overall climate of the interview experience (Creswell, 2009).
Viewed through the Disability Theory interpretive lens (Creswell, 2012) and grounded within the Transformational framework (Mertens, 2009), this study was propelled by the following research questions: 1) How does the current mandated standards-based curricular requirements and functional, life-skills curriculum allow individuals with Severe/Profound Intellectual Disabilities to realize their post-graduation goals? and 2) What are the perceptions of family members of students with Severe/Profound Intellectual Disabilities on how the current mandated standards-based curricular requirements and functional, life-skills curriculum allow their child to realize their post-graduation goals? This chapter presents the opinions and viewpoints of immediate family members of individuals with SID/PID as well as how these opinions, observations, and experiences of post-secondary success align with the high school IEP of each of the then-students. This case study employs rich descriptions as recommended by Stake (1995) and Geertz (1973) through notations made within the pre-interview questionnaire, interview excerpts, and personal journal notes by the researcher and through background information gleaned through the document analysis for each unit within this case study.

Overview of the Chapter

The purpose of this chapter is to review and analyze the data collected to answer the research questions. The chapter is organized in the order of events and in chronological order. The pre-interview questionnaire was discussed in Chapter 3, so the interviews are analyzed and discussed first in this chapter. Although it was the hope of the researcher to review the documents prior to the interviews, none of the families
submitted the paper work to the researcher until the time of the interview or after.

Finally, the document review and analysis is memorialized. The documents are presented in chronological order by grade level: psychoeducational report, 9th grade IEP with Transition Plan, 10th grade IEP with Transition Plan, 11th Grade IEP with Transition Plan, high school GAA Scores Report, and lastly the 12th Grade IEP with Transition Plan.

Table 4 contains the documents submitted by each family. The analysis and discussion of the data collected formulates a discussion of both research questions.

Table 4

*Special Education Documents Provided by Families*

<table>
<thead>
<tr>
<th>Document Description</th>
<th>Woody</th>
<th>Esther</th>
<th>Luke</th>
<th>Mark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most Recent Psychoeducational Report</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>9th Grade IEP with Transition Plan</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>10th Grade IEP with Transition Plan</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>11th Grade IEP with Transition Plan</td>
<td>No</td>
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<td>No</td>
</tr>
<tr>
<td>11th Grade GAA Scores Reporting Form</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>12th Grade IEP with Transition Plan</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><em>Special Education Eligibility Report</em></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

*Note.* Special Education Documents submitted by Families at the request of the Researcher for purpose of document analysis. Items marked with an *asterisk were not requested but provided by the family.
The next section of the chapter describes information shared by participants through informal small-talk before, during, and after the interviews as well as direct responses to the semi-structured interview questions, and from the pre-interview questionnaire. Information from the analysis of the Psychoeducational, GAA Scores, the IEP, and Transition Plan documents will also provide insight to each individual’s journey, the goals the academic team held for them and the rationale for those goals, and how these goals align with what each participant is doing now. Each families loved one is represented and focused upon individually. The goal of this section is to give true insight to capabilities and apparent limitations while considering the appropriateness of the mandated curriculum.

The chapter provides closure to the reader by providing a comparison, discussion, and analysis of the participants in totality in regard to the research questions and with the theoretical framework in mind. A summary is provided for the reader’s convenience.

Semi-Structured Interviews Review and Analysis

The purpose of the semi-structured interviews in this study was to ascertain the viewpoint of the immediate family members of individuals with Severe or Profound Intellectual Disability who graduated from a metro-Atlanta public school system on the impact of both the functional life-skills curriculum and the functional academic curriculum had on meeting their post-secondary goals and aspirations. For the reader’s convenience, the research questions are provided at the beginning of the sections in which they are directly addressed.
After completion of the interviews, the researcher transcribed each of the interviews from audio to text utilizing an artificial intelligence online software called Sonix. After the audio to text transcription by Sonix was complete, the researcher then used the program to listen, review, and correct inaccuracies within the text transcription. In order to protect respondent confidentiality, the researcher used the “find and replace” feature to search for identifying information (i.e., first and last names) and replaced them with pseudonyms. Once the transcription was accurate, the researcher exported each interview into separate Word Documents. The researcher then uploaded each interview to QDA Miner Lite, an online qualitative data analysis software. The researcher entered codes with notes and subcategories, and then using the program, identified and highlighted portions of the data that align with themes determined by the researcher. Figure 7 was captured from the program to illustrate the categories and subcategories determined while coding the participant interviews.
After multiple reviews of the interviews through the transcription process, the researcher noted categories that emerged across each of the families’ experiences. Some of these categories were similar across each of the stories (i.e., Independence category), and some of the themes were in sharp contrast, but were mentioned (i.e., Academic Curriculum and Functional Curriculum categories). Each of the categories contain subcategories that have different implications. For example, the main category of “Independence” has six subcategories of “daily living skills, vocational and financial, residential, communication, social life and further education/training.” This category and subcategories were similar across several or all of the interviews, and the researcher wanted to provide a highlight of how many times these were mentioned, and in what
capacity they were mentioned. However, the main category of “Academic Curriculum” has subcategories of “helped” and “did NOT help.” The main category marked how often academic curriculum was mentioned, but the subcategories defined the climate in which the category was mentioned—whether it was helpful or not helpful in meeting post-secondary goals. Appendix I contains the meaning assigned to each of the categories and subcategories by the researcher during the coding process. These meanings include notes made by the researcher at the time of coding within QDA Miner Lite. Given the individual lens through which each interview was viewed, the researcher coded each one by highlighting and assigning a category and subcategory to each portion identified. The overall frequency with which each of the categories (and subcategories) were identified can be found in Figure 8.

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>% Codes</th>
<th>Cases</th>
<th>% Cases</th>
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<tr>
<td>Independence</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>daily living skills</td>
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<td>12.8%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>vocational and financial</td>
<td>10</td>
<td>5.8%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>residential</td>
<td>11</td>
<td>6.4%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>communication</td>
<td>9</td>
<td>5.2%</td>
<td>3</td>
<td>75.0%</td>
</tr>
<tr>
<td>social life</td>
<td>17</td>
<td>9.9%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>further education/training</td>
<td>13</td>
<td>7.6%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>Academic Curriculum</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>academic curriculum helped</td>
<td>3</td>
<td>1.7%</td>
<td>1</td>
<td>25.0%</td>
</tr>
<tr>
<td>academic curriculum did NOT help</td>
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<td>8.7%</td>
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<tr>
<td>Functional Curriculum</td>
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<td></td>
<td></td>
<td></td>
</tr>
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<td>functional curriculum helped</td>
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<td>3.5%</td>
<td>3</td>
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<td>functional curriculum did NOT help</td>
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<td>1.2%</td>
<td>1</td>
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<tr>
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<td>12.8%</td>
<td>4</td>
<td>100.0%</td>
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<tr>
<td>societal perceptions success</td>
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<td>0.6%</td>
<td>1</td>
<td>25.0%</td>
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<td>18.0%</td>
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<td>100.0%</td>
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<td>2.9%</td>
<td>1</td>
<td>25.0%</td>
</tr>
<tr>
<td>Mortality</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>parent mortality</td>
<td>2</td>
<td>1.2%</td>
<td>2</td>
<td>50.0%</td>
</tr>
<tr>
<td>student mortality</td>
<td>3</td>
<td>1.7%</td>
<td>2</td>
<td>50.0%</td>
</tr>
</tbody>
</table>

Figure 8. The QDA Miner Lite Coding Frequency Table
Figure 8 (above) includes the actual number of times across all of the interviews for which a subcategory was coded and the number of cases (interviews) in which that category occurred. The program also included the percentages for each of those counts. Analysis of each of each of these categories and subcategories in this way is documented after the subheadings to follow. Both research questions are addressed within the following sections and sub-sections.

Review of the Categories and Subcategories Addressing Research Question #1

RQ1: How does the current mandated standards-based curricular requirements and functional, life-skills curriculum allow individuals with Severe/Profound Intellectual Disabilities to realize their post-graduation goals?

The researcher reviewed the information shared within the categories of Academic Curriculum, Functional Curriculum, Success, and Failure to answer the first research question. Academic Curriculum and Functional Curriculum both had subcategories of ‘helpful’ and ‘not helpful.’ Using QDA Miner Lite, the researcher coded portions of the interviews where the words of the family and the interview climate indicated that the Academic Curriculum was helpful in allowing their family member to reach their post-secondary goals and in ways that the Academic Curriculum was not helpful in allowing their family member reach their post-secondary goals. The same approach was taken when coding for the category of Functional Curriculum.

Academic Curriculum: Helpful and Not Helpful

Discussion regarding academic curriculum accounted for 10.4% of the codes across the study. One family stated that they felt that the academic curriculum was
beneficial. However, all four families discussed their misgivings on the benefit of the academic curriculum on aiding their loved one with SID/PID attaining their post-secondary goals. The following accounts by family members highlight their experiences and perceptions of the impact of academic curriculum in the life of their loved one.

Of the benefit of academic curriculum, Mark’s mother stated, “You want to expose [students] to everything because you don’t know what might be that lightbulb.” Only one family mentioned the benefits of academic curriculum, but all four families mentioned at least twice within their interviews that academic curriculum did not help their loved one achieve their goals and aspirations. Mark’s mother stated, “I don’t think it [academic curriculum] prepared him…I don’t think he understood it…as far as math and reading…he didn’t even care. He couldn’t even sit still for me to read a book to him; so, that kind of stuff…no.”

When Woody’s mother was asked about what she thought of the academic curriculum, she said, “It sucks…it’s stupid. It would make more sense if they would allow the academic to be what he can learn academically and not waste [his] time…” Luke’s Mother responded, “I don't know what Luke knows intellectually. I don't know how the GAA score helped him because he has a 43 IQ and communication eight-to-nine months old.” When asked if she could impact the law, would she still have him participate in academics, Luke’s mother thoughtfully replied “No. No. Because it means nothing to him…unless [he was] going to get a job.”

The interview with Esther went much differently, though. Overall, Esther’s mother and father were very unhappy with her high school career as they felt that the
teachers did not work with her as they should have. When asked about the academic curriculum, Esther’s father replied, “The curriculum is very important, but the staff is the most important part of the curriculum. The curriculum is one thing, but if the staff doesn’t do what needs to be done, [students] won’t go anywhere with it.”

Functional Curriculum: Helpful and Not Helpful

All but Esther’s family found merit in functional life-skills curriculum in providing skills necessary for post-secondary success. Esther’s family, speaking very specifically about the development of daily living skills (a component of functional life-skills curriculum) recalled, “One of the skills I asked [staff] about was brushing her teeth independently. Her mother recalled, “[The teacher] finally just said-- and I know they weren’t doing it because I bought a toothbrush and toothpaste, and at the end of the year I got it back and it was still brand new, and that really pissed me off. I should have never sent anything! And so anyway [the teacher] said ‘don't force her if that's something she's not going to learn.’ So now she's 24 years old and cannot brush her teeth.”

Esther’s family did not declare that either type of curriculum supported her as the effectiveness of any curriculum is contingent upon effective implementation by staff. Esther’s father provided an example to illustrate their feelings about the curriculum and the effectiveness of staff: “As the teaching profession goes, there are things that you want to learn [but it is up to] the person imparting the knowledge as whether [students] absorb it or not…this is just the basics of it. It's just like on a job you get someone training you on a job, and if they are a bad trainer, you won't learn the job.” Esther’s parents could not discern whether the academic or life-skills curriculum helped or hindered because
they felt that the instruction and skillset of the staff was so lacking that it would be unfair to judge a curriculum that was not effectively implemented.

However, Esther’s mother did state that Esther’s instruction during her elementary and middle school years were effective and when she made the most progress. During the high school years, Esther’s mother appealed to the staff to let Esther go in with higher functioning students like she did in elementary and middle school. Her mother recalled, “It didn't work out at all. So, we could see her going down. You know she was so interested in everything. She wasn't speaking [any] more. She wasn't doing her arts and crafts [any] more. They would do things that wasn't interesting to her on her level…she's been doing things [in middle school like] arts and crafts [displayed] outside on the wall--I kept everything you know. And then I would use those as examples of what [the teacher] in middle school did with her and they would not…they said they could not do that with her.” The focus of Esther’s family for Esther’s post-secondary success was for her to be “self-maintaining” with her daily living skills. Although Esther’s parents could not describe either curriculum as beneficial, overall their responses indicated that acquisition of life-skills were most important to them for post-secondary success.

Luke’s mother stated that in his case, “The life skills were more helpful than academic skills.” If given the option of going back and again participating in a functional life skills curriculum as well as an academic curriculum, she thoughtfully replied, “No. No. Because it means nothing to him.” After some thought she said, “And that's what we need to do is. I guess when these guys get older and we see more of what they're going to
be like to when they need those life skills. Give it to them and not focus so much on the academics…I mean, of course, unless they are going to get a job.” Mark’s mother answered similarly about her son: “I don't think...a lot of things Mark did, I don't think it prepared him. I don't think he understood it.” Ultimately, Mark’s mother desired that he “be more independent, to be able to take care of the stuff I do like bathe himself, feed himself completely, go to the bathroom…those kind of things. Those daily living things.” Woody’s mother concurred that the life-skills curriculum was more beneficial to him than the academic curriculum, adding, “They want our teachers to be proficient in linear functions instead of how to make a choice and how to tell me what [the students] want on the menu!”

Review of the Categories and Subcategories Addressing Research Question #2

RQ2: What are the perceptions of family members of students with Severe/Profound Intellectual Disabilities on how the current mandated standards-based curricular requirements and functional, life-skills curriculum allowed their child to realize their post-graduation goals?

The researcher reviewed the information shared within the categories of Independence, Success, and Failure to address the second research question. The Independence category contained six subcategories: daily living, vocational and financial, residential, social life, communication, and further education/training. The concept of Independence was mentioned a total of 82 times and accounted for 47.7% of the codes across the entire study. Independence was mentioned by all four families in five of the subcategories (daily living, vocational and financial, residential, social life, and further
education/training), and by three of the families in the remaining subcategory of communication. Review of Independence subcategories and the relation to the research questions follows. The end of this section culminates in the analysis and discussion of the families’ views of overall Success or Failure in conjunction with the data gleaned from the Independence Category. Success and Failure were coded based on the words and overall emotional timber of the conversation and are an indication of the families’ true perceptions of whether their loved one has achieved success or whether their loved one has not met their goals, and examples of why they feel this way.

Independence: Daily Living Skills

The concept of daily living skills was the most frequently mentioned within the Independence category and was the second most frequently discussed topic across all of the subcategories from the study. Further education/training was mentioned the least within the category. The researcher coded for the subcategories when the concept was mentioned; coding was not based on a specific word or phrase, and it was not based on reported success or failure within that subcategory.

Analysis of the data reveals that independence in daily living skills was a priority when planning post-secondarily for their loved one with SID/PID, with all four families mentioning this topic in response to the interview protocol. Esther’s strength in daily living skills is highlighted by her Mother in this way: “We try to make her clean up after herself…she can do some things around the house.” Her mother shared that Esther can pick up her dirty clothes and put them in the laundry basket and can pick her toys up out of the floor. However, Esther is unable to independently toilet or bathe herself, and she
still requires assistance with brushing her teeth. Woody’s mother reported that while he “knows to put the dishes in the sink when he's finished…” he is unable to discern between a paper plate from a China plate.

To compensate, after Woody finishes eating, “He will put the dish in the sink because he's not sure what else to do with it.” Woody also requires support in the restroom. Luke’s mother shared that her son required care twenty-four hours a day, seven days per week. However, she excitedly shared that where he resides now (in an assisted living group home) is “a huge success because he gain[ed] his independence!”

He completes chores in his current living situation with assistance from others, and has developed the capability of going to his bedroom “when he’s tired and [will] lie down on his bed…so he has gained his independence, and so with the school system would he be where he is today? Probably not, because [teachers] worked with him.”

Mark’s mother thoughtfully replied she would want him “to be more independent, to be able to take care of the stuff I do like bathe himself and feed himself completely…I didn’t expect for him to be completely changed—that was not going to happen—but I did want him to try to be able to take care of himself.”

Mark also requires assistance in the restroom. A common theme across each family is that they hoped and strived for independence in daily living and personal management skills. Unfortunately, this independence was met with such scarcity that Woody, Esther, Mark, and Luke all require maximum supports to meet their daily living needs.
Independence: Vocational and Financial

Upon review and analysis of the vocational and financial subcategory of the Independence category, all four families mentioned this topic in response to the interview protocol, but at a lower frequency than daily living skills. Woody’s mother recalled a time that she witnessed him working with a job coach through the community-based vocational program through the school system during the school day. She reminisced, “I will never forget watching him do that job and [Woody] loving it and knowing what to do next…,” and then surmised that she “knew he was never going to be independent” not only vocationally, but in terms of post-secondary living arrangements as well (discussed later in this section).

Esther’s father recalled that while in middle school Esther was capable of “administrative tasks--she would take attendance down to the office, and things like that. She would do it independently! At the high school, all of a sudden, that was a problem.” When asked if they ever considered whether Mark could hold down a job or live independently, his Mother replied, “Actually I didn't. I didn't think about that until after he graduated…and it was so hard to get him into different day programs. I had to take off of work and go on FMLA [Family Medical Leave Act] after he graduated because a lot of day centers weren't prepared for him.” At the time of this study, none of the former students discussed in this study were employed, meaning that one of their three post-secondary goals were not met. Table 5 is a reference of each student’s employment goal and the outcome of each goal. Given the data from the parental accounts and documentation of post-secondary vocational/employment goals from the
Transition Plan within the IEP, a third of the total post-secondary goals set for students were NOT met. The other two goals are addressed in subsequent sections.

Table 5

*Desired Measurable Post-Secondary/Outcome Completion Goals: Employment*

<table>
<thead>
<tr>
<th>Employment Goals</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody: Upon graduation from high school, Woody will participate in supported employment with an emphasis in assembly or housekeeping skills.</td>
<td>Not Met: Unemployed</td>
</tr>
<tr>
<td>Esther: After graduation, Esther will attend a day habilitation program which provides an opportunity for employment performing basic clerical duties.</td>
<td>Not Met: Unemployed</td>
</tr>
<tr>
<td>Luke: After graduation, Luke will work as a department store greeter with the support of a job coach.</td>
<td>Not Met: Unemployed</td>
</tr>
<tr>
<td>Mark: After graduation, Mark will work with the assistance of a job coach, as an assistant in a day habilitation program providing assisting with a variety of tasks.</td>
<td>Not Met: Unemployed</td>
</tr>
</tbody>
</table>

*Note.* List of employment goals from Transition Plans

Independence: Residential

Analysis of the data reveals that independence in residential skills was addressed by all four families during the interview. When asked if they anticipated Mark’s ability to move out of their home and live with some independence in a group home, his parents responded that they never even considered that as a possibility. However, they have been pleased with his performance since he moved out, as evidenced through their responses during the interview. Mark’s mother stated, “For them he does a lot more than he’ll do for us—even in the store he’ll go through the store with a grocery cart! Whatever they expect! I can see that…since he’s moved out he is capable of a lot more because they
expect him to do it!” The researcher asked Esther’s parents about their perception of success for Esther’s post-secondary activities, including the goal that she would live at home and attend a day-habilitation center. They answered, “She does go to the adult day center every day for six hours, eight thirty to three thirty…and] Esther loves it; She actually picked it out. I knew that that type of facility was what we were looking for for her, and I think it works out well.” Luke’s mother was also pleased with the residential independence developed by her son. She shared her innermost questions while Luke was in high school: “If he didn't live at home where would he be placed? [A] mental institution? [A] nursing home?” After working with exceptional caseworkers, Luke’s mother said, “It was so great because I kept thinking: he's in his home and all the stress went off of me! All of it! And that's why I say there is a God—you have to work for it but you get it done right, you will be blessed.” The thought continually crossed her mind that “Luke would be at school right now. He'd be at school right now, but he’s at home [and at] day care; [the staff is] all so loving and they were so loving to me.” When asked what Woody’s post-secondary residential goal was, his mother replied that “he was going to be with me.”

All four former students, as illustrated in Table 6, met the post-secondary residential goal documented in their Transition Plans. Woody and Esther live at home with their parents, and Luke and Mark live independent of their family in group homes. Given these outcomes as compared with their post-secondary goals, each former student successfully achieved one third of their total post-secondary goals. Further analysis
reveals, however, that although they met their goal, Esther and Woody still live with their parents, and are dependent upon their parents for their residential needs.

Table 6

*Desired Measurable Post-Secondary/Outcome Completion Goals: Independent Living*

<table>
<thead>
<tr>
<th>Independent Living (as appropriate) Goals</th>
<th>Outcome</th>
</tr>
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<tbody>
<tr>
<td>Woody Following graduation, Woody will remain at home with his family until such a time that they are unable to provide care for him.</td>
<td>Met: Lives with family</td>
</tr>
<tr>
<td>Esther Following graduation, Esther will remain at home with her family until such a time that they are unable to provide care for her.</td>
<td>Met: Lives with family</td>
</tr>
<tr>
<td>Mark After graduation, Mark will live with his family until he is able to live in a group home that can meet his needs.</td>
<td>Met: Lives in group home</td>
</tr>
</tbody>
</table>

**Note.** List of independent living goals from Transition Plans

Independence: Communication and Social Life

Communication and social life subcategories accounted for 15.1% of the coding across the study and are discussed together for this analysis. While both are critical components to a healthy and well-balanced life, neither of these subcategories directly answer either of the research questions. However, they are included in this study for a few reasons. Primarily because all individuals with ID have deficits within the communication domain; together, both subcategories were mentioned across all four interviews as a concern. Secondarily, communication and social skills indirectly support an individual’s ability to receive further education or training, to hold down a form of
employment, and to maintain residential independence. These are the three facets from
the Transition Plan that quantifiably indicate post-secondary success within this study.

Each of the individuals that this study focused on have severe expressive and
receptive language and communication deficits. All of the individuals are functionally
non-verbal; two of the individuals can utter limited single-word communications, and two
of the individuals have demonstrated no linguistic utterances. Esther’s parents identify
that their daughter is very perceptive and that “she can understand what you’re saying.”
This strength allowed Esther to determine the day habilitation program that she attends.
Her mother explained, “Esther loves it. She actually picked it out! I took her to some
other facilities…and [she] wouldn’t even sit down. There’s just something about that
facility; she can feel the spirit in there.” According to her father, Esther is thriving
socially at her day habilitation center. “Her engagement is watching folks. That’s why
she likes being around people all the time. She even reunited with a friend from high
school at her center last year! On the first day, they [led] ‘Sam’ out to go to another
class, and [Esther] had a fit! They had to put them together, and then she was quiet!”

Luke continues to struggle with self-expression. He punches himself in the face
on a frequent basis and has none of his front teeth left. When asked why he does this, his
mother responded, “Because he can’t talk, and when he hurts he can’t tell you. So, he’s
having to endure all this pain, and he can’t tell you what it is.” Socially, Luke has hit his
stride. His Mother reported, “He’s so happy where he is, and he’s so busy! They even
go to church on Sunday, and they’ll go to the park…after church, and on Saturday they
go out to lunch! He’s so happy—he has a full life!” Mark’s mother spoke of
community-based trips in high school as a beneficial activity in building his communication and social skills. When his class would go to a restaurant, “They took him up to order the food…it taught him to go out in the community. And even now with the outings, it helps him a lot. He thrives when he does those kind of things.”

Woody’s mother explained that one of his strengths is changing his voice depending on who you are. “So when it comes to people—it doesn't matter if you're black, it doesn't matter if you're white, it doesn't matter if you're a cover girl, it doesn't matter if you're bald, fat, wrinkled—doesn't matter! If you are a human being, he will acknowledge you and he will change the tone of his voice. He respects you enough that he let you know he sees the difference.” She shared that Woody’s tone would go higher for females and children when he extended greetings or goodbye; for men, he would lower his voice. She also shared that if he is not sure if you are male/female/child/adult, he will respond with one greeting of each (one high, one low goodbye).

Woody’s mother also recalls her experience when he was in school of trying to ascertain a speech-output device to enhance Woody’s communication. “[The county] did an evaluation and found that it wouldn’t be good for him, and I disagreed. I didn’t want a Big Mac—all that stuff was not good for him. I needed more. Some of these dynamic devices…are good. I [wouldn’t] have to change out the [word] twenty million times [like on] the Big Mac. I think that would have helped him a great deal with making choices.”

The staff in the day center he currently attends continue to tell his mother that a voice-output communication device would benefit him, a point that she agrees with, but that the school system did not endorse.
Social and communicative skills aid an individual in moving about society with ease, while also maintaining a job, navigating problems, and enjoying time with friends. Individuals that live with expressive and receptive language impairments have a much more difficult time with these tasks, to the point of relying on others for their needs, as the individuals in this study must do. Even understanding their strengths gives insight to how far below the normal range of functioning is and illuminates the struggle that they live with daily to belong and thrive.

Independence: Further Education and Training

The subcategory of ‘further education’ was mentioned a total of 13 times and was mentioned by all four families. This subcategory provides data that allowed for the third of three transition goals to be addressed. Some of the activities in Esther’s program include fine motor tasks, reading, and going to the library. According to her mother, Esther’s program does not “force her to do the activities they have in place and set for her to do.” When asked if they felt that Esther reached her transition goal in the place that she currently attends during the week, her father responded, “The adult setting is so drastically different because they’re not working on goals at that point…it’s just bigger, so it’s really difficult to get anything progressed.” Her mother added that the center does implement a plan for Esther on which “they still have their goals on there for her that she is supposed to work towards for them to show [parents/families]” that they are busy during the day. Luke’s mother is pleased with his current placement, as he resides in a group home, and attends a day care program for adults with developmental disabilities during the day. Prior to settling on the most recent education/training goal, Luke’s
mother recalled that the school was working with him on being a greeter at a store, and training was occurring for that. However, she understands why they changed it to the most recent goal as he was unable to fulfil the duties required to be a greeter. “He doesn't have the dexterity in his hands. He doesn't know where he is in space, so you couldn't leave him at the doors—he would just walk off. So, it's for his protection.” Mark’s mother recalled that she wanted him to go to a day program, and hoped that “he’ll learn more…as far as how to take care of himself and further his education.” Mark’s family considers Mark’s current placement a success, as the staff assists him with hand-over-hand guidance to complete his daily living tasks, and “he does a lot more [for them] than he’ll do for us!” Woody’s mother shared the struggle that training has been because of the shift from being labeled Severely Intellectually Disabled (four standard deviations below the mean) to ‘Developmentally Disabled,’ and that his daily activities are akin to those of a child. She shared, “He’s out of the school system and he’s now being called developmentally delayed again. He’s back with the little toys…on the wires that you see in the pediatrician’s office. He’s back with having pictures from regular coloring books…because there’s no money.” She further shared her frustration and displeasure with not only the curricular requirements in the public school system, but the result post-secondarily: “Once we leave the school system—because [we are] spending all this money and time worried about GAA—to put them in a warehouse where he has to get on a van that’s got holes in the seats and stuffing coming out of it.”

The further training and education components theme that emerged from each of the interviews speaks to the value of these skills to the families of loved ones with
disabilities. After analysis, only two of the individuals with disabilities met their post-secondary goal of further training (refer to Table 7) outlined in their Transition Plans.

While all four of the individuals do attend some sort of a day program for adults with developmental disabilities, only Mark and Luke are working on the training goals set forth in their Transition Plans (technically Luke’s does not contain a training component, only a participation requirement) while Woody and Esther do not receive vocational training in their day programs.

Table 7

*Desired Measurable Post-Secondary/Outcome Completion Goals: Education/Training*

<table>
<thead>
<tr>
<th>Education/Training Goals</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody</td>
<td>Upon graduation, Woody will attend a day habilitation center that will provide continued training in assembly tasks and housekeeping skills.</td>
</tr>
<tr>
<td>Esther</td>
<td>After graduation from high school, Esther will participate in a day habilitation program with an emphasis in clerical work.</td>
</tr>
<tr>
<td>Mark</td>
<td>After graduation, Mark will attend a day habilitation program for continued training in self-care skills.</td>
</tr>
</tbody>
</table>

*Note.* List of education/training goals from Transition Plans.
Success and Failure: Parent Opinion and Societal Perceptions

The families each shared experiences that happened during high school and after high school that had one of two tones in the conversation: that of success, and that of failure. When coding, the researcher relied not only on the words that were said, but the overall emotional tone of the conversation to assign a code. All four of the families expressed notions of success and failure in their interviews. Some of these notions are directly tied to the curriculum, some to staffing, and others to personal experiences. Each of the families were asked to revisit times in their lives that were at times trying and scary, and at other times triumphant and joyous. The families were gracious enough to share those experiences with the researcher, and she wanted to include those elements here. This section will illustrate families’ perceptions of success and failure to bolster understanding of their experiences.

The families all shared concepts of success. For example, two of the families favorably discussed the fact that their sons both earned a high school diploma. Woody’s mother shared, “I know he has that diploma, and it shouldn’t just say record of attendance—absolutely it should be a high school diploma! He did what he had to do to get it!” Luke’s mother recalled that she was told that “kids with the degree of disability [Luke] has don’t usually graduate from high school. That’s why I posted it on Facebook—this is his lifetime achievement award! It’s not just a high school diploma!” In theme with success in achievement, three of the four families appeared to have a positive view of the current circumstances of their loved one. Each family was asked if they would characterize their loved one’s current circumstance as positive. When asked
how she could work to make Luke’s goals a reality, his mother said “I think that we did! We did it—I did it!” She spoke of how Luke loves his life. She spoke of picking him up to attend an event that he used to attend in high school, and she recalled not picking him up because “he’s so happy where he is, and he’s so busy!” In typical young adult fashion, he had moved on from the things of his youth for his new, adult life. Esther’s parents shared that they were pleased with her day care, and that it was “the type of facility [they] had in mind for her.” Mark’s mother shared that he is “thriving” and is more cooperative with his housemates than with his family in their home. According to their families, Woody and Mark have shown more initiative and capability since interacting with outside agencies. Each of the families indicated that their loved one was capable than more than they were initially given credit for. According to his mother, Mark is “capable of a lot more” than their family previously thought. Woody’s mother shared that “he can do more than it looks like.” Esther’s parents also shared that “she understands things that are more complex.” Mark’s mother similarly shared “Just knowing Mark—he is very smart. He can do things that we don’t even think he can do. He can probably read, but [just] can’t read to us.” Luke’s mother, as shared earlier, feels that he has shown his capabilities by attaining a high school diploma. The researcher was grateful for the glimpses of positivity and recollections of success for each of the families.

While there were these markers of success, there were also documentations of failures. Over 60% of the perceptions of failure were shared by Woody’s mother. Overall, her main concern is that society needs to be “more aware socially [as to] what
the injustices [are] and ways we could help [students] once [they] leave the school system.” She very passionately discussed this concept as something that is overall lacking within the school system and within society as a whole. She feels that additional training for teachers in how to work with and explain concepts to parents is needed, and that funding should be drafted away from seemingly meaningless academic ventures and more towards independence, self-sufficiency, and vocational endeavors for individuals with ID. She recalled what a doctor said to her when she took Woody for an eye exam as indicative of how society views her child, and others with significant disabilities as well. She reported, “This young doctor who was actually part of a very important pediatric group that works with children with disabilities says to me ‘it's not like he's going to be a rocket scientist anyway.’ So because my son had a serious disability he didn't need all of his functions. The idea that someone would look…that's how people perceive our children.” Luke’s mother recalled something that she was told that coincided with some of Woody’s mother’s concerns: “I was told when he was in high school that as the kids age and get older but are still there, a lot of times the parents resort to that as babysitting services.” She did not share if this was said to her by another parent or by a staff member. The perception of individuals functioning within the SID/PID range of functioning in society is troubling and weighs heavily upon the families.

An interesting and unanticipated theme emerged as the interviews were reviewed and coded—the idea of further training for teachers was mentioned across three of the four interviews. The theme of further teacher training emerged exclusively from portions of the interviews coded in the subcategory “parent opinion failure.” Throughout their
interview, Esther’s parents shared their frustrations about the inability of staff to connect with their daughter, as evidenced previously. In reference to a line of conversation regarding utilizing documented student progress within the IEP as evidence of access to the curriculum instead of implementation of the GAA, Woody’s mother stated “I’m sorry, but you need better trained teachers…trained properly. We need better training for darn sure at the high school level.” She also spoke of being in an IEP meeting where inaccurate information was shared regarding the GAA, and that the information resulted in a student repeating a grade because of the misinformation shared by staff. She recalled another time in which a parent, in regard to his parent rights, stated “I trust you” when asked about a decision being made by a teacher about his child. When asked if she felt that there were shortcomings in his education that the school system was responsible for, part of Mark’s mother’s response was also in regard to the lack of understanding that parents have in regard to their rights and about the services their student is receiving and are entitled to. She shared that there was “a lot of the stuff I didn't understand, like as far as IEP meetings. What different things meant, and how it was explained to me. It was way over my head. I didn't... I never understood... him coming up, I never understood it. I knew I had rights, but I really never understood them. It's kind of like: ‘okay, these are your rights.’ But I think it should be explained more to parents. I think it should be that [parents] should understand it. I think things need to be explained more so [parents] can understand what their child's disabilities are, but [parents] don't [have] that understanding.” Conversely, when asked if the school system did not prepare him for graduation, Luke’s mother responded “No. No—I think the school did everything for
him because it’s hard to figure out, and I did.” There was no indication in the interview with Luke’s mother that further staff training was needed. However, although she did not indicate that additional staff training was needed, she stated that she was the one to figure out how to attain his post-secondary goals and aspirations, and that the goals on his Transition Plan was a “shot in the dark” in planning for him.

While there were glimpses of success and happiness within each of the interviews, there were also reports of failure and perceptions of shortcomings that each of the families had to endure. Overall, the successes can be found in the abilities of the students, not in their disabilities; what all they can do, not what they can’t do. The failures, conversely, tend to be recalled when others do not recognize or celebrate the abilities that are so celebrated by the students’ loved ones.

Mortality: Parent and Student

Mortality was mentioned in two of the four interviews and was coded as a category. While only half of the interviews included this topic, it is safe to assume that all four families must make arrangements for the time when the family is no longer capable of providing care. This alludes to the theme that emerged regarding the need for teacher training. In this study, immediate families shared that they felt unprepared and ill-equipped at one time or another in their journey with their loved one with SID/PID. Upon initial contemplation, the researcher heard the families discuss the need for additional teacher training. However, the type of teacher training was lost on the researcher until well into the defense of this dissertation. The mention of mortality was the least coded theme in the entire study, yet the most impactful. And a theme that
emerged was the need for teacher training, yet not anticipated or asked about by the researcher. Analysis of these themes in tandem revealed the need for teacher training on the idea of parent mortality, and how to prepare not only the student, but also the family on post-secondary options for an individual with the significant needs. This concept of mortality emerged again within the analysis of the documents, and bolstered the assertion that perhaps the needs of these former students and their families extend beyond anything that the standards-based or functional life-skills curriculum can provide.

Document Review and Analysis

The families shared documents with the researcher, including Psychoeducational Reports; 9th, 10th and 11th Grade IEPs with Transition Plans; 11th Grade GAA Reporting Scores; and 12th Grade IEPs with Transition Plans. The following sections include review and analysis of these documents.

Psychoeducational Report

Each of the four participants submitted the most recent psychoeducational report for their loved one served through special education. The purpose of a psychoeducational evaluation is to conduct a whole-person evaluation of an individual to determine current level of functioning in all domains related to cognition, communication, and adaptive functioning. The IEP team then uses the scores and findings to determine if a student is eligible for special education services and, if so, what services and supports students are entitled to. The strengths and weaknesses identified within the psychoeducational report are included in the Present Levels of Academic Achievement and Functional Performance (hereafter, PLAAFP) of the IEP and should influence and drive the goals
and objectives within the IEP. The tests used within each psychoeducational assessment are at the discretion of the evaluator. The autonomy allowed to the evaluator results in differing psychoeducational reports from one student to the next. The only similar thread found within a psychoeducational report in this study is the documentation of the students’ IQ measures, adaptive behavior functioning, and communicative functioning, in accordance with the federal and state requirements for an Intellectual Disability eligibility. A student that has a current eligibility is entitled to have a new psychoeducational evaluation performed every three years, or the parent/guardian has the right to request an evaluation as often as they wish. Each of the evaluations submitted for this study were all conducted at the request of the parent. The demographic information included in each of the psychoeducational reports can be referenced in Table 8.

Table 8

Demographic Information at the Time of the Psychoeducational Evaluation

<table>
<thead>
<tr>
<th></th>
<th>Woody</th>
<th>Esther</th>
<th>Luke</th>
<th>Mark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at the time of evaluation</td>
<td>21 years, 5 months</td>
<td>21 years, 6 months</td>
<td>17 years, 6 months</td>
<td>15 years, 5 months</td>
</tr>
<tr>
<td>Grade at evaluation</td>
<td>12</td>
<td>12</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Reason for referral</td>
<td>Parent Request</td>
<td>Parent Request</td>
<td>Parent Request</td>
<td>Parent Request</td>
</tr>
</tbody>
</table>

*Note. Demographic information from the psychoeducational report for each of the Participants.

The information of interest from each of the psychoeducational reports that was of interest for this study was documentation of the determined level of functioning and
recommendations for each of the individuals being considered. Each of the former
students are similar in that they have IQ levels ranging in the Severe or Profound Range
of Intellectual Disability. Quantitatively, these scores fall four and five standard
deviations below the mean IQ score. Typically, individuals functioning within the Severe
and Profound ranges of ID are grouped together because the population sample is so
small (equal to or <0.1% of the population). Two of the students (Esther and Luke) had a
nonverbal IQ score of 42, falling four standard deviations below the mean. The other two
students (Woody and Mark) demonstrated functioning five standard deviations below the
mean. As is evident in Woody and Mark’s cases, it is difficult to determine a specific IQ
when measuring five standard deviations below the mean, so the psychologist may elect
to place a standard deviation rating in place of an IQ measure.

The DSM IV (used until May 17, 2013) and the DSM V (published May 18,
2013, and still used today) define Moderate Mental Retardation/Intellectual Disability as
an approximate IQ measure of 36-49, Severe Mental Retardation/Intellectual Disability
as an approximate IQ measure of 20-25 to 35-40 and Profound Mental
Retardation/Intellectual Disability as an IQ measure less than that of 20-25. When
considering eligibility, the IEP team does consider their nonverbal IQ measures, but also
take into consideration another IQ measure as well as adaptive behaviors. Given the
totality of all of their scores, both Woody and Esther were both overall found to function
in the Severe Intellectual Disability range. However, the IQ measure alone does not
determine the eligibility classification. Later in the psychoeducational report, Luke’s
cognitive functioning was stated to be “commensurate with his current special education
disability placement,” which was Profound Intellectual Disability. Esther’s special education disability placement, like that of Woody and Mark, was documented as Severe Intellectual Disability.

In addition to a cognitive rating, the federal definition for Intellectual Disability requires that an individual’s adaptive functioning be significantly limited as well. Each of the students’ psychological evaluation found that their adaptive functioning was significantly limited. Woody’s psychological report states “overall adaptive delays;” Esther functions in the “extremely low range;” Luke also functions in the “extremely low range” with ratings consistent with an individual functioning within the Profound range; and Mark demonstrated “significant delays” in his adaptive skills. In conjunction with the IQ measures, the adaptive functioning of an individual also attributes to the special education eligibility.

Finally, in addition to the IQ cognitive measure and adaptive functioning levels, communication must be considered for an individual to be found eligible for an ID label. The psychoeducational report and speech evaluations for each of the former students indicated a severe expressive and receptive communication delay. Given these results, each of the students have an overall performance falling four or five standard deviations below the mean and have an overall label of Severe Intellectual Disabilities (Woody, Esther, and Mark) and Profound Intellectual Disabilities (Luke).

9th, 10th, and 11th Grade IEPs with Transition Plan

When originally planning the methodology and the types of data needed to completely tell the story of each of these families, the researcher requested the IEPs with
Transition Plans from the entire duration of high school (9th—12th grade). Esther and Luke’s parents submitted each of the IEPs requested while Woody and Mark’s parents submitted only the 12th grade IEP. Given the plentiful information provided by the 12th grade IEP alone and the lack of consistency of having only 50% of the paperwork to review, the researcher has decided to omit review and analysis of IEPs with Transition Plans other than the most recent 12th grade IEP submitted by each of the families. The participants who provided all of the high school IEPs were notified that not all of the documents would be used; the original paperwork was returned to the parents, and copies were destroyed.

11th Grade GAA Reporting Scores

None of the families participating in this study had a copy of their former students’ high school GAA Score Report. The researcher found the summarized performance level ratings within the current testing portion of the PLAAFP but was unable to gain access to the actual scores the students achieved on the academic elements of the GAA. The summarized performance ratings for each of the former students can be found in Table 9.
Table 9

*Performance Level Ratings for the High School Administration of the GAA*

<table>
<thead>
<tr>
<th></th>
<th>Woody</th>
<th>Esther</th>
<th>Luke</th>
<th>Mark</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>English/Language Arts:</strong></td>
<td>Passed: Established Progress</td>
<td>Passed: Established Progress</td>
<td>Passed: Scale Score: 3 Extending Progress</td>
<td>Did Not Pass: updated scores/ratings not provided</td>
</tr>
<tr>
<td>American Literature and Communication (Writing or Speaking/Listening)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mathematics:</strong></td>
<td>Passed: Established Progress</td>
<td>Passed: Established Progress</td>
<td>Passed: Scale Score: 3 Extending Progress</td>
<td>Did Not Pass: updated scores/ratings not provided</td>
</tr>
<tr>
<td>Coordinate Algebra or Algebra 1 and Analytic Geometry or Geometry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Science:</strong></td>
<td>Passed*: Extended Progress</td>
<td>Passed*: Extended Progress</td>
<td>Passed: Scale Score: 2 Established Progress</td>
<td>Did Not Pass: updated scores/ratings not provided</td>
</tr>
<tr>
<td>Biology and Physical Science</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Studies:</strong></td>
<td>Passed: Established Progress</td>
<td>Passed: Established Progress</td>
<td>Passed: Scale Score: 2 Established Progress</td>
<td>Did Not Pass: updated scores/ratings not provided</td>
</tr>
<tr>
<td>U.S. History and Economics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Notes.* Summary of GAA summary scores documented in 12th grade IEP for each former student. Items marked with an asterisk* indicate a re-test score result (first submission did not pass).

The GAA Score Interpretation Guide for the years of administration for each of the participants’ students (2012-2013 and 2014-2015 administration years) were not available to the researcher, so the GAA Score Interpretation Guide (hereafter SIG) for the 2017-2018 school year was used. The information gleaned from the SIG is simply the description of each of the summarized scores rendered and reported for each of the students within this study. Using the GAA scoring rubric (refer to Figure 4 in Chapter...
2), ‘dimension scores’ are assigned and then an overall score is designated for each entry. The dimension scores assigned using the rubric are then ‘patterned’ using the elements within the rubric, and then a Performance Level is assigned (see Figure 9).

![Scoring Portfolios](image)

**PERFORMANCE LEVEL DETERMINATION**

The scores for each of the dimensions are not combined to form a single numeric score. Rather, the individual scores are used to identify a score pattern that represents a combination of the dimension scores. The score patterns are organized by rubric dimension, reading left to right (see below). Fidelity to Standard, Context, Achievement/Progress, and Generalization. In the example below, a student’s score pattern would be represented as 2332 based on the four dimension scores.

Score patterns then determine the performance level classification for a student. The three performance levels, referred to as Stages of Progress, are Emerging Progress, Established Progress, and Extending Progress. The Appendix of this document lists each possible score pattern and its associated Stage of Progress based on grade and content area.

*Figure 9. Performance Level Determination captured from the GAA SIG (2017-2018 Administration)*

There are three Performance Levels: Emerging Progress (Basic/Does Not Meet), Established Progress (Proficient/Meets), and Extending Progress (Advanced/Exceeds); these levels were used for this study as this is what the researcher has access to. The reader should note that it is possible for a ‘Non-Scorable’ to be assigned if all entries for a content area do not meet the technical requirements of the GAA (Non-Scorable items can also be interpreted as “no valid score was possible”), in which that entire section is not passing. Reasons for Non-Scorable entries are teacher errors such as not submitting evidence for the entry, making a mistake on the entry sheet, or not allowing enough time between Collection Period 1 and Collection Period 2.

A Non-Scorable label will not fall under a Performance Level but causes an entire section of the portfolio to fail. An overall score of ‘3’ in a content area results in a Performance Level of Extending Progress (Advanced/Exceeds), and is characterized by a student’s demonstration of increased understanding of the fundamental knowledge and skills within a content area (English/Language (hereafter, ELA), Mathematics (hereafter, Math), Science or Social Studies) through the evidence submitted within the portfolio (tasks, captioned photos, etc.). The evidence suggests that the student is working on meaningful academic content “at an entry level or a level that approaches basic grade-level expectations,” and that are age- and grade-appropriate in form. (GADOE, 2016).

Twenty-five percent of Woody and Esther’s portfolios fell in the Extended Progress range in Science. Half of Luke’s portfolio demonstrated Extended Progress (in ELA and Math). None of Mark’s portfolio demonstrated Extended Progress. An overall score of "2" in a content area results in a Performance Level of Established Progress
(Proficient/Meets) and is characterized by a student’s demonstration of basic understanding of the fundamental knowledge and skills within a content area (ELA, Math, Science or Social Studies) through the evidence submitted within the portfolio (tasks, captioned photos, etc.). The evidence suggests that the student is working on meaningful academic content at a basic access, or entry, level and that are age- and grade-appropriate in form. Seventy-five percent of Woody and Esther’s portfolios fell in the Established Progress range in ELA, Math, and Social Studies. Half of Luke’s portfolio demonstrated Established Progress (in Science and Social Studies). None of Mark’s portfolio demonstrated Established Progress.

An overall score of “1” in a content area results in a Performance Level of Emerging Progress (Basic/Does Not Meet) and is characterized by a student’s demonstration of beginning to understand the fundamental knowledge and skills within a content area (ELA, Math, Science and Social Studies) through the evidence submitted within the portfolio (tasks, captioned photos, etc.). The evidence does not necessarily demonstrate that the student is working on meaningful academic content, or that it may be at a very basic ‘access’ level, and that materials are not necessarily age- nor grade-appropriate in form. (SIG, 2017-2018).

A score earning a Performance Level of Emerging Progress is not considered a passing score, and at the time that the students in this study took the GAA, this meant that they had to re-take the portion(s) of the portfolio scored as a “1”. None of Woody, Esther, and Luke’s portfolios fell in the Emerging Progress range. Mark’s IEP indicated that he did not pass any of the portions of his portfolio, but it was not documented if this was due
to a score of “1” or due to Non-Scorable elements. Regardless, 100% of Mark’s portfolio did not pass. At some point, Mark completed a re-take of the GAA and passed in order to graduate and receive a diploma, which he did accomplish.

12th Grade IEP with Transition Plan

Each of the participants submitted an IEP from their student’s 12th grade year. Parents are entitled to attend, participate, and encouraged to have input in the IEP and Transition Plan development for their child. There was an indication of parental involvement in each of the student IEPs reviewed for this study. Each of the IEPs contained a PLAAFP section that included recent state and local testing results, strengths, weaknesses, goals and objectives, special factors, and services provided. Each IEP also included a Transition Plan that outlined present levels of performance as related to vocation and post-secondary concerns. Based on teacher observations, conversations with the parents and any information that could be gleaned from the student, an education/training, employment, and independent living goal was developed and documented in the Transition Plan. Based on these post-secondary goals, goals and activities were considered and written to meet these expectations in the domains of education/training, development of employment, community participation, adult living skills and post school options, and related services.

Table 10 provides an overview of the academic goal domains and number of objectives (percentage of the goals) addressed for each student. In analyzing the domains that are addressed within each of the IEPs, the researcher found that every student was exposed to direct instruction in the areas of self-management skills, and community
skills. IEP goals and objectives are written to address specific deficits listed within the PLAAFP section of the IEP as well as within the psychoeducational report. However, given the clear and significant delay in both cognition and communicative skills in each of the students, only half of the IEPs contained a goal addressing functional academics, and one IEP addressed the communication deficit with which all individuals with ID live.

Table 10

*Annual Goal Domains Addressed in 12th Grade IEP*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Woody</th>
<th>Esther</th>
<th>Luke</th>
<th>Mark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Management Skills</td>
<td>Yes: 25% (3/12 objectives)</td>
<td>Yes: 55.55% (5/9 objectives)</td>
<td>Yes: 33.33% (3/9 objectives)</td>
<td>Yes: 25% (2/8 objectives)</td>
</tr>
<tr>
<td>Community Functioning Skills</td>
<td>Yes: 16.66% (2/12 objectives)</td>
<td>Yes: 22/22% (2/9 objectives)</td>
<td>Yes: 22.22% (2/9 objectives)</td>
<td>Yes: 25% (2/8 objectives)</td>
</tr>
<tr>
<td>Vocational Skills, Career Prep Skills</td>
<td>Yes: 8.33% (1/12 objectives)</td>
<td>Yes: 11.11% (1/9 objectives)</td>
<td>Yes: 22.22% (2/9 objectives)</td>
<td>Yes: 25% (2/8 objectives)</td>
</tr>
<tr>
<td>Functional Academic Skills</td>
<td>Yes: 41.65% (5/12 objectives)</td>
<td>Yes: 11.11% (1/9 objectives)</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Recreation/Leisure Skills</td>
<td>No</td>
<td>No</td>
<td>Yes: 22.22% (2/9 objectives)</td>
<td>Yes: 25% (2/8 objectives)</td>
</tr>
<tr>
<td>Communication Skills</td>
<td>Yes: 8.33% (1/12 objectives)</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

*Note.* Overview of the domains of the goals and objectives within the IEP of each of the Participants’ former students. Also included is the percentage of objectives for each domain.
In Woody’s IEP, 49.98% of the objectives addressed academics and communication and 11.11% of Esther’s IEP addressed academics, but not communication. Neither Luke nor Mark’s IEP addressed deficits in the academic or communication areas at all. The highest percentage of the objectives addressed for Woody was the functional academic domain (41.65%). Esther and Luke’s IEPs self-management skills occupied the lion’s share of objectives (55.55% and 33.33%, respectively). Mark’s IEP indicated an equal focus on each of the four domains addressed by goals and objectives (25% each) in his document.

Using the percentage of the objectives within each IEP as a guide, self-management skills yielded the highest percentage of objectives for two of the four students, and the second highest for another. Given this frequency, the researcher gleaned that self-management skills are not only a deficit for each of the students, but a critical component of development as these were the goals for their final year in school. Following this line of thinking, 100% of the four different IEP teams, on different dates and in different schools, consistently addressed self-management, community functioning, and vocational/career preparation skills as critical components that needed to be addressed prior to graduation. When viewed through the lens of the research question, the IEP teams, with the student and the family as members, consistently placed emphasis on self-management, community functioning, and vocational/career prep skills as most helpful in preparing the student to meet his/her postsecondary goals and aspirations. Of all of the objectives combined, self-management skills occupy 34.19% of the objectives, community functioning 21.04%, and vocational/career prep skills 15.78%. Had all of the
IEPs addressed deficits in functional academics, on average 13.19% of the objectives would have been assigned to that domain, and, on average, only 2.08% of the objectives would have addressed communication deficits. The lower frequency and percentage of the functional academic domain could be viewed as indicative that IEP teams do not put emphasis on the impact of functional academics, but rather that of self-management, community functioning, and vocational/career prep skills.

The Transition Plan is also a requirement within the current IEP of a student turning sixteen years old or going into 9th grade, whichever comes first. Transition is the movement from school to post-school environments. The State of Georgia cites that transition “requires support from multiple sources for the student and his/her family to make choices, develop connections, and access services” (GADOE, 2015). The Transition Plan states the preferences, strengths, interests, and course of study based on present levels of performance and age appropriate transition assessments. These components should include “the skills necessary for the student to be successful in education, employment, and independent living after completion of high school” (GADOE, 2015). The State of Georgia states that “the student should be involved in the transition components of the IEP and should be invited to this portion of the IEP meeting” (GADOE, 2015). More often than not, students functioning within the cognitive range of the students being addressed within this study are not included in their own Transition Planning, and goals are set at the discretion of the IEP team, hopefully to include input from their parents. In these cases, the State of Georgia mandates that “if the student does not attend the IEP meeting, the school system must take other steps
including verbal and written input to ensure that the student’s preferences and interests are considered before developing the transition aspects of the IEP” (GADOE, 2015). This is critical because when the student graduates or ages out, the entity responsible for the individual with disabilities is the family. Based on the present levels and input from the student, parents, and staff, the IEP team develops desired measurable post-secondary outcome completion goals. These goals are to be achieved after graduation and must address education/training and employment. Independent living goals should be determined as appropriate. Students with the cognition and adaptive functioning within the range of the students within this study require that independent living goals be determined. Table 11 delineates the Transition Plan goals for post-secondary completion goals for each of the students.
These goals are to be determined with the input of the parent, the student, and staff. Woody’s Transition Plan cites development of the plan “based on student preferences, teacher observation and parent interview.” Esther’s Transition Plan contains

<table>
<thead>
<tr>
<th><strong>Education/Training Goals</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody</td>
</tr>
<tr>
<td>Esther</td>
</tr>
<tr>
<td>Luke</td>
</tr>
<tr>
<td>Mark</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Employment Goals</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody</td>
</tr>
<tr>
<td>Esther</td>
</tr>
<tr>
<td>Luke</td>
</tr>
<tr>
<td>Mark</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Independent Living (as appropriate) Goals</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody</td>
</tr>
<tr>
<td>Esther</td>
</tr>
<tr>
<td>Mark</td>
</tr>
</tbody>
</table>

*Note. List of post-secondary goals from Transition Plans*
evidence of parent input, “Community Based Vocational Instruction data and teacher observation” as the source of development. Luke’s Transition Plan is based on input from his mother, teacher observation, and Luke’s responses on the Reading-Free Vocational Interest Inventory-2nd Edition. Mark’s Transition Plan does not cite the method in which his interests were documented or how his goals were developed.

In review of the education/training outcome, 100% of the IEP teams felt that further training within a specific vocational area through a day habilitation program was an appropriate and acceptable goal. The experience of this researcher enables an understanding of the meaning “day habilitation” in this case to reference any sort of adult day care facility that will work with individuals on goals that may or may not lead to employment, based on the independence of the individual. The implication of this goal of further training indicates an inability on behalf of 100% of the students within this case to leave high school ready to search for a job and be successful within employment. The employment goal, while skewed and not common in the area of employment, has a common theme that each of the individuals will require support and supervision when employment is achieved. Within the context of the psychoeducational reports, PLAAFPs, and documentation of parent concerns, this is to provide safety for each of the then-students on the job as they are unaware of potentially harmful situations (i.e., physically harmful chemicals or situations like crossing a parking lot), threatening situations (i.e., abduction situations), an inability to communicate wants and needs and a deficit in decision-making skills. These concerns (not exhaustive) are life-long factors that must be considered for an individual with significant cognitive impairments.
anywhere at or four or more standard deviations below the mean range of functioning. The focus of the job being trained for is based on documented strengths and areas of interest.

The independent living goal was split down the middle with the students in this case study. The parents of two students cited that their children would live outside of the home in a supported situation or in a group home. The parents of the other two students resigned that their child would live with them until they (the parent) was no longer able to care for them. As the researcher initially read through the Transition Plans, a clinical understanding of the language within the independent living goal identified that the two families that elected for their child to remain at home with them would make provisions for these students to stay at home until they could no longer care for them. However, the language used in Esther and Woody’s IEP began to resonate and caused the researcher an unsettled feeling. The words “the student will remain at home until such a time that they [the parents] are unable to provide care for him/her” cycled over and over within the soul of the researcher. The impact of those words—the unsettled feeling—was finally revealed—“until such a time that they are unable to provide care for him/her.” The words were haunting. The “time” referred to in these goals addresses the mortality of the parent(s). “Until such a time…” and then what? What happens at “such a time?” As impactful as this concept was to this researcher, the implication of those few words on Esther and Woody were difficult to comprehend.

Three of the four Transition Plans analyzed were based on teacher observation of student skills and interests. These same three included input from the parent. One of
these included direct input from the student through a vocational inventory that he completed. One of the Transition Plans analyzed did not cite input from the parent or the student. The State of Georgia states that the Transition Plan should “include the skills necessary for the student to be successful in education, employment, and independent living after completion of high school” (GADOE, 2015).

Each of the participants were asked to submit various documents developed while their loved one with cognitive impairment was in the public school system. The researcher sent the email (see Appendix F) to inform the participants of their commitments in participating in this study, including the documents requested by the researcher. Overall, each participant submitted a psychoeducational evaluation and a 12th grade IEP with a Transition Plan. None of the participants provided a copy of the high school GAA report to submit, but those scores were available in the PLAAFP of each of the IEPs. The researcher elected not to use the 9th, 10th and 11th grade IEPs submitted by two of the families as the information gleaned from the 12th grade IEP and Transition Plan were sufficient, and comparable across all four participating families. Upon review of the documents, it was determined that each of the former students functioned four and five standard deviations below the mean given a whole-child assessment (cognition, adaptive behavior, and communication). An interesting finding was also that even though federal law mandates access to the general curriculum, that not all of the IEPs addressed functional academics through the annual goals. However, had all of the IEPs addressed deficits in functional academics, on average only 13.19% of the objectives would have been assigned to that domain. Making the assumption that the higher the
frequency, the more impactful the skill set for success in life, of all of the objectives combined, self-management skills occupied 34.19% of the objectives, community functioning 21.04%, and vocational/career prep skills 15.78%.

Results by Individual Participant

The following sections include descriptions of data analysis for each of the students in this study.

Participant #1: Woody and His Family

Access to Woody’s most recent psychoeducational evaluation, dated March 4, 2015, revealed that he exhibits significant developmental delays across all domains (physical, adaptive behavior, social-emotional, cognitive, and communication) as determined by the Developmental Profile 3 (DP3) assessment. Scores for the DP3 are derived utilizing input from parents and caregivers to provide information for each of the five key domains. Although the DP3 is designed to assess the functioning of children from birth through twelve years of age, the publisher also stipulates that the DP3 “has appropriate application through adulthood for cases where very serious delay is present and there is a need to document adaptive and developmental skills in the range assessed by the DP3” (Alpern & Boll, 1972). With the use of the DP3 in this manner, the age equivalency for each of the domains for Woody can be found in Table 1 below. The psychoeducational report included scores for the DP2 from the previous assessment in 2002. Those scores are included in the Table 12 as well as an example of the amount of growth typically achieved by an individual with an Intellectual Disability. This is simply for comparison to a typically developing individual to impact the reader’s understanding
of the participant’s strengths and struggles. The description of each domain will only address the scores from the DP3 in 2015 as this is the most recent testing information, and most accurately reflects Woody’s current level of functioning.

Table 12

Woody: Developmental Profile Age Equivalence for Intellectual Functioning

<table>
<thead>
<tr>
<th>Developmental Profile Scale</th>
<th>Age Equivalency of DP3: 2015</th>
<th>Age Equivalency of DP2: 2002</th>
<th>Change in Age Equivalence Over 12 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>28 months</td>
<td>20 months</td>
<td>+ 8 months</td>
</tr>
<tr>
<td>Adaptive Behavior</td>
<td>34 months</td>
<td>20 months</td>
<td>+ 14 months</td>
</tr>
<tr>
<td>Social-Emotional</td>
<td>20 months</td>
<td>18 months</td>
<td>+ 2 months</td>
</tr>
<tr>
<td>Cognitive</td>
<td>26 months</td>
<td>20 months</td>
<td>+ 6 months</td>
</tr>
<tr>
<td>Communication</td>
<td>20 months</td>
<td>18 months</td>
<td>+ 2 months</td>
</tr>
</tbody>
</table>

*Note. Age equivalence for Participant Woody, including change in score over 12 years. Scores obtained from parent ratings in 2002 and again in 2015.*

The Developmental Profile Physical Scale assesses gross (large) and fine (small) muscle coordination and movement, strength, stamina, flexibility, and sequential motor skills. Notation within the psychoeducational report indicates that Woody is sufficiently independent with his gross motor skills, but struggles with fine motor tasks, such as drawing shapes with accuracy, using a house key to open doors, or using scissors to cut paper. This rating concurs with the rating given by Woody’s mother in her questionnaire in that Woody has no significant motor dysfunction that requires adaptations; scales of
the DP3 reveal that even adaptations would not help because of Woody’s level of
dependence upon others for his needs attributed to his cognitive functioning (discussed
further as this section and the chapter progresses). Woody’s level of motor functioning is
not addressed in the PLAAFP, nor through his annual goals or objectives in his most
recent IEP provided for this study, dated March 12, 2014. An absence of addressing
motor skills in the IEP typically indicates that the fine and gross motor skills are adequate
for the educational setting and all that is included within that scope. Proving this
assumption accurate, the Transition Plan within the IEP indicates that “Woody’s interest
is in assembling items” and that at the time he “pans cookies at [the] Publix Bakery,” a
vocation that requires adequate fine and some gross motor independence. Woody’s
physical functioning increased over twelve years from an equivalent to a child of 20
months old (1 year, 8 months) at age 8 years to that of a child 28 months old (2 years, 4
months) at age 21 years, but he is capable of motorically accessing an educational setting,
including the vocational settings outlined in the Transition Plan.

The Developmental Profile Adaptive Behavior Scale assesses an individual’s
ability to cope independently with the environment (i.e. eating, feeding oneself, dressing,
working, using current technology in a manner intended, and overall ability to take care
of oneself and others). Results of the DP3 as well as from the questionnaire indicate that
Woody can toilet independently. His mother defines independent toileting as “toilet
trained” within the questionnaire, indicating that when Woody is prompted to use the
restroom, he will enter the restroom and eliminate in the toilet. The DP3 reveals that
Woody can use a fork and spoon to feed himself, snap fasteners, button buttons, and can
put a limited number of items in their place (i.e., dishes, laundry, etc.). Woody does require assistance with dressing, using a knife, dialing a phone, and accessing the Internet. His IEP states that “he will remain on task during vocational activities with no reminders…he enjoys sorting exercises…will put away materials at the completion of each task without verbal prompting” and that he participates in morning routines with verbal prompting when he arrived at school.

According to his mother’s interview, high school staff increased Woody’s skill set by capitalizing on his love of Disney movies by teaching him to sort and put items away using the VHS and DVD cases of his movies. This skill generalized from school to home. Woody’s Transition Plan indicates an implementation of this strength at his work site as “he has demonstrated the ability to perform a variety of multi-step vocational activities and…is a willing participant in vocational activities and remains on task until the activity is complete.” In the questionnaire, his mother shared that Woody did have school jobs in high school. Woody’s overall educational and training Desired Measurable Postsecondary/Outcome Completion Goal states that “upon graduation, Woody will attend a day habilitation center that will provide continued training in assembly task and housekeeping skills.” The Transition Plan reveals the team’s consensus regarding employment that, based on Woody’s strengths and interests, “upon graduation from high school, Woody will participate in supported employment with an emphasis in assembly or housekeeping items.” Woody was supported with attaining these overarching goals were supported by school staff through goals and activities outlined in his Transition Plan evidenced in Figure 10.
Overall, Woody’s adapted behavioral functioning increased over twelve years from an equivalent to a child of 20 months old (1 year, 8 months) at age 8 years to that of a child 34 months old (2 years, 10 months) at age 21 years, but he is capable of performing a variety of multi-step vocational activities given the tasks are set up and he has been given explicit instruction on the task and is not expected to make decisions regarding the task, his safety, or direction for others. He does require a structured schedule with someone to prompt him through the schedule and to monitor him for his safety.

The Developmental Profile Social-Emotional scale examines interpersonal skills, social and emotional understanding, functioning in social situation, and the manner in which the student relates to peers and adults. The psychologist indicated that human contact comforts Woody when he is upset, and that he is more likely to comply with requests from a familiar adult over a stranger but that he does not indicate a desire to play

**Figure 10. Transition Plan Education and Training Goals Captured from Woody’s IEP**

<table>
<thead>
<tr>
<th>Transition IEP Goal(s)</th>
<th>Transition Activities/Services</th>
<th>Person/Agency Involved</th>
<th>Date of Completion/Achieved Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>While participating in Community Based Vocational Instruction, Woody will receive</td>
<td>1. Perform community vocational training tasks with direct supervision.</td>
<td>teacher, paraprofessional</td>
<td></td>
</tr>
<tr>
<td>training in two community-based vocational training site’s moving from a direct</td>
<td>2. Perform in-school vocational training tasks with direct supervision.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>level of supervision to partial supervision.</td>
<td>1. Arrange a trial day at each of these facilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Learn and begin the process for entry into chosen option.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woody will make a trial visit to at least two different day habilitation programs to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>prepare for post-secondary support.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
with peers. Woody can watch television in 15-minute increments and he can remain working on a single task for a maximum of 30 minutes before losing focus. However, during the interview, his mother shared that Woody loves Disney movies, and will watch a movie in its entirety if he is interested. A portion of the psychoeducational report contradicts other evidence in regards to Woody’s participation or ‘play’ with others. In the questionnaire, his mother shared that Woody was a member of his high school’s flag football team for individuals with disabilities. This football team and the cheer squad was founded, initiated, and is run by special education staff on a volunteer basis in some of the high schools across the county (not a mandatory activity). In the interview, his mother shared that when Woody would show up for practice or a game that the other teammates would exclaim “Woody’s here! We can go play now!” and that Woody’s abilities and inabilities did not matter, but that “everybody wanted Woody to play! Everybody!” She also shared that when he arrived at practice “he would run down the stairs! I finally had to hold him back to get down there” so that she could help keep him safe while traversing the steps. His mother further shared that while the team waited on everyone to arrive to practice, they would play basketball and that “Woody learned to shoot…basketballs at high school. Who would think he could do such a thing?!” and that his enthusiasm was obvious before arriving and that he “loved to go.” So, although the responses to the clinical assessment did not indicate Woody’s social interest in interacting with others, his experiences and attitude demonstrated otherwise. However, for the purpose of post-secondary employment, the Transition Plan combined Woody’s community participation with social skills embedded, as evidenced in Figure 11. The
IEP team felt that these activities would increase Woody’s ability to meet his post-secondary goals and aspirations.

![Table]

**Figure 11.** Transition Plan Community Functioning Goals with Socialization Skills

Embedded Captured from Woody’s IEP

Woody’s social-emotional functioning increased over twelve years from that equivalent to a child of 18 months old (1 year, 8 months) at age 8 years to that of a child 20 months old (1 year, 8 months) at age 21 years. While his cognition certainly acts as a barrier for Woody to socially engage with others and maintain his emotionality as with typically developing individuals, he has shown some development that even clinical assessments that are normed for neuro-typical society do not detect.

The Developmental Profile Cognitive Scale assesses an individual’s abilities and skills prerequisite to academic achievement. The psychoeducational report states that while Woody can point to at least twenty different pictures or objects when named and can sort items by color, shape, and size, he is unable to count items, distinguish coin values, and tell time on an analog clock. Woody’s mother reported in the questionnaire
that Woody has no observable awareness or understanding of print, Braille, or use of numbers. Twenty percent of the description of academic, developmental and functional strengths in Woody’s PLAAFP addressed academic and cognitive elements while 80% addressed vocational and communicative strengths. The strengths addressed included answering questions following a short story using an AAC device and indicating this answer when given a field of one or two pictured choices with verbal cues. Ten percent of the description of academic, developmental and functional needs (weaknesses) in Woody’s PLAAFP addressed an academic/cognitive need: he sometimes needs a prompt to respond to a visual choice to indicate his answer. The other 90% of this portion of his IEP addressed communication, self-help and community functioning. However, one of Woody’s five annual goals addressed functional academics, and five of 12 (41.65%) of the short-term objectives within those annual goals focused on functional academics. The frequency of the goals and objectives are summarized in Table 13.
Table 13

Woody: Annual Goals and Short-Term Objective Frequency Analysis

<table>
<thead>
<tr>
<th>Annual Goal</th>
<th>Number of Short-Term Objectives/Benchmarks</th>
<th>Percentage within the IEP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Goal 1: Functional Academic Skills</td>
<td>5</td>
<td>41.65%</td>
</tr>
<tr>
<td>Annual Goal 2: Career Preparation Skills</td>
<td>1</td>
<td>8.33%</td>
</tr>
<tr>
<td>Annual Goal 3: Community Skills</td>
<td>2</td>
<td>16.66%</td>
</tr>
<tr>
<td>Annual Goal 4: Self-Management Skills</td>
<td>3</td>
<td>25%</td>
</tr>
<tr>
<td>Annual Goal 5: Communication Skills</td>
<td>1</td>
<td>8.33%</td>
</tr>
<tr>
<td>Total: 5 Domains</td>
<td>Total: 12 Objectives</td>
<td></td>
</tr>
</tbody>
</table>

Note. Analysis of the percentage of the IEP goals and objectives determined appropriate for Woody’s academic, behavioral, communicative and vocational success.

Although not addressed as a weakness within the PLAAFP, an annual goal for functional academics was written, and occupied the highest percentage of all the goals addressed that school staff documented, collected data on, and focused time on. However, these goals do not appear to impact, support, nor mirror the goals that were discussed earlier in the Transition Plan portion of the same IEP. The Transition Plan indicates the post-secondary goals and aspirations that Woody and his family have for his life after graduation. Yet, 41.65% of the short-term objectives are focused on access to the general curriculum as mandated in state and federal laws. Figure 12 illustrates the short-term objectives that are “measurable, intermediate steps or targeted sub-skills to enable student to reach annual goals” to improve Woody’s functional academic skills. Implications of these goals with respect to Woody’s cognition are discussed later in this
section as well as later in the chapter. However, the researcher feels that the observation of Woody’s mother bears repeating given the analysis just described: “Woody has no observable awareness or understanding of print, Braille, or use of numbers.”

<table>
<thead>
<tr>
<th>MEASURABLE ANNUAL GOALS &amp; SHORT TERM OBJECTIVES/BENCHMARKS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measurable Annual Goal 1 of 5:</strong> Will improve Functional Academic Skills to the criteria indicated below by each short term objective.</td>
</tr>
<tr>
<td><strong>Short term objectives/benchmarks</strong></td>
</tr>
<tr>
<td>1.1. After participating in supported reading of literature forms (i.e. chapter books, biographies, poems, fiction and nonfiction works), using communication devices will answer simple questions when presented with picture/symbol cues.</td>
</tr>
<tr>
<td>1.2. Will select a picture/symbol to correctly identify basic geographical locations/places (i.e. cities, states, land, water forms), using communication devices when given no more than 1 verbal cue.</td>
</tr>
<tr>
<td>1.3. Will use communication devices to select numbers and/or count objects within a two-step math problem in the context of a real-world scenario given 1 verbal cue.</td>
</tr>
<tr>
<td>1.4. Will use communication devices to actively participate in a scientific process related to science topics by performing the steps necessary to complete the task when given 1 verbal cue.</td>
</tr>
<tr>
<td>1.5. Will participate routinely in supported writing activities using picture symbols and communication devices or hand over hand guidance.</td>
</tr>
</tbody>
</table>

**Figure 12.** Annual Goal and Short-Term Objectives for Functional Academics Captured from Woody’s IEP

The Georgia Alternate Assessment was administered to Woody during his 11th grade year, and the results were returned to the school system in May 2013. Scores were documented in the Results of State and District Assessments within the PLAAFP and are contained in Table 14.
Table 14

*Woody: Georgia Alternate Assessment Scores During Eleventh Grade Year*

<table>
<thead>
<tr>
<th>Content Area</th>
<th>Result (Pass/Fail)</th>
<th>Progress Determination</th>
</tr>
</thead>
<tbody>
<tr>
<td>English/Language Arts</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Mathematics</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Science</td>
<td>Fail</td>
<td>No Progress</td>
</tr>
<tr>
<td>Social Studies</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Science (Re-test administered Fall 2015)</td>
<td>Pass</td>
<td>Extended Progress</td>
</tr>
</tbody>
</table>

During her interview, Woody’s mother indicated that the reason for the failure of the science portion in the initial administration was due to a clerical error on behalf of the teacher, not lack of progress on Woody’s part; the teacher inadvertently neglected to indicate the Characteristic of Science on the entry sheet of the portfolio. Upon review, Woody’s cognitive functioning increased over twelve years from an equivalent to a child of 20 months old (1 year, 10 months) at age 8 years to that of a child 26 months old (2 years, 2 months) at age 21 years. Woody’s mother reported in the questionnaire that Woody has no observable awareness or understanding of print, Braille, or use of numbers, and while the PLAAFP only contains minimal information and no baseline data regarding Woody’s cognition and academic functioning, 41.65% of the short-term objectives are focused on access to the general curriculum.

The Developmental Profile Communication Scale explores expressive and receptive communication skills. These skills include an individual’s abilities in written, spoken, and gestural language. Woody has an eligibility of Speech Impaired and is functionally non-verbal. However, the psychoeducational report documents that he does
look towards the speaker when someone begins to speak. He will imitate speech that he hears to the best of his ability and will use some simple sounds to indicate a desire for items (i.e., ‘wa wa’ for ‘water’). Woody does not string words together to form spoken sentences but can verbalize some phrases such as “love you” and “bye-bye.” The Functional Communication Profile (hereafter FCP) was also administered by a Speech/Language Pathologist (hereafter SLP) to Woody in 2015 and referenced as part of the psychoeducational report by the psychologist. This assessment tool is used to evaluate communication skills in individuals with developmental and acquired delays across a wide range. The SLP asserts that the FCP is “a comprehensive guide that assesses Sensory, Motor Behavior, Attentiveness, Receptive Language, Expressive Language, Pragmatic/Social, Speech, Voice, Oral and Fluency.” The SLP summarized that Woody is a non-verbal communicator who can express basic needs and wants through his AAC device as well as through pointing. He can produce a few single words, as stated earlier, and defined as “bye,” “stop,” “okay,” and “love you.” Woody can follow one-step commands. The SLP reported that her assessment showed that Woody does not interact socially with his peers, and that he enjoyed listening to music and drawing alone. Ultimately, Woody exhibits a severe receptive and expressive language impairment. Within the PLAAFP of Woody’s IEP, the speech portion indicated that his strength is that after listening to a short story from the adapted curriculum, that he can indicate his answer given a field of one or two with verbal cues and his weakness/need as requiring prompting to respond to a visual choice to indicate his answer. Given that Woody exhibits a severe receptive and expressive communication deficit, the IEP team
included an annual goal to address communication skills with one short-term objective of using a low-tech, two-button AAC device to communicate requests and responses to others 50% of the time. Woody’s Transition Plan does not have direct communication goals but could reasonably be embedded within several of the activities listed. Overall, Woody’s communicative functioning increased over twelve years from an equivalent to a child of 18 months old (1 year, 8 months) at age 8 years to that of a child 20 months old (1 year, 10 months) at age 21 years. While Woody cannot functionally speak, he can make very simple wants and wishes known through limited one-word utterances and gestures as well as through pointing.

The psychoeducational report summarizes the results in this way: “Results of the DP3 indicate that Woody exhibits significant developmental delays across all domains,” and in consideration of his level of functioning with each of the five domains previously discussed and calculated using a ratio developed specifically for the DP3, the ratio quotient “falls more than five standard deviations below an average quotient for each scale. This would indicate that his current level of functioning falls within the severe range of Intellectual Disability.” The results of the 2015 testing were commensurate with previous testing that indicated global developmental delays.

Participant #2: Esther and Her Family

Access to Esther’s most recent psychoeducational evaluation, dated December 7, 2015, reveals that she exhibits significant developmental delays across all domains (physical, adaptive behavior, social-emotional, cognitive and communication) as determined by several assessment measures, including the Stanford-Binet Intelligence
Scales-Fifth Edition (hereafter, Binet-V), the Behavior Assessment System for Children-Second Edition: Teacher/Parent Rating Scales (hereafter BASC-2: TRS/PRS), the Functional Communication Profile (hereafter, FCP), and the Adaptive Behavior Assessment System-Third Edition (ABAS-3). An overview of each of the domains for each of the assessments for Esther can be found in Table 15. Esther was not administered a formal assessment for her gross (large) and fine (small) muscle coordination and movement, strength, stamina, flexibility, and sequential motor skills. The questionnaire completed by her mother and father revealed no significant motor dysfunction that requires adaptations. The psychoeducational report stated that Esther is unable to open containers or prepare food, but that she can feed herself with eating utensils and is ambulatory.
Table 15

*Esther: Levels of Functioning Based on 2016 Psychoeducational Evaluation*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Assessment Administered</th>
<th>Score/Rating</th>
<th>Qualitative Rating/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Learner Characteristics Inventory (not administered as part of the psychoeducational report)</td>
<td>No rating issued</td>
<td>No significant motor dysfunction that requires adaptations</td>
</tr>
<tr>
<td>Adaptive Behavior</td>
<td>ABAS-3</td>
<td>General Adaptive Composite (GAC) Teacher: 47 Parent: 50</td>
<td>Teacher and Parent rated in the extremely low range</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Binet-V (reported in standard score)</td>
<td>Binet-V: Nonverbal IQ: 42</td>
<td>Binet-V: Moderately Delayed</td>
</tr>
<tr>
<td>Communication</td>
<td>FCP</td>
<td>Formal score not provided</td>
<td>Presents with a severe receptive and expressive language disorder</td>
</tr>
</tbody>
</table>

The Special Education Eligibility Report dated 2/24/2016 listed “she is mobile” as a motor strength for Esther, and “she is not writing information and has difficulties with opening food packages, lids, etc. She needs help with dressing” as motor weaknesses.
Her mother stated that Esther is mobile and very independent at home with certain tasks. Further understanding of these tasks were revealed during the interview. Esther is motorically capable of brushing her teeth and bathing herself, but she elects not to, and requires full support from her parents. In summary, Esther has sufficient gross motor skills to navigate her surroundings and environments that she commonly visits. Esther’s fine motor skills are in tact but in combination with her cognition and behavioral issues, she requires assistance in many daily living tasks such as opening food containers and dressing herself.

As part of a comprehensive evaluation, the ABAS-3 was administered to Esther to determine her adaptive behavioral functioning. The ABAS-3 is a rating scale used to assess daily living skills in individuals with, among other disabilities, developmental delays and intellectual disabilities. The assessment revealed several personal strengths for Esther. Esther can independently feed herself and she is ambulatory. She is “trip trained” for toileting, meaning that when taken to the restroom, she will eliminate in the toilet. However, she typically does not initiate or indicate that she needs to use the restroom; she will refrain from using the restroom until someone else initiates going. Esther can also indicate understanding by executing tasks that are familiar to her. The assessment also revealed struggles for Esther. The overall rating of Esther’s adaptive behavioral skills is illustrated in Figure 13.
Figure 13. Annual Goal Addressing “Self-Management” and Short-Term Objectives from Esther’s IEP Addressing Adaptive Behavior Deficits

An element of interest from the interview arose as Esther’s mother and father discussed some of Esther’s struggles and how they worked with the school to improve her adaptive behavioral skills. Esther’s mother spoke with the teacher about strategies for helping to build Esther’s independence in brushing her teeth. According to Esther’s mother, the teacher advised to not “force her if that's something she's not going to learn…don't beat yourself up trying to force her to do that...just pick the skills that she can handle.” Esther’s mother concluded by saying “So now she's 24 years old and cannot brush her teeth.” The researcher wanted to highlight this part of the discussion as the frustration on behalf of the parent was palpable—there is a documented area of deficit, and the teacher advised against working on it. Esther’s Transition Plan also addressed her deficits in adaptive behavioral functioning by assigning the task of performing a
weekly chore at home and within the classroom. Figure 14 illustrates the expectation the IEP team held for Esther to transition from school to post-secondary options regarding her adaptive behavior skills.

Figure 14. Adult Living Skills & Post School Option Goals and Activities from Esther’s Transition Plan

Esther does demonstrate some strengths in her adaptive behavior skills such as feeding herself independently and performing simple clerical duties (shredding and filing) with partial physical assistance, but overall functions in the extremely low range. Function within the extremely low range indicates that Esther’s overall adaptive behavior can be characterized as lower functioning than that of almost all individuals her age.
The BASC-2 was administered to Esther to determine her social-emotional functioning. The BASC-2 is a multi-method assessment used to Esther’s social, emotional, adaptive, and behavioral functioning with the school, home, and community settings. The method of assessment for Esther were rating scales completed by her teacher (TRS) and by her parent (PRS). Teacher ratings indicated that Esther was ‘at-risk’ for difficulty relative to attention problems and her social skills. Parent ratings completed by Esther’s mother showed significant difficulty in regard to her social skills. Specifically, Esther does not show interest in the ideas of others. The score used for this study from the BASC-2 provides ratings in the form of t-scores based on a mean of 50 and a standard deviation of 10. Figure 15 shows a bell curve with these specifications; 50 is considered average. Notations have been made on the bell curve to illustrate where the teacher and parent ratings fell for Esther’s social functioning.

Figure 15. T-Score Bell Curve of Esther’s Social Skills Indicated
The Special Education Eligibility Report states Esther’s general strength in the social-emotional domain is that she has a preference and can discriminate between people that she is comfortable with. Her weakness is that she has difficulty in adjusting to changes with the introduction of people with whom she is unfamiliar or to an unfamiliar task. A documented social strength within the PLAAFP states that Esther “can be very affectionate with adults and responds positively to verbal praise and attention.” She also “increased her interactions with…peers who intermingle with her.” However, social-emotional deficits listed includes that Esther “does not initiate social interactions with her peers.” Although listed as a deficit, an annual goal was not included in the IEP to improve this skill. Esther’s social-emotional deficits were not addressed at all within her Transition Plan nor within the goals and activities. Although the observations that drove the rating scales within the psychoeducational report indicated at-risk and significant difficulties within Esther’s social-emotional functioning, Esther’s mother and father shared that they are pleased with the social aspect of her current placement in the day center. They feel that “it works out well” because Esther is “more like a people watcher…she likes to watch and observe,” and the caregivers allow her to do that. Clinical ratings for Esther’s social-emotional functioning falls several standard deviations below that of the average person. However, given a real-world situation, Esther enjoys watching others and appears to want to engage; it simply seems that she doesn’t understand how to do so.

The Binet-V was administered to determine Esther’s cognitive functioning. Esther obtained a Nonverbal IQ score of 42, which gives the estimate of her as
functioning intellectually in the moderately delayed range. This is given that the domain score has a mean of 100, and a standard deviation of 15. Given these parameters, Esther’s performance on the Binet-V is equal to, or exceeds, 0.1% of the individuals in her age range in the general population, as evidenced in Figure 16. Esther’s IQ is 42 and is indicated on the bell curve in Figure 16.

*Figure 16: Bell Curve of IQ Ranges: Esther*

Within the Binet-V are nonverbal subtests that include the Fluid Reasoning scaled score that Esther achieved. A score of 10 is considered as average, and a range of one to 19 is possible. Like the Nonverbal IQ measure, the scaled scores on the subtests further validate Esther’s level of cognitive functioning to be equal to, or exceed, 0.1% of the population in Quantitative Reasoning, Visual-Spatial Processing, and Working Memory.
Each of these subtests are given a scaled score based on Esther’s performance. Table 16 illustrates the scaled scores and percentiles of these subtests.

Table 16

*Esther: Scores of Binet-V Nonverbal Subtests*

<table>
<thead>
<tr>
<th>Nonverbal Subtests</th>
<th>Scaled Score</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluid Reasoning</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Knowledge</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Quantitative Reasoning</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Visual-Spatial Processing</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Working Memory</td>
<td>1</td>
<td>0.1</td>
</tr>
</tbody>
</table>

*Note.* Nonverbal subtests for Binet-V for Esther. A score of 10 is considered average, with a range of 1 to 19 possible.

Academically, Esther’s teacher reported that while she can sort objects, Esther does not demonstrate the ability to identify letters or numbers nor does she print her name. She does not consistently match pictured objects with corresponding pictures.

The response on the questionnaire is commensurate with these observations, as Esther’s parents shared that they have not observed an awareness of print, Braille, or use of numbers with Esther. There were no academic/cognitive strengths nor weaknesses addressed within the PLAAFP portion of the IEP. Of the four measurable annual goals, one addresses functional academics. In all, there are nine short-term
objectives/benchmarks; one of these addresses functional academic skills for Esther, accounting for 11.11% of the short-term objectives. The focus of the objective is questionable as to whether it actually addresses functional academics, but rather compliance and behavior (see Figure 17).

![Measurable Annual Goals & Short Term Objectives/Benchmarks]

*Figure 17. Annual Goal and Short-Term Objectives for Functional Academics captured from Esther’s IEP*

The manner in which the goal is written requires only participation, not progress within academics. Esther participated in the Georgia Alternate Assessment during her 11th grade year. Scores were documented in the Results of State and District Assessments within the PLAAFP and are contained in Table 17. In accordance with federal and state mandates, Esther accessed a modified depth and breadth of the general education high school standards, and a portfolio with her work evidencing this access was submitted. She failed the first submission of the science portion (Biology and Physical Science), but the researcher did not have access to the GAA score sheet to investigate why that portion was failed. Esther was re-administered the science portion in the next semester and passed.
Ultimately, Esther functions within the Severely Intellectually Disabled range, and her scores are commensurate with this functioning. As expected with a diagnosis and/or exceptionality of Intellectual Disability, Esther’s Special Education Eligibility Report documents that there is no area of strength in regard to her intellectual functioning. Esther functions at the same level or exceeds just 0.1% of the population her age. Her academic and functionality in academic settings reflect the accuracy of this score.

Esther’s communication skills were measured with the Functional Communication Profile, a test used to gain an overall inventory of an individual’s communication abilities, mode of communication and degree of independence. Results of this assessment indicates that Esther is a functionally nonverbal communicator. She demonstrates understanding of words, phrases, and simple sentences. She is able to respond to her name and attention commands such as “look” and “stop” upon request. At times she will produce words and phrases such as “good girl,” “bye-bye,” “mad,” and “I’m sad.” However, Esther has been diagnosed with a severe language impairment (impacting both her receptive and expressive language sets). This impairment impacts

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**Table 17**

*Esther: Georgia Alternate Assessment Scores During Eleventh Grade Year*

<table>
<thead>
<tr>
<th>Content Area</th>
<th>Result (Pass/Fail)</th>
<th>Progress Determination</th>
</tr>
</thead>
<tbody>
<tr>
<td>English/Language Arts</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Mathematics</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Science</td>
<td>Fail</td>
<td>No Progress</td>
</tr>
<tr>
<td>Social Studies</td>
<td>Pass</td>
<td>Established Progress</td>
</tr>
<tr>
<td>Science (Re-test administered Fall 2013)</td>
<td>Pass</td>
<td>Extended Progress</td>
</tr>
</tbody>
</table>

---
her ability to verbally produce her needs and wants, and she often to verbally produce her needs and wants, and she often requires moderate to maximum prompting to complete academic related tasks in the classroom. She also often needs for instructions to be repeated and prompting to follow directions/commands orally presented to her.

Through the questionnaire, Esther’s mother and father indicated that she expressively “uses intentional communication, but not at a symbolic language level” and that she “uses understandable communication through such modes as gestures, pictures, objects/textures, points, etc., to clearly express a variety of intentions.” They also indicated that Esther does use an AAC device to assist in communication.

Documentation of the use of the AAC device in the IEP indicates that Esther “will not access the communication device independently, nor will she respond to questions or made requests without frequent verbal prompts.” There are two communication goals embedded in two of the short-term objectives/benchmarks in her IEP; both objectives include the use of the AAC device. Receptively, Esther’s parents indicated that she can “independently follow 1-2 step directions presented through words (e.g. words may be spoken, signed, printed, or any combination) and does NOT need additional cues. This is inconsistent with the PLAAFP in her IEP, but the IEP was written in 2015, and the parents completed the questionnaire in 2018, so progress may have been achieved over this time. Another explanation is the difference in behavioral cooperation at home compared to school. These are speculation on behalf of the researcher as to why these inconsistencies are present; these inconsistencies are inconsequential to the outcome of this study. Esther’s communication deficits are not indicated nor addressed within the
Transition Plan. While Esther is functionally nonverbal, individuals that are familiar with her can communicate quite effectively with her, both receptively and expressively. For example, during the interview, Esther’s father shared, “She's very perceptive. We get the feeling that she can understand what you're saying. She just can't respond like everyone else, [but] she understands things that are more complex.”

In summary, Esther can expressively communicate by pointing or sometimes using limited one- to two-word utterances. There is evidence that she has a degree of receptive language functioning as she will follow some directives and comply with requests. However, Esther presents with a severe expressive and receptive language deficit and is functionally nonverbal. She does use an AAC device with support to make some requests and opinions known.

Participant #3: Luke and His Family

Access to Luke’s most recent psychoeducational evaluation, dated November 14, 2013, reveals that he appears to function within the Profoundly Intellectually Disabled range, and exhibits significant developmental delays across all domains (physical, adaptive behavior, social-emotional, cognitive, and communication) as determined by several assessment measures, including the Stanford-Binet Intelligence Scale: Fifth Edition (hereafter, Binet-5), Comprehensive Test of Nonverbal Intelligence—Second Edition (hereafter, CTONI-2), the Beery-Buktenica Developmental Test of Visual-Motor Integration-Sixth Edition (hereafter, Beery), and the Adaptive Behavior Assessment System-II (hereafter, ABAS-2). An overview of Luke’s functioning can be found in Table 18.
Table 18

*Luke: Levels of Functioning Based on 2013 Psychoeducational Evaluation*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Assessment Administered</th>
<th>Score/Rating</th>
<th>Qualitative Rating/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Beery:</td>
<td>Beery:</td>
<td>Beery:</td>
</tr>
<tr>
<td></td>
<td>Learner Characteristics</td>
<td>No standard score obtained</td>
<td>Significantly below same-aged peers</td>
</tr>
<tr>
<td></td>
<td>Inventory (LCI)</td>
<td>LCI: Not applicable</td>
<td>Needs personal assistance for most/all motor activities</td>
</tr>
<tr>
<td></td>
<td>(not administered as part of the psychoeducational report)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adaptive Behavior</td>
<td>ABAS-2</td>
<td>General Adaptive Composite (GAC)</td>
<td>Teacher and Parent rated in the extremely low range, consistent with PID</td>
</tr>
<tr>
<td></td>
<td>(reported in standard scores)</td>
<td>Teacher: 41 Parent: 40</td>
<td></td>
</tr>
<tr>
<td>Social-Emotional</td>
<td>ABAS-2</td>
<td>Social Domain:</td>
<td>Extremely low range, and are consistent with PID</td>
</tr>
<tr>
<td></td>
<td>(domain reported in standard scores, composite reported in scaled scores (average range 8-12))</td>
<td>Parent: 55 Teacher: 54 Social Composite: Social category: Parent: 1 Teacher: 1</td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>Binet-V</td>
<td>Binet-V:</td>
<td>Binet-V: No score obtained</td>
</tr>
<tr>
<td></td>
<td>(reported in standard score)</td>
<td>No score obtained</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CTONI-2</td>
<td>CTONI-2:</td>
<td>CTONI-2: Extremely low range, commensurate with special education placement (PID)</td>
</tr>
<tr>
<td></td>
<td>(reported in index scores; average range: 90 to 109)</td>
<td>Full Scale Score: 42</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>ABAS-2</td>
<td>Conceptual Domain: Parent: 49 Teacher: 48 Conceptual Composite: Communication category: Parent: 1 Teacher: 1</td>
<td>Extremely low range, and are consistent with PID; may indicate deficit in speech, language and listening skills required for communication</td>
</tr>
<tr>
<td></td>
<td>(domain reported in standard scores, composite reported in scaled scores (average range 8-12))</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Luke’s motor skills, both gross motor and fine motor, were attempted to be measured by the Beery and rated by his mother on the Learner Characteristics Inventory. On the Beery, the psychologist asked Luke to copy increasingly difficult geometric designs to measure visual-perception and visual-motor coordination. No standard score was obtained because Luke was unable to grasp and hold the pencil. While he participates in writing activities in the classroom with maximum hand-over-hand assistance, Luke was unable to participate in the Beery due to such significant fine-motor deficits. However, the evaluator found that Luke’s skills in this area are significantly below those of typically functioning, same-aged peers. Luke’s mother indicated on the pre-interview questionnaire that he requires personal assistance for most or all motor activities. The most recent IEP dated November 13, 2017 addresses the extent of Mark’s motor needs in the PLAAFP, as illustrated in Figure 18.
Figure 18. Description of Academic Achievements and Functional Performance

Strengths Section from Luke’s IEP

Luke’s IEP also contains motor skills goals embedded within his self-management skills and in the activities to increase independence through his Transition Plan goals. These goals require that Luke increase independence in spearing a fork to take bites, placing his drink on the table after drinking, walking from the garage to the car at home, and to walk to and from class at school. While Luke still requires maximum support to complete activities and requests that involve motor skills, he has made significant progress from when he was born, according to his mother during her interview. She shared “he was born a quadriplegic, tight fisted, tight scissor [legs]. Now when you see him in the group home, he can get up from the couch, go where he wants…walk to the table and have a seat in his chair…so he's gained his independence!”
Overall, Luke requires support to complete gross and fine motor tasks, but he has made considerable strides from childhood.

Luke’s overall adaptive behavior was formally measured by the ABAS-2. Luke’s mother and teacher gave very similar scores resulting in a General Adaptive Composite of 40 and 41, respectively. The calculated scores from both the parent and the teacher rendered scores that are in the extremely low range. Relative, personal strengths were documented in leisure skills, social skills and school living; weaknesses were reported in the areas of communication, functional academics (cognition), self-direction, and health and safety. Because Luke is nonverbal, the rater had to make assumptions about the implications of the scores rendered by the parent and the teacher. The rater suggested a deficit in speech, language, and listening skills needed for communication. There were also suggested deficits in reading, writing, mathematics, and other academic skills that impact independence in daily living tasks such as telling time, measurement, writing notes, etc. It was also suggested that Luke lacks the skills needed for independence, responsibility, and self-control (in situations such as task completion, adhering to a schedule, making choices, and following directions.) The IEP also addressed these deficits. A clear example of other skills impacting his independence in daily living skills can be found in his PLAAFP (see Figure 17) with regards to his eating and feeding skills. Because Luke’s motor skills are not proficient, it hampers his ability to independently feed himself. Goals for his daily living are addressed throughout the Transition Plan, either directly (within the Daily Living Skills domain) or indirectly through each of the other domains. These goals cover feeding, ambulating and navigating within his
community and participating in chores at home and at school. Overall, the calculated scores from both the parent and the teacher rendered scores that are in the extremely low range, and consistent with an individual functioning five standard deviations below the mean (Profound Intellectual Disability).

Luke’s social-emotional functioning was assessed in the Social Domain of the ABAS-2. The Social Domain measures both interpersonal and social competence skills. Both the standard scores and the scaled scores indicate that Luke functions in the extremely low range. In her pre-interview questionnaire, Luke’s mother shared that he responds with social interaction, but does not initiate or sustain interactions.

Documentation in the PLAAFP of the IEP revealed that Luke enjoyed participating in Special Olympic events and participating in his county’s touch football program for athletes with significant disabilities. There were no specific social or emotional needs listed in the weakness section of the PLAAFP. In the Transition Plan, Luke’s mother shared that his preferred activities at home included playing the piano, electronic toys, playing with his bead chain, and watching television, all of which are isolated, non-social activities. The Transition Plan community participation goal was for Luke to participate in two school organizations (Special Olympics and the flag football team). The IEP contained an embedded social/emotional objective of “maintain appropriate behavior in the community” within the Community Functioning annual goal. During her interview, Luke’s mother shared a memory of when she and Luke visited what is now his group home, and in meeting with the liaison, “he kept looking at her and flirting with [her]” by smiling and laughing in her direction.
However, there are times that Luke’s emotions rise, and his behavior becomes self-injurious. When sharing their experience about the end of Luke’s high school career, Luke’s mother recalled that she could tell he was tired of going to high school because he would drag his feet, not walk, and was generally resistant. He would also “beat his face up” in frustration. Although much progress has been made, ultimately Luke’s social-emotional functioning is consistent with an individual with a Profound Intellectual Disability, and he relies on others to help him maintain his social-emotional functioning.

Luke’s cognition was attempted to be formally assessed through the Binet-V and the CTONI-2. No standard score was obtained on the Binet-V as Luke was not able to successfully complete any of the required tasks. The CTONI-2, a language-free measure, was subsequently administered to gain additional information regarding his cognitive functioning. The CTONI-2 uses pictures of common objects and images of geometric shapes to measure a blend of three different cognitive abilities: analogical reasoning, categorical classifying, and sequential reasoning. Luke’s full scale score was 42, where the average range is 90-109. This is commensurate with his special education disability placement in the Profound Intellectual Disability program. The results of the Beery also recorded academic functioning through observation and interviews as Luke was unable to successfully complete any of the traditional academic assessments. Academically, he can solve four-piece puzzles with knobs, complete written activities with hand-over-hand support, typically point to the correct picture of his choice when given a field of two, and take balls from one container and place them into another container. However, according to his teacher, Luke was often opposed to completing work, and would engage in self-
injurious or would tantrum at academic times. During her interview, Luke’s mother reported similar behavior when a non-preferred task was presented. She also indicated that he sometimes engaged in self-injurious behaviors when he was in pain but could not communicate that in any other way. This level of communication is also commensurate with an IQ ranging five standard deviations below the mean. Luke’s IEP identifies that he continues to require hand-over-hand support when making choices during academic tasks as well as when he is asked to identify his wants and needs; his Transition Plan further defines the type of support that required in this way “Luke participates through full physical and verbal assistance.” None of the activities within the Transition Plan addressed his cognitive deficits nor through his annual goals and objectives. Through the pre-interview questionnaire, Luke’s mother characterized his cognitive functioning and academic achievement in this way: no observable awareness of print, Braille, or the use of numbers. Overall, Luke’s cognitive function and academic achievement are commensurate to that of an individual functioning within the Profound range of Intellectual Disabilities. He has not demonstrated development of literary nor mathematical skills and is nonverbal to the point of being self-injurious out of frustration and to communicate his wants and needs.

As eluded to when discussing Luke’s cognitive skills, his communication skills are consistent to those of individuals functioning within the Profound Intellectual Disability range. In formal testing that occurred in 2000 when Luke was four years of age, his communication skills were found to be within the eight-to-nine month level. The more recent testing in 2013, communication (along with functional academics, self-
direction, and health and safety) was determined to be an area of weakness for Luke. Due to the significant cognitive impairment and his inability to consistently respond in meaningful ways to test items, the evaluator could only assume that a communication deficit was present. This communication deficit, if present, hampered his communication with other people, including vocabulary, responding to questions, and conversational skills. With the totality of the evidence through formal assessments, interviews and observations, Luke’s parent and teacher gave a rating of 49 and 48, respectively, where the mean standard score for average communication skills fall between 90-109.

Luke does demonstrate relative strengths within communication according to the PLAAFP within the IEP by using some sign and gestural movements to indicate his wants and needs. The PLAAFP records “Luke will put his hand to his mouth or touch his food to indicate he wants more when eating. He will also tap the person feeding him on the arm to indicate he is ready for another bite of food.” The Speech/Language Pathologist noted that some progress was made over the academic year in participation of speech sessions, and that Luke appeared to be aware that he should make a choice when presented with options (typically pictures to indicate an answer or make a choice), but that hand-over-hand assistance was still required to perform these activities. His Transition Plan documented that at the time of the IEP in 2017, he served at a greeter at his church with his mentor. Staff implemented an activity of “indicate his wants/needs through pictures with verbal prompting” as a daily living and self-management skill within the Transition Plan, with a similar objective for the annual goal of increasing his recreation/leisure skills. The objective limited the field of choices to four.
In her pre-interview questionnaire, Luke’s mother characterized his expressive communication skills in this way “uses symbolic language to communicate: student uses verbal or written words, signs, Braille, or language-based augmentative systems to request, initiate, and respond to questions, describe things or events and express refusal.” While this description of his expressive communication does not appear to be consistent with formal measures and observations at school, Luke’s mother gave a reason for this discrepancy during her interview. While sharing how she knew Luke was fed up with being in high school, she clarified the method of communication that revealed that: “He was done. Because when I walked him [to catch the bus], he would not walk with me, and I’d have to pull him to the bus…And he was always so happy going. He would tell me in his ways, you know? But you have to work with him one-on-one to know what he wants because otherwise, you’re just thinking he’s crazy.”

Luke’s mother explained his receptive language in this way: “alerts to sensory input from another person (auditory, visual, touch, movement) BUT requires actual physical assistance to follow simple directions.” This characterization was more in line with the formal assessments and observations at school. With regard to communication, Luke’s abilities to understand others, participate in conversations and make his wants and needs known are commensurate with his cognitive functioning in the profoundly impaired range. Individuals that know him the best are capable of anticipating his needs and wants through observation of his behavior and through past experiences, but Luke is not as adept at communicating with unfamiliar individuals expressively or receptively.
Participant #4: Mark and His Family

Access to Mark’s most recent psychoeducational evaluation, dated August 20, 2007, reveals that he appears to function within the Profoundly Intellectually Disabled range, and exhibits significant developmental delays across all domains (physical, adaptive behavior, social-emotional, cognitive and communication) as determined by several assessment measures, including the Developmental Assessment for Individuals with Severe Disabilities—Second Edition (hereafter, DASH-2), the Informal Adaptive Behavior Rating, and the Scales of Independent Behavior—Revised (hereafter, SIB-R).

The DASH-2 is a criterion-referenced system for measuring developmental maturity in five domains of functioning (language, social-emotional, basic academics, sensory-motor, and activities of daily living), culminating in an overall developmental age. This assessment was administered to Mark when he was fifteen years and five months during the 2007 re-evaluation as well as during his previous evaluation in 2000 when he was eight years old. Both sets of scores are included in Table 19 as an example of how much progress was achieved over seven years. This is for comparison to a typically developing individual to impact the reader’s understanding of the Participant’s strengths and struggles. Items within this assessment are designed to pinpoint developmental equivalents ranging from birth through 96 months.
The DASH-2 assessed Mark’s language and communication abilities. At age seven, Mark’s linguistic developmental age was three months. Over a seven-year span, his developmental ability increased by 24 months. At age 15, his language and communication level was commensurate with that of a two year, three month old child. The PLAAFP within Mark’s IEP documents that he “has difficulty communicating his needs,” and that this will sometimes result in unrelenting and insistent behavior to obtain what he wants. His communication deficit is also mentioned in the Special Factors portion of the IEP, and that he “is non-verbal [and] utilizes communication/Augmentative
and alternative communication (AAC) devices, pictures, and gestures that are available in the classroom to communicate more independently.” The Transition Plan also documents that Mark “communicates his needs through facial expressions and body language.” The IEP team included a communication goal that focused on use of an AAC device within the Transition Plan as they felt that it was essential to his development of vocational skills. And, even though there were no weaknesses or deficits included within the PLAAFP, the IEP team included a communication objective within his vocational annual goal that mirrored the Transition goal. In the pre-interview questionnaire, Mark’s mother documented that expressively, he will use intentional communication but not at a symbolic level; he uses understandable communication through such modes as gestures, pictures, objects/textures, points, etc. to express a variety of intentions. For Mark, he is motivated primarily by his ‘wants.’ Mark’s mother answered that receptively he alerts to sensory input from another person (auditory, visual, touch, movement), but requires actual physical assistance to follow simple directions. Overall, Mark is non-verbal, but can communicate his wants and needs to those that are familiar with him through facial expressions, body language and gestures.

Mark’s social-emotional abilities, as evidenced through the DASH-2, increased from a developmental age of three months at age seven to 34 months at age 15. Mark’s IEP indicated that he was a good-natured student who got along with his peers and teachers, and that his self-control had increased as evidenced by his ability to walk down the school hallways with minimal outbursts. The IEP also documents that Mark greets people by hugging them “always in a good-natured way” but that it would sometimes
“startle people.” The PLAAFP also documents that Mark demonstrates “occasional outbursts” at times of transition. The PLAAFP did not define “outburst.” There is also a notation that Mark needs constant supervision during all activities. His Transition Plan indicates that Mark’s mood is “almost always…good [and] up-lifting.” The team included a community functioning goal that addressed Mark’s social-emotional functioning that he would “refrain from screaming or laughing loudly when in public places where that behavior is not acceptable.” Through her pre-interview questionnaire, Mark’s mother indicated that Mark initiates and sustains social interactions. Most current assessments indicate that Mark presents socially and emotionally akin to that of a typically developing 34-month old child, but he has shown some progress at school, although he continues to require constant supervision to maintain these skills and for safety purposes.

Mark’s basic academic functioning, as measured by the DASH-2, remained static at less than 27 months. His psychoeducational report documents that academics are a relative weakness for Mark. Cognitively, Mark appears to function within the Profoundly Intellectually Disabled range of intelligence, or five standard deviations below the mean IQ score (see Figure 19). Functioning five standard deviations below the mean indicates significant delays in all areas of development, with no statistically significant strengths, only relative strengths and weaknesses.
Academically, Mark is at a pre-primer level. This is supported by Mark’s family’s response on the pre-interview questionnaire in which they indicated that he demonstrated no observable awareness of print or of the use of numbers. Outside of the recent evaluations portion of the PLAAFP, there is no mention of Mark’s cognition except that he will listen attentively during academic instruction. When Mark’s family was asked about academic curriculum during the interviews, Mark’s mother shared, “I don’t think he understood it. As far as math and reading, he didn’t even care. He couldn’t sit still for me to read a book to him. So, that kind of stuff [academics]—no.”

An individual functioning in the Profound ID range, as Mark does, requires constant supervision for all activities. This ensures that the individual is safe and accounted for as their ability to maintain that for themselves is significantly delayed.
Mark’s sensory-motor skills were measured by the DASH-2 within three different scales: sensory, gross motor and hand skills (fine motor). The psychoeducational report documents a relative strength in gross motor skills for Mark. As evidenced through the results in Table 19, Mark’s current gross motor functioning falls within the developmental range of 42-48 months. The psychologist elected not to administer the fine motor (hands skills) portion during the 2007 administration. There is no documentation of why this choice was made. The SIB-R documented that Mark’s motor skills were observed to be slightly better developed at home (age three years, two months) than at school (age one year, seven months). The SIB-R established that activities to enhance Mark’s gross motor skills of balance, coordination, strength and endurance would be beneficial. A similar suggestion was made in the development of his fine motor skills, including tasks which require eye-hand coordination utilizing the small muscles of the fingers, hands and arms. The Informal Adaptive Behavior rating assessment documents that Mark’s gross and fine motor skills were areas in which he had developed. His running skills had improved over the course of the school year, and his fine motor skills varied given his attention and motivation to the task. Mark’s mother documented in her pre-interview questionnaire that he did not demonstrate any significant motor dysfunction that would require adaptations. There is no mention of Mark’s motor skills within his IEP or Transition Plan, indicating that while there are deficits as documented through the psychoeducational report, he is able to function successfully within the school and related settings.
Mark’s adaptive behavioral skills were measured within the DASH-2 within the Pinpoint Scale titled Activities of Daily Living. These skills included the categories of feeding, dressing, toileting, home routines and travel and safety. Mark’s current developmental age for each of these activities range from 20-30 months with the exception of toileting, which ranges from 12-18 months. The Informal Adaptive Behavior Rating indicates that Mark can eat finger foods, drink from a cup without assistance, and fill his cup with water from a sink. It was noted that Mark’s food must be cut into small pieces for him. Maximum support was required for Mark to use the restroom. An improvement in Mark’s ability to sit in a chair without assistance or supports was noted. The SIB-R documented that Mark’s overall level of functional independence at home and school fell within the Very Low range of scores. The SIB-R specifically focused on behaviors and skills beneficial and necessary for independent functioning at school and at home, including personal living skills such as eating and preparing meals, maintaining personal hygiene and appearance, and maintaining an orderly environment. Commensurate with the developmental ages documented by the DASH-2, the SIB-R documented that, regardless of relative strengths, Mark required maximum assistance with eating, toileting, dressing, and grooming himself. The PLAAFP within the IEP asserts that Mark “cooperates with daily activities such as cleaning the table and throwing away trash.” The IEP team proposed that Mark would receive further training at a day habilitation program for continued training in self-care skills after graduation within his Transition Plan.
This goal was supported through the activities listed within his Transition Goal Domain of Daily Living Skills, found in Figure 20.

Figure 20. Mark: Transition Plan Goal and Activities for Daily Living Skills

When asked what her aspirations for Mark include, his mother shared “mainly I would want [Mark] to be more independent—to be able to take care of the stuff I do like bathe himself, feed himself completely” and function in the bathroom independently. Overall, Mark demonstrates a significant delay of development in the area of adaptive skills and requires constant supervision during all activities.

Discussion of the Research Questions: Answers from the Data

The purpose of this section is to tie every component of this study together. As the reader has likely surmised, the data collection process rendered rather specific findings. However, the raw data sets and even the explanation of these sets do not fully identify the answers to the research questions. A glimpse into the life of each of the participants was necessary for the reader to have a true understanding of the implications of the mandated curriculum on the lives of students and family members living with
Severe or Profound Intellectual Disabilities. The researcher’s aim within the previous major section “Results by Individual Participants” was to attempt to give the reader a glimpse at the visceral decision-making that goes into planning post-secondarily for a loved one functioning at this level. It is important that all students are given the opportunity to access the general curriculum; however, it is duly important to acknowledge and honor the current functions, strengths and limitations of individual people. The subsections below discuss the results of the data as viewed through the Transformative lens: the families and former students represented in this study are a cultural group with acceptable values, beliefs that enable them to uniquely participate in society (Mertens, 2009). This lens begs the reader to consider “normalcy,” a tenant of the Transformative Framework, the scaffolding of this study (Trede, Higgs & Rothwell, 2009). Is the mindset of society positive towards individuals and families impacted by significant Intellectual Disability? Is the Board of Education? The researcher implores the reader to consider these lenses as the next two sub-sections are presented.

Research Question #1

Using the interviews and document analyses to review the benefits and pitfalls of both the standards-based and life-skills curriculums in attainment of post-secondary goals, the researcher found similarities across the data sets that indicate a pattern of preference on behalf of the families. The research question seeks to understand how the two types of curriculum explored throughout this study, standards-based and life-skills, allow individuals with SID/PID to realize their post-secondary goals. Through the data rendered from the analysis of coded categories within the interviews and documentation
within the data, this study analyzed how each of these curriculums activate success for individuals in the SID/PID range of functioning.

In review of the IEP and Transition Plan documents, the researcher found that 100% of the former students accessed and showed progress within a modified scope of the standards-based curriculum as evidenced by their passing GAA scores. These scores provide evidence that each of the former students were in compliance with federal mandates in accessing the same curriculum as their grade-level counterparts. Upon more critical examination, the researcher reviewed the annual goals and objectives as well as the activities supporting the Transition Plan goals to determine the true focus of the IEP team—academic or life-skills? Only two of the former students’ IEPs contained annual goals that addressed academics, while all four IEPs contained life-skills goals (i.e. self-management, community functioning, vocational skills). In fact, given 38 total objectives across six domains, across all four IEPs, a majority of the objectives, 13 of 38 total, addressed self-management skills, eight of 38 addressed community functioning skills, and six of 38 objectives were in the vocational/career prep skills domain. Collectively these skills fall within the life-skills curriculum, and accounted for 27 of the 38 objectives across all four IEPs. These figures stand in stark comparison to the frequency of objectives addressing functional academics; across two of the four IEPs reviewed, six of the 38 objectives focused on increasing academic skills. The IEP teams, at different points in time, in different schools, with different team members and unbeknownst to each other, committed over 70% of the objectives for students sought to
increase functional life-skills. Just less than 16% of the objectives were reserved to increase academic competencies.

While reviewing the interviews, the families quantitatively also responded more favorably to the helpfulness of the functional, life-skills curriculum for their loved one with ID than to the academic curriculum. Regarding the three families that indicated that the functional curriculum helped, this accounted for 3.5% of the codes across the study, and 23.1% across the categories of Academic Curriculum and Functional Curriculum. In comparison, the subcategory academic curriculum did NOT help accounted for 8.7% of the codes across the study, and 57.75% across the categories of Academic Curriculum and Functional Curriculum. The subcategory academic curriculum helped accounted for 1.7% of the codes across the study, and 11.55% across the categories of Academic Curriculum and Functional Curriculum. Functional curriculum did not help accounted for 1.2% of the codes across the study, and only 7.7% across the categories of Academic Curriculum and Functional Curriculum. Figure 2 contains a visual representation of the percentage of each of the subcategories confined within the categories of Academic Curriculum and Functional Curriculum.
To answer how the current mandated standards-based curricular requirements and functional, life-skills curriculum allow individuals with Severe/Profound Intellectual Disabilities to realize their post-graduation goals, the researcher looked at the data gleaned from the interviews and supporting data from the document analysis and the questionnaire. A majority of the families felt that the academic curriculum did not help their loved one meet their post-secondary goals, while 23% of the coding indicated that the functional curriculum helped in some way in the realization of post-secondary goals and aspirations by individuals with SID/PID. The current mandated curriculum for students functioning three to four standard deviations below the mean average IQ is to access the general academic standards. However, families that graduated a loved one under that mandate, when asked, indicated that that curriculum did not support the realization of those goals; approximately 12% of the conversations indicated that there

Figure 2. Percentage of Codes Across the Academic and Functional Curriculum Categories

To answer how the current mandated standards-based curricular requirements and functional, life-skills curriculum allow individuals with Severe/Profound Intellectual Disabilities to realize their post-graduation goals, the researcher looked at the data gleaned from the interviews and supporting data from the document analysis and the questionnaire. A majority of the families felt that the academic curriculum did not help their loved one meet their post-secondary goals, while 23% of the coding indicated that the functional curriculum helped in some way in the realization of post-secondary goals and aspirations by individuals with SID/PID. The current mandated curriculum for students functioning three to four standard deviations below the mean average IQ is to access the general academic standards. However, families that graduated a loved one under that mandate, when asked, indicated that that curriculum did not support the realization of those goals; approximately 12% of the conversations indicated that there
was some benefit to the implementation of general curriculum academic standards. Coding from the interviews were commensurate with the focus of time, energy and effort as measured by the number of IEP objectives within each of the former students’ IEPs.

The structure of this question does not require a yes or no answer, or to pick a curriculum that is better; this research question simply sought to understand how well families felt that the academic curriculum and the functional curriculum supported their loved one with SID/PID post-secondarily. Simply, over half of the responses in the interviews indicated that the academic curriculum was not effective in helping their loved ones after high school, and approximately a quarter of the responses from families indicated that the functional curriculum was helpful. In addition, nearly 75% of the IEP objectives sought to increase the life-skills functioning of each student. Given these findings, the data suggests that the families felt that mastery of the life-skills curriculum would be more beneficial in realizing post-graduation aspirations than mastery of the mandated, standards-based curriculum.

Research Question #2

Using coding and themes from the interviews and information gathered from the questionnaire and document analyses to examine the impact both the standards-based and life-skills curriculums in meeting post-graduation goals, the researcher determined perceptions of family members to answer the second research question. This research question sought to understand what the perceptions of the immediate family members are when considering how both types of curriculum explored throughout this study, standards-based and life-skills, allow individuals with SID/PID to realize their post-
graduation goals. Analysis of the codes and themes that emerged from the interviews as well as documentation of goals within the IEP and the Transition Plan painted the picture of how they felt the standards-based curricular requirements and functional, life-skills curriculum allowed their child to realize their post-graduation goals.

Based on the interviews and document analysis, achievement of these post-secondary goals is documented in Table 20 and indicate that the independent living goal was met across the board; the employment goal was not met by any of the former students, and the employment and training goal was met by three of four of the Participants. Given the information contained within Table 20, 50% of the goals were met across all four individuals.
Table 20

**Documentation of Achievement of Post-Secondary Goals**

<table>
<thead>
<tr>
<th></th>
<th>Education/Training</th>
<th>Employment</th>
<th>Independent Living</th>
<th>Percentage of Goals Achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woody</td>
<td>Not Met: Attends a day habilitation center for individuals with developmental disabilities, but does not receive vocational training</td>
<td>Not Met: Not employed</td>
<td>Met: Living at home with parents</td>
<td>33.33%</td>
</tr>
<tr>
<td>Esther</td>
<td>Not Met: Attends day care facility for individuals with developmental disabilities, but does not receive vocational training</td>
<td>Not Met: Not employed</td>
<td>Met: Living at home with parents</td>
<td>33.33%</td>
</tr>
<tr>
<td>Luke</td>
<td>Met: Attends adult day care center for individuals with developmental disabilities</td>
<td>Not Met: Not employed</td>
<td>Met: Living in supported group home</td>
<td>66.66%</td>
</tr>
<tr>
<td>Mark</td>
<td>Met: Attends adult day care center for individuals with developmental disabilities and works on self-help skills</td>
<td>Not Met: Not employed</td>
<td>Met: Living in supported group home</td>
<td>66.66%</td>
</tr>
</tbody>
</table>

*Note.* Based on parent interviews and the questionnaire, the table summarizes the failure of not meeting or success of meeting and/or exceeding the goals of each Transition Plan.

To share the perceptions of family members of students with Severe/Profound Intellectual Disabilities on how the current mandated standards-based curricular requirements and functional, life-skills curriculum allowed their child to realize their post-graduation goals, the researcher looked at the data gleaned from the interviews and supporting data from the document analysis and the questionnaire. These are the result of implementation of the current mandated curriculum for students functioning three to four
standard deviations below the mean average IQ. The current mandated curriculum is access to the general academic standards. According to the participants, there was also some instruction in functional life-skills curriculum. Given this information, half of the sample achieved 66.66% of their post-secondary goals while the other half only met 33.33% of their post-secondary goals. The overall tone and coding of the interviews (Success and Failure categories) also share that half of the sample felt positive and successful about the attainment transition goals while the other half tended to have a bleaker tone and sense of failure about their loved ones’ transition into adulthood from high school. Mark and Luke’s families felt that his transition was successful with the curriculum that was implemented but did report that focus on increasing independence skills would have been desirable. Esther and Woody’s families had a more subdued tone in which they were displeased with the preparation for transition as well as some of the post-secondary issues have brought up. Both families identified that an increased focus on development of functional, life-skills would have been desirable. However, given that the data collected in this study revealed that all of the participants agreed that the academic curriculum did not help their student post-secondarily, the fact that none of the students studied met all of their goals is telling.

The researcher, in collaboration with her dissertation committee, discovered that neither curriculum completely prepared the individuals in this study for post-secondary success. With this realization, the search for a solution within the data emerged. How can individuals with SID/PID be successful post-secondarily? How can families of individuals with SID/PID prepare for life—for themselves, their children with SID/PID
and for their typically functioning children—not only during the years that their children are in school, but for the years subsequent? As discussed in Chapters 1 and 2, it is the purpose and function of the school system to prepare students to be functional, contributing members of society. Is this same standard held for those that are developmentally delayed? Research exposited in Chapter 2 indicates that perhaps the current mandates are not promoting this same standard. Perhaps the pendulum has swung so far into uncharted territory academically that policy no longer recognizes the needs of the individual student. The fact is, the needs of students are not all the same. The findings of this study have determined that the implementation of the standards-based curriculum, as evidenced through passing scores on the GAA, does not promote post-secondary success for students with SID/PID. The implementation of functional, life-skills curriculum, as evidenced through the majority of the IEP goals and objectives, also falls short of promoting total success secondarily. The conclusion of this realization, then, leans to the necessity of training teachers in a third, family-centered curriculum in which the school system and the families work collaboratively in developing a skill set for the individual with SID/PID that capitalize on their strengths and promotes their independence while also creating an effective plan for the family to provide the necessary supports post-secondarily.

In summary, none of the individuals with SID/PID met 100% of their goals; half achieved 66.66%, and half achieved 33.33% of their goals while taught the required academic curriculum and some instruction on the functional, life-skills transition. Overall family opinions mirror that, with half of the population feeling successful and the
other half left wanting that could perhaps be met by the implementation of a family-centered curriculum.

Summary

The purpose of this study was to describe the understanding of family members of four individuals with SIP/PID on curricular requirements, and how these mandates provided a basis to meet post-secondary goals as outlined in high school IEPs as well as how the outcomes measured up in the opinion of said family members. This study sought to begin filling the gap in the body of existing literature concerning the curricular requirements of individuals with Intellectual Disabilities, specifically within the Severe and Profound ranges of intellectual functioning, and the functionality and appropriateness, according to these graduated students’ families, of said requirements. The methodology sought to determine and describe the lasting impact that these mandates have on individuals functioning within the SID/PID range, specifically the attainment of post-secondary goals held by the student and their family. This qualitative case study employed rich descriptions as implemented by Stake (1995) and Geertz (1973) through notations made within the pre-interview questionnaire, interview excerpts, and personal journal notes by the researcher and through background information gleaned through the document analysis for each family unit within this case study. Four willing and concerned families elected to participate in each of these methods to propel this study to publication for the aid and improvement for families to follow in the educational system; their stories are documented using rich description throughout the chapter. Data were analyzed using a priori codes to create categories and subcategories. Through these
categories and subcategories, the researcher then identified themes interwoven between each of the families’ experiences. Both directly and indirectly, all of the families discussed the need for teacher training. However, even training teachers in the basics of IEP development and instructional practices will not meet the needs and challenges that impacted each of the families within this study. The need for a family-focused curriculum emerged as the true answer to both research questions.
CHAPTER 5

DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

This qualitative case study aimed to give voice to family units that include an individual with Severe or Profound Intellectual Disabilities about curricular requirements in the public school setting. Compulsory education in the United States focuses on making the student a successful, productive member of society or ready for entry into a post-secondary institution upon graduation (Courtade et al., 2012), and federal law outlines that every student is entitled to a free, appropriate, public education (20 USC §1400 et seq). The problem that this study focused on centers on the appropriateness of the mandated curriculum for students with severe and profound intellectual disabilities; the purpose of this study was to add to the body of literature about the perception of students with the most significant disabilities and their opinion of whether or not the curricular expectations are appropriate for their personal post-secondary goals. The needs of individuals functioning within the SID/PID range vary greatly from the needs of those that are not Intellectually Disabled; the needs of those functioning in the SID or PID range of functioning vary greatly compared to even those with a milder form of Intellectual Disability (Bouck, 2012; Biklen and Moseley, 1998). Given the diverse needs of this population, should curricular expectations really be the same? The implementation of laws such as IDEA and ESEA are to ensure a meaningful educational
experience for students functioning four to five standard deviations below the average mean of IQ (20 USC §1400 et seq). This study specifically aimed to define how the students and their families within this case study define “success,” and to articulate whether or not curricular requirements of access to the general curriculum provided an effective means of attaining success, and if so, to what extent. With consideration of the cognitive, adaptive, and communicative functioning of the individuals at the heart of this study, participation of the immediate family was critical to post-secondary success in that studies show that expectations held by parents was strongly associated with whether their student with significant cognitive impairments was successful in meeting post-secondary goals after graduation. Within this study, the purpose of education in the United States must be considered. Federal mandates are, of course, implemented. Students were exposed to a significantly modified scope and sequence of the Georgia Standards of Excellence as compelled by the IDEA and NCLB/ESEA. Due to deficits in abilities, some functional, life skills were expected to be addressed through the IEP. This study gathered research to determine if success was achieved by the four individuals studied.

Discussion of Findings: Research Question #1

The first research question sought to find how the post-graduation goals of individuals with SID/PID were met with regard to the standards-based academic curriculum in comparison to the functional life-skills curriculum, was answered through the analysis of themes emerging from categories from the semi-structured interviews. The themes that emerged revealed that the skills taught through the functional, life-skills curriculum provided a more meaningful basis for life after graduation than the academic
curriculum. While one family ventured to speculate how the academic curriculum could provide meaning for their loved one, all four families described how the academic curriculum did NOT provide the skills needed to live and function independently after graduation. In fact, the theme of “Independence” guided the researcher to realize that the most important skill, as identified by the families for their loved ones with SID/PID, was independence in a plethora of settings. Sub-headings for this category included the families’ perceptions for the need of independence in daily living skills, vocational and financial skills, residential skills, communication skills, and in the area of further education and training.

Quantitatively, the families responded more favorably to the helpfulness of the functional, life-skills curriculum for their loved one with ID than to the academic curriculum. Regarding the three families that indicated that the functional curriculum helped, this accounted for 23.1% across the categories of Academic Curriculum and Functional Curriculum. Within the same categories, 11.55% of the codes accounted for ways that the mandated, standards-based academic curriculum was helpful in attaining these goals. In comparison, the subcategory academic curriculum did NOT help accounted for 57.75% across the categories of Academic Curriculum and Functional Curriculum. Specifically, within the discussion of the two different types of curriculum, a quarter of the codes indicated that the functional, life-skills curriculum provided the skills necessary to meet the post-secondary goals of the individuals within this study. In comparison, over half of the codes within the same categories described how the
academic curriculum was ineffective and not helpful in allowing their loved ones meet their post-secondary goals.

Discussion of Findings: Research Question #2

The second research question, which sought the perceptions of family members of students with SID/PID on how the standards-based curricular requirements and functional, life-skills curriculum allowed their child to realize their post-graduation goals, measured “success” by whether or not the student post-secondarily met their Transition Plan goals from their IEP Transition Plan and related documentation, and the impact this has had on the families, as deduced through the themes uncovered within the semi-structured interviews and the pre-interview questionnaire. The first step in answering this question was to determine if each former student met their post-secondary goals. Two students mastered/met one of three of their goals set forth in the Transition Plan, and two of the students mastered/met two of three of their goals set forth in the Transition Plan. None of the students met the employment goal, as they were all still unemployed at the time of this study. All of the students met the independent living goal set up by the IEP team. Two of the students met the further training and education goal within their Transition Plans, while the other two did not. When engaged in a conversation as to why or why not post-secondary goals were met, the families expressed that the concept of independence was most important to them. A majority of the codes are attributed to the “Independence” category from the interviews indicated independence in daily living as being the most important skill set for post-secondary functioning. The document analysis of the transition plans and the goals and activities included there were written to address
daily living, functional, life skills. Although federal law and state law mandate access and progress in the academic, standards-based curriculum, a majority of the concerns written within the PLAAFP, transition plans, and annual goals and objectives implemented work on functional, life-skills. Mark and Luke’s families felt that his transition was successful with the curriculum that was implemented but did report that focus on increasing independence skills would have been desirable. Esther and Woody’s families had a more subdued tone in which they were displeased with the preparation for transition as well as some of the post-secondary issues have brought up. Both families identified that an increased focus on development of functional, life-skills would have been desirable.

Relationship to Literature

Themes and major findings within this study are not unlike much of the unrest documented in Chapter 2 about the purpose and effectiveness of the different types of curriculum presented in this study. The first documented instruction and implementation of an IEP, of sorts, was documented with Dr. Itard in 1801 with his work with Victor, a seemingly incurable, uneducable individual with clear delays in his development. Dr. Itard’s goal for Victor was attainment of normalcy. This carries through to today. Although vocalized in more politically correct terms, “normalcy” in life is the ultimate goal for each student graduating from high school each year, regardless of intellectual functioning. The concept of “success” subsequent to graduation is still being debated—since 1801, society continues to debate what constitutes success, and what work and milestones should mark the way to that level of success. Sloan (2012) defines success as
preparing individuals in “developing the skills, the knowledge, and the dispositions that will allow them to be responsible, contributing members of their community” (p.2).

Through this lens, only half of individuals in this study were moderately successful in their attainment of skills to be a contributing member of their community. Why is this?
The parents within this study clearly stated that academic curriculum was NOT helpful in the realization of post-secondary goals and aspirations by their loved ones. However, this curriculum is mandated. Functional, life-skills curriculum was favored among the participants in this study, yet it is not mandated nor required. Only the skills outlined in the IEP provide documentation of the skills being worked on in class, and a majority of the parents in this study are not convinced of the level of skill of the teachers writing and implementing these documents.

Ford, Schnoor, and Black (1989) posit that the minimal outcome of a student’s academic program should be the achievement of useful “skills that will allow the student to enjoy a greater degree of participation in an enjoyable life-style” (p. 90). The overall perception of the researcher is that two families are pleased with the post-secondary achievements of their loved ones. They shared how their lives were full, and that they sometimes came home to visit, but that they happily went back to their new homes with no hesitation. They are engaged during the day, and met not only their independent living goals, but their training goals as well. The overall tone of those conversations was upbeat and happy. One of the families was only moderately pleased. Their loved one was where they expected they would be, but the overall feeling of the conversation was disillusioned—the idea of greater success for their loved one hung heavily in the air as
they discussed the potential their loved one had in comparison to the education they received. They mused about what could have been in a sad and disheartened tone. The overall tone of the fourth conversation was displeasure. The family succinctly identified ways in which their loved one’s time was wasted. Their loved one is now in a center where the family feels that the environment is indicative of how society views him. The researcher listened as this mother poured her heart out and could not help but feel the double entendre with which she used her words. The mother described the furniture in the center that her son attends each day as “garbage—garbage that we would throw out,” and the researcher couldn’t help but think that the fear and rage in the mother’s voice was because of the disparity of the expectation in high school, and the results after high school.

The researcher wishes to close this section by revisiting a hallmark argument between two opposing sides of the curriculum. Some curriculum specialists posit that not only is it the right of every student to have access to general curriculum, but also that increased academic skills may provide students with severe intellectual disabilities additional options for the future such as employment requiring basic math skills, an ability to engage in leisure activities (e.g., reading or hobbies involving science knowledge), and the ability to function more independently by reading their own mail or voting (Courtade et al., 2012); however, pro-functional academic curriculum authors argue that making progress on grade-level standards accessed with a modified scope and sequence may not lead to more independent functioning for those students with severe intellectual disabilities (Ayers et al., 2011). Additionally, while standards-based
curriculum may provide guidance for educators as to what skills and knowledge should be taught in order for students with disabilities to progress with their typical peers, the curriculum focused on academic content standards does not clearly align with post-secondary outcomes for these students (Ayers et al., 2012). The question is not if students with severe and profound intellectual disabilities can participate in academic standards (Browder et al., 2012). This is evidenced through performance on the GAA. “The imperative question to be answered is ‘at what cost do they learn these standards?’ Will these skills help the students get a job? Choose where to live? Actively participate in their community?” (Ayers, Lowery, Douglas & Sievers, 2011, p.15). The participating families in this study embody these arguments, and the overall sentiment gleaned by the researcher through the data analysis and through her experiences with the families is that implementation of a life-skills curriculum as the primary instructional focus for their children would have been preferred.

Research within the framework of Disability Theory gives the “power of using the perspective of people with disabilities as a socio-cultural group as [a lens] for research with people who have disabilities,” while also allowing the opportunity for a “transformative experience for the researchers” themselves (Mertens, 2009, p. 289). Every child, indeed has the right to a free, appropriate public education. The intent of this study was to define “appropriate” within educations with consideration of individual needs and while considering the realization of post-secondary goals and aspirations. The voices of individuals functioning within the Severe/Profound range of intellectual functioning are noticeably absent from not only scholarly literature (Sweetman et al.,
2010, p. 298), but also absent from the legislative decisions made regarding their education and futures beyond. This study, however, has given four of those individual’s families’ a voice through this study. Their voices have challenged the status quo, just as the Emancipatory Framework theorizes, and if shouted loudly enough, can affect change (Trede, Higgs & Rothwell, 2009). For this bounded case of families living with the decisions made in accordance with mandated law, the law may need to be reconsidered. The preponderance of the data indicates that if success was realized, at whatever amount, it was not due to the mandated academic curriculum, but rather to the instruction in the functional, life-skills, independence-building curriculum not currently required by federal or state law.

Implications for Practice

The following section includes themes from this study’s findings followed by discussion of relevant educational practice implications.

Families desire the development of independent life-skills over the development of academic skills for their loved one with Severe/Profound ID.

The quantifiable portions of the interviews and documents (IEP, transition plan, and psychoeducational reports) within this study support the need for direct instruction to increase independence of functioning the area of daily living skills for individuals with SID/PID. These daily living skill’ are taught within the functional, life skills curriculum. Parents want their children to be able to communicate effectively, brush their teeth, bathe themselves, wipe themselves after eliminating in the toilet, and pick up after themselves. With the exception of one statement by one family, none of the families felt that
academic instruction is of any value to their children now in their post-graduation lives. The families care that their loved one can maintain their personal hygiene and live cooperatively in a group home more than whether they can identify the main idea of literary passage. Three of the four families said that the academic curriculum did not provide the skills that their loved one needed to be successful after graduation day. The implication of this finding should weigh heavily upon IEP teams and upon policy makers. This case study found that the individuals would have focused more intensely on functional, life-skills to achieve independence rather than developing academic, standards-based knowledge. In no way is this study advocating for unlawful dismissal of mandates by educators, but the implication for practice within the classroom and at home through educators and care givers is to maximize the time spent on developing independence of self-management and life-skills, and less time on standards that do not provide meaning or a springboard to post-secondary living. 

All of the individuals passed the Georgia Alternate Assessment, but none met all of their post-secondary goals.

All four of the individuals studied passed all portions of the Georgia Alternate Assessment. According to the State of Georgia, the successful achievement of a passing score on each academic domain serves as proof that these students had access and showed progress in skill mastery in the general curriculum. A passing score on the GAA, at the time that these students graduated, was partial fulfillment in earning a general diploma. Each of the former students successfully completed all requirements, including making progress in the general curriculum, to earn a diploma. However, a review of the
transition plans and input from families through the interviews revealed that none of the former students met all of their post-secondary goals. All of the former students met their independent living goals (two live in group homes, two live with their families). Two of the individuals with ID are receiving training in a vocation as the goal indicates, while the other two are not. None of the students met the employment goal as all remain unemployed at the date of this study’s publication. The implication for practice is to bring the realization to parents, educators, and policy makers that even with access and sufficient progress on a modified scope of high school standards, the former students from this study are still unable to read, cannot calculate numbers, and have not yet applied the academic content on which they were assessed through science and social studies. However, the need for independent life skills is seemingly endless.

*Families feel that there is a need for additional teacher training in special education.*

A theme emerged across three of the four interviews that additional teacher training is needed. This training included topics from how to write an accurate and thorough IEP, to explanation of portions of the IEP, implications of the IEP and transition plan, to implications of scores on psychoeducational reports and meaning of the area of disability for which their children are eligible. One of the parents did not understand what it meant to be “Profoundly Intellectually Disabled,” and all that range of functioning entailed, until her child was in high school. Another parent did not understand what their student was entitled to in terms of inclusion with less-disabled and non-disabled peers. Several family members mentioned that they would sit in meetings, and that the information would be “above their head,” and they were too intimidated to ask for an
explanation. One participant in this study is very well versed in her rights and recalled sitting in multiple meetings where misinformation was shared. Two families felt that further training on implementation of instructional strategies, meaningful inclusion, communication improvement and behavior management is woefully overdue. One of those families felt that this lack of training begins at the college level with the change of requirements in teacher training programs. Although unanticipated and unforeseen as a theme, this study determined that the families feel that current training for teachers is lacking. The implication for practice is for teachers and local boards of education, and it is simple: never stop learning. In-service should be planned as an effective, relatable tool that directly applies to the audience. One of the interviews revealed that the parent, who is an educator for a school in metro Atlanta, would face negative consequences professionally if she did not obtain a gifted endorsement. At the time, this parent was a low-incidence, self-contained teacher for students with Intellectual Disabilities. How is this appropriate? The researcher urges local school systems and building level administrators to carefully consider the audience when planning staff development, and don’t be afraid to differentiate.

A need exists within the public school system for a “family curriculum”.

The discussion surrounding the need for additional teacher training was evident within three of the four interviews. However, the need for an additional curriculum was indirectly addressed throughout all four interviews. The need for this additional curriculum was hidden deep within the recesses of the codes indicating the need for teacher training. Although teacher training is needed in very obvious ways, such as
developing an appropriate IEP, in the discussion of test results and those implications, an additional type of training emerged as needed to respond to the concerns that the participants shared, the need for training in a family-centered curriculum. A family-centered curriculum encompasses everything from the initial eligibility meeting to the final meeting on their child’s 22nd birthday. This curriculum should address what parents do not know that they do not know; so much information slips past the parent and is inadvertently not addressed explicitly by the staff. A family curriculum needs to be taught to educators in how to explain test results and what this will look like in practice in the immediate present all the way through graduation and below. Parents need to learn answers to such questions as: What is the vocational expectation for my student functioning one standard deviation below the mean? What about my student that functions five standard deviations below? These individuals look very different, but teachers are not equipped to inform and then guide a parent through that reality. This family-centered curriculum should allow parent education opportunities such as how to read and understand scores within a psychoeducational, and what an IEP is and how to fully participate in the IEP meetings. Overton (2005) identified that while parents will not voluntarily become involved when they can sense that they are unwanted or misunderstood. However, parents are “drawn to teachers who take the time to recognize the family’s efforts and who show concern for them as people (Overton, 2005, p. 27). This curriculum would need to focus on the needs of the students and of their families when decisions are being made for life beyond high school. Parents want the best for their child, as do teachers. Even with this very critical agreement, most school systems

Beyond training in procedures and protocols, instruction in standards-based implementation and instruction and in application of functional, life skills instruction, the development and implementation of a ‘family-centered’ curriculum emerged as a desperate need from this study.

Recommendations for Future Research

Based on the findings and conclusions of this study, the researcher wishes to make the following recommendations for future research:

- Replication of this study on a larger scale. Four participants is not a representative sample, and the results of this study cannot be generalized to represent the whole population. Replication of a study with a similar focus and aim would bolster the findings of this study and provide impact for the population being studied.

- Replication of this study with the addition of a focus group interview method. The triangulation of the pre-interview questionnaire, document analysis, and semi-structured interviews provided a solid base on which this study was conducted. As data analysis progressed, the researcher reflected on how the families would have interacted with each other, and how that interaction would have impacted the tone of the conversations.

- Additional research is needed regarding students with Severe/Profound Intellectual Disabilities with the input of teachers, educational professionals, post-
secondary service providers and/or educational policy makers regarding current and meaningful curricular requirements.

- The researcher would be interested in receiving input from post-secondary service providers; the researcher anticipates that this would add a depth of interest and impact that could not be considered in this study due to constraints of time and focus of study.

- A need for a longitudinal study of individuals with SID/PID beginning their 9th grade year and ending at age 25 is evident. Discussion of transition begins when the student is fourteen years of age, and by the time the student turns sixteen or enters 9th grade (whichever occurs first), a transition plan is in place. The evolution of the transition plan from 9th grade to just prior to graduation from the school system would provide invaluable insight into the development of the goals and expectations for the student as they approach adulthood. The longitudinal concept should occur past graduation to take inventory of the impact of the school system, and the mandates in existence therein, on the post-secondary success of individuals functioning in the SID/PID range of functioning.

Final Thoughts: Mortality—An Unanticipated Category

Although not an anticipated answer to the research questions, mortality was mentioned in two of the four interviews, and was mentioned in two of the four transition plans. Mortality was coded as a category and included in this study as the heaviness of the subject on families was palpable during the interview process, and it would be remiss not to include those responses here. The concept of mortality was brought up in Esther
and Woody’s transition plans. Within the independent living goal, staff used similar language when stating that both “will remain at home with [his/her] family until such a time that they are unable to provide care for [him/her],” alluding to the decline of health or mortality of immediate family members. While only half of the interviews included this topic, it is safe to assume that all four families must make arrangements for the time when the family is no longer capable of providing care. As an example, Woody’s mother shared a recollection of a conversation with a colleague taking care of their mother in the end stages of a terminal disease, and remembered the colleague asking how she (Woody’s Mother) remained strong in her care of Woody and the rest of her family on a daily basis. Woody’s Mother shared her encouragement with the co-worker but recalled thinking “this is the order of things—your mother took care of you, and now you’re taking care of your mother. I’m not being cold, but it’s finite. Woody’s not. So you take this almost as a gift to give back to your mother what she gave to you, and her pain will stop and your stress will stop, and you will get a chance to say goodbye. I don’t have that. I just wanted her to see the weird blessing that she had…and then I thought ‘I actually want my son to predecease me’ [long, thoughtful pause]…and you know I don’t think I have ever said that out loud before.” The stress on the families to provide for their loved one cannot be quantified within this, or any other, study. The trajectory of consideration of postsecondary goals and aspirations for these parents is far past the concern that can be addressed through three post-secondary goals in a transition plan. When the realization that parents must force themselves to think of the implications of their child out-living them sets in, the consideration of the focus of their student’s
curriculum suddenly becomes much less political, and a lot more individualized and personal. Luke’s mother was forced to look headlong into his long-term care and the sustainability of maintaining that care. Given not only Luke’s cognitive, communicative, and adaptive functioning deficits, he also lives with Autism, Epilepsy, and Cerebral Palsy. His mother frankly stated, “Without the funding either he would die on my hands or something detrimental would happen.” She recalled during a particularly difficult time in the process of establishing long-term care asking her counselor “is life really worth living? [long pause]…because nothing is going to amount to Luke. Don’t parents live for their kids?” Luke’s mother recalled calling on her faith to reconcile this dilemma. “I look back into God and just said ‘you know from the beginning I have said to You [God] “Okay—You give me this child who isn’t supposed to do all these things—show me what to do, because I have no clue. I don’t know what I’m doing.”’ And so now, you know, Luke is what God gave to me.” Fortunately, Luke’s Special Needs Trust was approved shortly thereafter, allowing for Luke’s needs to be covered financially, and assistance for his family to continue to care for him.

Consideration of long-term care eventually becomes the focus of families of students with significant deficits. The school system is commissioned with initiating these considerations through the implementation of the transition plan within the IEP process. While children and young adults are still enrolled in school, the school system is tasked with helping to meet the goals within the transition plan. However, it is ultimately incumbent upon the family to carry out the day-to-day operations and the long-term care plan. The transition plan is just that—a plan for transition from high school into
adolescence; what happens after this transition is shouldered by families and loved ones. Has the school system, abiding by federal and state guidelines, set our students up for success immediately following high school and beyond? This question is beyond the scope of this particular study, but begs to be addressed, as evidenced through the concerns and impassioned pleas of the families within this study.
REFERENCES


Kleinert, H., Towles-Reeves, E., Quenemoen, R., Thurlow, M., Fluegge, L., Weseman, L., & Kerbel, A. (2015). Where students with the most significant cognitive disabilities are taught: Implications for general curriculum access. *Exceptional Children, 81*(3), 312-328.


APPENDICES
Learner Characteristics Inventory

Directions: Please provide the best and most accurate answer in reference to your family member with a cognitive impairment. The questions in this inventory are written for someone who’s family member is still in school; for the purpose of this study, please complete the questions with the respect to the functioning of your family member when he/she was in their last year of high school. Please contact the researcher, Meghan Lowe at 404-308-4963 or phdarticles9@gmail.com with any questions or concerns you may have.

1. Student’s Grade:
2. Student’s age in years:
3. Student’s primary IDEA disability label:
   - ☐ Intellectual Disability/Mental Retardation (includes Mild, Moderate, Severe and Profound)
   - ☐ Multiple Disabilities
   - ☐ Autism
   - ☐ Speech/Language Impairment
   - ☐ Hearing Impairment
   - ☐ Traumatic Brain Injury
   - ☐ Emotional Disability
   - ☐ Deaf/Blind
   - ☐ Other Health Impairment
   - ☐ Orthopedic
   - ☐ Other
4. Is your student’s primary language a language other than English?
   - ☐ Yes
   - ☐ No
5. If yes, what is your student’s primary language (the dominant language spoken in the student’s home)?
   - ☐
6. What is the student’s primary classroom setting?
   - ☐ Special school
   - ☐ Regular school, self-contained special education classroom, some special inclusion (students go to art, music, PE) but return to their special education class for most of school day.
☐ Regular school, primarily self-contained special education classroom, some academic inclusion (students go to some general education classes (such as reading, math, science, in addition to specials) but are in general education classes less than 40% of the school day).

☐ Regular school, resource room/general education class, students receive resource room services, but are in general education classes 40% or more of the school day.

☐ Regular school, general education class inclusive/collaborative (students based in general education classes, special education services are primarily delivered in the general education classes)—at least 80% of the school day is spent in general education classes.

7. Expressive Communication (check the best description)

☐ Uses symbolic language to communicate: Student uses verbal or written words, signs, Braille, or language-based augmentative systems to request, initiate, and respond to questions, describe things or events and express refusal.

☐ Uses intentional communication, but not at a symbolic language level: Student uses understandable communication through such modes as gestures, pictures, objects/textures, points, etc., to clearly express a variety of intentions.

☐ Student communicates primarily through cries, facial expressions, change in muscle tone, etc., but no clear use of objects/textures, regularized gestures, pictures, signs, etc., to communicate.

8. Does your student use an augmentative communication system in addition to or in place of oral speech?

☐ Yes

☐ No

9. Receptive Language (check the best description)

☐ Independently follows 1-2 step directions presented through words (e.g. words may be spoken, signed, printed, or any combination) and does NOT need additional cues.

☐ Requires additional cues (e.g. gestures, pictures, objects, or demonstrations/models) to follow 1-2 step directions.

☐ Alerts to sensory input from another person (auditory, visual, touch, movement) BUT requires actual physical assistance to follow simple directions.

☐ Uncertain response to sensory stimuli (e.g., sound/voice; sight/gesture; touch; movement; smell).

10. Vision (check the best description)

☐ Vision within normal limits.

☐ Corrected vision within normal limits.

☐ Low vision; uses vision for some activities of daily living.
☐ No functional use of vision for activities of daily living, or unable to determine functional use of vision.

11. Hearing (check the best description)

☐ Hearing within normal limits.
☐ Corrected hearing loss within normal limits.
☐ Hearing loss aided, but still with a significant loss.
☐ Profound loss, even with aids.
☐ Unable to determine functional use of hearing.

12. Motor (check the best description)

☐ No significant motor dysfunction that requires adaptations.
☐ Requires adaptations to support motor functioning (e.g., walker, adapted utensils, and/or keyboard).
☐ Uses wheelchair, positioning equipment, and/or assistive devices for most activities
☐ Needs personal assistance for most/all motor activities.

13. Engagement (check the best description)

☐ Initiates and sustains social interactions.
☐ Responds with social interaction, but does not initiate or sustain social interactions.
☐ Alerts to others.
☐ Does not alert to others.

14. Health Issues/Attendance (check the best description)

☐ Attends at least 90% of school days.
☐ Attends approximately 75% of school days; absences primarily due to health issues.
☐ Attends approximately 50% or less of school days; absences primarily due to health issues.
☐ Receives Homebound Instruction due to health issues.
☐ Highly irregular attendance or homebound instruction due to issues other than health.

15. Reading (check the best description)

☐ Reads fluently with critical understanding in print or Braille (e.g., to differentiate fact/opinion, point of view, emotional response, etc.).
☐ Reads fluently with basic (literal) understanding from paragraphs/short passages with narrative/informational texts in print or Braille.
☐ Reads basic sight words, simple sentences, directions, bullets, and/or lists in print or Braille.
☐ Aware of text/Braille, follows directionality, makes letter distinctions, or tells a story from the pictures that is not linked to the text.
☐ No observable awareness of print or Braille.

16. Mathematics (check the best description)

☐ Applies computational procedures to solve real-life or routine word problems from a variety of contexts.

☐ Does computational procedures with or without a calculator.

☐ Counts with 1:1 correspondence to at least 10, and/or makes numbered sets of items.

☐ Counts by rote to 5.

☐ No observable awareness or use of numbers.
APPENDIX B

SEMI-STRUCTURED INTERVIEW PROTOCOL
Question 1. Tell me a little about your child. For example, what are some of his/her strengths? Hobbies? Favorite things to do? Personality traits? Chores around the house?

Question 2. What are the post-secondary goals for your child?

Question 3. How do you define success for your child after graduation from high school?

Question 4. In what ways has the school prepared your child to realize these goals?

*Follow-up A to Q4: How did the academic curriculum prepare your child to realize his/her goals?

**Follow-up B to Q4: How did the functional curriculum prepare your child to realize his/her goals?

Question 5. In what ways has the school NOT prepared your child to realize these goals?

*Follow-up A to Q5: How did the academic curriculum NOT prepare your child to realize his/her goals?

**Follow-up B to Q5: How did the functional curriculum NOT prepare your child to realize his/her goals?

Question 6. How will your child and your family make your child’s goals reality?

*The researcher will provide the participant with the definition and an explanation of the term “academic curriculum.”

**The researcher will provide the participant with the definition and an explanation of the term “functional curriculum.”
APPENDIX C

IRB APPROVAL
Tuesday, August 28, 2018

Mrs. Meghan D. Lowe-Wincham
Office of Research Compliance
Tift College of Education
1400 Coleman Avenue
Macon, GA 31207-0001

RE: Perceptions of Immediate Families on Current Curricular Expectations for Individuals with Severe or Profound Intellectual Disabilities [H1808199]

Dear Mrs. Lowe-Wincham:

On behalf of Mercer University’s Institutional Review Board for Human Subjects Research, your application submitted on 17-Aug-2018 for the above referenced protocol was reviewed in accordance with Federal Regulations 21 CFR 50.10(b) and 45 CFR 46.110(b) (for expedited review) and was approved under categories 05, 07 per 45 CFR 46.104

Your application was approved for one year of study on 28-Aug-2018. The protocol expires on 27-Aug-2019. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

Item(s) Approved:
A new student application for a bounded case study qualitative methodology design using semi-structured interviews, document analysis, parent/family questionnaires, and personal journaling to document and analyze the perceptions and experiences of families and individuals functioning within the SID/PID IQ range who have graduated from high school and were exposed to academic, standards-based curriculum as well as to functional, life-skills curriculum on the success of their individual post-secondary goals.

NOTE: You MUST report to the committee when the protocol is initiated. Report to the Committee immediately any changes in the protocol or consent form and all accidents, injuries, and serious or unexpected adverse events that occur to your subjects as a result of this study.

We at the IRB and the Office of Research Compliance are dedicated to providing the best service to our research community. As one of our investigators, we value your feedback and ask that you please take a moment to complete our Satisfaction Survey and help us to improve the quality of our service.

It has been a pleasure working with you and we wish you much success with your project! If you need any further assistance, please feel free to contact our office.

Respectfully,

Ava Chambless-Richardson, Ph.D., CIP, CIRM
Director of Research Compliance
Member
Institutional Review Board

*Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice.*
APPENDIX D

RECRUITMENT LETTER
Dear Respondent,

My name is Meghan Lowe. I am a doctoral candidate enrolled in the Tift College of Education in the area of Curriculum and Instruction. I am conducting a research study about the perceptions and experiences of families and individuals functioning within the SID/PID IQ range who have graduated from high school and were exposed to academic, standards-based curriculum as well as to functional, life-skills curriculum on the success of their individual post-secondary goals. The title of this study is Perceptions of Immediate Families on Current Curricular Expectations for Individuals with Severe or Profound Intellectual Disabilities. I am emailing to ask if you would like to participate by completing a survey for this research project.

Mercer University’s IRB requires investigators to provide informed consent to the research participants. If you would be interested in taking this survey, please click the following link for more information on how to participate: https://www.surveymonkey.com/r/7MHKFPD.

If you have any questions about the study, contact the Principal Investigator Meghan Lowe by phone, 404-308-4963, or by sending an email to Meghan.lowe@live.mercer.edu.

Mercer University’s Institutional Review Board (IRB) reviewed study #H1808199 and approved it on 28-Aug-2018.

Questions about your rights as a research participant:

If you have questions about your rights as a research participant or if you are at any time dissatisfied with any part of this study, you may contact, anonymously if you wish, the Mercer University Institutional Review Board (IRB) by phone at (478) 301-4101 or by email at ORC_Research@Mercer.edu.

Thank you in advance for your time and participation!
APPENDIX E

INFORMED CONSENT LETTER
Perceptions of Immediate Families on Current Curricular Expectations for Individuals with Severe or Profound Intellectual Disabilities

Informed Consent

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators

Meghan Lowe-Windham, Doctoral Candidate Tift College of Education, Curriculum and Instruction
1501 Mercer University Drive, Macon, GA 31207, 404-308-4963

Purpose of the Research

It is the purpose of this study to add to the body of existing literature concerning the curricular requirements of students with Intellectual Disabilities, specifically within the Severe and Profound range of intellectual functioning, and the functionality and appropriateness, according to the families of these students, of said requirements as well as to serve as a transformative piece for these students and their families. This study seeks to understand the impact that these mandates have on students functioning within the SID/PID range, specifically the attainment of post-secondary goals held by the student and their family. To determine whether the purpose of education in the United States, specifically within a county located in the state of Georgia, is being achieved for students functioning within the SID/PID range; the researcher intends to accomplish this through: (1) parent/family questionnaires, (2) document analysis, (3) semi-structured interviews, (4) personal journaling.

Procedures

If you volunteer to participate in this study, you will be asked to complete a pre-interview questionnaire, to participate in an interview that will last no more than 60 minutes and to request special education paperwork (specifically their IEP (including the Transition Plan), most recent psycho-educational report and most recent GAA score sheet).

Your participation will take approximately 30 minutes for the pre-interview questionnaire, 60 minutes for the interview, 15 minutes to complete and submit the request for special education records.

Potential Risks or Discomforts

Because the questionnaire and interview ask personal questions about your child with cognitive impairments, some emotion will surely be attached. Minimal emotional discomfort is a possible adverse condition that may arise from this data collection. There may be some inconvenience when requesting special education records from the local educational agency.

You absolutely have the right to discontinue your participation in this study if at any time the discomfort and/or inconvenience becomes too burdensome.

Mercer IRB Approval Date 08/28/2018
Protocol Expiration Date 08/27/2019
Potential Benefits of the Research
While there may not pose immediate and direct benefits to the participants in this study, it is the researcher’s hope that this study will add to the body of literature for future curricular decisions for students with SID/PID.

Confidentiality and Data Storage
I will keep all of my notes, documents and recordings secured, password protected and coded with pseudonyms for the protection of your privacy. Your name will not be associated with your responses and will be identified only by an assigned coded number. At no time will your name be associated with the results of the research. Further, any identifying information you provide while being videotaped will not be used as part of the research or associated with the results of the study.

Your responses will be stored in a locked location and will only be used for research purposes by Mercer University. I will store all of your audio recordings in a secured location, and each case will be coded with a pseudonym. The Investigator (me) and my Advisor (Dr. Kelly Reffitt) are the only individuals that will have access to the data. If you request to have your audio recording(s) destroyed before data can be collected, this will forfeit your participation in this study. I will keep the audio recording(s) on my password protected iPad in a secure location at my home under lock and key. I will delete/destroy all audio recordings before or on 12/01/2019.

NOTE: Data must be stored at Mercer University for at least three years after completion of the study.

Participation and Withdrawal
Your participation in this research study is voluntary. As a participant, you may refuse to participate at any time. To withdraw from the study please contact Meghan Lowe-Windham, 404-308-4963, phdarticles9@gmail.com.

To withdraw from the study, please contact the primary investigator Meghan Lowe-Windham by phone call or email at the given contact information to alert her to your withdrawal from the research study.

Questions about the Research
If you have any questions about the research, please speak with primary investigator Meghan Lowe-Windham or research advisor Dr. Kelly Reffitt (reffitt.ke@mercer.edu, 478-301-5389).

Audio Taping
I will audio record the interviews with you and with your parent/guardian. If you are uncomfortable with me audio recording, you can tell me that and I will stop the recording immediately. After the interview is over, I will lock your interview and password protect it. I will destroy/delete the recordings after 10/01/2019.

Any questions regarding the purpose of the videotape should be directed to Meghan Lowe-Windham, 404-308-4963, phdarticles9@gmail.com or Dr. Kelly Reffitt, reffitt.ke@mercer.edu, 478-301-5389.

This project has been reviewed and approved by Mercer University’s IRB. If you believe there is any infringement upon your rights as a research subject, you may contact the IRB Chair, at (478) 301-4101.

You have been given the opportunity to ask questions and these have been answered to your satisfaction. Your signature below indicates your voluntary agreement to participate in this research study.

<table>
<thead>
<tr>
<th>Research Participant Name (Print)</th>
<th>Name of Person Obtaining Consent (Print)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Rev. January 2017

Mercer IRB Approval Date 08/28/2018
Protocol 08/27/2019
<table>
<thead>
<tr>
<th>Research Participant Signature</th>
<th>Person Obtaining Consent Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td>Date</td>
</tr>
</tbody>
</table>

Rev. January 2017

Mercer IRB
Approval Date 08/28/2018
Protocol
Expiration Date 08/27/2019

Page 3
APPENDIX F

INFORMATIVE EMAIL
Hi!

I am so excited to move to the next phase of my dissertation--the interview of participants!! I truly appreciate your willingness to commit your time and energy to help me with this endeavor. It is my sincere hope that, in the long run, my study will positively impact literature and possibly legislation to advocate for our students with special needs. These aspirations, however, could not even be possible without you and your selfless participation. From the bottom of my heart, thank you so much.

Below are the elements that I need your help with. I have attached consents for your review; I can mail hard copies of these to you or bring them to you when we meet for the interview for you to sign. An important facet of this study that I would like to highlight is that the participant pool of this study are immediate FAMILIES of individuals with special needs; I would love for any member of the immediate family (mom, dad, stepmom, stepdad, siblings, step-siblings, grandparents, other very close family members or caregivers) to feel free to participate in the interview portion of this study. Please make sure to invite them when we determine a date/time that we can meet!!!

1. Pre-Interview Questionnaire (anticipated duration of 20-45 minutes); access the Questionnaire at the following link: https://www.surveymonkey.com/r/7MHKFPD
2. Date, time and location preference for the Interview (anticipated duration of 1 hour)--please respond to this email with that information, or feel free to text me (404-308-4963).
3. Request of Student Records from [Henry County School System](#) (a couple of ways to accomplish this):
   A. Provide the Investigator (Meghan Lowe) with Senior Summary of Performance packet provided by the high school upon graduation (should include most recent IEP, Psychoeducational Report, Eligibility Report); I can pick this up from you at the location of your choosing.
   B. Provide the Investigator (Meghan Lowe) with saved copies of IEPs, Psychoeducational Reports, Eligibility Reports and GAA scores saved from the student's annual review each year; I can pick this up from you at the location of your choosing.
   C. Report in Person with identification to [Henry County School System](#) Exceptional Student Education Building A off of Tomlinson Street in McDonough, and request the following: IEPs from 9th grade through 12th grade, most recent Psychoeducational Report, most recent GAA scores, most recent eligibility report and initial eligibility report; I can pick this up from you at the location of your choosing.

Please don't hesitate to call, text or email me with any questions or clarifications on anything that I have asked of you! I would like to conduct the interviews by Saturday, October 20, 2018 if at all possible. I look forward to hearing from you soon!!

Thanks, Meghan Lowe Windham (404-308-4963)
APPENDIX G

PRE-INTERVIEW QUESTIONNAIRE RESPONSES
This questionnaire is titled *The Learner Characteristics Inventory* and was developed by Towles-Reeves, et. al (2012) through the University of Minnesota, a product of the National Center and State Collaborative validity evaluation.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10/09/2018</td>
<td>10/14/2018</td>
<td>10/15/2018</td>
<td>10/20/2018</td>
<td></td>
</tr>
</tbody>
</table>

- **Time spent completing questionnaire:**
  - 38 mins:12 secs
  - 35 mins:11 secs
  - 14 mins:53 secs
  - 04 mins:49 secs

- **Q1: Do you agree to participate in the questionnaire?**
  - Yes
  - Yes
  - Yes
  - Yes

- **Q2: Grade**
  - 12
  - 12
  - 12
  - 12

- **Q3: Student’s Age**
  - 25
  - 24
  - 21
  - 26

- **Q4: Primary IDEA disability eligibility**
  - ID
  - ID
  - ID
  - ID

- **Q5: Primary language other than English?**
  - No
  - No
  - No
  - No

- **Q6: If Q5 yes, then what language?**
  - Skipped
  - Skipped
  - Skipped
  - Skipped
<table>
<thead>
<tr>
<th>Q7: Primary Classroom Setting</th>
<th>Regular school, self-contained special education classroom, some special inclusion (students go to art, music, PE) but return to their special education class for most of school day.</th>
<th>Regular school, self-contained special education classroom, some special inclusion (students go to art, music, PE) but return to their special education class for most of school day.</th>
<th>Regular school, self-contained special education classroom, some special inclusion (students go to art, music, PE) but return to their special education class for most of school day.</th>
<th>Special school</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q8: Expressive Communication</td>
<td>Student communicates primarily through cries, facial expressions, change in muscle tone, etc., but no clear use of objects/texture, regularized gestures, pictures, signs, etc., to communicate</td>
<td>Uses intentional communication, but not at a symbolic language level: Student uses understandable communication through such modes as gestures, pictures, objects/texture, points, etc., to clarify express a variety of intentions.</td>
<td>Uses symbolic language to communicate: Student uses verbal or written words, signs, Braille, or language-based augmentative systems to request, initiate, and respond to questions, describe things or events and express refusal.</td>
<td>Uses intentional communication, but not at a symbolic language level: Student uses understandable communication through such modes as gestures, pictures, objects/texture, points, etc., to clarify express a variety of intentions.</td>
</tr>
<tr>
<td>Q9: Use an augmentative communication system?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Q10: Receptive Language</td>
<td>Requires additional cues (e.g. gestures, pictures, objects, or demonstration/s/models? To follow 1-2 step directions.</td>
<td>Independently follows 1-2 step directions presented through words (e.g. words may be spoken, signed, printed, or any combination) and does NOT need additional cues.</td>
<td>Alerts to sensory input from another person (auditory, visual, touch, movement) BUT requires actual physical assistance to follow simple directions.</td>
<td>Alerts to sensory input from another person (auditory, visual, touch, movement) BUT requires actual physical assistance to follow simple directions.</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Q11: Vision</td>
<td>Corrected vision within normal limits</td>
<td>Vision within normal limits</td>
<td>Vision within normal limits</td>
<td>Vision within normal limits</td>
</tr>
<tr>
<td>Q12: Hearing</td>
<td>Hearing within normal limits</td>
<td>Hearing within normal limits</td>
<td>Hearing within normal limits</td>
<td>Hearing within normal limits</td>
</tr>
<tr>
<td>Q13: Motor</td>
<td>No significant motor dysfunction that requires adaptations</td>
<td>No significant motor dysfunction that requires adaptations</td>
<td>Needs personal assistance for most/all motor activities</td>
<td>No significant motor dysfunction that requires adaptations</td>
</tr>
<tr>
<td>Q14: Engagement</td>
<td>Responds with social interaction, but does not initiate or sustain social interactions</td>
<td>Initiates and sustains social interactions</td>
<td>Responds with social interaction, but does not initiate or sustain interactions</td>
<td>Initiates and sustains social interactions</td>
</tr>
<tr>
<td>Q15: Health Issues and Attendance</td>
<td>Attends at least 90% of school days</td>
<td>Attends at least 90% of school days</td>
<td>Attends at least 90% of school days</td>
<td>Attends at least 90% of school days</td>
</tr>
<tr>
<td>Q16: Reading</td>
<td>No observable awareness of print or Braille</td>
<td>No observable awareness of print or Braille</td>
<td>No observable awareness of print or Braille</td>
<td>No observable awareness of print or Braille</td>
</tr>
<tr>
<td>Q17: Mathematics</td>
<td>No observable awareness or use of numbers</td>
<td>No observable awareness or use of numbers</td>
<td>No observable awareness or use of numbers</td>
<td>No observable awareness or use of numbers</td>
</tr>
</tbody>
</table>
APPENDIX H

GEORGIA ALTERNATIVE ASSESSMENT BLUEPRINT BY GRADE: 2016-2017
<table>
<thead>
<tr>
<th>Grade</th>
<th>Content Area</th>
<th>Course</th>
<th>Strand/Standard</th>
<th>Collection Period 1</th>
<th>Collection Period 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Communication</td>
<td>Entry 2: Teacher Chooses 1 Standard From: Writing: ELA-ASSE11-12.W.1a,b,c; ELA-ASSE11-12.W.2a,b,c,d,e</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>and</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>and</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td>Science</td>
<td>Biology</td>
<td>Entry 1: Teacher Chooses 1 Standard From: Biology: SBH8.a,b,c,d, SBH9.a,b,c,d,e,f, SBH10.a,b,c,d,e,f, SBH11.a,b,c,d,e,f</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical Science</td>
<td>Entry 2: Teacher Chooses 1 Standard From: Physical Science: SP51.a,b,c,d,e,f, SP52.a,b,c,d,e,f, SP53.a,b,c,d,e,f, SP54.a,b,c,d,e,f, SP55.a,b,c,d,e,f, SP56.a,b,c,d,e,f, SP57.a,b,c,d,e,f, SP58.a,b,c,d,e,f, SP59.a,b,c,d,e,f, SP60.a,b,c,d,e,f</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td>Social Studies</td>
<td>U.S. History</td>
<td>Entry 1: Teacher Chooses 1 Standard From: U.S. History: (all elements) SUS1H1-SUS1H25</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Economics</td>
<td>Entry 2: Teacher Chooses 1 Standard From: Economics: (all elements) Fundamental Economic Concepts: SSEF1-SSEF6, or Microeconomic Concepts: SSEM1-SSEM6, or Macroeconomic Concepts: SSEMA1-SSEMA3, or International Economics: SSEEI-SSEEI, or Personal Finance Economics: SSEPF1-SSEP6</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>and</td>
<td>1 primary piece</td>
<td>1 secondary piece</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8 Entries</td>
<td>16 Pieces of Evidence</td>
<td>16 Pieces of Evidence</td>
</tr>
</tbody>
</table>
APPENDIX I

MEANINGS, DEFINITIONS, AND IMPLICATIONS OF CATEGORIES AND SUBCATEGORIES
<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Meaning, Definition and/or Implication</th>
<th>Researcher Notes in QDA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
<td>Daily Living Skills</td>
<td>Personal hygiene, dressing, meal preparation, toileting, housekeeping, laundry, taking medication, safety</td>
<td>Toileting brushing teeth dressing oneself making food feeding oneself grooming/hygiene taking medication washing clothes driving getting to appointments obtaining employment participating in training for employment</td>
</tr>
<tr>
<td></td>
<td>Vocational and Financial</td>
<td>Keeping a job, maintaining a budget, paying bills, transporting to a job</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Residential</td>
<td>Living with parents, independently or in supportive living (group home)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>Receptive and expressive communicative abilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Life</td>
<td>Maintaining friendships, going into the community (church, out to eat, etc.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Further Education</td>
<td>Having the goal or aspiration to attend a post-secondary institution (trade school, vocational school, university) to build vocational skills.</td>
<td></td>
</tr>
<tr>
<td>Academic Curriculum</td>
<td>Academic Curriculum</td>
<td>“A curriculum that is developed by looking at the standards (district, state or national); identifying the skills knowledge and dispositions that students should demonstrate to meet these standards; and identifying activities that will allow students to reach the goals stated in the standards” (Lund &amp; Tannehill, 2014, p. 7). Given the overall definition of Academic Curriculum, the subcategories imply:</td>
<td>no notations</td>
</tr>
<tr>
<td></td>
<td>Academic Curriculum Helped</td>
<td>Family’s opinion that academic curriculum helped loved one meet post-secondary goals and aspirations.</td>
<td></td>
</tr>
<tr>
<td>Academic Curriculum Did NOT Help</td>
<td>Family’s opinion that academic curriculum did NOT help loved one meet post-secondary goals and aspirations.</td>
<td></td>
<td></td>
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<tr>
<td>----------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
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</tbody>
</table>

**Functional Curriculum:** “…instructional content that focuses on the concepts and skills needed by all students with disabilities in the areas of personal, social, daily living, and occupational adjustment.” (Clark, 1995). Given the overall definition of **Functional Curriculum**, the subcategories imply:

<table>
<thead>
<tr>
<th>Functional Curriculum Helped</th>
<th>Family’s opinion that functional curriculum helped loved one meet post-secondary goals and aspirations.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Curriculum Did NOT Help</td>
<td>Family’s opinion that functional curriculum did NOT help loved one meet post-secondary goals and aspirations.</td>
</tr>
</tbody>
</table>

**Success:** a subjective measure (in this case, that of the family) on the attainment of attempts at goals in school and with post-secondary goals and aspirations. Given the overall definition of **Success**, the subcategories imply:

<table>
<thead>
<tr>
<th>Parent Opinion Success</th>
<th>The family’s opinion of success for their loved one.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Societal Perceptions Success</td>
<td>The family’s opinion of how success for their loved one by society is viewed or measured.</td>
</tr>
</tbody>
</table>

Parent perception of what success for their child looks like. This may have been while in school or since graduation. If related to a specific type of curriculum, then it will be coded under that curriculum. If not, it will be coded here--these are marked events that families fondly recollect as a success for their loved one and their family.
**Failure:** a subjective measure (in this case, that of the family) on the inability to or lack of success in achievement both in school and with post-secondary goals or aspirations. Given the overall definition of **Failure**, the subcategories imply:

<table>
<thead>
<tr>
<th>Parent Opinion Failure</th>
<th>The family’s opinion of failure for their loved one.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Societal Perceptions Failure</td>
<td>The family’s opinion of how failure for their loved one by society is viewed or measured.</td>
</tr>
</tbody>
</table>

Parent perception of what failure for their child looks like or how an entity failed their child and/or their family. This may have been while in school or since graduation. If related to a specific type of curriculum, then it will be coded under that curriculum. If not, it will be coded here—these are marked events that families recollect as a failure or cause for a failure (a stumbling block) for their loved one and their family.

**Mortality:** conversation with an overt discussion or a covert implication of death. Given the overall definition of **Mortality**, the subcategories imply:

<table>
<thead>
<tr>
<th>Parent Mortality</th>
<th>Discussion regarding the death of the parent/family, and the implications this death has on the well-being of their loved one with SID/PID.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student Mortality</td>
<td>Discussion regarding the death of the individual with SID/PID, and the implications that the family’s care has on their loved one with SID/PID.</td>
</tr>
</tbody>
</table>

Conversations about mortality are coded as a driving force for the need for independence; these codes will not necessarily be used to answer a research question,
but rather offer explanation as to WHY opinions are held and decisions are made.

*Note.* The meaning, definition and/or implication for each of the subcategories are included, along with notes entered into QDA Miner Lite by the researcher to further define each of the categories.
The researcher attempted to obtain explicit permission to use the Learner Characteristic Inventory (LCI) as the pre-interview questionnaire for this study. Emails were sent to the authors of the LCI on two different occasions with no response to those correspondences. The researcher then attempted calling using the phone number provided by the University of Kentucky to reach the author for authorization. The researcher was redirected to email the authors and was provided a direct email address for Dr. Kearns. The researcher emailed this author and did not receive a response. The researcher referenced the National Alternate Assessment Center webpage (http://www.naaccpartners.org/publications/LCI.aspx) and read the guidelines in full. After reading the guidelines, the researcher signed up to use the LCI, and a copy of the LCI was provided for use.

Terms of Agreement for LCI Use

To utilize the LCI, the state must agree to the following terms and conditions in writing by reading the Terms of Agreement and clicking agree when prompted to do so:

1. State agrees to use the LCI in its entirety without altering any of the items (a state may add or delete entire items, but cannot change any of the existing questions or response options).

2. State agrees to use the LCI only for the purpose for which it was intended (validity documentation for the population of students taking the alternate assessment based on alternate achievement standards).

3. The LCI belongs to the University of Kentucky/National Alternate Assessment Center and should be cited appropriately (see citation below).

4. Subsequent use of the LCI is available by permission only from the University of Kentucky/National Alternate Assessment Center.

5. The LCI is proprietary and should only be used by the requesting state. It should not be shared with other states and/or their contractors without permission in writing from the author(s).

Citation for the LCI should be:


Name: ___________________________
E-mail: __________________________
State: ____________________________

[ ] I have read these terms and conditions for use of the LCI.

Access Verification Code: ________
Please confirm the access verification code: ________

[ ] Proceed [ ] Reset