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Exploring parents' experiences of postsecondary education for their children with disabilities

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EXPLORING PARENTS' EXPERIENCES OF POSTSECONDARY EDUCATION FOR THEIR CHILDREN WITH DISABILITIES

by

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DEDICATION

This document is dedicated to the remarkable students of the Threshold Program, past, present, and future, and their equally remarkable parents, without whom I could not have found a career as fulfilling and sustaining as the one I am honored with. I hope I have done justice to your experiences.

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EXPLORING PARENTS' EXPERIENCES OF POSTSECONDARY EDUCATION FOR THEIR CHILDREN WITH DISABILITIES

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ABSTRACT

This study explored the expectations and experiences of parents whose adult children graduated from a comprehensive college-based postsecondary education program for students with intellectual or developmental disabilities. Seventeen parents of graduates from the Lesley University Threshold Program in Cambridge, MA were interviewed in the style of narrative inquiry. Subjects were asked to describe their expectations for their sons' and daughters' futures as they grew up, the role of a college program in their children's development and in the evolution of their own expectations, their hopes and concerns for the future, and their opinions of college inclusion and how greater inclusion might have impacted their sons and daughters.

Interview subjects were found to share common goals for their children: independence and fulfillment in life. While they faced great uncertainty about the future when their children were young, they wanted to help them achieve as much independence and fulfillment as possible, and expected that postsecondary education would help them progress toward these ends. Parents wanted their children to have a college experience that felt authentic, while also providing comprehensive and intensive supports and specialized skill development. Parents reported that their children's postsecondary experiences surpassed their expectations. They saw growth in their sons and daughters in the areas of independent living, vocational skills, and social skills, as well as advances in self-esteem, positive decision making, and problem-solving. While parents emphasized the value of life skills, friendships, and employment over inclusion at the university, every subject also stated that greater integration with undergraduates, facilitated by staff and peer mentors, should have been available to Threshold students, regardless of whether they thought their own son or daughter would have benefited.

Implications for practitioners and research are discussed, with an emphasis on the study’s relevance to current trends in the field of inclusive higher education.

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Chapter I: Introduction

Overview

Postsecondary education for young adults with intellectual and/or developmental disabilities (ID/DD) is a new opportunity in the United States and one that is experiencing rapid growth and change (Grigal, Hart, Smith, Domin, Sulewski, & Weir, 2014; Plotner & Marshall, 2015). The overall goal for serving this population of students is fairly consistent across postsecondary programs: to give young adults with ID/DD access to college experiences like those of their same-aged peers, while increasing their capacity to live and work independently. Strategies used to achieve these goals vary greatly from one program to the next (Grigal & Hart, 2012; Grigal, Hart, & Weir, 2012; Katovitch, 2009). Differences exist in: the degree to which the enrolled students are included in college coursework and dorm life; the availability and format of vocational curricula; and the way credits, certificates, or diplomas are conferred (Grigal et al., 2014; Grigal et al., 2012).

Whereas separate facilities and coursework for students with ID/DD were once the norm for the small number of college-based programs in the United States, programs now exist on a continuum from very highly inclusive, where students with ID/DD may experience only mainstream college coursework, dorm life, and social activities, to the highly separate extreme, where students with ID/DD take coursework, use facilities and services, and participate in activities designed only for them (Grigal et al., 2014; Grigal, Sax, Martinez, & Will, 2006). In the middle of the continuum are programs with some experiences only for students with ID/DD and some opportunities for inclusion into mainstream campus life. As highly inclusive postsecondary programs for young adults with ID/DD have emerged, programs that utilize specialized (separate) programming have begun facing competition and criticism (Grigal & Hart, 2012; Grigal et al., 2014; Uditsky & Hughson, 2012).

To date, little comparative research between specialized models and more recently established and more inclusive models has been published. It remains relatively unknown whether data will support the emerging ideology that separate programs are less desirable and effective than inclusive ones. Even once newer programs have been in operation long enough to have several years of graduates to study, comparative research will be difficult because of the variety of programs in each of these broad service delivery models. For now, the field can turn to the personal accounts of graduates and their parents to explore how these programs are experienced by families and help to inform future research efforts. Although the results of single-site experiential research cannot tell us whether one model is better than another in helping graduates achieve positive adult outcomes, it can help to inform the question of whether traditionally separate models have value for graduates and their families. This study seeks to capture parents' expectations for and experiences of the postsecondary education (PSE) of their adult sons and daughters with disabilities. The site of the research is the Threshold Program at Lesley University, a postsecondary program with both specialized elements and some opportunities for inclusion of its students into mainstream campus life. Understanding what parents expect out of a college program and asking them to reflect on how a PSE experience impacted their graduates' lives will help new and existing programs understand one of their major target audiences and structure their programming more effectively. Furthermore, parents' thoughts about the possible impact on their graduates of more or less mainstream college integration can help inform national conversations about the value of inclusive vs. separate experiences. Programs can use this insight to weigh the pros and cons of inclusion and specialization and thoughtfully design or re-organize their models in ways that respond to their target student populations and fit the missions of the colleges or universities within which they operate.

Problem Statement

Parents' expectations and opinions on the role and efficacy of postsecondary education for their young adult children with disabilities have not been thoroughly explored and documented (Stodden & Whelley, 2004). Parent expectations have significant impact on achievement and levels of independence for their children with disabilities, and on their awareness of and access to postsecondary education options (Newman, 2005; Grigal & Hart, 2012; Martinez et al., 2012). In recent years, the purpose, goals, and characteristics of postsecondary education programs for young adults with disabilities have been shaped by federal grant opportunities funded by the Higher Education Opportunity Act of 2008 (Grigal et al., 2014; HEOA, 2008). As a result of these new programs and the advocacy efforts of Think College, the national coordinating center designed to support them, the field of postsecondary education for young adults with ID/DD is trending toward maximum inclusion in university coursework and campus life (George Mason University, 2016; Think College, 2013; U.S. Department of Education, 2012). The national coordinating center reports "it is concerning that the majority of college coursework being accessed [by students at postsecondary programs funded by the HEOA] remains academically specialized and not academically inclusive" (Grigal et al., 2014, p. 17). The use of the term "concerning" suggests a value judgment that ranks inclusive coursework as more desirable than specialized (academically non-inclusive) coursework. Research on the efficacy of inclusive vs. specialized programs in improving the adult outcomes of their graduates is sparse and difficult to conduct with academic rigor, and therefore support of inclusive programs over specialized programs is currently an issue of social justice and a reflection of inclusive ideology, and is not yet based in research.

It is possible that specialized programs are both less effective and less ideologically desirable than inclusive programs, as has been suggested in national conversations about postsecondary educational opportunities for adults with ID/DD, but this has not been investigated and cannot be assumed as fact. Before the legitimacy of specialized programs is negated by this shift in the field, the stories of parents whose adult children attended these programs can help us learn whether there remains some value in specialization.

Parents' opinions, expectations, and experiences of their children's colleges have increasingly been documented for mainstream student populations (College Parents of America, 2007; Ruffalo Noel Levitz Higher Education Consultants, 2012; Spence, 2012), and should be considered equally valid for college students with disabilities. Decision makers in postsecondary programs serving students with intellectual or developmental disabilities should understand how parents view the purpose of a postsecondary experience in their children's lives in order to ensure that they are offering needed and desired programming, satisfying their students' families, targeting the appropriate prospective students, and hiring staff with the expertise necessary to support program goals. Furthermore, parents are often the driving force behind the development of new programs (Leuchovius & Roy, 2016), and should have literature available to them that represents the experiences of other parents as they consider what types of program to advocate for in their communities.

Research Questions

This study seeks an answer to the research question: How do parents of alumni of a postsecondary program for young adults with disabilities describe the expectations they have had for their children's postsecondary education and later adulthood, and how have their actual experiences compared to their expectations?

Sub-questions include:

1) In what ways did parents' expectations for their sons' and daughters' adult lives develop and evolve as they grew up? What role did a college program play in the evolution of their expectations?
2) What do parents view as the critical impacts of a college program on their sons and daughters?
3) How did parents' actual experiences of their children's college program compare with their hopes and expectations, and how do they imagine a more

inclusive experience may have compared?

Overview of Methodology

This study is a narrative inquiry into the experiences of parents whose adult children with intellectual or developmental disabilities (ID/DD) graduated from a college-based postsecondary education program. Parents whose sons and daughters graduated between 2008 and 2014 (inclusive of both years) were recruited. This range of years was chosen because it reflects the time period during which the field of higher education for people with ID/DD began to grow quickly and trend toward maximum inclusion. Consequently, parents whose children attended a postsecondary program during these years may have an awareness of other programs with varying levels of inclusion, and may have considered multiple programs when helping their children make a selection. Participants were selected using maximum variation sampling to ensure diversity in the group of participants and the graduates they represented. Seventeen parents were interviewed and audio recorded by the researcher using semi-structured interviews.

Significance of the Study

This study aims to explore parents' perspectives of the postsecondary experiences of their adult children with disabilities, those experiences' effects on their transitions into adulthood, and their opinions on inclusion in college experiences for this population. National trends in the field of postsecondary education for young adults with ID/DD are rapidly changing, with more emphasis than ever on academic and social inclusion on campus. The literature surrounding this recent movement is largely focused on the advocacy efforts, experiences, and research of professionals, and to a lesser extent on the voices of young adults with disabilities and their families. As traditional college programs are increasingly seeking parent input on their children's college experiences, it is time for programs for students with ID/DD to follow suit. It is important to learn about what parents hope for in their children's adult lives and postsecondary education in order to design programs that support them effectively and to inform future studies comparing various program models. While previous studies have investigated either parents' expectations for (Griffin, McMillan, & Hodapp, 2010), or their experiences of (Hughson, Moodie, & Uditsky, 2006) their intellectually disabled children's involvement in postsecondary education, no study has explored both.

Definition of Terms

Due to the complex and variable language used to describe the types of students served by the programs discussed in the following pages, a definition of key diagnostic terms and an explanation of their application to the research site and other programs in the field are offered first. This section also provides a justification for referring to academic literature on intellectual disability, which is a diagnosis given to only a small percentage of students in the Lesley University Threshold Program, the site of the research.

The term "intellectual disability" (ID) is used to describe all children and adults who previously would have qualified for a diagnosis of "mental retardation" (MR).

People with diagnoses of ID (formerly MR), according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), score two standard deviations or more below the mean on tests of intelligence quotient (IQ); in other words, they score 70 or below (American Psychiatric Association, 2013). To qualify for diagnoses of ID, individuals also need to demonstrate deficits in adaptive functioning, i.e., impairments in the way they cope with typical issues that an average person of their age would be expected to deal with. Impairments may be in the areas of physical self-care, personal safety, social interaction, etc. An intellectual disability may be mild, moderate, or severe depending on an individual’s level of adaptive functioning.

Threshold students have deficits in adaptive functioning but also typically have IQ scores between 70 and 85, although some students are admitted with overall IQ scores outside of that range. An IQ score above 70 typically disqualifies a person for a medical diagnoses of an intellectual disability, simultaneously disqualifying many of them from some of the major state and federal services and benefits programs designed to support children and adults with ID. Threshold targets this particular population for admission specifically because of the major gap in services they face following high school completion. Individuals with IQ scores between 70 and 85 are sometimes referred to as having borderline intellectual functioning (Kaufmann, 2013), but this term is rarely used in medicine, education, or academic literature. Borderline intellectual functioning is listed in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), but is not a billable code for insurance companies and is generally not an eligible diagnosis for receiving state or federal disability benefits, and therefore is very rarely assigned to young adults who fit its characteristics.

Threshold students are usually described in medical and educational records by specific diagnoses other than ID, although a small number of Threshold students do have a medical diagnosis of ID. Cerebral palsy, autism, traumatic brain injuries, epilepsy, specific learning disabilities, and nonverbal learning disabilities (all combined with a below average IQ score) are the most common diagnoses among Threshold students. Other diagnoses include Williams syndrome, velocardiofacial syndrome, and spina bifida. These diagnostic terms are useful for understanding a particular student's experience and potential needs, but each term covers a broad range of possible intellectual and adaptive abilities. For example, a person with cerebral palsy may have very severe intellectual impairment or no intellectual impairment at all, and anywhere from very severe to very mild physical impairment. In order to talk about all Threshold students as a group, they are variably referred to in Threshold's marketing materials, presentations, and publications as having "learning challenges," "special needs," "learning disabilities," or as scoring "below average on tests of intellectual ability." These are all appropriate descriptions of Threshold students in general, but are too vague to provide a clear picture of the profile of a "typical" Threshold student.

Most Threshold students are not given diagnoses of intellectual disabilities due to relatively higher IQ scores that have not historically been consistent with a diagnosis of ID. However, the recently released DSM-5 emphasizes the importance of adaptive functioning over IQ score in the diagnosis of an intellectual disability more-so than previous editions, so individuals with IQ scores above 70 and notable deficits in adaptive functioning may now qualify for a diagnosis of ID that they would not have received under previous DSM editions (Kaufmann, 2013). This change in diagnostic criteria could apply to some potential Threshold students who have IQ scores slightly above 70 but show marked impairments in key areas of adaptive functioning. Furthermore, all Threshold students have characteristics consistent with a recent definition of intellectual disability used in the federal Higher Education Opportunity Act (HEOA) of 2008, other implications of which will be discussed in the literature review.

From here on, this document uses the term “intellectual disability” as defined in Part D, Section 760 of the HEOA:

‘‘(2) STUDENT WITH AN INTELLECTUAL DISABILITY - The term ‘student with an intellectual disability’ means a student—

‘‘(A) with mental retardation or a cognitive impairment, characterized by

significant limitations in—

‘‘(i) intellectual and cognitive functioning; and

‘‘(ii) adaptive behavior as expressed in conceptual,

social, and practical adaptive skills; and

‘‘(B) who is currently, or was formerly, eligible for a

free appropriate public education under the Individuals with Disabilities Education Act." (p. 291)

The postsecondary programs described in this literature review typically serve students who fit the broad HEOA definition of an intellectual disability, and therefore include students with IQs below 70 and medical diagnoses of mild intellectual disabilities as well as students with higher IQ scores (McEathron & Beuhring, 2011), who are more similar in profile to Threshold students and who may not have medical diagnoses of ID. These programs generally do not distinguish between students with IQ scores of 70–85 and those with scores below 70, and often do not require IQ testing for admission at all. Therefore, students fitting the profile of a Threshold student are often accepted into these programs and are included among the students involved in research studies referenced throughout this literature review, even when those studies describe their subjects as having ID. Furthermore, there is a dearth of statistical information and literature on people with IQs between 70 and 85, and almost no literature at all on this specific population's involvement in postsecondary education. Finally, recent changes to the DSM have blurred the diagnostic line between students with IQ scores above 70 and those with slightly lower IQ scores. For these reasons, the following literature review uses literature about students with mild intellectual disabilities, specifically, and sometimes developmental disabilities or special needs more broadly, recognizing that this literature may not perfectly represent the specific population of students served by Threshold.

The term "students/graduates with borderline intellectual functioning" is the most accurate description of Threshold students and alumni as a whole. However, borderline intellectual functioning is a term very rarely used in the literature, sounds inherently negative, and is not a term Threshold students/graduates or their parents generally use as a descriptor. Almost all Threshold students and graduates could be described as having a developmental disability, as that broad term covers almost all the specific diagnoses they may carry, with the exception of a traumatic brain injury sustained in late adolescence. In the research question and in most of this text, Threshold students/graduates and their similarly developing peers will be described by the term "students/people with intellectual disabilities or developmental disabilities (ID/DD)", or, for simplicity, as "students/people with disabilities". Research referring to people with intellectual disabilities will be referenced and will be treated as applicable to Threshold students/graduates and their families, acknowledging that the diagnosis is not a perfect fit.

Innumerable educational and vocational programs exist to serve young adults after high school and could be described as "postsecondary education" (PSE) programs. The term will be used in this study to describe postsecondary programs that admit students with ID/DD and are based at public or private, two or four-year colleges and universities.

Finally, the term "exceptional parenting" will be used in this text to refer to parenting a child with disabilities, although it is also used in other literature in reference to children who are gifted.

Chapter II: Review of the Literature

Postsecondary Education for People with Intellectual/Developmental Disabilities

Attending college is an opportunity for academic enrichment, career exploration, and social growth. It is a rite of passage into adulthood and an investment into the future. Historically, people with intellectual or developmental disabilities have not been able to participate in higher education because of high school graduation and standardized testing requirements for college admission (Hart et al., 2006). Barriers to higher education for people with ID/DD have increasingly been seen by special education advocates, self-advocates with disabilities, and families of youth with disabilities as socially unjust, unnecessary, and damaging. As a result of grass-roots efforts and legal advocacy, college access for people with ID/DD has increased over the last few decades, and there are now around 250 college-based postsecondary education (PSE) programs in the United States serving students in this population (Think College, 2016). Recently, many programs have begun focusing on how to support students in maximally inclusive college experiences, i.e., experiences that bring them as close to being traditional undergraduate students as possible (Hart & Grigal, 2013).

Early research has suggested that students with ID/DD who participate in postsecondary education have more employment opportunities, higher wages, and more independent work than students with the same disabilities who do not participate (Grigal & Dwyre, 2010; Grigal, Hart, & Migliore, 2011; Migliore, Butterworth, & Hart, 2009; Zafft, Hart, & Zimbrich, 2004). Most of the postsecondary education programs now in operation for this population were developed within the last 15 years and many of them emphasize inclusive, individualized education, allowing or, in some cases, requiring students with disabilities to enroll in mainstream university courses and designing appropriate academic supports on a case-by-case basis (Grigal, Hart, & Weir, 2011). In some older programs, which were established as separate experiences for young adults with disabilities on college campuses at a time when even minimal inclusion in college life was unheard of, students with ID/DD have remained largely separate from undergraduates.

Background. Students with intellectual disabilities are not generally expected to attend college (Grigal & Hart, 2010; Newman, 2005) and as a result have postsecondary education stated as transition goals in their federally-mandated Individualized Education Programs (IEPs) less than students in any other disability category (Grigal et al., 2011; Cameto, Levine, & Wagner, 2004). Despite generally low expectations for students with ID, college programming for this population has existed since at least the 1980s. Programs allowing students with ID/DD to participate in college experiences, with or without inclusive college coursework and social activities, were developed in Massachusetts in 1982, New York in 1987, Alberta, Canada in 1987, California in 1995, and Australia in 1999, among other places (Lesley University, 2013; O'Connor, Kubiak, Espiner, & O'Brien, 2012; Taft College, 2013; VanBergeijk, 2012).

College-based postsecondary education options for students with intellectual disabilities vary in their structure, goals, funding, and methods. They have typically been founded by parents, educators, or disability service providers looking to address the gap in educational services available to students with ID/DD after or toward the end of high school (Grigal et al., 2011). These grassroots mobilizers often visited established programs in order to learn what other schools were doing but did not have the benefit of validated best practices to guide the development of new programs (Grigal et al., 2011; Hart, Mele-McCarthy, Pasternack, Zimbich, & Parker, 2004).

All colleges receiving federal money have been tasked by law since 1973 with providing reasonable accommodations to support academically eligible students with disabilities in accessing coursework, physical spaces, and extracurricular activities (U.S. Department of Education, Office for Civil Rights); however, it was not until 2008 that access to college for people with *intellectual* disabilities was specifically addressed in federal law. The Higher Education Opportunity Act of 2008 included provisions for funding the establishment of model demonstration programs for students with intellectual disabilities at institutes of higher education. The HEOA does not specifically include students with borderline intellectual functioning, although they are often among the student population of programs funded through the HEOA because of the relatively broad definition of ID/DD used in the law.

The HEOA does not guarantee access to higher education for students with disabilities who are not academically eligible; i.e., it does not give a student with an ID/DD who did not pass his state’s required standardized testing and instead received a certificate of high school completion the right to be admitted to a college or university that requires a high school diploma or GED. Rather, it encourages institutes of higher education to investigate ways to include students with intellectual disabilities in campus experiences and funds a cohort of institutions engaged in such work.

In 2010, twenty-seven institutes of higher education were granted funding to establish or expand HEOA model demonstration programs, called transition and postsecondary programs for students with intellectual disabilities (TPSIDs). The TPSID projects were tasked with providing educational, vocational, and/or independent living services to young adults with ID/DD on college campuses. Some grant recipients started more than one program site, resulting in forty-three model demonstration program sites in the first round of HEOA funding (Hart & Grigal, 2013). A second group of twenty-five TPSID projects received funding in 2015; eight of the projects were previous grant recipients (Think College, 2015). Each TPSID must show that their students are “socially and academically integrated with non-disabled students to the maximum extent possible” (HEOA, Section 760, 20 U.S.C. 1140) and, over a five-year period, must develop, implement, and evaluate inclusive college programming and make evaluation results available to others seeking to develop or remodel similar programs.

Models of postsecondary education programs. Hart et al., (2006) describe PSE options in the US as falling into three models: the “substantially separate model,” the “mixed/hybrid model,” and the “inclusive individual support model” (p. 1). Classes in substantially separate programs are only for students with disabilities. Students may have some opportunities to participate in inclusive campus activities or use college facilities, but most of their experience is separated from matriculated college students. These programs often have a vocational component with on or off-campus internship opportunities, typically unpaid.

Mixed/hybrid programs have vocational components as well but also have opportunities for students to participate in inclusive college classes with matriculated students without ID/DD (Hart et al., 2006). They may have more opportunities for social inclusion than substantially separate programs, but they generally still offer or require some coursework or social experiences that are separate from matriculated college students. In both substantially separate and mixed/hybrid programs, supplementary supports such as independent living skill building, transportation assistance, vocational education, and social skills training are often offered by the PSE program itself, and by extension the college or university it is based at, rather than by outside organizations. The Threshold Program uses a mixed/hybrid model overall. A few students each year take college classes and many students participate in campus activities, clubs, and NCAA sports with undergraduates, but the overall curriculum, residential facilities, staffing, and other aspects of the program are separate from the undergraduate experience.

Programs following the inclusive individual support model provide tutoring, mentoring, advising, or other academic services as determined by individualized plans developed with students, with the goal of maximum possible inclusion in mainstream college coursework and campus life (Hart et al., 2006). These programs generally operate out of an existing department or office at the institute of higher education, rather than out of a specifically designed program base, making the college experience as mainstream as possible. The role of the institutions of higher education under this model is to include students in mainstream education and provide supports to make that possible. Supplementary supports may be offered by the program or by non-profit organizations or government agencies that collaborate with each student with ID/DD and his or her family and program mentor. While the programs will typically collaborate with local school districts, vocational rehabilitation offices, and disability service agencies to share operational costs and to arrange disability services such as independent living assistance, mobility coaching, and employment support, such services may or may not be offered directly by the college. These programs have little or no specialized coursework or activities only for students with intellectual disabilities (Hart et al., 2006).

Both inclusive individualized and mixed/hybrid models include students with ID/DD in campus coursework and activities with non-intellectually disabled peers, providing them with an “inclusive higher education” (Grigal et al., 2011, p. 1). The level of inclusion experienced in programs of these models varies widely by the college or university and by the student.

While the model by Hart et al. (2006) provided the field with a way to group programs based on their overall level of inclusion in mainstream college practices and experiences, it stops short of describing and categorizing actual program practices and components. There exists such variability in program characteristics that practitioners will find it challenging to determine how relevant research or practices from one program might be to another. McEathron and Beuhring (2011) addressed this issue by proposing a taxonomy for describing and classifying PSE programs. By exploring the existing publications in the field, they identified four major domains addressed by PSE programs; Vocational, Social, Independent Living, and Academic. Within each domain are individual practices that may exist at a PSE program and that lie on a spectrum ranging from fully inclusive with undergraduate students or integrated with university practices to entirely separate from undergraduate students or university practices. The authors suggest that experts in the field convene to test the use of the taxonomy in research and to develop a set of definitions for variably used terms like “intellectual disability” and “inclusive” (p. 11). If this has occurred, results of those conversations have not yet been published.

Emerging trends and standards of practice in PSE programming. The Institute for Community Inclusion at the University of Massachusetts, Boston, was awarded grant funding by the federal Office of Special Education Programs and the Office of Postsecondary Education to create a national coordinating center and oversee the planning, operation, and evaluation of the TPSIDs (Lee, 2009). The center, called Think College, has also come to serve as a major resource to other PSE programs and a trend-setter in the field. In 2011, Think College released standards of practice to guide the development and operation of TPSIDs and other PSEs (Grigal et al, 2011). Think College consulted with thirty-eight experts in the field of PSE programming in an anonymous Delphi process to outline the development of standards, quality indicators, and benchmarks for inclusive PSE programs. The authors of the document acknowledge that it is based on the experiences, knowledge, and opinions of professionals who have direct experience with PSEs and that the practices they recommend are not all based in research. TPSID programs are tasked with evaluating their operations and outcomes and reporting back to Think College, which will amend the document as necessary to reflect research as it becomes available. Although the authors qualified the document with the caveat that it has not been validated by research, the standards both reflect and promote the field's movement toward highly inclusive PSE programs.

The Think College standards are designed to inform the planning and operation of programs following the mixed/hybrid or inclusive individual support models and for guiding mixed/hybrid and substantially separate programs in becoming more inclusive (Grigal et al., 2011). Think College publications and conferences about PSE programming regularly highlight inclusive programs over substantially separate ones, and Think College administrators speak openly and often about the value of making college coursework and experiences accessible to students with ID/DD (Hart & Grigal, 2013; George Mason University, 2016; Think College, 2013; U.S. Department of Education, 2012). Since Think College was funded to oversee the development of programs and disseminate information about PSE opportunities, they are the source of much of the current literature on the topic, maintain the main database families and educators use to look for PSE programs, and sponsor many of the related conferences. With such key involvement in the field, much of the information available to families and educators is influenced by the value Think College places on inclusion, particularly inclusion in mainstream college coursework alongside students without ID/DD. Their values simultaneously act as a response to and a catalyst for a national shift in interest from substantially separate PSE programs to inclusive higher education opportunities.

In addition to the creation of highly inclusive college experiences for students with ID/DD, trends in the field include increasing the ethnic, racial, and socioeconomic diversity of students in PSE experiences, studying the effects of inclusion on students with ID/DD and their classmates without ID/DD, lowering the cost, creating a process for accreditation, developing meaningful credentials, increasing the number of students participating in PSE experiences nationwide, initiating state-wide efforts to promote PSE development, and encouraging conversations about college early in the transition planning of students with ID/DD (Griffin, Summer, McMillan, Day, & Hodapp, 2012; Grigal & Smith, 2014; Hart & Grigal, 2013; May, 2012; Parent-Johnson et al., 2014).

Emerging research on PSE programming. The literature on PSE programming is still in its nascent stage, and most of the publications on the topic are program descriptions (Folk, Yamamoto, & Stodden, 2012; Grigal et al., 2014; Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013), policy briefs (Vanbergeijk & Cavanagh, 2015), news articles (Holohan, 2015; Lefferts, 2013; Lefferts, 2014), editorials (Grigal & Hart, 2012), and fact sheets (Grigal & Hart, 2013; Grigal et al., 2011), with little academic research published to date. Two literature reviews on postsecondary education for people with ID/DD have detailed the available peer-reviewed journal articles on the topic from the 1970’s until 2001 (Neubert, Moon, Grigal, & Redd, 2001), and from 2001 through 2010 (Thoma et al., 2011). In total, 60 articles were found, with 47 published from 2001 on; most were descriptive studies of PSE programs (McEathron

& Beuhring, 2011). McEathron and Beuhring (2011) cautioned against comparing results of the few research studies that did exist at the time of their publication, and even against taking single studies on PSE outcomes at face value, due to inconsistency in how key terms related to diagnoses, program components, and outcomes are defined across studies.

Furthermore, it is inadvisable to try to compare research results across studies, and even difficult to understand the meaning of study results, since many studies, including this one, use a broader definition of intellectual disability than the medical community, leaving some uncertainty for the reader about who the subjects of the study are and how they might compare with other groups of students (McEathron & Beuhring, 2011). Outcomes for PSE students may seem especially positive in some studies that claim to describe subjects with ID, but which also include students with IQs that are higher than two standard deviations below the mean, the requirement for a diagnosis of ID.

The broad definition of intellectual disability used in the wording of the HEOA has contributed to the lack of clarity around the diagnoses of students in PSE studies. Research has also been influenced by the HEOA requirements that TPSIDs offer opportunities for students with intellectual disabilities to participate in mainstream college experiences alongside non-intellectually disabled peers. Much of the research published on PSE programming in the years since the HEOA was passed has focused on establishing a case for why students with intellectual disabilities should be able to access mainstream college experiences (Griffin et al., 2012; Hafner, Moffat, & Kisa, 2011; May, 2012; O’Connor et al., 2012); these studies aim to disprove common concerns about students with ID/DD attending college, not to measure the outcomes of PSE graduates.

One exception to the lack of comparative and outcomes research is a study that investigated an inclusive individualized program and a substantially separate (referred to in the study as “specialized”) program, comparing them against each other and against data on young adults with ID overall from the National Longitudinal Transition Study-2 (Moore & Schelling, 2015). This study surveyed a small number of graduates from each program and found that the programs resulted in comparable employment rates, and that both programs had better alumni employment rates than young adults with ID overall. However, graduates from the specialized program worked more hours on average, but had lower wages, than graduates from the inclusive program. Both groups of graduates worked fewer hours than young adults with ID overall, although graduates of the inclusive program worked for better wages than both other groups. Graduates of the inclusive program also tended to work in jobs that were outside of the most common job types for people with ID (food preparation, factory/production work, and janitorial/custodial services), which the authors cite as a positive outcome in the eyes of many advocates. This study used sample sizes and two programs with similar, but not identical, admissions processes and student bodies. The comparison group of students with ID from the NLTS-2 represents a limitation in the research, as the comparison group included students with all severities of ID, whereas PSE programs largely serve students with mild ID. More research of this type needs to be done on a larger scale, and with more accurate comparison groups, in order to confirm or challenge these results and further explore differences in outcomes between inclusive and specialized programs.

In addition to the dearth of research backing up inclusive higher education as an effective practice, another barrier to inclusive opportunities is the fear (among college administrators) that involving students with ID/DD in typical classes will reduce the academic rigor of the classroom, is against the wishes of matriculated students without ID/DD, or would create a negative environment for students without ID/DD in some way (Eisenman & Mancini, 2010). In fact, while students with disabilities enrolled in college courses for credit (whether the student has an ID/DD or not) are legally entitled to reasonable accommodations in order to access the coursework, altering the requirements or standards of the course is not required (Americans with Disabilities Act, 1990; Section 504 of the Rehabilitation Act, 1973). When a student with ID/DD enrolls in a course for credit, the rigor of the coursework should not change for that individual or for other enrolled students. When a student with ID/DD enrolls in a course on an audit basis, the course expectations might change for that student, but that should not affect the expectations of students enrolled for credit (Eisenman & Mancini, 2010).

Recent studies have shown that university students were open to the idea of including students with ID/DD in class. A large survey of 456 college students who had shared at least one class with a student with ID/DD showed that 96% of the students without ID/DD felt comfortable or very comfortable having that student in class (Hafner et al., 2011). A study of 256 Vanderbilt students without ID/DD revealed that those students who had close relationships with people with ID/DD were more interested in interacting with them and saw more benefit in including them than people with less experience. The study also found that students who took a college class with someone with ID/DD saw more benefits to their inclusion and had more positive views of their abilities than those who had not (Griffin et al., 2012). Another study found that students who took a class with a student with ID/DD were more open to and comfortable with diversity after that class than before, and more comfortable after than students in other sections of the same course who had not shared it with someone with ID/DD (May, 2012). The results of these studies were corroborated by a similar inquiry into the experiences of eight peer mentors to students with ID/DD done by Izzo and Shuman (2013).

Faculty, too, can be impacted positively by having students with ID/DD in class. Interviews with 11 faculty in an inclusive college program in Dublin, Ireland found that instructors felt that including students with ID/DD in college classes was a social justice issue and that denying anyone access to something they could benefit from would be wrong (O’Connor et al., 2012). Instructors appreciated the liveliness that students with ID/DD brought to the dynamic and found that other students seemed more comfortable asking questions because of the spontaneity shown by some of the students with ID/DD. Instructors also made their course content more accessible in response to the needs of the students with ID/DD, and valued being pushed to consider new ways to present material and make it clearer for all types of learners.

While research on the outcomes of people with ID/DD who attended a PSE program is limited, what has been published suggests that postsecondary education, in general, may be linked to better adult outcomes for this population in several areas (Miller, DiSandro, Harrington, & Johnson, 2016; Newman et al., 2011), with employment being a major focus of recent studies (Grigal et al., 2011; Migliore et al., 2009; Reisman, Yuan, & Osten, 2006). A 2007 study of young adults with ID/DD enrolled in vocational rehabilitation services showed that 48% of those who had participated in some kind of postsecondary education experience (including substantially separate PSE programs and postsecondary opportunities that were not college-based) were employed for pay when they stopped receiving services, compared with 32% of those who did not participate in PSE (Migliore et al., 2009). The students with postsecondary experience who were employed for pay also earned an average of $121 per week more than those without it who were employed for pay. Similarly, Grigal et al. (2011) found that having attended a two or four-year college in any capacity was a predictor of employment for people with ID/DD.

Data from a 2006 survey of Threshold Program alumni showed that 80% of respondents who graduated between 1996 and 2005 were employed for pay, and 84% of respondents who completed the optional Transition Year program, an additional year of support for graduates living in apartments off campus, were employed for pay (Reisman et al., 2006). Results from a 2016 survey of graduates posted on the Threshold Program website show even higher employment rates, with an overall employment rate of 85% for the 137 survey respondents (Lesley University, 2016). These numbers appear significantly higher than employment data from Migliore et al. (2009), but also likely represent students with higher average IQ scores, so no meaningful comparison can be made. However, it is still notable that these employment statistics are for individuals who graduated from Threshold before inclusive coursework and activities were an option, and therefore represent outcomes of graduates from a substantially separate program.

In addition to having a positive correlation with employment, postsecondary education is positively correlated with several other important adult outcomes. Eight years out of high school, adults with disabilities who had completed some type of PSE were significantly more likely to live independently, have a checking or savings account, see friends weekly, take additional coursework, and participate in volunteer work than those who had not (Newman et al., 2011). Initial data on employment and independence among graduates of an inclusive individualized program at the University of North Carolina Greensboro also show promising outcomes on similar measures. A small sample of alumni who were between six months and five years post-graduation showed rates of employment, independent living, and several measures of self-determination that were stronger than national data for similar populations (Miller et al., 2016).

Research is also beginning to be done on the first person experiences of students with ID/DD accessing college. Paiewonsky (2011) conducted a participatory action research study in which nine students with ID/DD in a PSE program were able to describe their college experiences through digital storytelling. Students reported that college access made them feel more independent and mature, freer to make choices, and more responsible for their work. They learned how to pick courses that would interest them and help further their career goals, manage their time and workloads, and meet the high expectations of professors. Students also identified ways to improve the experience, including training educational coaches to assume students could do the work and only offer help when asked, rather than giving too much help.

Parents' perceptions of their children's PSE experiences are also important to explore, although research on this subject is very limited. One study of inclusive college programs in Alberta, Canada richly described the experiences of alumni and their parents and reported that study participants felt that graduates' work opportunities, participation in the community, and independent living outcomes were all significantly improved by their experiences in the programs (Hughson et al., 2006).

Parent Expectations for Children with Special Needs

Parents are key partners in setting educational goals for their children with disabilities (Russell, 2003) and have significant impact on their children's postsecondary plans, levels of independence, and academic achievement (Newman, 2005; Grigal & Hart, 2012; Martinez et al., 2012). Parents of children with disabilities are also often catalysts for the development of new PSE programs for students like theirs (Leuchovius & Roy, 2016). Just as college and university administrators are seeking input from parents about their mainstream undergraduate students as they consider ways to improve programming and increase retention (College Parents of America, 2007; Ruffalo Noel Levitz Higher Education Consultants, 2012; Spence, 2012) so, too, can PSE programs (Stodden & Whelley, 2004).

Exceptional parenting. Historically, a major focus of the research on exceptional parenting (i.e., parenting a child with special needs) has been on the burden and emotional distress it can place on parents (Green, 2007; Heiman, 2002). Parents have reported frustration, social isolation, and fatigue (Heiman, 2002); feelings of being outside of the normal parenting experience (Broberg, 2010); rejection by family members and society (Papageorgiou & Kalyva, 2010); concerns about future caregiving burdens on their other children without disabilities; stress on their marriage; and concerns about the quality of their child's life (Heiman, 2002). Conversely, the capacity for parents to experience psychological and emotional benefits from raising a child with a disability has also been explored. Parents have reported that even after initial reactions of anger, fear, and feelings of loss, they have come to feel love, joy, and satisfaction from parenting a child with special needs (Green, 2007; Heiman, 2002). Parents are able to appreciate their children for who they are and find pride and fulfillment in their hard-earned achievements (Green, 2007). They also report that they and their other children became more accepting of difference and more tolerant of others as a result of sharing their lives with a child with a disability (Green, 2007), and that they themselves feel more thankful for their own abilities and more aware of their own areas of struggle (Messer, 2010).

Parenting is not conducted in a vacuum, and societal stigma and cultural expectations not only play a role in forming parents' expectations for their children, but also impact how parents experience their role as caregivers (Broberg, 2010; Green, 2007). Mothers of children with special needs who experience stigmatization tend to have higher levels of emotional distress (Green, 2007). Societal expectations and stigmatization can also prevent parents from recognizing any benefits to raising a child with special needs. Parents who recognize benefits to exceptional parenting may experience protective impacts on their health, both physical and psychological, and therefore society's focus on disability as a negative characteristic and a cause of suffering for a family may contribute to poorer coping among such families (Green, 2007). Parents who do recognize benefits of exceptional parenting and who are coping well may experience frustration when met with a negative societal view of disability that does not match their positive experience (Broberg, 2010).

Parents report concerns about their children's inclusion in society, their levels of independence, their ability to work or get an education, and their ability to cope and thrive after the death of their parents (Heiman, 2002). The type of disability a young adult has influences how concerned their parents are about their employment, living options, social involvement, and dependence on their family, as well as how significantly those concerns impact their well-being and daily life, with parents of children with autism having the greatest concerns and highest impact of those concerns when compared with parents of children with Down's syndrome, cerebral palsy, or severe undifferentiated learning disability (Blacher, Kraemer & Howell, 2010).

Parents' expectations. Parents' expectations for the futures of their children with disabilities have been found to predict children's level of autonomy and a number of outcomes for life after high school (Doren, Gau & Linstrom, 2012). Parents' expectations that their children will graduate from high school (Doren et al., 2012), attend postsecondary school (Doren et al., 2012), and have paid employment (Carter, Austin & Trainor, 2012; Doren et al., 2012; Papay & Bambara, 2013) are all correlated with an increased likelihood that each of those outcomes will be reported. Papay & Bambara (2013) found that youth with intellectual disabilities whose parents thought they would be employed after high school were in fact 58 times more likely to be employed two years out than youth whose parents did not expect them to be employed. Previously referenced studies did not control for the severity or etiology of the intellectual disability, although Blacher et al., (2010) found that parents of young adults with Down's syndrome had higher expectations for post-school employment, and parents of young adults with cerebral palsy had lower expectations, than parents of children with either autism or severe undifferentiated learning disabilities. Parents of students with intellectual disabilities tend to have lower expectations for future outcomes than parents of students with learning disabilities (Doren et al., 2012).

Parents of minority adolescents with disabilities have been found to have lower expectations for their sons' and daughters' future employment than parents of white adolescents, and parents from lower income backgrounds have lower expectations for their sons' and daughters' high school graduation, employment, and postsecondary school attendance than parents from higher income backgrounds (Doren et al., 2012). Parents with lower levels of education are also less likely to expect their children with disabilities (primarily physical disabilities) to attend college (Masino & Hodapp, 1996). Youths' expectations for themselves are related to their parents' expectations for them, and youth with high expectations also tended to have parents with high expectations

(Wagner, Newman, Cameto, Levine, & Marder, 2007).

Despite the correlation between high parent expectations and high student expectations, the same study from the large National Longitudinal Transition Study-2 dataset has revealed that parents' expectations for the adult outcomes of their children with disabilities are lower than their children's expectations for themselves in the areas of employment, high school graduation, postsecondary education, and financial self-sufficiency (Wagner et al., 2007). Although the NLTS-2 did not include an explanation of why this is the case, part of the cause may be that some parents of children with disabilities believe their children's expectations for the future are unrealistic (Hogansen, Powers, Geenen, Gil-Kashiwabara & Powers, 2008).

Parents' expectations for their children's adult lives both influence and are influenced by the transition planning they engage in during high school. The transition planning experience for families varies immensely by state, school, student, and family, but transition planning overall is often described by families, researchers, and advocates as inadequate or ineffectual (Cameto et al., 2004; Martinez et al., 2012; Smith & Routel, 2010). Parents report receiving little guidance or information from school staff about postsecondary education for their children with intellectual disabilities (Griffin et al., 2010). While half of the parents of students with ID in one study reported a desire for their child to engage in postsecondary education, many of them did not expect that desire to be realized, and/or believed their child's school staff did not expect it to be attained (Martinez et al., 2012). In the same study, parents who viewed their children with severe

ID as very capable and who had high expectations for their futures displayed more aptitude in managing service systems and seemed to experience the transition process more positively.

Equally important to maintaining high expectations for students with special needs is ensuring that students are given appropriate opportunities for showing their abilities (Messer, 2010). Parents with high expectations and adeptness with understanding and interacting with systems have been key change-makers and have played important roles in developing, expanding, and improving PSE opportunities for students with disabilities. Interviews of five parents who spearheaded the development of PSE programs revealed that all of them held expectations of college attendance for their children from early in their lives, and used personal and professional networks to create opportunities that matched their children’s needs and dreams (Leuchovius & Roy, 2016).

High expectations should not equate to unreasonable or unachievable expectations, but should challenge students to continuously grow and learn while the necessary supports for doing so are provided. In order to determine what those supports should be, both on an individual level and program-wide, school personnel need to understand their students’ abilities as well as parents’ expectations for their children and for the school they attend (Russell, 2003). Similarly, understanding how parents view their child’s school experience in hindsight and triangulating their perspectives with alumni outcome data, when available, can help schools evaluate the efficacy of their programming. This type of research effort can be valuable for PSE programs, particularly as questions arise about the desirability of certain program models over others.

Griffin et al. (2010) conducted a study to document parents' perceptions of, and perceived barriers to, PSE for their children with intellectual disabilities. The authors surveyed 108 parents of transition-aged students with ID in Tennessee. The survey measured parents' level of concern for the following aspects of PSE attendance, arranged in order of highest to lowest level of concern: their child's safety, their child's ability to function without them, a focus on employment after program completion, the cost of the program, distance of campus from their home, their child's physical health, and the program's similarity to a typical college experience. The survey also measured parents' desire for the following PSE program components, arranged in order of most to least desired: focus on employment after completion, structured social activities, individual choice in curriculum, inclusive learning environments, opportunity for certification in a vocational area, access to college campus, and residential options. The authors noted that based on these findings, programs should prioritize employment preparation and safety. They also hypothesized that students' opinions would vary markedly from their parents' relative lack of interest in the PSE program providing a typical college experience, and suggested that students' preferences be documented directly.

Parents of college students. In recent years there has been a growing focus on research into parents' experiences of their children's college attendance (College Parents of America, 2007; Ruffalo Noel Levitz Higher Education Consultants, 2012; Stodden & Whelley, 2004). Students are considered adults at 18 and communication between schools and parents is not only not required, but restricted by the Family Educational Rights and Privacy Act (U.S. Department of Education, 2015), except in cases where students sign waivers or parents retain legal guardianship of a student (as may be the case with some students with ID/DD). Reaching the legal age of adulthood does not automatically result in a cessation of parent involvement and the many effects that involvement has on student success. With the ease of modern communication (via cell phone, e-mail, social networking, Skype, etc.), physical distance no longer limits parents' involvement in their college students' daily lives as it once did; one third of parents of college students talk to their student daily, and almost three quarters communicate at least two or three times per week (College Parents of America, 2007). College administrators are realizing that so-called "helicopter parents" may be having an impact on student retention and satisfaction (Ruffalo Noel Levitz Higher Education Consultants, 2012). Students with more involved parents tend to have higher levels of school satisfaction and engagement with learning opportunities (Shoup, Gonyea, & Kuh, 2009). Exploring how college parents experience their adult children's education can help us learn more about how they are impacting their children's outcomes and can help triangulate student experience data, in turn helping to inform college recruiting, retention, and programming initiatives.

As parents of traditional college students are being increasingly included in research on their satisfaction and experience with, and involvement in, their children's education (College Parents of America, 2007; Ruffalo Noel Levitz Higher Education Consultants, 2012; Spence, 2012), so, too, should parents of children with intellectual disabilities attending specialized postsecondary programs on college campuses (Stodden & Whelley, 2004). Professionals in college-based programs for this population need to be knowledgeable about parents’ expectations for their children’s postsecondary education and adult lives in order to maximize student retention, optimize program-parent communication, and orient their outreach, marketing, and programming toward the needs and expectations of families (Stodden & Whelley, 2004). This study provides rich descriptions of parents’ expectations and experiences of postsecondary education for their adult children with disabilities, gathered through semi-structured interviews as described in the Methods section.

Chapter III: Methods

Methodological Framework

This is a qualitative study following the tradition of narrative inquiry. Narrative inquiry involves exploring individuals' experiences and identity, using interviews and other types of qualitative data, and creating a rich description of the individuals and the stories that make up their lives. Narrative inquiry helps the researcher learn about and explain how people create and define meaning in their lives. It is well-suited to the exploration of the "nuanced and complex" experience of parenting a child with disabilities (Green, 2007, p. 152).

The Role of the Researcher

The researcher has been an employee of the Lesley University Threshold Program from August, 2007 to the date of this writing. She has worked primarily in the Residence Life and Alumni Center departments of the program, and has also taught courses to current students and alumni. From August, 2007 until June, 2009 she worked part time as a Resident Assistant in the dormitories and then transitioned into a full time administrative position as Director of Residence Life and Student Services. Since then, she has been a full time administrator and is currently an Associate Director and the Director of Alumni Programs. She has had leadership responsibilities on major initiatives including fundraising and grant proposals, the establishment of an Alumni Center to serve graduates of the Threshold Program, the development of Threshold courses offered for college credit, the development of cognitively accessible online courses, and the organization of a program self-study for accreditation review by the New England

Association of Schools and Colleges. Most of her daily work is centered around creating and implementing services and interventions for Threshold alumni. Her close work with graduates and their families means that she will inevitably bring to this research study her existing understanding of the subjects. Her experiences and beliefs will be presented in the discussion section of this paper in order to clarify how they influence her interpretation of the interviews, although she will endeavor to be as objective as possible in her analysis. Her history with the program provides positive benefits to the study, as she will have a foundational understanding of the sons and daughters of the research participants and will be able to conduct more fruitful interviews as a result. She has also facilitated focus groups of parents of Threshold alumni in the past, and these panels have established her as someone who asks families about their experiences.

Threshold Program Description

The Threshold Program at Lesley University was one of the first residential and vocational programs to serve students with developmental disabilities and other special needs on a college campus and will be the site for this research study. Threshold was founded in 1982 to support the independence and vocational success of young adults ages 18–26 with IQ scores generally in the range of 70–85, a group that was, and remains, underserved by state and federal disability service agencies and by institutions of higher education. Young adults with IQ scores in this range often do not qualify for Social Security benefits, Medicare coverage, and disability-related housing supports available to people with other types of disabilities, even though their disabilities significantly impact their ability to live on their own and work enough to support themselves financially.

Although most other college-based postsecondary programs of this kind serve students with mild intellectual disabilities (i.e., students with IQ scores from around 50 to 70 and impairments in their daily functioning), who qualify for financial and residential supports from most states and from the federal government, Threshold serves students with slightly higher test scores and functional independence because of their drastic nation-wide underservice. IQ scores fit the standard curve, and IQ scores between 70 and 85 are between one and two standard deviations below the mean; statistically, students who score in this range should make up almost 14% of the population, versus the 2% of the population accounted for by people with mild intellectual disabilities (i.e., two standard deviations below the mean). The lack of services available for such a large and in-need portion of the population is cause for concern and was the impetus behind Threshold's founding.

When Threshold was established in 1982 it was one of the only programs of its kind and was recognized as being highly innovative. Threshold offered young adults who would be ineligible for or unlikely to succeed in a traditional college program the opportunity to live on a college campus, take courses designed to teach life and vocational skills, explore career options, make friends, and prepare for maximally independent adults lives. Designed during a time when students with disabilities were generally separated from their typically developing peers in school, Threshold was organized in a way that mirrored the relatively separate experiences that its students were used to. Students were able to use university facilities and live in dorms on campus (albeit in buildings that were, and still are, separate from undergraduates), which meant more access to a college experience than would be possible for them almost anywhere else at the time. However, the rest of a Threshold student's experience remained separate from the undergraduates.

Some aspects of the Threshold experience remain separated from the undergraduate experience, while other areas have seen more integration. Threshold students still enroll in a curriculum separate from University undergraduate coursework, are taught by their own faculty, and live in dorms separate from undergraduate dorms. Resident staff are separate from the undergraduate residence life office and offer activities that are only for Threshold students. However, over the last eight years Threshold students have had more opportunities to participate in mainstream university activities than ever before. Four students have obtained National Collegiate Athletic Association waivers to play Division III sports on Lesley teams, many have participated in Lesley clubs and intramurals, and one or two students per year take college courses with undergraduates, although without formalized supports from Threshold.

Threshold accepts around 24 new students each year into its two-year residential program, and students who complete their second year can opt for a third year on campus (Bridge Year) and/or the post-graduate Transition Year program, during which they receive vocational and independent living supports while living in the community in apartments. There are typically around 52 students living on campus each year and another 10–15 enrolled in Transition Year. First year students attend classes 3 days per week and work in internships 2 days per week. Second year students attend classes 2 days per week and work in internships 3 days per week, and Bridge students attend classes one day and work 4 days. All classes are separate from undergraduate courses and only enroll Threshold students, and all internships are unpaid. Transition students have two classes per week, meet at least weekly with advisors who assist them in achieving independent living goals in their apartments, and regularly work one-on-one with a Threshold employment coordinator to find paid jobs.

Threshold remains distinctive from almost all other college-based postsecondary programs for young adults with ID/DD because of its residential capacity for all students, federal financial aid, easy access to extensive public transportation, comprehensive post-graduate services, high fundraising capacity, student participation in NCAA sports, and its focus on students with IQs in the range of 70–85. Threshold's mission is generously supported by parents of alumni, who make up some of the biggest donors to the program and who assist with program governance through service on the Parent Advisory Board. Through the years, Threshold has seen some curriculum and programmatic changes, has sought greater inclusion of its students in Lesley University activities, and has invested heavily in infrastructure and in developing supports for graduates. The fundamental model of the program has remained fairly stable since its inception, particularly when compared with rapid changes in the field.

Participants

All participants were parents of graduates of the Threshold Program at Lesley University. Parents were determined to be eligible if they are available for an in-person, phone, or Skype interview and if their son or daughter graduated from the program between 2008 and 2014 (inclusive of both years). This span of graduating years was recent enough that parents may have had knowledge of trends toward inclusive PSE experiences, which began with the passing of the HEOA in 2008, and broad enough that many parents would be able to comment on outcomes of the program several years after graduation. Parents of alumni who were still enrolled in one of Threshold's post-graduate programs at the time of data collection were not be eligible to participate.

Recruitment

Participants were recruited from among all parents of alumni who graduated from 2008 to 2014 for whom contact information was known (156 households). Potential participants were sent an invitation to participate (Appendix A) by mail and email. Interested parents who were selected to participate were sent a follow-up email (Appendix B) with additional information about the study. Interested parents who were not selected were sent the alternate follow-up email in Appendix C.

Sampling

Twenty-five parents responded to the recruitment letter, with five of those parents offering that they and their spouses be interviewed either together or separately, yielding thirty possibly subjects. This study used maximum variation sampling. The final participant group of seventeen subjects reflects the greatest diversity possible, among both subjects and their son/daughter graduates, based on the potential participants who responded to the recruitment letter. The researcher purposefully selected participants from among the interested respondents, with weight given first to respondents who increased the diversity of the sample, and then to respondents based on the order in which they replied. Only one parent of the same graduate was able to participate. In cases where a respondent offered that they and/or their spouse be interviewed, together or separately, the researcher requested that they select who should be interviewed, and only that parent was considered in the sampling process.

Informed Consent

Although informed consent was not required for this study, an informed consent form (Appendix D) was sent to all participants in advance of their interview, and then discussed verbally before the start of the interview. Participants were given an opportunity to have their questions answered before audio recording was initiated. Participants were not required to sign the form; the researcher signed each form to record the name of the participant and the date of the interview.

Data Collection

Data collection consisted of interviews scheduled between February 4, 2016 and March 8, 2016, and demographic information about the research participants and their sons and daughters who graduated from Threshold. All interviews were recorded using a digital recorder and then transcribed. Subjects were told that follow-up phone calls may be made to clarify details, but following the interviews the researcher determined that no such calls were necessary.

Interviews. Interviews were conducted in person or over the phone, depending on the preference of the participants. Each participant was scheduled for one interview lasting about an hour. The general interview questions were:

1) When your son/daughter was an adolescent, what were your expectations for his/her adult life?
2) How did your expectations form?
    a. Have they changed over time? In what ways?
    b. How did your son/daughter's postsecondary experience(s) impact your expectations for adulthood, if at all?
3) When considering postsecondary education, what programs were considered and chosen, and why?
4) What are your thoughts about college programs that include students with special needs in mainstream courses, dorms, clubs, and other programming?
    a. What impact do you think more time spent with Lesley undergraduates, in classes, activities, and tutoring or mentoring partnerships, might have had on your son or daughter?
5) What are your concerns and hopes for your son/daughter's future now that he/she is an adult?

In the tradition of narrative inquiry, the researcher asked additional questions as needed in order to develop a full understanding of each participant's experience. The researcher also used her knowledge of the Threshold alumni whose parents were being interviewed in order to tailor additional questions and develop richer detail, as appropriate.

Data Analysis

Audio recordings were loaded into the NVivo software platform and transcribed. Names and other identifying characteristics of participants and their alumni sons and daughters were changed during transcription to protect their anonymity. Transcriptions were coded using an inductive content analysis process. A codable unit is generally a single sentence, but may be smaller or larger as long as it is one distinct idea that can be categorized into a single code (Davy, Gugiu, & Coryn, 2010). Inductive analysis allows patterns to arise from the data rather than being identified from a predetermined set of codes (Moretti et al., 2011). Units of transcribed data were coded in NVivo and codes were continuously re-named and their corresponding units of data re-organized and re-assigned as transcripts were re-read. After all data were coded, the full data set was re-analyzed with the code list and codes were added, removed, combined and renamed once more to yield a refined list of codes.

In order to determine whether the researcher's interpretation of the data was accurate and consistent, Cohen's kappa coefficient, an inter-rater reliability statistic, was computed. The kappa coefficient measures the agreement between two raters, factoring in the likelihood that such agreement happened by chance (QSR International, 2016).

A Lesley University professor with entry-level knowledge of Threshold (Coder B) was recruited to code a sample of raw data using the refined list of codes. A random sample of eight non-consecutive pages of data, coded by the researcher (Coder A), was provided for coding. This amount of data was expected to yield enough coding opportunities to produce an inter-rater reliability statistic that represented the entire data set. Data was randomly selected by saving each interview transcript as a word document numbered 1–17. A random number generator was used with a range of 1–17 to select the document from which to take a coding sample. The number of pages in that document was used as the max number in a new random number generation to pick a page number. All data from that page of the transcript was added to a new document. This was done eight times total to yield an eight-page sample of transcribed data for Coder B to analyze.

Coder B used the review function of Microsoft Word to highlight units of sample data and label each unit with a comment bubble containing either a code from Coder A's refined coding list, or a new code if she deemed it necessary. The researcher (Coder A) loaded the sample data set into NVivo as a new project with two users, Coder A and Coder B. Logged in as Coder A, the researcher loaded in the coding she had previously done by matching the original codes on each transcript to the data sample. She then logged in as Coder B and loaded the coding provided by Coder B from Microsoft Word. Using the Coding Comparison Query function of NVivo, she ran a coding analysis that yielded a kappa coefficient of .63, indicating fair to good agreement (QSR International, 2016).

In order to increase inter-rater reliability, the researcher then analyzed each coded section of data individually to compare differences between Coder A and Coder B. In any case where a unit of data was coded the same way, but differed in size, Coder A determined whether to adjust her own coding to match, or come closer to, Coder B's selection. In some cases the unit size was adjusted; in situations where Coder A did not agree with Coder B's selection, the unit size was not changed. Next, Coder A analyzed all sections of data that she had not coded, but which had been coded by Coder B; any that she agreed should have been coded were adjusted. Coder A then analyzed data that she had coded but that had not been coded by Coder B; in almost all cases Coder A retained her codes. Finally, Coder A analyzed units that had been coded by both coders using different codes and determined whether to change any of her coding choices, and which ones. Most of the changes made during this process were to the sizes of the units being coded, rather than to codes themselves. A new Coding Comparison Query was run using the adjusted Coder A data and resulted in a kappa coefficient of .83, indicating excellent agreement (QSR International, 2016).

Using the modified data analysis perspective generated through the process of re-visiting and adjusting codes in light of a second rater's approach, the researcher read through all of the transcription data again and made minor adjustments to her original coding.

Data Management and Confidentiality

All data was stored electronically on a password-protected laptop owned by, and used only by, the principal investigator, Cara Gorham Streit. Data were also backed up on a password protected flash drive. Audio data, containing identifiable voices, as well as the names of Threshold program graduates, were downloaded from recording devices immediately upon the conclusion each interview, saved to password protected devices, and deleted from the recording devices. Files containing identifiable information were not distributed in any format. Data will be saved on the password protected flash drive for 7 years, as required by Boston University.

Identifiable information for this study is considered to be information that anyone inside or outside of the Threshold Program could link to a particular participant. No identifiable data was collected from study participants in any written form, other than consent forms with their real names. These forms were kept in a locked drawer in a locked office, to which only Cara Gorham Streit had access. Names of the parent participants, their children, and Threshold faculty or staff were changed in file names and transcriptions in order to protect anonymity. Years of graduation of the subjects' sons and daughters were kept intact whenever possible; if an exact year of graduation, combined with the data being discussed, would be enough to identify an alum, year of graduation was not paired with the transcript. Data that identified an individual and could not reasonably be altered is not included in the final analysis and will not be published in any form. Only the principal investigator has access to a list of pseudonyms and other alterations. Data shared with Coder B was stripped of all identifiers.

Chapter IV: Results and Discussion

Introduction

This section will describe the participants who were interviewed, discuss themes from the interviews, and tell participants' stories. In order to maintain the rich details of each parent's experience while also presenting thematic content in a way that can be used by researchers and practitioners, this section will be organized into an analysis and discussion of the themes derived from the interview data, followed by a narrative presentation of each subject's personal story. The thematic analysis will include a discussion of the meaning and relevance of the themes, while implications of the data for other postsecondary programs and for researchers in the field of inclusive higher education will be discussed separately in the final chapter.

Participants

Seventeen participants were interviewed for this research study. Demographic data about the participants are described in Table 1 and the years of graduation of their sons and daughters are in Table 2. In order to protect the identities of the participants and their sons and daughters who graduated from Threshold, only limited demographics are presented. Two participants were interviewed in person and fifteen were interviewed over the phone.

Table 1
Demographics of Participants

Demographic	Male	Female	White	Black or African American	Graduate is Male	Graduate is Female
# of Subjects	4	13	15	2	8	9

Table 2
Years of Threshold Program Graduation of Participants' Sons and Daughters

Son/Daughter's Year of Graduation	2008	2009	2010	2011	2012	2013	2014
# of Subjects	2	1	5	3	2	1	3

Data Analysis

Interviews were audio recorded and transcribed into NVivo, a qualitative research software platform. Names and other identifying characteristics of participants and their alumni sons and daughters were changed during transcription to protect their anonymity. Transcriptions were coded by the researcher using an inductive content analysis process and a sample of transcript text was coded by a second rater. Cohen's kappa coefficient was calculated to determine inter-rater reliability, and the double-coded sample of text was then re-coded by the researcher. The kappa coefficient was calculated again and showed excellent agreement between the raters. The final list of codes was organized into themes and subthemes.

Thematic Discussion of Results

The following discussion is based on themes derived from the data analysis. A list of codes, organized into categories, can be found in Appendix E. The discussion begins with the most pervasive theme, parents' shared dreams for their children's futures. While the other themes identified tend to represent distinct periods of time, the shared dream spans the 20–30 years each parent has spent as mother or father of their child with special needs. Other themes are considered within the context of the pervasive shared dream.

A shared dream. Through descriptions of their children and the paths each of them had taken to adulthood, it was clear that every parent interviewed held, and had always held, similar hopes and goals for them: primarily, independence and a sense of fulfillment in life. These common goals made up the major theme of the interviews and were pervasive throughout each parent's story. While some parents identified characteristics of a fulfilling life that they had held early on—such as an enjoyable, paying job—no parents articulated exactly what they had hoped their child's future would be like before they attended a postsecondary program. Their hopes for independence and fulfillment were overall very general, as they were moderated by the uncertainty of what their sons and daughters could reasonably be expected to do in life.

Even without knowing exactly what independence and fulfillment would look like in the future, every parent described making choices about their child's education with those nebulous goals in mind. Several parents spoke of wanting to help their children be as independent as possible, become contributing members of society, or be the best they could be. While they all held common goals for their sons and daughters, parents took various, and in some cases, directly opposite, routes toward goal attainment. Some parents fought for mainstream education and inclusion from the early years on; others took their school districts to court so that their children could attend specialized programs only for students with special needs. Every parent was able to articulate why their choices seemed like the right ones for their family at the time they were made, and seemed confident in hindsight that their decisions had been right.

All parents told their stories chronologically, and as they described postsecondary education and their sons' and daughters' transitions into adulthood, the meaning of independence and fulfillment was articulated more clearly in every case. For all parents, independence included living away from family members and without in-home staff. Parents believed that support from family members and, in some cases, paid (but not live-in) staff, were important to maintaining their adult child's independence, and were not a sign of dependence. Even though all the adult children represented were being supported in one way or another by family and/or paid staff, they were all able to handle many adult responsibilities on their own. Most of them shopped, cooked, cleaned, managed medical appointments, traveled around the Boston area by themselves, and even paid bills on their own or mostly on their own, and these functions were considered signs of independence by their parents.

As parents progressed through the story of their children's lives, "fulfillment" also became clearer as a goal and included meaningful work, satisfaction with life, self-esteem, and an array of interests, skills, and past-times. Parents were happy to see their children have reciprocal friendships, jobs they enjoyed and could grown in professionally, experiences traveling, and social activities to engage in.

Early uncertainties. All parents were asked to talk about the expectations, hopes, and concerns they held for their children's futures during their childhood and adolescence. Parents described the very early years with their children and how they came to learn about what their diagnoses might mean for them. Five parents knew or expected at birth that their child would have some type of disability or developmental delay due to premature delivery, genetic condition, or birth defect. Two of these parents faced uncertainty about whether their children would even survive due to the extent of their health complications at birth. Six parents suspected delays in infancy or toddlerhood due to late milestones, and the remaining six noticed academic or social delays, or were alerted by educators, in preschool or later.

Every parent described some uncertainty about what the future of their son or daughter would look like. For most parents, questions about the future arose as early as their realization that their child was not developing “normally”; three parents actively pushed thoughts of the future aside in the early years and described trying to live in the moment and focus only on getting through whatever challenge was most critical at each phase of their child’s development.

> *To be honest there were so many hurdles socially; the school dances, the stuff on the weekends that maybe he wasn't included in, you're just trying to get through the day to day. I don't think I thought that far ahead, and I was afraid to, I think. –Kim*

When their children were adolescents, or even younger, all the parents interviewed had held uncertainties about their future levels of independence. Some parents had assumed their children would live with them well into adulthood, or even forever. Kim described moving to a house with an attached guest house when her son was in high school, assuming he would live there forever and wanting him to have some semblance of independence from his parents. Other parents thought their children might be able to live in an apartment of their own but close to the family home for support. One parent had thought a staffed residence was most likely.

Whether, and how much, their children would work as adults was another uncertainty parents described. Questions about employment tended to develop in adolescence and ranged from whether their child would be employable for pay at all to whether they would someday be able to support themselves financially without help. Two parents spoke specifically of hopes that their child would find “meaningful work” and defined this as work they enjoyed and were good at. Heather described her own love of her career as a nurse and wanted her daughter to feel the same fulfillment.

Daring to consider higher education. Parents’ expectations of whether their children might attend college, and what they could achieve there, varied widely. While some parents always expected their children to go on to some type of college, others did not think college, at least in a traditional sense, would be a possibility for their son or daughter with disabilities when they were adolescents. All parents expected that some type of additional education, training, or structured programming would be necessary for their children after high school in order for them to maximize their employment and independent living skills. They received varied feedback from their children’s transition coordinators and other high school educators about what type of postsecondary experience would be appropriate. While some were told about Threshold and other college-based programs specifically for students with special needs, others were referred only to community-based life skills programs, only to community colleges, or to some combination of options. Some parents were offered no assistance with planning for a postsecondary transition and explored options on their own or with the help of a privately paid educational consultant.

The purpose of college. Once a college-based program was identified as their son or daughter's next step after high school, all parents viewed higher education as a means of achieving the primary dream of an independent and fulfilling life. While their children having the experience of attending college was important to most of them, all of them wanted that experience to help them attain friendships, work, and the skills to live away from home. Many parents noted that they believed the achievement and experience of going to college was in itself a primary goal of critical importance to their son or daughter. These students wanted to have the experience their brothers, sisters, and school peers were having, and for most that meant living away from home to go to college, not commuting to a local community college as they may have been advised to do by high school personnel.

No parents interviewed described college-level academics as a priority when searching for the right postsecondary program, and a few stated that college-level academics would not be compatible with their son or daughter's learning styles or capabilities. Most parents did believe, in hindsight, that some type of modified access to college classes would have been beneficial to students in the Threshold program, or to their son or daughter specifically, as will be discussed in a later section.

Pursuit of higher education. All parents spoke at length about the process of exploring postsecondary options with their children with disabilities, and what went into the ultimate decision of which program to attend. Every family considered multiple programs, and most visited between two and four other schools. Four graduates whose parents were interviewed attended other PSE programs in addition to the Lesley University Threshold Program; three before attending Threshold and one after. The experiences of these parents will be described in a later section.

Finding the right student population. All parents referenced the student population of the PSE programs they visited as an important factor in choosing the right school. Almost all parents specifically mentioned meeting current students in the program while visiting Threshold, typically through recruiting and admissions events. Parents reflected that they could see their son or daughter would fit in socially and academically with the other students, and several expressed that they believed Threshold was the right fit for their son or daughter once they heard from or talked to students.

> *But it was the young adults in that meeting after we listened to the Admissions Director and we got to ask them questions, and then they interacted with us, that really sealed it for me. -Joan*

Most parents were looking for a school where their son or daughter's cohort in the program would be students with similar academic, social, and functional profiles. Two parents specifically stated that they did not want their son or daughter to be either the "highest" or the "lowest functioning". Multiple parents referred to this perceived likeness between students as "the right fit" or their child being with her or his "peers."

> *Going to Threshold meeting just the people who we met, Mallory felt like, for lack of a better way to put it, these are my people. I feel comfortable. I can be me. -Tori*

Parents who mentioned similarities in students' profiles also tended to have looked at multiple other programs and compared the students at those programs with the students at Threshold in terms of intellectual or academic ability, or the level of support needed by students in order to live away from parents. While these types of similarities between students were important to parents, they also wanted students to experience people different from themselves in terms of culture and background.

> *A college experience, bonding with other kids that come from wide ranges of family, wide ranges of areas of the United States, and all over the world [...] I figured he would get a more broad view than just here, [his home town.] He'd get the experience of kids from other places. How they lived, their culture, things like that and be able to have a wider worldview of other things. -Simon*

Balance of support and independence. Eight parents commented that Threshold provided the appropriate balance of support and opportunities for independence for their son or daughter. Three parents whose children visited the same three other college-based programs commented that they felt the other programs were more sheltered than Threshold, and that Threshold provided opportunities for students to explore the city, manage their own time, and practice their independence in ways the other schools did not.

> *[My son] said "If I went to [the other program], I feel like I would be taking a step back" because it was so protected and so sheltered, and he was able to say that he felt the energy in Harvard Square and in Cambridge and that's how he made the decision that he wanted to go to Threshold. – Danielle*
>
> *I could see that these children had been given a chance to bloom and to move into adulthood, with many supports, but at the same time helping them to become independent. -Joan*

Traditional college environment. Threshold’s status as a program within a University, and one in which students lived on campus, was an important factor in every student’s decision to attend, according to parent participants. Many parents reported that their son or daughter's desire to attend a college was related to wanting the "normal" young adult experience of going away to school as their siblings had done and their peers were doing.

> *Jackson wanted to go to college. You know, he wanted the experience that his brother had. He wanted to go away to school, he wanted to live in a dorm, and he was stuck on college, college, college. –Cheryl*

Several parents also commented that the college environment was an important factor for them as parents, as it provided opportunities for their children to practice independence with structure and safety, but enough freedom to push themselves and grow. These parents specifically stated how important it was for their young adult children to be physically separated from them in order to make their own choices and manage their own time in a way that never could have happened near their family homes.

Expectations for postsecondary education to turn dreams into realities. Parents expected that a college experience designed for students like their sons and daughters would provide them with something more than a typical undergraduate experience. They shared an overall expectation that postsecondary education would help their sons and daughters realize their (the parents') dreams for them of independence and fulfillment as adults. They also shared more specific expectations on how the Threshold Program would help students gain the skills and knowledge necessary to achieve their adult goals.

Balance of academics and life skills. Almost all the parents interviewed identified vocational, social, and independent living skill development as important aspects of postsecondary programming and expected that their sons and daughters would experience growth in these areas, while also being academically challenged (although not at a college level).

> *…Life skills, job skills, independence, socializing, those were things he needed that we were looking for. And we were hoping, and we were confident, that he would be constructively engaged. -Mark*

Growth in skills for independent living. Every parent interviewed expected that their son or daughter would learn how to be more independent from them during their PSE experience, with the exceptions of: Elaine, who did not know what to expect from the program, but did hope that her daughter Lilly would become more independent; and Tia, who thought her son Dylan was already as independent as he was likely to be when he started the program. Parents expected that their children would develop better understandings of how to be safe in an apartment and in a city, how to get around on public transportation, how to manage money, how to cook and clean, and other critical life skills. No parents expected that their son or daughter would become entirely independent of them as a result of the PSE experience.

Self-esteem and personal fulfillment. Several parents said they expected their sons and daughters to develop better self-esteem and to have successes socially, vocationally, and academically that they could feel good about. They wanted their young adult children to be proud of their accomplishments and develop goals for life that were meaningful to them.

Social engagement. Their sons' and daughters' social engagement was critically important to parents, and they expected that attending Threshold would help their students make friends, learn how to maintain friendships, and develop skills for making new friends in the future. Most parents did not expect that social engagement would come hand in hand with frequent interpersonal problems or "drama", as several parents said their children called it. Parents who mentioned "drama" had expected that there would be more direct staff involvement in preventing and solving interpersonal conflicts.

A supported college experience. All parents expected that their children would have an experience that felt like a traditional college experience, but with additional supervision and support. Characteristics of a college experience mentioned by parents included the development of a peer group, the continuation of academic life, living away from home, gaining independence from parents, and learning to solve problems. Some parents mentioned interaction with undergraduates as an experience they were expecting their students to have.

Contrary to a traditional college experience, parents expected that program faculty and staff would engage with students more frequently and about a wider array of issues than they would with an undergraduate student. They expected that resident staff would be involved with making sure students got up on time for their day, were getting along with their roommates, and were keeping their dorm spaces neat and organized. One parent mentioned expecting program personnel to identify and acquire adaptive technologies for her son, and to have expertise in educating young adults with autism. Several parents had expected the program to facilitate their students' involvement in university clubs and social events.

Development of employment skills and a career path. All but two parents expected, from their son or daughter's admission into Threshold, that a postsecondary experience would result in better employment outcomes, and that the Threshold curriculum would focus heavily on helping students develop employment skills. Curt's expectations for Amelia were focused entirely on improving his daughter's self-image and independent living skills, and he does not recall considering her vocational future as a priority until Amelia was well into the program, and he began to see that she was developing skills that would make her employable. Elaine recalled not really knowing what to expect from the experience, and certainly was not focused on employment at the time Lilly started the program.

Most parents expected that the types of jobs their sons and daughters would be able to attain after graduation would have a career track of some kind, where they could develop and grow as professionals. Several parents hoped their young adult's internships in the program would turn into paid employment.

Achievement of the dream. All parents found that the postsecondary experience helped their children achieve, or begin to achieve, the ultimate dream of an independent and fulfilling life. Parents reported many impacts of postsecondary education on their sons' and daughters' development as adults. The following topics apply to graduates' experiences at the Threshold Program specifically, except for the final subtheme, which addresses other postsecondary experiences for the four alumni who attended multiple schools.

Social relationships. The majority of parents commented that their sons' and daughters' social lives had improved because of their time at Threshold. Parents felt that their children had more friendships and that those friendships were more genuine and reciprocal than their earlier friendships, for the most part. Many parents reported that their children continued to live with or spend social time with friends they met in the program. Only two parents mentioned their children having friends from one of the undergraduate schools at the University, and for both of these students those connections were made through involvement with integrated extracurricular activities. Several parents said that their sons and daughters actively made plans with others to explore a wide range of activities in the Boston area. These parents also expressed appreciation of the Threshold Alumni Center and its role in offering social events for graduates.

Employment. All parents reported that their children's vocational skills and employment prospects had improved as a result of their postsecondary educations. Only one parent reported that their adult child was unemployed at the time of the interview, but she felt a down economy was the reason he had not found a job and believed he was in a better position to find employment than he would have been without his postsecondary experience. Some parents felt their adult children could be employed with more hours or in jobs that were more fulfilling, but most felt that the positions their sons and daughters had attained were meaningful to them and were satisfied with their current level of employment.

> *Being a working woman out in the world and doing this job that I had nothing to do with at all, you know, it's... I mean I facilitate and have facilitated everything*

> *for her entire life, you know, and I feel like I still do a lot of that and I will do a lot of that forever and that's fine, but I think she's really the driver of her work life[…] and, you know, it's um, it's phenomenal, it's great. –Elaine*

Independence. All parents reported that their children's abilities to live independently and manage adult responsibilities improved as a result of their postsecondary experience.

> *She's a truly independent adult at this point, and she could never have, I can't imagine how she could be living in a city in an apartment with friends around. I don't know how we would have accomplished that, trying to make that happen without a program like the Threshold Program to kinda kick start her into that life. She just, just watching how comfortable she is maneuvering around Boston is really remarkable to us. –Barbara*

Only one of the graduates represented was living at home with a parent at the time of the interview, and it was for financial reasons; he would have been able to live on his own if it was financially feasible. Parents reported that graduates were able to grocery shop, cook, clean their apartments, travel, and manage their free time with minimal or no assistance. Graduates were better able to understand and manage their finances, although many parents reported that they still had room to grow in this area. Six parents mentioned Threshold's personal finance courses as being particularly impactful to their sons and daughters, and said the courses helped teach them the value of money, which is a concept they had thought their children might never understand.

Personal growth. Most parents reported that their adult children had experienced personal growth, beyond that related to employment, independent living, and social engagement, as a result of their postsecondary experience. Parents identified improved self-esteem, self-advocacy, assertiveness, problem solving skills, confidence, and self-direction as areas of growth they recognized in their graduates after completing the program. Parents credited their students' postsecondary experience with fostering this growth.

> *Threshold just… that bloom on the rose that once you give it some heat and sunshine it opens up, well that's what happened at Threshold. That's the best analogy for me. It was this little bud that went there and she just bloomed into a beautiful rose. –Joan*
>
> *Threshold has saved Lacy's life and mine. I mean as a parent, I could never have taught her all that stuff. I could never have made her the confident young woman that she is. –Penny*

Experiences at other programs. Four children of parents who were interviewed attended another postsecondary program, three before attending Threshold and one after.

Grace attended a community college and earned over twenty credits towards an associate's degree before applying to Threshold. Her schoolwork required a lot of academic support, but she was determined and she persevered. Her community college had on-campus housing, and she was able to live in the dorms, returning to her nearby home on weekends. Although she never participated in campus social activities or clubs, she did make a few close friends; her mother, Nora, describes them as other "unusual" students, and believes that in any mainstream setting Grace would gravitate toward other people whose life experience was outside of what might be considered normative.

Although Grace was able to manage her workload at school, her independent living skills were not strong enough for her to live outside of her parent's home after school, and so she and her family changed their focus from academics to life skills, and searched for a program that would help her move toward a more independent life.

Liam attended a residential postsecondary school that was not college based before he applied to Threshold. His experience was positive, but he was still young, twenty, when he completed the program and needed more practice with life and vocational skills in order to be an independent adult. He could have enrolled in the adult programming at his school, but his mother, Ramona, wanted him to be closer to home, and together they applied to Threshold.

Dylan enrolled in a college-based program that was designed to transition students with learning disabilities into a bachelor's degree program after one year. While he had always loved school before going to college, he rapidly became withdrawn and disorganized in his first semester. The headmaster of the program saw him struggling and told his parents that the program did not seem to be the right fit for him. Luckily, he had already been accepted to Threshold and was admitted mid-semester. His mother, Tia, believes he needed much more support, supervision, and assistance with socializing than he had at his first program, and that the first program was too academically rigorous for him. The first program was also fairly new at the time, and Tia thinks the administration had not yet determined how to identify its ideal student population and was therefore admitting students it was not prepared to educate.

Hadley was the only child of an interview subject who attended a different postsecondary program after completing her time at Threshold. She desired more inclusive, rigorous academics than she had access to at Threshold, and therefore enrolled in a college program designed to support students with intellectual disabilities in auditing undergraduate courses. She attended for three years and took courses in women's studies, art, literature, and other topics that interested her. Her mom, Heather, believes her experience at the other college would not have been a success if she had not attended Threshold first, because her second college was close to home and not as supportive residentially, and she needed the experience of being far from home and living independently in order to get the most out of her next program.

For all of these students, Threshold's life skills curriculum and individual supports from faculty and staff were important program characteristics. The three parents whose children attended another college-based program first felt that those strong academic programs were valuable, but that their child also needed life skills training in order to become independent adults. Ramona, whose son Liam attended a non-college program first, valued the college atmosphere he was able to be part of by attending Threshold and wanted him to experience college while also learning skills for independence.

Suggestions for enhancing dream achievement. Parents were asked to describe anything about the program that could have worked better for their son or daughter, or for them as parents, in order to help them maximize their growth and development as adults. Other than greater integration with undergraduates, previously discussed, most critiques were unique to individuals or shared by only a small number of parents, and tended to be very specific to each student's particular circumstances, interests, and social experiences. For example, Elaine would have liked her daughter Lilly to be able to opt out of the required adult sexuality course, which she found uncomfortable and overwhelming, while Ken expressed disappointment that his daughter Adrianna was paired with roommates that she did not get along with well. A few exceptions to the individuality of critiques are described in the following subthemes.

Improvements to Threshold's postgraduate Transition Year program. Almost half of the parents interviewed expressed negative opinions of Threshold's Transition Year program, the community-based year of employment and independent living supports following graduation from the first two years. Parents stated that the time from enrollment in the postgraduate program to employment in a paying job was too long, the process of finding local apartments was overwhelming, students' time was not structured enough, and there was not enough administrative oversight. Overall, these parents still had positive opinions of the apartment-based independent living supports offered by Threshold's Independent Living Advising faculty. Possible solutions to these challenges with Transition Year included better expectation-setting with families before the year begins, more aggressive job-seeking by program staff, and more structured activities early in the academic year while students look for work. All of these improvements were made in the Transition Year after the subjects' sons and daughters completed Transition, and before this study began.

Improvements to program facilities. Several parents named the physical condition of the program's facilities as a negative aspect of the program, with one father referring to the dormitories as "the pits." Dormitories and office spaces were run-down and not physically accessible, and parents believed their poor condition resulted in students being less motivated to keep their dorm and lounge spaces clean and organized. [1]

Improvements to curriculum, materials, and technologies. About half of the parents interviewed expressed a critique of specific materials used in courses, the lack of availability of adaptive technologies, or the overall program curriculum. Some parents stated that materials were out of date or that course content was not being delivered in a modern and accessible way. Specific suggestions for improving content delivery included more integrated use of smart phone technology and training for students interested in using adaptive technologies. One parent suggested that faculty work individually with students to identify adaptive technologies that would work well for them in any areas they struggle with, and teach those students how to use the technologies.

Views on college inclusion. All parents were asked to discuss their views on the inclusion of students with intellectual disabilities in mainstream college experiences, including clubs, athletics, residence life, and academics. While only one parent, Wendy, had been expecting opportunities for inclusive activities and academics from the time her son started the program, every parent stated that, in hindsight, they believed inclusion of Threshold students in mainstream experiences should be an option for students who are interested. Most parents stated that their son or daughter would have benefited from more inclusive experiences in academics and in social, leisure, and club activities. Three

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[1] It should be noted that a complete renovation of all of the program's facilities was done after the interview subjects' sons and daughters completed the program, and not as a result of this study.

parents reported knowing that their children had desired more inclusion while enrolled. Parents who mentioned inclusive academics stated that their children would have needed support selecting appropriate classes, communicating needs with their instructor, studying, and completing assignments.

> *For Jackson, I think that [inclusion] probably would have been a good thing where it was appropriate. I'm not saying, you know, every class would be appropriate. It would have to be specific classes because he would need support, and it's college, and I don't think it would be appropriate to be in, you know, to decide 'Oh, I want to take an accounting class' and think he'd be able to do that. If it was a course of something where he was interested and he had the knowledge and he had the support, then I think it would be great. I think that's very individual. -Cheryl*

About half of the parents interviewed believed that their children's friendships with other Threshold students were deeper, more genuine, more reciprocal, and/or longer lasting than friendships they had or could have developed with undergraduate students, or that their son or daughter would have been unlikely to have been included or befriended by mainstream undergraduates.

> *At Lesley to be part of the bigger program, I'm not so sure that Grace would have necessarily been really included with groups in the greater part of Lesley[...] I think that she would find her own group of students, similar to those that are in Threshold, that are also maybe socially needy or awkward. I mean, I think it's nice for them to be there but I'm not so sure they would be really included, I'm not so sure that they would be. I think if they were capable of participating in an english class or a sociology class, if they were able to do it I think it would be great. -Nora*

Other parents thought social integration would have been a positive thing, either for students in the program, or undergraduates, or both.

> *She did have some interaction with kids at Lesley, she developed some relationships if you will, who were not in the Threshold program. I like to think*

> *that the kids in college are a little bit more mature and understanding than kids in high school. I can't imagine, I may be naive, but I can't imagine that limited integration would ever be a negative thing for these kids, it all depends on with whom they're integrating. But it would be something that I would, you know, I would have liked to have seen happen maybe a little bit more for my daughter. –Curt*
>
> *I think [inclusion] would greatly enhance the program, and you know, as we were just talking our daughter did participate [in activities], so that was a plus for her, but I mean that was really the only facet of university life where she kind of integrated that way, but, and I think she really enjoyed it, she got a lot out of it, she made friends, and I think the friends got a lot out of having her participate, so I mean I think it would be a good thing. –Barbara*

Curt and Tia also specifically mentioned the power of the friendships their children had in high school with students without ID/DD, and both felt that these relationships had helped their children integrate socially. Tia believed her son Dylan’s friendships with athletes in high school prepared him for seeking out friendships with Lesley University undergraduates during his time at Threshold.

Six parents specifically suggested mentoring relationships between undergraduates and Threshold students as a way to support inclusive social and academic experiences on campus. They referred to this type of arrangement as “big sister”, “best buddy”, or “mentoring” relationships and believed they would be positive for both the undergraduates and the Threshold students involved. Several parents stated that they did not believe meaningful social inclusion could occur without formalized relationships of this kind. Perceived benefits of these relationships included better access to student activities for Threshold students, the development of relationships with non-disabled peers who could model appropriate social behaviors, greater academic success of

Threshold students taking undergraduate courses, and personal growth of undergraduates matched with Threshold students.

Five parents said that inclusion, particularly academic and residential, might have been appropriate for some students and should be available, but that it could have been overwhelming or otherwise negative for their son or daughter.

> *I have a college junior right now. She's not a big drinker [...] But two rooms down and the room above them, they're huge partiers. They're up all night, huge drinking parties, k? Mallory, if she was down the hall would she have known enough to stay out of that? I don't know. Could she have gotten, if she was integrated in that dorm, could she have gotten into more trouble? Possibly. Possibly. Would she have known enough to stay out of it? I'm not quite sure. Could she have gotten taken advantage of more? Possibly, quite possibly. So, the dorming would concern me. –Tori*

Since Threshold is not marketed as a highly inclusive college experience and parents were not expecting their sons and daughters to be "mainstreamed" by any measure, it is especially notable how universally they believed that more integration should be an option supported by Threshold staff and faculty. Even if they did not think it would have been something their son or daughter would have been interested in or benefited from, they still believed it should have been available to others and could have had positive impacts.

Reflections on supporting a child with special needs in reaching the shared dream. Parents in the study offered reflections on how they fostered independence in their children with special needs, their approaches to parenting, and gave advice for other parents exploring postsecondary options.

Ensuring opportunities to thrive. All the parents interviewed discussed their efforts to ensure that their son or daughter with a disability had every opportunity to reach his or her full potential in all aspects of life, even when it was entirely unclear what the manifestation of "full potential" might be. In addition to helping their children seek appropriate postsecondary options, many parents described times when they had to advocate with doctors, therapists, and educators to access services and opportunities. Several parents had to act as advocates from their child's infancy to receive a medical diagnosis or evaluation; others fought for educational services, inclusion, or out of district placements, with at least three parents taking legal action against their home school districts. Most parents also discussed focusing on their child's strengths and building their self-confidence, even while addressing challenges.

> *I never looked to her doing something less than somebody else and I never set her expectations to do something less than anybody else, and I've never set that up even to this day, she's 25 and I've never made her feel like what she does is less than anybody else. -Tori*

While parents took different approaches to inclusion and separate programming throughout their children's years of education, all parents expressed that their approaches were aimed at helping their child, with his or her unique strengths and needs, have the education that they believed would best prepare them for adult life.

> *We decided to […] mainstream her as much as we could, the reason being that we knew that she would have to live in the same world as everybody else. When school ended there was gonna be no paraprofessional there for her. She needed to know how to interact with a variety of people and get the help she needed if she couldn't solve the problem, from a variety of people. -Penny*

> *We started looking for programs outside of the high school and actually got a*

> *consultant because the high school wanted to put a program together in the high school and I said "No, he's not gonna spend another 2 years here with peers who have nothing in common with him and he has nothing in common with them and he's going to have no life other than going to school and coming back." So it was a difficult struggle with that town and we got a consultant who actually started to look at programs and looked at the program the high school was going to put together, which was really nothing, they were just gonna kinda cobble something together… And the consultant came back and said "What you put together is not gonna work for him. He needs to go to a program, possibly residential even, not a day school." We had suggested [a private school for kids with special needs] because it was a boarding school and had a program we had heard was great and there were some people we had known who sent their children there and she came back and after actually going there she said "He needs to go and you need to pay for him to go," and that's what they did. -Ramona*

Advice for other parents exploring postsecondary options. All parents were asked what advice they would give to other parents exploring PSE with a child with special needs. All parents said they would encourage families to help their children attend a postsecondary school; most parents stated that they would specifically recommend Threshold and several had done so to other families. Seven parents said they would recommend that students live away from home during the postsecondary experience and discussed the importance of "letting go." Most parents described how they and their children determined whether a program was the right "fit" and said they would advise other parents to explore a lot of options, assess their child's reaction to each program, and really understand each school's structure and offerings to make sure they had the type of programming their child wanted and needed.

Worries about maintaining the dream, and hopes for even greater dream achievement. All parents were asked to talk about the expectations, hopes, and concerns they held for their children's futures at the time of their interview. Their responses fell into the domains of employment, financial dependence/independence, romantic partnership, independent living, and their child's ability to manage without them after they die.

Employment. Following the PSE experience, all parents believed their children were employable for pay in a field that interested them and at a level that would keep them busy and fulfilled; all but one of the alumni represented were employed at the time of the interview. Most parents' concerns about employment had advanced from whether their children would be employed in a meaningful job to what type of career advancement, benefits, and longevity would be possible in their chosen field. One parent specifically hoped his son would have the security and benefits of a civil service job someday. Several others expected their adult children to pursue continuing education in order to increase their likelihood of career advancement.

Finances. Most parents believed that their children would always need some financial assistance from them, a sibling, a trust fund, or Social Security to supplement their work income, although a few of the graduates represented were close to being financially self-sufficient. Most parents interviewed had set up special needs trusts or made similar arrangements to provide for their children financially in the future. However, this was not feasible for all parents, and several expressed concerns about how their son or daughter would afford to live when parental support is no longer available. A few had struggled to access Social Security benefits, or worried about what would happen if their son or daughter lost benefits later in life. While most parents reported that their children’s ability to manage their personal finances had improved during their PSE experience, there remained, for almost all parents, concerns about how their sons and daughters would manage complex financial issues like filing tax returns without parental support.

Romantic lives. Parents did not describe romantic fulfillment as a concern that they held for their children early in their lives, but eight parents described hopes and concerns for their children’s romantic life now that they are adults. All of these parents hoped their children would find a supportive romantic partner, and some of them also expressed uncertainty about what would happen if their adult child had his or her own children, or stated that they hoped their son or daughter would be able to have children if they wanted to.

> *I really do hope that he can find a romantic relationship, a partner, and have that kind of a... I'd like to see him get married and have children. I'm not worried that he would have a child that has disabilities, you know, because in his case it was because of the brain damage at birth as opposed to hereditary... so I'm not worried about him not being able to have normal children. But I am worried about him being able to find a partner who could appreciate him for who he is and what he is and have that kind of a life, and I've seen that in other Threshold graduates who have been able to find that and get married and have a successful relationship and that's what I hope for him. -Tia*
>
> *I do worry, I do worry about [his romantic future], because he would really like to meet a girl and I'd like him to have a relationship with someone and someone to share his life with… he needs to meet a really really really nice, special girl, that really wants a career and he can be a stay at home dad. That's my theory, ha ha ha. -Cheryl*
>
> *The question of marriage and children, I think probably many people who have children want grandchildren. That's not a decision for me to make. In some conversations about sexuality and things like that, I've talked to him about pregnancy and what have you and I think he's very careful about that, and he says*

> *"I want kids, but I can't take care of myself right now." I think he's very mature from that perspective. Although in time I think he'd be a great parent. We've been different places, even when he was a Threshold student, we were driving, it was in [our home area] and this tot was walking down the street with a stick and his hand and he said "Stop! We have to get the stick out of his hand!" Children love him. I think he would be really good. If he had to parent a teenager and help him do homework... on the social issues he'd be fine, but helping a kid do homework, that would be a real challenge. Also finding the right person, meeting the right person... He's had a number of relationships, different qualities, different things. He's attracted to people who are intelligent and well spoken. -Danielle*

> *I fully expect that someday she will want to find a partner and get married, and I think she very much wants to have children because she's very close to children and she's actually very nurturing, and for the most part, you know, the young men that she has dated we have thought well of. She does attract an array of fellas, and we find that the ones who do not have any type of learning challenge at all, um, find it more difficult to maintain a lasting relationship with Adrianna. –Ken*

Independent living. Despite having gained confidence that their children could live away from them, most parents still expressed fears or uncertainties about their son or daughter's abilities to manage responsibilities of adult life without some type of parental oversight, even from a great distance. Responsibilities most commonly cited as concerns were paying bills (both affording their bills and the physical act of paying them correctly and on time), maintaining healthy lifestyles, staying safe in a city, and handling emergencies. All parents described being the go-to person (or people, in the case of two-parent households or co-parents) for their child's questions and continued to act as critical supports and problem-solvers on a wide range of issues in their child's adulthood.

What happens when I'm/we're gone? Every parent had questions and concerns about what would happen to their children when they passed away. Ten parents who had other children expressed ideas or plans for the roles their children without disabilities would play in the later lives of their children with disabilities. For parents with no other children, there was great concern about who would check-in with their child with a disability and help them with the complex responsibilities of adult life. All parents who talked about what would happen when they were gone worried about how anybody else, even another adult child, could provide the same level of support they do.

> *I'm thinking about more and more as he gets older and as I get older and his dad gets older and his sister gets older, more about what's it gonna be like when we're gone? I mean, this week […] he lost his phone, he got so mad he broke the home phone, so we have no way of communicating with him except by email, so he's coming and going from work, I have no idea where he is. The refrigerator's broken, we're dealing with that. Who is going to do this when I'm gone? And I've taken care of all of this by myself this week. Who's going to do this when I'm gone? […] It's the day-to-day checking in with him, "My roommate looked at me cross-eyed," "The cleaning lady didn't come," all that stuff that I listen to. Who's gonna do that? –Ramona*
>
> *One of the things [my wife] and I are dealing with right now, not dealing, I guess discussing at this point, as we get older at some point when we're not here, and we presume that's going to be while Adrianna and [her brother with special needs] are still alive and functioning, they're going to need someone to provide them with general support. Neither of them needs a guardian, but they need help with some executive functioning skills. If left to their own devices they wouldn't be filing taxes or getting their insurance in order and all that stuff. You know there's other things they can do very very fine, you know Adrianna does all her own banking, she pays her car payments and all that, and that's all routine, predictable activity. But things like preparing your taxes or higher level executive skills, she needs someone to provide that oversight. And we're trying to figure out how that gets provided when we're gone, because neither one of our family structures are in a position to be expected to provide that. Do we go to a private professional third party? We don't know. It's a big question for us. -Ken*
>
> *I guess the greatest concern for us is just when we're gone. I want him to continue to thrive, live independently, and live. I'd hate to see him have to move in with his brother at some point. I don't think that's gonna happen, but I don't know, you know? -Kim*
>
> *My concern long range is of course who will be the person who will be there to help her when I'm no longer here. But my husband and I have, you know, set up our wills as such to prepare, so that our other children are not burdened with our*

> *children who have disabilities, but like Mallory's sisters understand what Mallory's issues are, they know that well, they've grown up with her. That is a real concern of mine, always. I think that's the biggest concern. –Tori*

Stories of Parenting

The seventeen research participants shared many common experiences, as discussed in the thematic analysis, but despite commonalities, each of their journeys was unique and, at times, laden with emotion and touched by personal joys and struggles. In order to capture the stories of these exceptional parents, each interview is described individually in this section as a narrative.

Barbara. Barbara and her husband adopted their daughter Eva when she was almost a year old. Because she was adopted from an orphanage overseas, they expected that she may present with developmental delays. At the age of 4, her teachers reported that her social interaction was behind her same-aged peers and recommended testing, which provided Eva's parents and teachers with some strengths and challenges to be aware of, but no diagnosis. When Eva reached 2nd grade her academic skills were delayed enough that she began receiving special education services. With supports, Eva was able to "keep up," for the most part, and Barbara believed she would someday go to college, a goal Eva held for herself. Midway through high school Barbara realized that without constant support, it was unlikely Eva would thrive in a traditional college setting, and they began meeting with guidance counselors to identify possible next steps. School staff were not aware of postsecondary options that Barbara and Eva believed would be a fit for her, and the schools they subsequently visited were found through Barbara's own research.

Eva and Barbara visited five college-based postsecondary programs. Every program except Threshold was designed to transition students into an associate's or bachelor's degree granting program. Eva spent a summer at one of these programs but was not subsequently accepted into the core program because the admissions director was not confident that she would be able to keep up academically with the curriculum. After rejecting Eva's application, the admissions director suggested she consider the Threshold Program. When Eva and her parents initially visited Threshold, Barbara thought there was no way Eva "could handle the city and just the bigness of everything," and sensed that Eva felt overwhelmed as well. However, they were immediately reassured by the panel of students who spoke at the admissions information session, and after touring the campus and hearing from the admissions director, they felt that it was the right fit.

In describing what Barbara hoped Eva would get out of her postsecondary education, she reflected:

> *I think what we were most hoping for was social interaction, friends, peers, true peers, a continuation of academic life, um, that she could manage on her own, we were looking for that and I think she did get that. And also the opportunity to live way from home and to learn how to do that.*

Eva was one of the few alumni whose parents were interviewed who had a truly inclusive experience with extracurricular activities on campus. She was involved in sports and had daily interaction with undergraduate athletes. Barbara believed that the experience was very positive for her daughter and reported that Eva gained lasting friendships with undergraduates as a result. While Eva had not been seeking an inclusive academic experience, necessarily, Barbara believed that opportunities for inclusion in coursework would have been positive for Eva as well.

Barbara believed that the education Eva received matched her expectations, and was particularly thrilled with Eva's level of independence as a young adult. She credited the post-certificate Transition Year program at Threshold with helping Eva make the move into a highly independent lifestyle.

> *She's a truly independent adult at this point, and she could never have, I can't imagine how she could be living in a city in an apartment with friends around. I don't know how we would have accomplished that, trying to make that happen without a program like the Threshold Program to kinda kick start her into that life. She just, just watching how comfortable she is maneuvering around Boston is really remarkable to us.*

Eva was working part time in a hospital at the time of this interview, and Barbara hoped she would advance to full time, but was satisfied with the type of work Eva was doing and reflected that her internship experiences at Threshold were positive. Barbara hoped Eva would always push herself to grow vocationally by asking how to do new things at work and by taking the initiative to find opportunities to be challenged.

Barbara's hopes for Eva's future were that she would continue to have a rich social life, grow vocationally and attain full time work, and continue to grow academically through adult education of some kind.

Cheryl. Cheryl's son Jackson began Early Intervention at 15 months old and was later diagnosed with an Autism Spectrum Disorder, but Cheryl knew much earlier on that his development was not what would be considered "normal". Jackson experienced almost constant ear infections as an infant and Cheryl believed his early speech was delayed long before his pediatrician agreed to refer him to an ear, nose, and throat specialist. The ENT referred him to EI immediately and within six months he had received a full evaluation from a neurologist that indicated developmental delays.

Cheryl's approach to parenting Jackson was to help him be the best he could be. Throughout his childhood and into adulthood she advocated for any service or therapy that might help him. During his school years she hoped that he would become an independent and happy adult, and all of her efforts to support him were aimed at that goal. When Jackson expressed that he wanted to go to college like his brother had, Cheryl wanted to help make that happen, even while his guidance counselors were telling him that college was not an option.

Together, Cheryl and Jackson visited three college-based postsecondary programs. While all of them were affiliated with colleges and located on campus-owned property, Cheryl felt that only Threshold was physically integrated into the campus space and that it also promoted the most student independence of the three schools.

Cheryl believed that Jackson always felt integrated into the university culture and remarked that he made friends with undergraduates on campus because of his outgoing nature and aptitude for sports. She reported that inclusion in campus courses that interested him would have been beneficial "where appropriate" and with supports.

Cheryl reflected that she and Jackson were looking for a school where he could experience college in the way his brother did, while also gaining the skills necessary to live independently. Cheryl was highly satisfied with the impacts Jackson's postsecondary education had on his adult life. She marveled at his ability to safely and competently navigate complex public transportation systems in multiple cities and credited that independence to Threshold. She believed that his self-esteem and social skills had dramatically improved as a result of his postsecondary education and finds that he makes more responsible decisions and copes with challenges better than he used to.

Cheryl’s one critique of Threshold was the job placement supports Jackson received after graduation. He was employed in multiple positions with the help of Threshold staff, but was not able to earn enough money to continue to live in the Boston area. Finances have always been tight for Jackson’s family, making his underemployment a significant challenge. To further exacerbate their struggle, he was denied social security and was appealing the decision at the time of this interview. Cheryl described being worried about Jackson’s future and how he would support himself. She indicated wishing she could leave him a trust fund and stated that she deeply regretted the impossibility of doing so.

Throughout her interview, Cheryl spoke openly and emotionally about the many ways in which society made life more difficult for her son. She gave examples of government programs that punish Jackson’s efforts to work and of young women who have rejected him because of his disabilities. Despite her instincts to help and protect him, she spoke about the critical importance of “letting go” as a parent and allowing Jackson to learn how to be independent. Her advice to other parents helping their children with disabilities pursue postsecondary education was to “absolutely go for it,” and to pick a school that will require them to live away from home.

Cheryl expressed hope that Jackson would find romantic love someday. She said he would be a great father with the right partner. In the meantime, she described the close friendships he developed in high school and at Threshold; she described valuing the impact of those friendships on Jackson's life and said she hoped he would continue to maintain them.

Curt. Reflecting on Amelia's early childhood, Curt remembered that his wife had concerns about her development as early as 6 months old, but it was not until she was 4 years old that she received a diagnosis of a neurological impairment. She began receiving speech, physical, and occupational therapy immediately. Amelia attended a kindergarten program for children with special needs but then entered the public school system and was mainstreamed for much of each day, sometimes with and sometimes without an aid, through high school. Curt remembered that in middle school Amelia made friends with a group of girls without disabilities who included her in everything they did and also helped her to socialize with other students. She remained close to this group through the end of high school, and Curt credited these friendships with helping her to have a more positive school experience than she may have had otherwise.

Curt recalled that Amelia struggled immensely with academic subjects, with math being especially difficult. Curt spent hours with her each night in middle and high school helping her complete homework assignments. He remembered this time not as a struggle for Amelia, although it was, but as an incredible opportunity to bond with his daughter in a way that he had not with his sons without disabilities. When she was 16 or 17, Amelia stopped wanting help with homework and began to do poorly in school. She became depressed and Curt began to worry that she would not bounce back and would have few choices after graduation other than continuing to live at home forever. Amelia’s parents began taking her to therapy twice each week and her mother advocated with her school to build a program with her that would interest her and encourage her talents. Amelia began working in a day care each afternoon as part of her high school program and thrived as a result.

Amelia’s high school offered very little support in her transition out of high school, only recommending that she try taking a class or two at the local community college. Amelia wanted to have a full college experience, and Curt wanted her to learn how to live away from him and her mom, so the idea of commuting to a local school for one or two classes did not appeal. Amelia’s mother researched colleges that offered dorm living and support to people with special needs and she applied to several. Curt recalled that after visiting three or four schools Amelia felt like Threshold offered the most authentic college experience.

Curt expected Threshold to help Amelia build her self-esteem, learn how to live on her own, and learn how to solve problems independently. He knew she would succeed in the right environment because of her extreme perseverance. On top of the programming offered by Threshold to support independence, Threshold’s location in Cambridge, MA and its proximity to Harvard University appealed to Curt. He was not worried about Amelia’s safety- in no small part because of her black belt in karate- and appreciated all the opportunities available in a college town. He expected that she would have the feeling of being in college by sharing space with undergraduates and living in a dormitory. Remembering Amelia’s acceptance into the program, Curt said “it was almost too good to be true… we felt very lucky.” Curt remembered feeling comfortable leaving Amelia at school because the staff showed interest and concern for her and because she immediately connected with other students. He recalled:

> *When our boys went away to college it was almost sad as we pulled away, you know drove away, I told [my wife] that ‘when we drop Amelia off make sure you have a big box of tissues in the car cuz I'm sure we're gonna be sobbing and crying for an hour.’ Well, we dropped Amelia off […] and one by one kids are popping in to see her, kids with whom she's been communicating all summer[…]and at some point Amelia assures us she's fine, tells us to leave, and we reluctantly agree to leave. We knew she was making arrangements with friends to go to the cafeteria and then we see them walk down the road from where our car was and they're all smiling and laughing and there was this group of girls and it was just phenomenal, made us feel so good. We didn't shed one tear. We were giddy, we were laughing in the car we felt so good. But, anyhow, so....I like talking about this! It makes me feel so good about Amelia.*

Curt did not recall specifically hoping that Amelia would develop her vocational skills, but he realized in her first semester that it was happening and was impressed. He reported that Amelia did develop skills for independent life during her time in the program, even learning the value of money, which he was not sure would ever happen. She also developed friendships that have been sustained through the eight years since her graduation.

Curt did not offer any critiques of the program and said he was thrilled with its impact on Amelia, but when asked his views on the inclusion of students like Amelia with undergraduates, he thought it could be very positive in the right setting. He thought in a small setting, carefully thought out and with the right group of students with and without special needs, it could be positive and he would have liked to see that for Amelia.

Without intentional inclusion, Amelia did make some undergraduate friends, although her closest relationships are with Threshold alumni.

In discussing his concerns for the future, Curt noted that as Amelia becomes more physically and financially independent, she also seeks her parents' counsel and takes their advice less often. While the shift from asking for help immediately to making mistakes and then disclosing them actually represents growth in her independence and self-efficacy, it also means more worry for her parents and a greater likelihood of interpersonal problems, financial trouble, and getting taken advantage of by others.

Curt's advice to other parents considering postsecondary education with their children with special needs was to put distance between themselves and their son or daughter. Find a supportive setting and "get the kids away from you," he advised, so that they can learn skills for independence.

In closing, Curt again compared Amelia with his sons without disabilities:

> *My two boys are highly accomplished, but it's almost like, big deal. They're personable, smart kids, you know, they all have advanced degrees […] and they're both married, one's got a kid, the other one's expecting with his wife […] they've both bought houses, you know it's nice, but they're a dime a dozen. Everyone does well! You know, kids like this, big deal! They got dealt good hands. Amelia didn't get dealt a good hand, and she's gotta play the cards she's dealt, and she's the one that is so much more accomplished, and has exceeded our expectations; she is the real success story, and I just hope it continues.*

Danielle. When Tod was a child, Danielle did not know what the future would hold. His diagnosis was largely unclear, other than a language-based learning disability that explained some of his academic trouble but not his below average IQ score. Tod showed limited ability to understand abstract concepts and struggled to read and write throughout childhood and into adulthood, but other aspects of his development were normal and even advanced. He was exceptionally coordinated and athletic and very outgoing. From a very early age he was able to enter a room of other children and immediately make friends. He belonged to many teams and was often recognized for his leadership skills.

In high school, Tod’s family hired an educational consultant who recommended several non-degree, college-based postsecondary programs. Tod had attended residential summer programs previously and Danielle and Tod’s father believed it was important to find a school where he could live away from home and practice the independent living skills that he had shown a capacity for during the summers. It was important to Tod and to his family that he go to school at a college. Tod was always aware of his disabilities, painfully so, according to Danielle. He knew he would not be pursuing a college degree, but deeply wanted the college experience that his friends from high school would be going on to have. It was important to Tod not to feel like he was being treated differently than same-aged peers because of his disability. Tod visited several schools and Danielle recalled listening to him process his feelings about one school with curfews, bed checks, and other systems in place to ensure the safety of their students with special needs:

> *And on the way back to our house, it was a long trip, I asked him how the day went and he said everything was very nice and people were very good to him and encouraging to him, nothing negative, but I sensed something hesitant about it, and I said ‘there's something that I hear that doesn't... the tone of your voice isn't consistent with what you're telling me. Is there something you're reluctant to say?’ Maybe I have to explain this first. [The school] is a beautiful, rural setting,*

> *the facilities are magnificent. A quarter mile down the road is a crossroads, and there's a pizza place, and they were telling the people in the program 'you can't cross the road by yourself and you can't walk 1/4 mile down the road to get pizza.' He had a driver's license at that point, and he said 'If I went there, I feel like I would be taking a step back' because it was so protected and so sheltered.*

For Danielle, it was important that whatever school Tod attended helped him to develop self-esteem, vocational skills, and independent living skills that would help him to manage adult life. This was especially important for Tod; with no siblings or close relatives other than his parents, he would need to build a network that would continue to support him after his parents pass away.

Danielle knew within a few weeks that Tod's postsecondary experience was improving his self-confidence. On a visit six weeks into the school year, she could see a physical difference in the way he held himself. He was proud of the work he was doing at his internship and his success positively impacted his whole personality. At the time of this interview, Tod was working a steady, full time job that he loved and was able to pay most of his expenses himself. He maintained a healthy lifestyle and a relatively clean apartment, had good friends, and could solve problems better than ever before. Danielle wished he had been given opportunities at Threshold to improve his reading and writing through specific coursework and adaptive technology supports; he still read and wrote around a second grade level and needed help filling out paperwork, completing written tasks for work, and understanding important documents he received in the mail. Danielle also would have liked to have seen him offered more choice in the courses he took, and more flexibility in the program structure overall. Tod participated in extracurricular activities with undergraduates and Danielle reported that some of his teachers in the Threshold program were not flexible in allowing him to miss classes for required meetings of his activities. Danielle believed he would have benefited from being able to take undergraduate classes with supports and that the principle of least restrictive environment should continue to apply for a program like Threshold. The “cross-fertilization”, as she described it, of students with and without disabilities would have been positive for all students involved.

Danielle talked about her worries for Tod’s financial future and his ability to support himself eventually. She also wondered what would happen if he ever decided to live on his own instead of with friends. His roommates had different strengths than him, and together they managed apartment maintenance, paying bills, and dealing with emergencies. Danielle was uncertain whether Tod could manage all those areas of adult life without support. She also wondered whether he would find a romantic partner and decide to have children; she believed he would be a wonderful father in many areas, but would struggle to parent a teenager, with all the complex issues he would have to handle. She believed strongly that his choice whether or not to have children is one he should make with his future partner and she did not intend to weigh in one way or the other.

After considering what advice she would give to other parents of young adults with disabilities seeking a postsecondary education, Danielle said she would tell them to listen to their son or daughter, understand their needs, and once they find the right fit, to let go.

Elaine. Elaine reported that Lilly was born a big, happy, healthy baby. Elaine recalled that many of her developmental milestones were moderately delayed, although at the time neither she nor Lilly's pediatrician were concerned enough to pursue a developmental evaluation. When Lilly started preschool her teachers noticed that she seemed overwhelmed by noises and activities, and preferred to be by herself. Her language regressed around this time and her teachers suggested she be evaluated. Just before she turned four, Lilly was diagnosed with pervasive developmental disorder and sensory integration disorder and began receiving speech, occupational, and physical therapies. Lilly showed many behaviors and characteristics associated with autism spectrum disorders, including hand flapping, memorizing movie scripts, inability to engage socially, and aversion to loud sounds and other stimuli. She did not develop conversational language until she was ten and was involved in intensive therapies throughout her school years.

Lilly attended public school through 5th grade and was included in the general education classroom with support from a one-to-one aid. After 5th grade, the classrooms in Lilly's school district had higher enrollment and more academic subjects, and Elaine did not think she would thrive in that environment. Elaine fought the school district to have Lilly placed in a school for students with special needs where she was matched with students in various grades grouped by academic ability. Lilly thrived in this environment through junior high school and high school and continued to make academic, social, and functional gains. As Elaine described it,

> *She was in this really great school, multisensory, very hands on, you know they integrated all of the special, you know speech therapy and occupational therapy into the curriculum. So she thrived. I mean, the thing about Lilly is she's just always been making progress, you know, it's like she never plateaued, she never, you know and she was always sweet and people like her, and that was a saving grace for her, that she just has this sunny spirit. She liked school, she never felt stigmatized by going to a school for kids with special needs, she was like "Wow! I get extra help with this and that."*

When the end of high school drew close, Elaine began researching next steps for Lilly. Her school's personnel were not aware of appropriate college-based options at the time, but a friend of Elaine's recommended she look at Threshold.

> *I went home and got on the website and was just like in tears immediately because it felt like exactly, you know, perfect for Lilly. And I had never felt that way about anything. Every program she was in, every school, all the different things that I had gotten her into, camps, were never… they never felt quite right. They always felt like she was more or less disabled than the cohort that the program was designed for, or, I don't know, it just wasn't right. And Threshold felt like exactly her people.*

Despite Lilly's gains in school, most of her family members doubted she could succeed in a residential college program far away from home. Elaine, however, believed she would continue to thrive. When Lilly and Elaine initially looked at programs, Elaine was mainly hoping Lilly would have the opportunity to have a college-like experience away from home and become part of a community. She remembers worrying about Lilly getting lost in the city or being so homesick she would not be willing to stay at the program, and although she believed in her daughter, she really did not know what to expect from the experience. In reflecting on the impact of Threshold on Lilly's development into an adult, Elaine sees that Lilly gained much more from the experience than she had ever imagined. Just one year out of the program, Lilly's independence is "mind blowing" to Elaine. Elaine described her daughter as always "clinging" to her even to the end of her high school years and living a life that Elaine heavily managed in many ways. Now, Lilly lives far from home with friends, works a job she attained without her mother's help, manages her own space and schedule, and is a happy adult living the life of her choosing.

While Elaine believed the program was nearly perfect for Lilly, she saw other students who did not find jobs as quickly as Lilly floundering during their time in Transition Year and believed there should have been more supervision and support for those students. Elaine also would have liked Lilly to have had more flexibility in course selection and wished she had had more experiences with undergraduates. Elaine did not mention integrated coursework or residence halls, but wished Lilly had been matched with an undergraduate to help her navigate the student activities she was interested in trying.

During the interview, Elaine reflected on how her parenting style with Lilly impacted her development:

> *I think one of the things I feel like I'm most proud of myself in terms of my parenting is that I've always, I have not looked to the future that much. You know, I've really tried and kind of it helped me be sane to just stay in the moment, just do the next thing and do the next thing. People would always ask "Do you think she's ever gonna be able to talk, do you think she's ever gonna be able to read, do you think..." and I was like "I don't know," you know. If I were to guess or go by the prognosis, if I had done that, I think she would have not done as well, because there were always these things that were sort of like oh, her IQ is whatever, and she's, you know, she has severe cognitive deficits that aren't going to allow her to do... So I, when she came here I was just holding my breath that she was going to like it and somehow not get lost, which was her biggest fear. But you know I don't really put anything past Lilly at this point. I think that the fact that she's working*

> *full time and commuting an hour to work each way on two different subway lines and […] making plans to have dinner here and go meet so and so there, and it's just like, it's still mind blowing, but I feel like, I think she may very well stay here and choose to be this far away from her home and, you know, she's really thrived, really really thrived. The independence, getting to go to college, "college", just like her cousins and all of that was just huge for her, and she's really very motivated and so proud of all of what she's accomplishing. So, no I don't think I would have anticipated it, but I'm not entirely surprised. I feel like if anybody could've done it or stood up to her own challenges it's her.*

Elaine commented that Lilly would never have been as independent as she is now without the opportunity to go away from home and be on her own. She would recommend that other parents of students with special needs build as much “scaffolding” as their children need and then let go and let their children develop their own lives as adults.

Elaine expressed being unsure whether Lilly would ultimately stay in the area of Lesley University, far from home, or move closer to her family. Being near the university meant that she had access to a community of other local friends and professionals who know and care about her, which Elaine described as critical to her ongoing success as an independent adult. She said Lilly would continue to need supports in some areas to maintain her independence, and was visited weekly by an advisor referred to her by the Threshold Alumni Center, who helped her with cleaning, meal planning, and negotiating challenging social situations. Elaine imagined Lilly would always need some type of support, but said she has also “learned not to put anything past her” and would continue to take one day at a time.

Heather. Hadley was diagnosed with a syndrome-based developmental delay (diagnosis omitted for anonymity) at birth. She was a happy, healthy, and peaceful baby. Her mother, Heather, described being surprised and concerned by her diagnosis, but by no means devastated. Having lost her mother in a traumatic accident just before Hadley's birth, Heather saw her daughter's diagnosis as "not the worst thing to have happened" in her family, and felt that her previous loss helped her put the diagnosis in a larger perspective.

From Hadley's early years, Heather involved herself heavily in her schooling and spent a lot of time volunteering in Hadley's elementary school classrooms. Heather did this to help Hadley have the best educational experience she could, but she balanced her involvement with work and with regular family activities, determined not make life all about Hadley's diagnosis. Heather ensured that her family had fun experiences together and that Hadley was exposed to concerts, skiing, culture, and anything else she and her family enjoyed.

Heather always believed that Hadley could have a happy and fulfilling life. Hadley learned to read on time with no trouble, so Heather had an idea that she was more of an intellectual, as she describes her, than her diagnosis might suggest to someone who did not know her. Heather had worked as a nurse her whole adult life and felt inspired and fulfilled by her work. Her primary goal for Hadley's adult life was for her to have an occupation that fulfilled and inspired her in the same way. For Heather, this did not necessarily mean that Hadley needed to go to college, but for Hadley, going to college was her dream. Seeing her cousins and friends go off to college intensified her determination. Hadley's high school offered little assistance with identifying appropriate college programs; her guidance counselors were well meaning but focused on gifted and talented students pursuing top tier colleges and had little knowledge about non-traditional schools for Hadley. Unable to pass the math portion of her state's standardized testing, Hadley graduated without a high school diploma, disqualifying her from most college programs. After exploring all the options near home, Heather and Hadley turned to Lesley University, on the other side of the country.

Upon visiting the Threshold Program for Hadley's interview, Heather recalled feeling welcomed and comforted by the staff she met, in particular the director and the director of admissions. They clearly knew and understood their students and had found a balance between providing them with opportunities to make independent choices and mistakes and ensuring their safety and success. Heather appreciated the neighborhood Threshold is located in and thought it had the feel of a safe village rather than a city. She was comforted to learn from the director that Threshold staff accompany students on their first use of public transportation and help them learn the system.

Heather hoped and expected that Hadley would receive an education that would help her achieve meaningful work after graduation. She was not expecting that Hadley would live independently after finishing the program and even had doubts about her ability to care for herself while at school. In hindsight, the independence Hadley gained is what Heather values most about her experience. Hadley was living on her own, managing her money, and making her own choices. Heather said she did not believe this would have been possible if Hadley had not attended a program away from home where she would be required to manage all the aspects of her life that her mother had previously helped with.

Heather did not expect that Hadley would be included in university coursework or experiences at Lesley, but in hindsight wished she had had more integrated opportunities. Heather reported that whenever she talks about Threshold, Hadley critiques the separation of the students from the undergraduates and expresses her wish that she had experienced more inclusion. Her desire for an inclusive experience was so strong that she attended a second college program after Threshold. The second program emphasized academic work over life skills and had structures in place to support students with ID/DD in taking undergraduate classes. After completing the second program, Hadley continued to take classes for credit at her local community college. Heather said she valued all of these postsecondary experiences. She supported her daughter's desire for intellectual stimulation and academic challenges; she also believed that Hadley would not be living independently today if she had not started with a program that taught life skills.

> *[Hadley] would've liked more freedom to pick classes [at Threshold]. Since she's left Lesley she's taken a lot of theater, she's taken art history, women's studies, history, you know... the fact that it's a segregated program is something that she complains about. When she went to the next college she said, you know, that it was the bees knees and she kind of poo pooed Threshold, but I always remind her about all the skills that she learned there, because they were enormous.*

Heather said she believed that supporting Hadley in attending postsecondary school was one of the best things she and her husband ever did for their daughter. Hadley developed a level of independence and self-determination that they do not think could have been possible without her experiences living away from home and challenging herself at school. Heather said she believed that Hadley is on the right path for having a lifetime of meaningful and fulfilling work. At the time of the interview, Hadley was working in early childcare and in disability advocacy and was working toward her associate's degree in early childcare. She had a social circle of people who Heather believed loved her genuinely, and Heather described her as a fun, independent, spirited person. Heather believed that Hadley would have these qualities, at least to some extent, no matter who her parents were, but attributes some of Hadley's success to the choices she and her husband made as parents. Heather expressed pride in herself for giving Hadley opportunities to learn and grow and she would recommend other families "cut the apron strings" as they did, whether by letting them go away to school or by practicing independence in some other way.

Joan. Joan and her husband adopted Kendall when she was seven days old. No developmental concerns were identified for Kendall during her early childhood years. When she entered kindergarten she was more "immature" than the other children, but was not evaluated for any disability. Kendall's family moved when she entered 2nd grade and she was far behind the students in her new classroom. Kendall was evaluated and diagnosed with an auditory processing disorder. She also had poor hand/eye coordination and executive functioning deficits and struggled with reading. Joan "fought" the school to get an IEP in place for Kendall, and when Kendall was approaching 4th grade her parents decide to move her to a different school with a stronger special education program. She did academically well in her new school, but was bullied by other students for being a student with special needs. This continued for years and Kendall often made up illnesses to avoid going to school.

When Kendall reached 8th grade, her school began to integrate all students with special needs into mainstream classes with the support of aids. Kendall's class had over 20 students, almost half of whom were on IEPs, and only one aid was assigned to support them. By this time she had been diagnosed with ADD, and her difficulty concentrating combined with her auditory processing disorder made the busy classroom a poor fit. Her grades dropped and she began to have even more social challenges. After such a poor experience with inclusion, Joan sought a specialized high school program for Kendall and enrolled her in a vocational technical high school where she was in a classroom of 10 students. Kendall received education in a trade (details omitted for anonymity) that could have led to a career, but Joan believed she needed to develop more maturity and independence before entering the world of work. After a friend suggested Threshold, Joan showed Kendall the admissions video from the program's website and Kendall became excited about the possibility of going to college.

Joan researched other programs for students with special needs and also looked into Kendall attending a state college, but ultimately believed that Threshold's size and focus on life skills was what Kendall needed. When they visited the program, Joan was impressed to see students and alumni, whom she perceived to have more significant disabilities than Kendall, doing extremely well. They were working in internships, going to class, managing their time and their space in the dorm, and making friends. Joan saw young adults who had “been given a chance to bloom” and wanted that for Kendall. Joan said Kendall herself was excited by her visit and could not wait to live in Cambridge and meet her classmates.

Joan expected Threshold to teach Kendall the skills to have a career as an early childcare educator if she chose that over the trade she was already trained for. The idea of Kendall having multiple career paths was appealing to Joan as an older parent; her daughter may need to attain financial stability earlier than other young adults, and Joan wanted to make sure she was prepared. Likewise, being able to live independently, make decisions, and solve problems were important goals for her to reach, and Joan expected Threshold to help. Joan liked the idea of “moving her into making good choices about her adulthood”, and believed that faculty and staff at the program would be able to do that more effectively than she could as a parent.

Joan said she believed that Kendall had learned everything Joan hoped she would during her PSE experience and more. Joan expressed astonishment at how well Kendall could maneuver public transportation and how well she handled herself in the city alone. Kendall was managing her finances, maintaining her living space, and had other skills she needed to live on her own. She was able to make good decisions for herself and control her impulsivity, allowing her to think before acting. Perhaps most importantly to Joan, she had confidence in herself that she never had as a child.

Joan said she believed that Kendall could have done well in undergraduate classes with the right supports and with instruction on how to study and keep up with college level work, and wished that she had had the opportunity to try. Kendall participated in a club at the university, but Joan never saw that participation translate into friendships with undergraduates. If Kendall had had more meaningful and positive experiences with undergraduates and the opportunity to take academically challenging classes, Joan thought she would be able to continue her education on her own if she chose to, potentially towards a degree. Joan also said difficult coursework could have helped Kendall learn strategies for studying and test taking that would have helped her get her driver's license, something she was struggling with at the time of this interview.

Joan said she hoped that Kendall would have "stability, a wonderful job, and a good partner" in her adult life and believed that her experience at Threshold, the support of her parents, and her own "stubbornness" came together to give her the right "foundation" for all three. Joan said she would highly recommend that other families pursue postsecondary education with their young adult children with special needs.

Ken. Adrianna was adopted from an orphanage in another country when she was four and began attending preschool immediately upon moving to the United States. She was not identified as having a learning disability until a few years later when she began to be regularly exposed to numbers, letters, and abstract concepts. She received an evaluation that revealed additional difficulties with sensory integration. Adrianna's school quickly developed an IEP for her and Ken found her public school educators to be responsive to her needs throughout elementary and middle school.

Adrianna next attended a vocational technical high school, but found that her chosen trade was not a good fit. In the absence of another offering that interested her, Ken advocated for the development of a new program in early childcare. He and Adrianna’s mother worked with her teachers and the administration to develop a specialized curriculum for her that included an internship working in a daycare. Adrianna did very well in the program and loved working with children. She wanted to pursue postsecondary education in the field of early childcare, but was unable to pass her state’s testing requirement and could not receive a high school diploma. Adrianna’s parents researched alternative college programs and, together with Adrianna, decided that Threshold was the right fit. The early childcare certificate track appealed to Adrianna, and her parents appreciated that the program emphasized life skills, was at a college, and was residential but still close to their home.

Ken was expecting that Threshold would help Adrianna develop enough vocational skills in her chosen field to be successfully employed as an early childcare professional. He also expected that she would learn to live independently and experience a growth in her self-confidence, self-esteem, and maturity. “By every measure”, Ken said, “it was a success.” Adrianna received a job offer as an early childcare teacher immediately upon graduation and moved into her own apartment not far from her parents. She was able to get her driver’s license and could travel to and from work and appointments on her own. She even sought out and acquired a second job to help her become more financially independent. While in the program, Adrianna had to navigate the public transit system to and from her internships several times each week, and can now travel anywhere on the system independently, safely, and with confidence.

Ken wished that Threshold had helped Adrianna develop a “big sister” type of relationship with an undergraduate student. He said he believed she would have benefitted from social role models and she may have more close friendships now if she had received more social supports. Adrianna experienced some tumultuous interpersonal issues, particularly in the dormitories, and Ken reported feeling like the program’s administration did not intervene quickly or actively enough to help her repair her social relationships.

In thinking about Adrianna’s future, Ken expressed worry about how she would manage complex adult responsibilities like filing taxes once he and his wife are gone. He said Threshold should have offered supports to parents to help them plan for the later adult life of their children. On a higher level, he would also like to see Threshold advocate at the state level on issues affecting students and graduates, like current community college regulations requiring students to have a high school diploma before enrolling in a degree program. Although Adrianna has a successful early childcare career and academic credits from Lesley University, she could not pursue an associate’s degree without a high school diploma and would need to attain her GED first. Ken said he believed that if Threshold administrators chose to do so, they could make a difference on issues like this.

Ken would advise other parents of young adults with disabilities to “be realistic”, “do the best they can”, and be supportive and accepting of their children. He would also caution other parents to take care of their marriages and find support to help manage the stress of parenting adopted children with special needs, in particular.

Kim. Steven was born three months premature due to complications in Kim’s pregnancy and spent his first two months of life in neonatal intensive care. He incurred a brain bleed and a bacterial infection while in the hospital, and Kim remembers those first months as being about basic survival. When his parents were finally able to take him home he weighed less than five pounds and his significant gross and fine motor delays were obvious. He received the full range of early intervention services from birth through age three and was given a diagnosis of cerebral palsy with ataxia.

Although Kim knew Steven would face gross motor, learning, and social challenges as a child, she initially believed he would catch up with his peers eventually. When he was around four years old she started to realize that he might not, but still did not have much sense of what his adulthood would look like. In eighth grade, with high school looming, school staff sat down with Kim and her husband at an IEP meeting and told them that college would probably not be possible for Steven and that they needed to help him work on acquiring life skills. During his high school years, an occupational therapist working with Steven suggested they consider supportive, residential postsecondary programs, and Kim began to set up visits to several nearby programs.

At first, Kim and Steven had their sights on programs that transitioned students with disabilities into a college degree program, or supported them comprehensively throughout a degree program. Steven was not accepted at these programs, and Kim reflected that she was in denial about how difficult college-level work would be for Steven until he was rejected from their choice schools. At that point, they visited Threshold, and Kim realized for the first time that Steven could both have a college experience that matched his academic level and also learn the skills he needed to live independently in a place where he would feel like he was among peers. While interacting with Threshold students during an informational session, Kim felt that Steven would fit in socially with the other students in a way that he never had in school. Although Kim had fought for Steven to be included in mainstream classes in high school and felt he had benefitted academically, she saw a different story, socially.

> *[Steven] really received nothing from the regular ed population, or at least very little. I mean, that was our experience. A couple kiddos who go out of their way, but other than that... and after school clubs, but nothing on the weekend.*

At Threshold, Kim believed Steven could build true, reciprocal friendships for the first time in his life.

Although Steven did not develop lasting friendships with students without disabilities in his school years, Kim believed it could have been possible with the right supports and the right peer group. She said that access to undergraduate classes at Threshold would have been invaluable if “done right”, with the appropriate academic supports to help Steven be successful without enabling him, and with social follow-up from undergraduate classmates. She stated that it would be difficult to create an environment where those two conditions exist, but that Steven could have learned social pragmatics from a peer role model in an inclusive class and believed it would have helped him function better in employment settings.

Kim said that Steven’s experience at Threshold positively and dramatically impacted his social life and his independent living skills. He developed many close friendships, learned how to live on his own safely, happily, and healthfully, and to navigate public transit comfortably. “In some ways he’s surpassed my expectations,” Kim said, “many, many ways, really.” Steven struggled vocationally after graduation and Kim wished that his path to paid employment had been a smoother one. Between his physical disabilities and learning challenges it has been difficult for Steven to find a job that he enjoys, can do well, and that can financially support his independent life. Steven had planned to enroll in Threshold’s postgraduate Transition Year program, but during the orientation process Kim and Steven decided it was not a good fit for him. Steven needed an apartment that minimized the distance he had to walk to public transit, which was not a priority of the students the administration had arranged for him to live with, and Kim felt that program staff did not respond adequately to her concerns. Now, six years post-graduation, Steven works two to three days per week at a clothing store. Kim wondered if Steven would have had more vocational success if he had participated in the Transition Year, and she worried that he might not be able to continue to live away from home if he could not acquire and maintain more substantive employment.

Other concerns Kim expressed for Steven’s future included his ability to handle stressful life events without parental support and to continue to live away from family members for the long term, particularly after she and her husband pass away. She hoped he would not have to move in with his brother, although acknowledged that that may be the reality someday. She also hoped he would find romantic love, something he wants for himself, but said she did not “pin [her] hopes” on him finding someone he’s compatible with.

Kim has suggested the Threshold Program to other parents with young adults or adolescents with special needs who might be a match for the program. She would recommend that all parents of children with disabilities help them have as much independence as possible by giving them an opportunity to live away from home and trusting their judgement.

Mark. Mark recalled that he and his wife had concerns about their son Cooper’s development from around eighteen months when delays in milestones became noticeable. Mark remembered that their focus was more on physical delays and less on learning until he reached kindergarten. His delays in learning were identified and he received special education services from that point on.

While traditional, academic learning was an important focus of schooling for Cooper, Mark always felt that it was secondary to helping Cooper develop the skills he needed to have a happy and fulfilling life. Cooper’s happiness was paramount to Mark and his wife, and they were devastated when he came home from elementary school each day frustrated and depressed. He was bullied at school and was not learning. After school each day he was tutored by a high school student who worked kindly and patiently with him one-on-one to help him master the material that he could not learn in the classroom. When all the academic supports possible in his local school district still could not create a positive learning environment for Cooper, Mark and his wife realized that a private elementary school placement might provide the kind of atmosphere he needed. Cooper's district disagreed and Mark and his wife sued them for tuition to a school for students with special needs.

In his new environment Cooper was much happier and was able to learn academic and life skills. When Cooper reached high school, Mark began to develop a clearer sense of what his postsecondary and adult life might be like. Mark knew that he and his wife could "get Cooper through" a community college degree with a lot of support and tutoring, but did not believe he would really benefit from the degree if he had to struggle immensely and be heavily supported through it. Instead, Cooper's family researched non-degree college programs designed for young adults with special needs. Cooper spent the summer at one such program near home, giving him and his parents the opportunity to try the school out before applying for the school year. Mark recalled that the program was perfect on paper, but after seeing Cooper experience it for a summer Mark no longer felt that it even "came close" to his expectations. The students there were not "constructively engaged" in his view, and were isolated from the rest of campus and from typical college life. The realization that the local program would not work for Cooper sent Mark into a panic, as he recalled, until family friends suggested he visit Threshold.

After visiting Threshold, Mark felt that it had all the components he and his wife were hoping for in a program. They believed Cooper would be “constructively engaged” in learning life, job, and social skills and in gaining independence, and Mark expected that Cooper would make gains in all these “indices of coping.”

> *…Job skills, life skills. He had no social life at home. He had really no friends, you know, a couple of aquaintances, but they weren't real friendships and a lot of his social life was with me because I tried to fill the void for him. And so we were hoping he would be able to live independently, learn those skills, have more of a social life. He hadn't worked, you know, he hadn't had you know, part time jobs[…] so on a scale of 0 to whatever he was pretty much down at the bottom on all of these things; social skills, social interaction, he had great social skills, very social person, always was, but you know, in terms of friendships and social life, close to zero. Job skills, zero. Independent living skills, close to zero. So, you know, our expectations and hopes were for rapid and extensive advancement along all those indices of life.*

When Cooper was a student at Threshold, Mark did not have pre-set expectations about what his level of social inclusion at the University would be. In hindsight, he wished that Threshold students were more intentionally included with undergraduates at whatever level seemed appropriate for each of them. For Cooper, Mark would have liked to see Threshold staff facilitate positive interactions between their students and undergraduates. Mark did not believe academic inclusion would have been a positive experience for Cooper and suspects that he would have spent more time being tutored and supported than he would have spent in class.

In describing how Cooper’s experience at Threshold impacted his development into an adult, Mark replied:

> *Oh that's easy, one word, maybe it's hyphenated, I don't know: Life-changing. He wouldn't be where he is, you know, he wouldn't be able to live independently, he's in a great place in terms of that, he has job skills, he's met challenges at work […] and he's been able to kind of meet and succeed at, you know, challenges […] He was able to grow and stretch and that's all from the base that he got at Threshold. You know, and socially to be able to interact, you know, in a work environment and deal with customers, and there was a lot of his friendly demeanor and he knew how to utilize those strengths of his, but in an appropriate way, and he knew where the lines were, so I think everything good that's happened to him, you know, I ascribe to his experience at Threshold, and that's why I, you know, I, it's not just me, my wife, my [other children], we all view Threshold as life-changing for him.*

As he described his thoughts about the future, Mark said he expected that Cooper would always need assistance with problem solving and dealing with adult responsibilities. Mark, his wife, and their other children have always supported Cooper instinctively and intensively, helping him solve problems and succeed in living a self-directed life, and Mark said his whole family would continue to do that. Mark said he believed Cooper would need financial support his whole life, but he also hoped that one day he might attain a civil service or other job with a pension or other such benefits that may allow him to be close to self-sufficient.

Mark said he worried most about Cooper's social engagement and reported that even though he often spent time with his friends from school, his social life is not as rich as Mark would like to see it, in part because he was working weekends. Mark said he hoped that Cooper will have opportunities to expand his social network and also to date someone he's compatible with, a desire Mark said Cooper holds for himself as well.

Mark said he often recommends Threshold to families with children “like Cooper,” and would also advise any family looking at postsecondary education to keep looking until they find the “right fit.”

Nora. Grace was born with spina bifida and her doctors and parents were expecting her to have physical implications or disabilities as a result. Her walking was very delayed, in part, Nora later realized, to impaired vision that was corrected when she reached eighteen months. Her dexterity was also impaired, and she began occupational therapy services at age three. Around the same time, her speech delay was noticeable and began speech therapy as well. Some of her delay was likely caused by total deafness in one ear, which was not diagnosed until she was nearly five years old and Nora realized that she was unable to localize sound. Grace would call “mama” and Nora would respond, but Grace would not be able to find her mother in the house even after hearing her reply.

Grace’s learning challenges were not clear until she began grade school and was exposed to reading and math. She could mechanically read, but was not comprehending what she read. Nora realized that she was able to understand books better when she heard them read to her while she followed along to the text. Writing was a challenge as well, and visual processing issues caused Grace to begin writing in the center of a page; she had to be taught and reminded to find the left side of the page and begin there. It was during these early school years that Nora began noticing that Grace had to be told to face someone when talking to them and that she did not pick up on social cues or understand jokes.

For much of Grace's childhood Nora expected she would live with her forever. Grace could not drive, and in their rural community this significantly limited her opportunities for independence. Even if she could physically get around on her own, she was not self-directed enough to take care of herself and had to be told to do almost everything. Still, Grace wanted to be like her older siblings and go to college and live in a city on her own, so Nora explored options.

First, Grace took courses at a local technical college. Nora read textbooks to her and gave her oral quizzes to help her understand the material, and she received course accommodations such as oral exams. As Grace accumulated credits her academic skills grew but her independent living skills did not. Nora began looking for a program that would teach Grace how to live on her own, something the young woman desperately wanted.

A family doctor suggested that Grace visit the Threshold Program, and upon doing initial research Grace and her family were excited to learn more. When they visited the program, Grace grew concerned that she would not fit in, as the students she met there seemed to have more significant disabilities and greater academic struggles than she did. Still, the curriculum seemed to be exactly what Grace needed to grow in her independence, so she applied and was accepted.

Nora expected Threshold to teach Grace all of the life skills that she had always seemed reluctant to learn from her mother. Even though Grace accepted Nora's help on homework throughout her school years, she rejected instruction in cooking, money management, physical wellness, and nearly everything else Nora knew she needed to learn to live on her own happily, safely, and healthily. Nora believed that Grace just did not want to learn these things from her mother, but would be receptive to learning them from teachers. Nora recalls:

> *I thought she was going to be receiving from Lesley everything that I couldn't give her, or that she wouldn't take from me. I really did believe that they were going to give her an element of independence that I could not provide.*

When she came to campus as a new student, Grace connected quickly with others and felt that she did belong, after all. The coursework was very easy for her, but she valued the content and developed critical skills. Nora was satisfied with the types of courses Grace took and believed they helped her to become more independent. Her experiences at Threshold, combined with her coursework at technical schools and community colleges before and after Threshold, taught her how to live on her own, manage her time, get along with others, problem solve, and pursue goals. Nora said she was thrilled with how far Grace had come and, despite always believing in her capabilities, was amazed with her progress.

> *I just think, sometimes when I'm with Grace now I think, it's almost... it's not that I... I fully recognize that she still has disabilities but I think she's functioning at a very high level at this point for her level of disabilities. I think she's functioning at a very high level and I'm so happy for her and I'm so pleased.*

Nora’s two critiques of Grace’s experience at Threshold were that she needed more assistance finding a job after graduation and more flexibility with roommate assignments during the program. After a difficult first year roommate match, Grace had a single room for her second year, and Nora believed this contributed to Grace’s difficulty making friends with other girls during the program. Following graduation, however, Grace made many close friends and has a busier social life than ever before.

> *Socially, Grace is doing better now than she ever has, but it's still mostly with the Threshold students, I mean that's her community, she loves them. She's engaged with the Threshold alumni and that's who she goes to parties with, that's who she goes to dinner with, that's who she goes to the mall with and to movies with.*

Social connectedness had long been a challenge for Grace, particularly in her fully inclusive high school and technical school, where she gravitated toward other students with disabilities or other notable differences. While Nora believed that Threshold students capable of taking an undergraduate class should be able to do so and would benefit from it, she was not as confident that students would be socially included. Even if Grace had been in undergraduate classes Nora thought she still would have only become friends with other Threshold students. If Threshold could contribute to helping undergraduate students at the university be more open minded and learn to reach out to students with disabilities, perhaps through a class designed to be shared by undergraduates and Threshold students, Nora thought that students like Grace could be more included in the mainstream culture.

Nora would advise other parents of children with disabilities to find out what is important to their children, understand their children’s abilities and capacity for growth to the extent that it is possible to do so, and find a school that feels right for them. Nora noted how important the student's own motivation to grow and learn is, particularly considering the large investment of time and money to pursue higher education. She was always confident that Grace was motivated and would not quit, but she also expected to continue to support Grace and was not looking for program staff to be surrogate parents.

> *We were prepared to support Grace in any way... I think you have to be able to remember that you can't rely completely on the schools to be there emotionally for your kids. I mean, we were at the other end of the phone for Grace two to three times per day, every day of the week, 24/7 every day of the year. And we still are. I still talk to Grace twice per day. She needs that connection. So I would say be prepared to provide the support that's needed.*

Financially, Grace has been able to support herself with income from work and Social Security and Nora said she hoped Grace would continue to be so self-sufficient. Nora described worrying about Grace's health in the future and hoping that she would be able to understand her own medical conditions and respond appropriately to emergencies. Some of Grace's health conditions make it challenging for her to become close to someone else romantically, but Nora said she hoped Grace would find the partnership she knows her daughter craves.

Penny. Penny realized that her daughter, Lacy, was not hitting milestones on time when she was a toddler. She received speech and occupational therapy through Early Intervention, but it was unclear whether she had any intellectual or learning disabilities. In third grade, Penny's teachers gave her parents the choice of mainstreaming her with a paraprofessional or putting her in special education classes.

> *So my husband and I discussed it, and what we decided to do was to mainstream her as much as we could, the reason being that we knew that she would have to live in the same world as everybody else. When school ended there was gonna be no paraprofessional there for her. She needed to know how to interact with a variety of people and get the help she needed if she couldn't solve the problem, from a variety of people. We specifically did not have her keep the same paraprofessional every year at school, I know a lot of parents do that, the reason being that we felt she needed to understand that people have different styles and that she needed to get used to more than one style and that she needed to be able to ask for help and understand when to ask for help from the appropriate people.*

Lacy was educated in mainstream settings through high school. She attended a technical high school where Penny advocated for the creation of an early childcare internship for her. Lacy excelled in working with children and wanted to go to college to learn more. She passed most of her state's standardized testing requirements, but time and time again was unable to pass the math portion, which prevented her from enrolling in a community college. Penny sought alternate forms of higher education and received no help from Lacy's high school.

> *I wasn't getting very much help from the people who were on her team and were supposed to be helping me. It became very frustrating and I just looked at them and said "You know she's not the first kid to have ever been in this situation, I'm positive she's not, what do people do?" And they couldn't really answer me. So I decided if I wasn't going to get any help there- it wasn't beacuse they were bad people or anything like that, it's just because this is not a, at least presently, it's not a function of the public school system if you're a special needs kid. Getting kids to go to college is a function of the public school system, or getting them into a career, if they're of normal intelligence, but for special needs kids, at least in our area, the ball gets dropped.*

Penny found Threshold on the internet and read about it with a disability services professional she was friends with. Together they agreed that the program sounded right for Lacy. Upon visiting, Penny and Lacy met students in the program and both felt that she would fit in perfectly. Penny was impressed and reassured by the informational meeting led by the director of admissions and was confident that, if accepted, Lacy would be in the right place and would be well supported. She felt “inspired to trust” the program staff and always knew she could reach out to the director or the director of residence life at any time with concerns.

Penny expected that Lacy’s time at Threshold would prepare her for a career in early childcare, help her attain her high school diploma and access continuing education at the community college level, and give her the skills and confidence to live independently. At the time of the interview, Lacy was employed in childcare and living with a friend who also graduated from Threshold. Penny said she had come to see a level of confidence in her daughter that she did not know was possible. Penny credited the program with Lacy’s ability to problem solve, try new things, take care of herself, and make good choices.

> *Threshold has saved Lacy's life and mine. I mean as a parent, I could never have taught her all that stuff. I could never have made her the confident young woman that she is. It doesn't phase her one bit to talk to somebody she hadn't known before and say, “I have special needs and I have to do this, that, or the other thing.” She's very matter of fact about it, and I think learning to live with your disability makes a huge impact on your life when you're disabled. I mean that was the decision that my husband and I made back when Lacy was going into third grade. She needs to be able to function in the same world that everyone else does, and in order to do that she's got to be able to feel ok about asking people for help and she's gotta own the cards that she was dealt.*

Penny was satisfied with Lacy’s experience at Threshold overall, but had several critiques of the program:

> *Let me start by saying that Threshold changed my daughter's life. I love this program, it's phenomenal. But I get the feeling that Threshold has rested on its*

> *laurels for quite a number of years. And there were some things that needed to be updated and changed as the world changes.*

Penny felt that program administrators dismissed her concerns about Lacy not passing her state's standardized test and was frustrated that Lacy did not receive help in attaining her high school diploma. The program also had too much free time built in, Penny said, and could have spent more time helping students learn city safety and become involved in community organizations to help prepare them to find their own social and leisure opportunities after graduation. Finally, Penny felt the Transition year program, an optional postgraduate year of independent living and employment support, needed to be re-organized and re-vitalized. The process for families to find apartments for their Transition students was too hectic, and students needed more support and more meaningful coursework once the academic year began.

Penny said she thought that access to undergraduate courses would be a positive opportunity for many students, although had reservations about other types of inclusion on campus, in particular shared housing. She reported that Lacy's biggest complaint about attending Threshold was that she did not feel like she was part of the larger university.

Even though Penny had some suggestions for how Threshold could modernize and improve, she would highly recommend it to other families. She said that Threshold's faculty and staff were talented professionals who wanted the best for their students. She also appreciated the program's longevity, and was confident that in order to have lasted so long in the field, the program must function well for students.

Penny described Lacy as an independent adult, and wanted her to maintain and grow in her independence. Lacy has considered moving home, and while Penny would love to be closer to her, she said she worried that moving home would stifle the independence Lacy has worked so hard to gain. Penny said she hoped Lacy would stay in the Boston area, where she has friends, work, and the supports of the Threshold Alumni Center. She would also like to see Lacy find love and possibly marry and have children.

Ramona. Ramona recalled suspecting that Liam had developmental delays from the moment he was born. She compared him to her older child from the start and noticed that he was consistently behind in reaching milestones. He walked late, and when he began to talk he displayed echolalia and Ramona could tell he did not understand the meaning of the words he repeated. He began Early Intervention at eighteen months, received speech therapy, and attended a nursery school for children with special needs. For Ramona, every achievement her son made was a source of amazement and pride. She did not remember holding particular expectations about his future when he was a child, although she always knew that school, work, and adult independence would be challenging for him. In a way, she recalled, she held a “worst case scenario” outlook from his very early years and was surprised every time he made a gain. Walking, running, potty training, riding a tricycle; each achievement astonished her. Without knowing what he might be able to accomplish, she just wanted him to be happy and have every opportunity to grow.

Liam’s school district had many high achieving students, and Ramona felt his schools were not adept at developing individualized programming that made sense for him. In high school, his IEP team suggested he stay for an additional two years, but the program they offered was not satisfactory to Ramona. She hired an educational advocate to suggest a more appropriate placement for Liam, and together they appealed to the district for funding for a three-year residential transition program. The district agreed to pay, and Liam spent the next three years learning life skills and developing independence at a private boarding school for students with special needs a few hours away from home. After he finished the program, Ramona could see he needed more education and practice living on his own, and Liam wanted to experience college. Ramona sought the next step. It was important to her that Liam live closer to her and have the support of family nearby, and the Threshold Program was local. Without seriously considering any other programs, Ramona and Liam applied to Threshold.

For Ramona and Liam, attending a program that was part of a university was “totally important; critical, actually.”

> *It was critical that he could see other kids, how other kids functioned, and I'm not saying pretend to be a college student, right, but at least have that kind of a life. It gave him a tremendous amount of pride that he is in a college-like environment and doing what every other guy or girl does at this age. Yeah, it was critical.*

As important as the college setting was for Ramona, she said she would be skeptical about whether there would be a positive impact on students with intellectual disabilities taking college classes and participating in activities alongside undergraduates. She said undergraduates could serve as social role models to students with intellectual disabilities, but she doubted that true friendships would develop. Liam, in particular, is shy and quiet, and hates being recognized as having a disability, and was certain he would not have participated in classes or activities shared by students without disabilities. Still, she said, students in Threshold should have the option and opportunity to be integrated if they want to be.

In addition to having a college experience, Ramona expected that Liam would learn how to live in an apartment without family or staff, learn how to work and maintain a job, and learn how to independently manage his day-to-day life. She also wanted him to gain a better awareness of city safety and self-defense. He gained almost everything she hoped he would, except for better safety and self-defense skills. She said she continued to worry about his safety in the city, but knew that the urban environment was critical to his independence. He could travel on public transportation, had stores and activities nearby, and had job opportunities far beyond what would be possible outside of a city setting. He has lived with friends and had other friends to spend time with, and she said she loved knowing that he was part of a local community of alumni with an Alumni Center he could turn to for support. She continued to be a “pillar” holding him up, in many ways, and she expected to be for life, but his independence has far surpassed what she would have hoped for early in his life.

Ramona’s biggest concern for Liam’s future was how he would manage once she is gone. She said she was confident that he would be supported by his sister, but she worried about putting such responsibility for Liam’s well-being on her daughter. Even with a job, travel skills, and his own apartment, Liam has still relied on his mother for almost daily support in one form or another, particularly around dealing with the unexpected issues that arise in normal adult life. Broken refrigerators, lost cell phones, health problems, aging; Ramona has always been his main support for these and many other problems.

> *Who is going to be there for him? Never to the level that we are… that's my biggest, biggest concern. That, and whether he's gonna be financially able to make it. Who's gonna care about him as he ages? …Is he going to have other physical conditions that I don't even know about? Could he get diabetes, could he have a heart condition, you know, things that everybody deals with, right? How's he going to deal with this?*

Ramona did not have an answer for these questions, but said she planned as much as possible for the future, and had a special needs trust and other tools in place.

Ramona's advice to other parents of children with disabilities was to remember that it does get better. She remembered "grim" days, wondering whether Liam would be able to have a life that was happy and independent, and wondering whether she would be able to live a life that was not only about Liam. She suggested that parents do their research, advocate for their children, persevere through difficulties, and believe that the future is brighter than it may look at times.

Simon. Luke was born with a range of medical issues that were not identified in utero, and was immediately placed in neonatal intensive care. Genetic testing revealed a condition with a range of symptoms and implications, including a hearing impairment and (later identified) cognitive impairment. Luke received early intervention for speech and attended a preschool for children with hearing impairments and other disabilities.

After preschool, he went to his local public school until high school and then transferred to a different public school that his family and the district determined would be better able to implement his IEP. In those early years, Simon assumed Luke would live at home forever. The medical issues caused by his genetic disorder were diverse and permanent, but not life-threatening, and Simon believed he would be able to live a happy and productive life.

A teacher at Luke's high school encouraged Luke's family to look at postsecondary options and suggested they consider Threshold. From their first visit at Threshold, Simon knew it was the right place for Luke. He felt an immediate trust in the director, and could see from the other students he met that Luke would fit in academically and socially. Simon expected Threshold to help Luke learn to live on his own and advocate for himself, as well as prepare him to continue his education later if he chose to. Threshold's student body and alumni community included students from around the world, and Simon was thrilled that Luke would be exposed to other cultures and perspectives. The program's location was ideal in Simon's eyes as well; he knew Luke would like being in a place with restaurants and plenty to do. He expected the program to provide adequate supervision to keep students safe, while allowing them the freedom to explore all the city had to offer and practice skills for independence. The program met all of these expectations for Simon.

Simon said he saw a range of impacts that postsecondary education had on Luke. The program helped Luke find employment, and he has worked successfully in a job he enjoys since graduation. Simon expressed being pleased with the friendships Luke has made and was happy to know he was part of a community. Luke learned how to travel independently and take care of many adult responsibilities on his own. Simon said that Luke is significantly more independent than he would have been if he had not attended school away from home. Luke continues to receive some supports from an advisor his family hires, particularly around managing finances and taking care of his medical needs. Money management and budgeting are ongoing struggles. Luke is able to pay his own rent through his income from work, although is burdened by student loans.

Simon’s biggest critique of Threshold was the cost. While financial aid and some scholarships are available, Simon said more support should be available to low-income students. Considering the cost, Simon also wished that Threshold had granted more college credits or otherwise prepared Luke to go on to enroll in a community college or other continuing education program. Luke has always wanted to go to trade school or learn about architecture, and Simon would have liked Threshold to help Luke pursue those goals.

For the future, Simon said he hoped Luke would continue to grow and master some of the adult responsibilities that he currently receives support for. He would also like to see Luke advocate for himself more, particularly around communicating with his landlord about maintenance of the apartment he rents. Simon said he felt “blessed” that Luke had the opportunity to go away to school, and would recommend Threshold to other families whose children have disabilities.

Tia. Dylan was born four months early with a severe brain hemorrhage. He was in the neonatal intensive care unit until his due date and was on oxygen for three months of that time. Tia knew her son would likely have a range of disabilities, and immediately enrolled him in early intervention for speech, occupational, and physical therapies. He received these throughout his early childhood and attended inclusive pre-school and kindergarten programs in the public school system, where he had supports both in and out of the classroom. By third grade it was clear to Dylan's teachers that while he could decode words very well, his reading comprehension was limited. He repeated the grade with extra supports in reading, but otherwise was able to keep up with his peers academically. As he approached fifth grade, he began struggling to master age-appropriate academic content, and Tia and her husband sought a new educational program. Dylan spent fifth through eighth grade in a specialized school with a low student to teacher ratio and intensive speech, language, and social communication instruction.

By high school, Dylan was socially ready to return to the public school where his friends from his younger years attended, and after much conversation his parents agreed. Dylan transferred from his school of 85 students to a high school of 2,200 students. He began his first semester in mainstream math and science with support from an instructional aide, and took language arts and social studies in a special education classroom. After about six weeks, he was able to implement the organizational strategies set up by the aide and no longer needed one on one support. In addition to his academic success, Dylan thrived socially in the public school. He was embraced by the students with whom had gone to elementary school and became manager of the football team, a position he held all four years. His senior year he was voted prom king.

When Dylan was a child Tia and his doctors expected he would be very dependent on his parents throughout his life, and did not believe he would be able to attain much independence. However, he surpassed expectations time and again, particularly in how well he integrated in social settings like boy scouts, church groups, and his public high school, despite what appeared to be significant social communication deficits. Tia’s expectations for his achievement and independence in adulthood rose as he progressed through school and continued to show gains beyond what his doctors had predicted. By the time he neared the end of high school, Tia had very high expectations for his postsecondary education. Dylan continued to struggle with abstract thought and language processing, and Tia and his teachers agreed that he would find a traditional college environment too challenging. Instead, she sought out college programs that were highly supportive of students with disabilities, including programs designed to lead to degrees. She believed a college experience would help Dylan develop a fulfilling career path, although she still did not expect that he would be able to live independently after school. Dylan applied to Threshold and another program and was accepted at both. He enrolled in the other school, which helped students with learning disabilities transition into a bachelor’s degree program. Tia believed Dylan would be challenged but thrive in the program, which, academically, was positioned between a traditional college curriculum and the less academically oriented Threshold curriculum.

> *In six weeks we watched a very confident, popular young man become completely withdrawn, no self confidence, began to miss classes, which is something he never did in any of his school experiences. We never had a day of struggling with getting him to want to get up and go to school. He never even used an alarm clock throughout elementary or middle or high school. He would always wake up when it was time for him to get up and get dressed and get ready for school because for him that represented a really positive experience. And he stopped going to classes and he stopped going to lunch and he stopped going to dinner…He was clearly lost and floundering.*

Dylan's parents struggled to determine what was wrong and were not sure whether the problem was homesickness, an academic mismatch, or something else. Even before they realized that the program was not going to work for Dylan, the head of school contacted them with concerns about Dylan's ability to succeed. Tia called the director of the Threshold program, hoping there was some way Dylan could transfer there mid-semester. When he had decided to attend the other program, the Threshold director had warned Tia that it was not the right match for him. She laughed recalling their conversation when that turned out to be the case. He was unsurprised to hear from Tia and "moved mountains" to accept Dylan into the program and make sure he was warmly welcomed by students and staff. Staff checked in with him regularly in the dormitories, other students visited him and invited him to join them in activities, and he was able to master the academics. Tia recognized a difference in Dylan immediately; he was his typical social self and began to thrive again.

Although Tia had not originally been expecting Dylan's postsecondary program to teach him life skills, she felt that was a critical component of Threshold's curriculum once he transferred. She recalled thinking that he was already as independent as she expected him to be, and realizing early into his experience at Threshold that there were whole aspects of independence she had not even thought of and that he needed instruction on, such as money management. She appreciated the life skills he learned and also valued Dylan, as an only child, being pushed to learn how to live amicably with other people and advocate for himself with his peers, and others, as needed.

Tia reported that her only critique of Threshold was resolved in the years since Dylan completed the program. When he was a student, there was a part-time employment coordinator who helped students find jobs during the Transition Year. Tia remembered the support being lacking for Dylan, who filled out job applications on his own and was not guided in finding positions that matched his interests well. Now, a full time staff person, additional staff and interns, and a structured curriculum are in place to support students in their postgraduate job searches.

Dylan’s experience as the manager of the high school football team prepared him well for making social connections around sports, and he sought out friendships with athletes at the university and was a strong supporter of several of the school teams. Tia felt that a more intentional approach to social and academic inclusion would benefit a lot of students in the Threshold program, although she noted that some students may be overwhelmed by such efforts. She also noted that Dylan was denied access to career services at the university since he was not an undergraduate student, and she believed services should be open to all students.

Tia said she recommends Threshold to other families regularly and describes to them the wrap-around supports of the program and the high job placement rate after graduation. She said the program made a tremendously positive impact on Dylan’s life. He lives away from home and works full time in a job he enjoys, and Tia said she loves knowing that he is happy, productive, surrounded by friends, and able to seek supports from the Alumni Center if necessary. He eats healthily, exercises, and gets along well with his roommates who graduated from the program.

Tia expressed worry about what will happen when she and her husband are gone. She said she’s “increasingly confident that [Dylan will] be able to make a life for himself after [they’re] gone”, but with no siblings it is uncertain who his supports would be without his parents. She said she hoped he would have a romantic partner and have children, if he wants to, and believes he would be a successful parent with the right partner.

Dylan’s independence and happiness are far beyond what Tia ever imagined when he was a child. She repeatedly commented on how he has surpassed her expectations, from traveling to Europe with other alumni, to working a full time job he loves:

> *I would never have imagined my son being able to go to Europe on his own with a group of other young adults without us. That he could discover other places and other cultures without being tied at our hip… I think it's fabulous… If someone had told me when he was younger what he'd be doing today, I would never have believed it.*

Tori. Mallory hit developmental milestones on time through infancy and toddlerhood and showed no signs of any disabilities until she reached preschool. Her teachers noticed that, while she could communicate verbally, she did not always understand them when they asked her questions. She would respond by dancing and singing in a way that distracted children and adults and hid the fact that she did not understand what she was being asked. Tori "thought it was cute and terribly talented, of course", and began enrolling her in classes for dancing and singing. Mallory's speech was also unusual compared with other children her age, and upon meeting her adults would often ask whether her parents spoke another language or whether Mallory spent a lot of time with grandparents from another country. When Mallory's preschool teacher suggested that she receive some testing, it "dawned on" Tori that the linguistic and behavioral quirks she had always just found unique and interesting might be more than that. Mallory began receiving speech therapy through Early Intervention shortly after.

Mallory received special education supports throughout school but never had a clear definition of what her disability was. She fell somewhere between students who could be expected to be able to go to college, and students with severe disabilities who would need supported housing and employment in adulthood. Looking for the appropriate next step for her after high school was

> *…A big challenge. It was a big challenge because, in my experience, most high schools aren't prepared to help parents and students who are at the level that Mallory is at. Quite possibly they might be at a level of helping students who have more issues than Mallory, and then students who are definitely college bound. But Mallory kind of seemed to fall within that range of 'I'm not sure what we're gonna do with her.'*

Without assistance from Mallory's school, Tori hired a private educational consultant to help her identify college programs that would be a match for Mallory. Options were limited. Tori did not want Mallory to be in a program where she would be "the highest functioning", but thought that a community college would be too academically rigorous, and there was little available in the middle ground. The consultant was able to identify three programs that seemed to fit Mallory's academic profile. Threshold was the last of the three that Mallory and Tori visited. Through all the visits, Tori tried to keep her opinions to herself to let Mallory's feeling about each school drive the decision making process. As they walked around the Threshold campus with a student tour guide, Mallory told Tori she could really see herself fitting in. Those were "the magic words" for Tori, and she was relieved to have found a place where Mallory would be "comfortable."

For both Tori and Mallory, the location of Threshold's campus in a neighborhood near a small city was comforting; it felt active enough to be interesting, while still being small and safe. The student population was also comforting, and Tori's perception was that Mallory felt like she was with "her people"; that is, people with a similar life and educational experience to hers, similar academic challenges, and similar hopes for the future. Tori felt like Mallory could be herself with the other students at Threshold. Finally, the staff at the program were comforting to Tori. She believed they would understand Mallory and had the right experience to help her become a productive adult.

Tori was expecting that Mallory would learn personal safety from Threshold. She wanted Mallory to be able to live safely on her own or with roommates. As an attractive young woman who was able to pass socially as a typically developing young adult, Mallory was an "easy target", in Tori's eyes, to people who wanted to take advantage of her. Tori hoped she would learn how to discern between good intentions and bad when meeting new people, and protect herself from people who did not have her best interests at heart.

The impact of postsecondary education on Mallory was broad; she can handle social relationships more maturely than before, knows how to manage her money well, has a career path, and is independent of her parents in more ways than her other siblings. Mallory is able to pay for half of her rent and most of her other expenses from working full time in child care. She lives on her own, by choice, and takes care of daily adult responsibilities on her own. She has many friends, a lot of whom are other Threshold graduates, and can navigate the intricacies of friendships and dating relationships. Tori said she “really cannot imagine where Mallory would be had she not gone to the program.”

Tori said she believed Threshold provided exactly what Mallory needed at the time she was there. She doubts Mallory could have handled more. She said that other students may have benefited from more inclusion in social and club activities on campus, although she would worry about the disappointment of students with disabilities if they were not truly welcomed by the undergraduates. She would have had safety concerns about integrated dormitories, because Mallory may not have been savvy enough to take care of herself in a typical college dorm environment:

> *I have a college aged, a college junior right now…She's not a big drinker, it's not that kind of thing. But two rooms down and the room above them, they're huge partiers. They're up all night, huge drinking parties, k? Mallory, if she was down the hall would she have known enough to stay out of that? I don't know. Could she have gotten, if she was integrated in that dorm, could she have gotten into more trouble? Possibly. Possibly. Would she have known enough to stay out of it? I’m*

> *not quite sure. Could she have gotten taken advantage of more? Possibly. Quite possibly. So the dorming would concern me. Could she have had more opportunities joining clubs and things like that? Yes. Would that be a great thing for students at the college and at Threshold? Yes, I think that would be great for both of them, as long as it wasn't putting too much pressure on them, yeah, I think that's a nice idea, but that, too, can be disappointing. I remember Mallory wanted to go and try out for the dance team or something like that, but she probably wasn't gonna make the dance team, so that was probably going to be very disappointing too, so there are pluses and minuses with it.*

In thinking about her concerns for the future, Tori said she worried about Mallory's safety, even more than she worried about the safety of her other daughters. According to Tori, Mallory's judgement has improved as she's matured, in no small part thanks to her postsecondary education, but Tori said she still considers her to be quite vulnerable. Her biggest concern, though, is what will happen to Mallory when she's gone. Tori has planned ahead for Mallory's future and has money saved; she said she does not want Mallory to feel like a burden to her sisters, but expects they will be important supports in her life.

Tori would suggest that other families considering postsecondary education listen to what their child with a disability wants and needs out of the experience and be attuned to their comfort with the programs they visit. She said she would caution parents to set reasonable and appropriate expectations for postsecondary education and stay connected with their students to make sure they remain comfortable in the school of their choice.

Wendy. Having already raised a boy, Wendy suspected that Aiden was not developing in a typical way when he was very young. He did not hit milestones, including sitting and speaking, on time, and Wendy told his pediatrician repeatedly that she had concerns. He waived her off, chalking his late development up to being a boy and being a second child. Wendy sought a speech evaluation on her own when Aiden was almost four years old. He was referred for additional testing and received a diagnosis of autism. Wendy and her husband enrolled him in an integrated preschool with strong supports for children with disabilities, and hired someone to teach them applied behavioral analysis (ABA).

Aiden attended public school through seventh grade and was supported by a one-to-one aid. By seventh grade, Aiden was aware of his diagnosis and Wendy explained to him that he would need to learn how to manage in life without a one-to-one aid. Wendy and her husband advocated for an out of district placement for Aiden and he began attending a private school for students with special needs. He was able to do well there without a one-on-one aid, although the curriculum was largely focused on social skills, and Wendy realized he was sacrificing academics. Still, she was satisfied with the placement; she had been spending over four hours each evening helping Aiden with homework while he was in public school, and it was not sustainable.

In his high school years at the private school, Aiden was gaining work skills through internships. Wendy was not sure whether he would be able to work independently as an adult; his internships were very heavily supervised, and the tasks he needed to perform were basic. Wendy wanted him to have a postsecondary education that would help him develop his vocational skills further and learn how to live on his own. She researched all the programs close to New England that could support a student with autism and Aiden’s educational background, and they visited eight schools in total. Aiden decided to apply to three and was accepted at them all. He liked different aspects of all the programs. In the end, his priorities were that the program have public transportation nearby, be near a city, and accept students with many different types of disabilities. He chose to attend Threshold.

Wendy saw the dormitory living, vocational curriculum, and Transition Year as three of the most important components of the program for Aiden. Wendy hoped that Aiden’s postsecondary experience would help him develop his skills for independent living and work, learn how to take care of himself and his activities of daily living, learn how to be safe and comfortable in a city, and become accustomed to living with other people. She always planned for him to enroll in the postgraduate Transition Year and practice living in an apartment with the program’s support, and that component of Threshold was appealing to her from their first visit.

Aiden’s experience in the program would have been enhanced by greater oversight in the dormitories and better access to adaptive technologies. His deficits in executive functioning made it challenging for him to wake up for class and work on time, prioritize self-care activities, organize his space, etc. Wendy said these difficulties should have been expected by a program like Threshold, and staff should have helped Aiden put strategies in place to manage them. Instead, she ended up shopping for a vibrating alarm clock to get him out of bed on time in the morning, something that would benefit many students and could have been arranged by the program. She also would have liked to see more training in self-advocacy skills, particularly around how to speak up about roommate conflicts. Aiden was in a very uncomfortable roommate arrangement for nearly an entire academic year before Wendy herself realized what was going on and stepped in. More check-ins from resident staff, and more training in how to self-advocate, could have provided Aiden with relief much sooner.

When Aiden was accepted at Threshold, Wendy assumed he would experience some integration with undergraduates, either through coursework or clubs, or both. In reality, there was no push from the Threshold Program to include their students with undergraduates, and Aiden was not supported in accessing integrated experiences. Aiden was interested in taking music therapy classes, which are only for students in the major, and she feels he could have benefited greatly from those classes if tutored by a student in either the music therapy or special education program.

Aiden became a happier and more independent person thanks to his postsecondary experience, Wendy said. He developed strong friendships with other active alumni and travels all around Boston independently. Wendy said she was confident in his ability to live on his own and work in a job he enjoys; she does not expect that he will be financially self-sustaining, although still holds it as a goal for his future. She said that Aiden believes in his own abilities and has a self-confidence that he did not have in high school, and she credited that to his postsecondary experience.

Wendy would advise other families exploring postsecondary options to take the time to find a program that will be the right fit for their student and what they need. She said she saw Threshold as a program focused mostly on life skills. That is what Aiden needed at the time, although the option for more academics would have been nice, she said. For someone who wanted a strong academic curriculum, Wendy would not suggest Threshold.

Like so many parents, Wendy said her biggest concern for her son's future was how he would manage after his parents pass away. She has a special needs trust set up for him and a third party to help manage it when she's gone. He has an advisor who helps him in his apartment a few times each month with the more difficult responsibilities of adulthood, like paying bills, applying for jobs, and organizing his space. He continues to call his parents often, but Wendy said that is just fine. She said she worries about who he will live with in the future if his current roommate does not turn out to be a good match, and hopes he will find a girlfriend. She expressed hope that he will be happy, and follow his interests and dreams.

Discussion

This study sought an answer to the research question: How do parents of alumni of a postsecondary program for young adults with disabilities describe the expectations they have had for their children's postsecondary education and later adulthood, and how have their actual experiences compared to their expectations?

Sub-questions included:

1) In what ways did parents’ expectations for their sons’ and daughters’ adult lives develop and evolve as they grew up? What role did a college program play in the evolution of their expectations?
2) What do parents view as the critical impacts of a college program on their sons and daughters?
3) How did parents’ actual experiences of their children’s college program compare with their hopes and expectations, and how do they imagine a more inclusive experience may have compared?

Parents in this study all described wanting their sons and daughters to have independent and fulfilling lives. They held these goals from the early ages of their children and continued to hold them at the time of the interview, but the meaning of what “independence” and “fulfillment” meant evolved and became clearer over time for each of them. When their children were young, those goals were fairly vague and nebulous, as parents held many uncertainties about their children’s capabilities and what their disabilities might mean for them as they aged. In fact, they had very few concrete expectations early on and many of them expressed not knowing what to expect for the future. Rather than expectations, most of the parents interviewed held hopes. They hoped their sons and daughters would be happy, feel fulfilled, have meaningful work and past-times, and have social relationships with people who valued and understood them.

Parents’ expectations for the future began to develop in their sons’ and daughters’ adolescence and became concrete and definable as they progressed through postsecondary education. During the high school years, parents began to see that their children would need, and could handle, some type of continuing education and skill development after high school, but that this was unlikely to take the form of a college degree program. For many, it was still unclear whether their children would live independently as adults and work for pay in jobs they enjoyed, but these began to seem like attainable goals. Parents expected that a postsecondary program well-suited to their child's strengths and needs would be able to support them in attaining these goals, as well as in making friends, building self-confidence and self-esteem, and understanding and managing some adult responsibilities (e.g., grocery shopping, cooking, paying bills, cleaning, travelling). Parents also wanted their children to have a true college experience, but with the additional supports they believed were required to help them develop the skills they would need to live on their own someday and maintain work and a healthy social life. These supports included intensive and individualized attention from faculty and staff, life skills and vocational coursework, and assistance integrating socially into the Threshold and larger Lesley University communities.

While many parents expressed critiques of specific components of the program and of the lack of integration between Threshold and undergraduate students, all parents were glad their children had attended the program and expressed that their sons and daughters had greater independence, more engaging social lives, and better employment outcomes than they would have had if they had not attended the program.

> *I was blown away by Lesley and how perfect it was for Amelia, and my wife would tell you the same thing. –Curt*

> *I've been amazed, I mean really […] People that knew Lilly when she was little are just flabbergasted that she's doing what she's doing. Nobody in their wildest dreams would have expected her to be doing any of this. You never know. Give it a try and a little bit of a push at times and kind of hold your breath. –Elaine*
>
> *I am really grateful to the program at Lesley for the opportunity for her to mature in a safe and conscious place where people are specifically trying to help kids gain those life skills. –Heather*

Important positive outcomes of the postsecondary education for these parents' graduates included: more friendships, healthier relationships, broader variety of past-times, better decision-making, better problem-solving, higher self-esteem, better work outcomes (e.g., more meaningful and enjoyable jobs, better hours, and higher wages), and stronger independent living skills (e.g., the ability to pay bills, grocery shop, cook, clean, travel, and manage time). Every parent mentioned most or all of these positive impacts of the postsecondary experience. Although parents had expected their children's social, vocational, and independent living skills to improve as a result of their postsecondary experience, most parents also expressed surprise at how great the gains their children made actually were.

At the time of the study, all of the Threshold graduates represented were either living independently (not with family or staff), or living with a parent for financial reasons after having successfully lived independently since graduation (one alum out of seventeen). All of the parents interviewed have now seen their adult children live independently (without a family member or staff person), and did not express overall independence as a concern for their later adult lives, although one parent did acknowledge the possibility that her son with disabilities may need to live with her other son without disabilities some day. One alumnus was living with the interviewed parent at the time of the interview, but only for financial reasons following several years of successfully living on his own.

Parents expressed their beliefs that their children’s postsecondary experiences had greatly improved their abilities to live independently, work, and have social lives, and had higher and clearer expectations for their futures following graduation than they expressed having upon admission. They were able to imagine more complex and once-distant possibilities for the future after seeing their children’s success after graduation; some described romantic partnership, marriage, and children as possibilities, while others hoped their children would have full time, benefited jobs with pensions, allowing for full financial independence. These achievements are beyond what any parents dared to hope for, much less expect, when their children were young or even when they were beginning their postsecondary program.

Only one parent was expecting her son to participate in academic coursework with undergraduates when he enrolled at Threshold, but several others were hoping for a more integrated social experience from the beginning. Regardless of their initial hopes and expectations for integration, all parents said that greater social and academic integration should be available for students who want it and that they thought it would be positive for many Threshold and undergraduate students. Many would have liked to see it specifically for their son or daughter. None of the parents who expressed a desire for greater integration with undergraduates for their children identified residential inclusion (i.e., sharing dorms with matriculated undergraduates) as a type of integration they would have wanted their children to experience. Several parents said that they did not believe their own son or daughter would have participated in or benefitted from more integration, but still thought it should be an option, supported and facilitated by Threshold faculty and staff, for students who want it. Parents believed that integration would provide Threshold students with role models for appropriate social behavior and teach them how to interact with peers without disabilities, something many of them had limited experience with due to special education placements. Parents said that such practice would be useful to students entering the workforce and might improve their interview skills and interactions with coworkers. Two parents whose children participated in sports believed that experience had led to meaningful, reciprocal friendships with undergraduates. Two other parents said they did not think their children would have connected with undergraduates even if the program facilitated interaction, and a third worried that such interaction could have led her daughter into poor decisions, particularly around using alcohol. These parents did believe integration could have been positive for other Threshold students.

Overall, parents expressed common goals for their children: independence and fulfillment in life. The choices they made regarding their children's educations were aimed at helping their sons and daughters become their best possible selves, and they expected postsecondary education to help them progress towards their shared goals. Parents sought authentic college experiences that were also highly supportive and comprehensive, with specialized programming in life, social, and vocational skills. Parents reported that their children's postsecondary experience surpassed their expectations. They believed that their children had made positive gains in independence, self-esteem, positive decision making, social proficiency, vocational competence, and problem-solving. Every parent believed that greater inclusion at the university should have been available to Threshold students, regardless of whether they thought their own son or daughter would have benefited.

Study Limitations

Limitations of the study include a small and homogenous sample, recruitment bias, and possible inaccuracies in subjects' recall. Finally, the familiarity of the researcher with the subjects, their children, and the postsecondary program being discussed may have introduced additional bias in how data was collected and analyzed.

Small sample size. Seventeen interview subjects is not enough to allow for generalizability of results to the larger population of parents whose children attended Threshold. It was, however, a large enough pool of subjects to provide rich detail on a variety of parenting experiences and to uncover commonalities across the experiences of their children.

Homogeneity of the sample. The subjects of the study were mostly white women whose graduates were living independently in the Boston area. Ideally, an equal number of mothers and fathers would have been interviewed, and there would have been greater racial and ethnic diversity among the subjects. Furthermore, since all of the subjects were parents of graduates from the Threshold Program, they likely shared some common experiences or characteristics that influenced their selection of Threshold and their perceptions of the program’s impact on their sons and daughters. Subjects were also likely to have above average financial resources; while socioeconomic data was not collected for this study, financial aid to Threshold is limited, which has caused the student population to be disproportionately from upper middle class backgrounds.

Recruitment bias. The recruitment method used in this study (i.e., direct outreach by the researcher, a staff member at Threshold) is suspected to have disproportionately drawn subjects who had positive experiences with the program. A neutral researcher may have received responses from parents with poor experiences, who may have been more willing to share critiques with someone who did not know them and their son or daughter. This risk was believed to be outweighed by the benefits of the researcher’s familiarity with the program and the subjects, and the likelihood that recruitment by a familiar individual would result in more offers to participate.

Inaccuracies in recall. The interview protocol required subjects to reflect on events that happened in the past; in some cases, parents were recalling memories from thirty years ago for parts of the interview. It is difficult to know how issues with recall could have impacted the data collected; subjects may have remembered past events more or less positively than they experienced them at the time. It is also possible that they did not remember what they expected for their child’s future early on, and answered interview questions with their best guesses at what they had been thinking during the time period in question.

Researcher bias. The researcher has been a staff member at the Threshold Program for nine years and personally knows each of the parents interviewed and their children who graduated from the program. Although the researcher did not include any details about parents or children in this study that were known to her but not discussed in interviews, her knowledge and perceptions of each family could have impacted how she interpreted the data.

Chapter V: Implications and Conclusion

Summary of Results and Discussion

The parents interviewed shared common goals for their children: independence and fulfillment in life. Decisions they made throughout their children's schooling were directed at helping their sons and daughters become their best possible selves. Some parents pushed for mainstream experiences in public schools while others fought for specialized out-placements, but in either case they shared overall goals of helping their child achieve independence and fulfillment. They all faced uncertainty about what might be possible for their children in the future, but wanted to help them achieve as much as they could and test the perceived limits of their capabilities.

Since parents did not know what to expect from the future, and tended to intentionally take life one day at a time, they were not preparing for college as many families of children without disabilities do from an early age. By adolescence, all the parents interviewed knew that a traditional college degree program would not be a good match to their children's needs. They knew their sons and daughters would need further instruction in life, vocational, and social skills in order to achieve the dream of independence and fulfillment. Still, they wanted their children to have the type of college experience that their siblings and friends were able to have. This meant living away from home on a college campus, using campus facilities, having access to social and cultural events, and, for many, interacting with undergraduates. Parents wanted comprehensive and intensive supports from faculty and staff to ensure that specialized skill development could occur within the context of an authentic college experience.

Parents reported that their children’s postsecondary experiences surpassed their expectations, and all of them said they would recommend postsecondary education in general, and Threshold in particular, to other families. They saw growth in independent living, vocational skills, and social skills, as well as advances in self-esteem, positive decision making, and problem-solving. Many of them said that their sons and daughters matured and grew more significantly than they had imagined they would in just a few years. Some parents noted that their children had mastered tasks and concepts that they had not thought possible, such as money management.

All of the graduates whose parents were interviewed were capable of living independently and working for pay following their postsecondary experience, and all of them had more robust social lives, as reported by their parents, than they had in high school. Parents credited their children’s growth to the comprehensive nature of the Threshold curriculum, the college environment, the school’s location, the expertise and attention of the faculty and staff, the experience of living away from home, and their children’s determination and hard work.

With one exception, parents did not expect their children to have academic integration with undergraduates during their enrollment at Threshold, but several parents did expect that program staff would help facilitate social interactions and participation in undergraduate clubs and activities. A few parents reflected on positive experiences of integration their children had at the university. In hindsight, every parent believed that social and academic integration should be an option for Threshold students, whether or not they thought it would have been beneficial to their child. Some parents expressed concerns about residential integration and stated that they would not have wanted their son or daughter to be in an undergraduate dormitory.

Implications for Research

The results of this study provide some new perspective on previously conducted research. Previous studies (Carter et al., 2012; Doren et al., 2012; Papay & Bambara, 2013) have explored how parents' expectations for post-school outcomes correlate with students' expectations for themselves, and with actual outcomes. Parents in this study did not have clear or common points in their children's development where they began to expect that they would attend a PSE program. They described exploring different types of options for after high school, including work, community college, four-year college, and specialized programs, and not really having set expectations for what the future would hold until they and their children had chosen a program. This suggests that researchers should take caution when correlating parents' expectations to students' expectations and to actual outcomes, as parents expectations may be evolving over time, and may need to be measured at several points during their child's adolescence in order to form an accurate picture of what their expectations correlate with, and how.

Future research should explore what students and graduates of postsecondary programs expect from their education, and how their actual experiences compare. Considering the movement of the field toward highly inclusive college experiences (Hart & Grigal, 2013), it would be especially pertinent to know what types of inclusion students hope for when considering postsecondary education, and how they reflect on their inclusion after completing their programs. It would also be helpful to interview alumni and parents from other programs to determine whether their experiences and reflections are as positive as those described in this study; this would be particularly interesting in programs very different from Threshold (e.g., very specialized and not comprehensive, or very highly integrated with undergraduate schools).

Quantitative studies of graduates' and parents' experiences and outcomes from a variety of programs, using the same measurement tool, would be a key next step in the research, as it would provide direct comparison of outcomes from different program models and locations. Until this research is conducted, it will remain difficult to determine what the impacts of varying program characteristics are on graduates' outcomes, and professionals in the field will continue to base their advocacy and program development on ideologies and not on research.

Implications for Practitioners

Parents in this study expressed appreciation for the comprehensiveness of the Threshold program; they saw value in every part of the curriculum and every component of the student experience. Parents stated that their children needed everything the program offered, in particular life skills education, real-life internship placements, and the experience of living away from home.

While Griffin et al. (2010) found that parents who were considering PSE programs were least interested in residential options and the feeling of a typical college experience (of the characteristics they surveyed on), these features were critical to parents in the current study. Parents reported that their children wanted to have the same college experience their friends and siblings were having, and they considered similarity to a typical college to be an important feature of a PSE when searching for the right program. Not every parent in the current study identified on-campus living as something they were looking for in a program, but in hindsight every subject recognized the role of the dormitory experience in helping develop their son or daughter's independence. It would be interesting to survey parents before and after their children attend a postsecondary school to find out whether their perceptions of which program components are most important change over time, as the comparison between this study and Griffin et al. (2010) suggests.

Parents also highly valued the social gains their children made during the program and were pleased to see them develop social networks and close friends; these friendships were exclusively with other Threshold students in almost every case. It is not clear from this study whether social gains would be made more or less successfully in highly inclusive PSE programs, although many parents commented on the student body at Threshold being an appropriate social fit to their son or daughter. Some parents did not think their son or daughter would have made reciprocal friendships with undergraduates even if interaction was facilitated by staff, while others said they would have liked to have seen a peer mentoring structure in place to pair undergraduates with Threshold students, and thought undergraduates would be helpful social role models. It is reasonable to assume that Threshold's relatively large cohorts contributed positively to social growth, as students were more likely to find other students they got along with and had interests in common with, than in a smaller program. Threshold has twenty to twenty-five students per graduating class, while many programs have five or fewer. College and universities with the capacity to serve a cohort of twenty to twenty-five students should weigh the social benefits against the staffing costs and the individual attention they are able to provide to each student. Programs should also find a balance between creating opportunities for students to socialize with other students in their program, and supporting their interaction with undergraduates, rather than limiting them to one social group.

In reflecting on their children's experiences, parents described the perfect program for their son or daughter as one that felt like a true college experience, but with individualized and comprehensive staff supports and a curriculum focused on employment and independent living. This type of program requires significant staff support, buy-in from university administrators, capital investments for housing, and community connections for internships. Programs with the resources to offer a comprehensive program should do so, while those that cannot should focus on program components most valued by their prospective students and families, and clearly define what they do and do not offer in their marketing and admissions materials.

Conclusion

Parents of Threshold Program graduates interviewed in this study believed that their children's comprehensive, residential, college-based postsecondary experience had contributed significantly to their social, personal, independent living, and vocational development. When their children were young, parents did not know what to expect from the future, although many thought their children might live with them as adults. They hoped they would learn to live independently and to find fulfillment in life, possibly through meaningful employment and friendships.

Parents expected that a postsecondary experience would help their children grow in their independence, improve their prospects for employment, and make friends; all parents stated that their children did achieve these outcomes, and were surprised and impressed by the significance of their gains. Every parent expressed pride in their child's growth and accomplishments, consistent with the positive experiences of parents of children with special needs described in Green (2007).

Interview subject said they would recommend postsecondary education in general, and Threshold in particular, to other parents of children with special needs. Parents continued to worry about how their children would manage adult responsibilities following their own deaths, and hoped they would be able to maintain their independence, be financial stable, and find romantic partnership.

This study revealed that parents of Threshold Program graduates valued their children's experiences at Threshold and believed that the program had positively impacted their development in a number of key ways. While Threshold does provide some opportunities for integration with undergraduates, including access to campus activities, and is physically integrated into University spaces, the program does not formally support students in accessing mainstream courses or match them with undergraduate peers to support social integration. Even though not every parent believed their son or daughter would have benefited from such efforts, everyone interviewed thought the program should offer more opportunities for inclusion. In other words, regardless of how much they valued their child's experience as it was, and even if they did not think more inclusion would have benefited their child, every parent still believed the program should promote more inclusion with undergraduates.

The number of college programs for students with ID/DD has more than doubled in the last ten years (Hart et al., 2006; Think College, 2016) as the result of professional, student, and parent (Leuchovius & Roy, 2016) advocacy and federal legislation (HEOA, 2008). As the field is growing it is also trending toward maximum inclusion in typical undergraduate experiences (Hart & Grigal, 2013). This trend is based in the ideology that students with ID/DD want, deserve, and will benefit from inclusion with their peers without ID/DD in social activities, coursework, and other aspects of college life. The idea of inclusion in higher education is appealing to students with disabilities, their parents, and professional advocates, but it needs to be based in research in order to appeal more broadly to administrators and decision-makers in traditional undergraduate programs, and to federal legislators in the position to re-authorize the HEOA. It is still unclear whether the outcomes of graduates of highly inclusive programs will match, exceed, or fall behind the outcomes of graduates of specialized programs, and research that has attempted to compare inclusive and specialized programs has yielded mixed results and little clarity (Moore & Schelling, 2015).

Quantitative research must be done to compare outcomes of many graduates from many different programs in order for practitioners to determine what the impacts of various program components are. Only then can standards currently in use by leaders in the field (Grigal et al., 2011b) be enhanced to reflect best practices and become truly evidence-based. In the meantime, qualitative research like the current study can help us explore the value that individual programs bring to students and families, and how those programs meet their expectations, or do not.

The support parents in this study expressed for inclusion, regardless of whether they believed their sons and daughters would have benefited from it, reinforces the ideology that students with disabilities should be included in typical undergraduate experiences. Still, every parent interviewed also stated the importance of the comprehensive, individualized, and intensive supports their students received beyond what a typical undergraduate experience would include, and highly valued the specialized program components focused on life, vocational, and social skills. Parents believed their sons and daughters had made dramatic gains toward the ultimate goals of independence and life fulfillment as a result of their postsecondary experience, and were able to imagine futures for them that were clearer and brighter than what they had ever imagined before.

Appendix A- Invitation to Participate

Date

Dear Threshold Alumni Parent,

I am writing to invite you to participate in a research project being conducted at the Threshold Alumni Center, in conjunction with Boston University.

The study will help us learn more about what parents expect for the adult lives of their sons and daughters who graduated from a college-based postsecondary education program.

We are seeking parents of alumni who graduated from Threshold between 2008 and 2014 (inclusive of both years). Participation would entail one phone, Skype, or in-person interview (at Threshold in Cambridge, MA), with up to two possible follow-up phone calls. The total time for participation is expected to be about 2 hours, and would be scheduled at your convenience.

We will be interviewing a maximum of 15 parents; to ensure a diverse group of participants, we will not be able to interview everyone who volunteers. If you are interested, please respond by ______(date)_____using the email address at the bottom of this letter. In the email, include:

- Your mailing address
- Your phone number
- Your email address
- The name of your son or daughter who attended Threshold
- The year of graduation of your son or daughter
- Whether you would be interested in a Skype, phone, or in-person interview.

Very sincerely,

Cara Gorham Streit
Alumni Center Director
617-349-8631
Cgorham2@lesley.edu

Appendix B- Follow-up Email and Instructions

[Date]

Dear _____,

Thank you so much for your interest in this research study. You have been selected to participate, should you decide to do so.

Participating in the study means that you will be interviewed for approximately 1–2 hours in person or by phone or Skype, whichever your preference. This interview will be scheduled at your convenience. There may also be up to two follow-up phone calls in the weeks or months following the interview if any information needs to be clarified. Your interview will be audio recorded, but any follow-up call will not be.

Your name and other identifying information, and the name and identifying information of your son or daughter who graduated from Threshold, will never appear in any circulated documents or publications. The audio recording of your interview will be transcribed, without names, and deleted as soon as data analysis is complete.

Please read the [enclosed/attached] Informed Consent form. If you have questions about the form, please call me at 617-349-8631 or [send me an email at cgorham2@lesley.edu/reply to this email]. I am conducting this research study in partial fulfillment of a doctoral degree in education from Boston University, so you may also direct questions to my dissertation advisor, Donna Lehr, at 617-353-3240 or dlehr@bu.edu.

I will follow up with you within 2 weeks to find out if you have decided to participate and, if so, to schedule an interview. At the time of your interview I will review the consent form with you, answer your questions, and ask whether you consent to participate.

Thank you again for your interest in helping us with this research study!

Sincerely,

Cara Gorham Streit
Alumni Center Director
cgorham2@lesley.edu
617-349-8631

Appendix C- Alternate Follow-up Email

(To be mailed or emailed, depending on how the potential subject contacted the researcher)

Date

Dear _____,

Thank you so much for your interest in Threshold's research study. Unfortunately, due to the number of responses we received and the need for participants to reflect a wide range of backgrounds and years of graduation, we will not be able to interview you for this study. We genuinely appreciate your willingness to help us!

Sincerely,

Cara Gorham Streit
Alumni Center Director
cgorham2@lesley.edu
617-349-8631

Appendix D- Informed Consent Form

Protocol Title: Exploring Parent Experiences of Postsecondary Education for their Children with Special Needs
Principal Investigator: Cara Gorham Streit
Description of Subject Population: Parents of graduates of a postsecondary program for young adults with special needs
Version Date: 12/17/2015

Introduction

Please read this form carefully. The purpose of this form is to provide you with important information about taking part in a research study. If any of the statements or words in this form are unclear, please let us know. We would be happy to answer any questions.

If you have any questions about the research or any portion of this form, please ask us. Taking part in this research study is up to you. We will give you a copy of the form.

The person in charge of this study is Cara Gorham Streit. She is a doctoral student at Boston University, and her Faculty Advisor is Dr. Donna Lehr. Cara can be reached at 617-275-6482 and cgorham2@lesley.edu. We will refer to her as the “researcher” throughout this form. Donna Lehr can be reached at 617-353-3240 and dlehr@bu.edu

Why is this study being done?

The purpose of this study is to learn about what parents of Threshold graduates expect from a postsecondary education program for their young adult children with special needs, how their experience compared with their expectations, and what impact a postsecondary education had on their sons and daughters.

We are asking you to take part in this study because you are the parent of a Threshold alum who graduated between 2008 and 2014 (inclusive), is not currently enrolled in a Threshold postgraduate program, and is not planning to enroll in the next year.

About 15 people will take part in this research study.

What will happen if I take part in this research study?

You will be asked to participate in one, two hour interview at the Lesley University campus, over Skype, or by phone. We will ask you questions about your expectations for your son or daughter's adult life and their postsecondary educational experience, and for your reflections on how the experience impacted them. We may make up to two follow-up calls to you within 6 months of the interview if we need to clarify any information.

Audio recording

We would like to audio record you during this study. If you are audio recorded it will be possible to identify you in the audio. We will store the audio file on a password protected computer and only researchers in this study will have access to it. We will name the file with a code instead of your name. The key to the code connects your name to your audio file. The researcher will keep the key to the code in a password-protected computer. The audio files will be kept for 7 years according to Boston University's Record Retention policy.

Do you agree to let us audio record you during this study? ___________

How will you keep my study records confidential?

We will keep the records of this study confidential by storing files pertaining to the study on a password protected computer and by separating your name and your son/daughter's name from any information collected from/about you and him/her. We will make every effort to keep your records confidential. However, there are times when federal or state law requires the disclosure of your records. Furthermore, while your name and your son/daughter's name will never be used in the final research document, and we will change key identifying information (gender, year of graduation, etc), we may use quotes or anecdotes that you share during your interview, and Threshold or Lesley University employees and other community members familiar with you or your son/daughter may be able to identify you when reading the final documents.

The study data will be stored on a password protected computer or locked file drawer.

The results of this research study may be published or used for teaching. We will not put identifiable information on data that are used for these purposes.

Study participation and early withdrawal

Taking part in this study is your choice. You are free not to take part or to withdraw at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential.

What are the risks of taking part in this research study?

The main risk of allowing us to use and store your information for research is a potential loss of privacy. We will protect your privacy by labeling your information with a code and keeping the key to the code in a password-protected computer or locked file drawer.

Although none of the interview questions are expected to cause emotional distress, it is possible that they may. You do not need to answer any question that you are not comfortable answering.

Are there any benefits from being in this research study?

There are no direct benefits to you for taking part in this study.

What alternatives are available?

You may choose not to take part in this research study.

Will I get paid for taking part in this research study?

We will not pay you for taking part in this study.

What will it cost me to take part in this research study?

If you participate in an in-person interview, you may need to pay for public transportation or parking close to Lesley University's campus.

If I have any questions or concerns about this research study, who can I talk to?

You can call us with any concerns or questions. Our telephone numbers are listed below:

Cara Gorham Streit: 617-275-6482

Donna Lehr: 617-353-3240

If you have questions about your rights as a research subject or want to speak with someone independent of the research team, you may contact the Boston University IRB at 617-358-6115 or Lesley University IRB members Robyn Cruz (rcruz@lesley.edu) or Terry Keeney (tkeeney@lesley.edu).

Statement of consent

To be signed by the researcher, in lieu of subject's signature.

I have explained the research to the subject and answered all his/her questions. The subject has given his/her verbal consent to participate in the study as described above. A signed copy of this consent form will be mailed or emailed to the subject for their records.

____

Name of Subject

____

Name of Researcher

____

Signature of Researcher Date

Appendix E-Categorization of Codes

Early years

- Early signs of disability
- Receiving a diagnosis

K–12 Experiences

- K–12 Educational experiences
- Inclusion in K–12
- Transition planning
- Experiences with vocational training before PSE

Uncertainty about the future pre PSE

- Early expectations for the future- College
- Early expectations for the future- Social
- Early expectations for the future- Level of independence
- Early expectations for the future- Employment
- Early uncertainty about the future
- Diagnosis and early education

Finding the right fit for PSE

- Exploring postsecondary options- General
- Important features of a postsecondary program- College setting
- Important features of a postsecondary program- Staff
- Important features of a postsecondary program- The Fit
- Important features of a postsecondary program- Social
- Important features of a postsecondary program- Independence
- Exploring Postsecondary options- Parent reactions to programs
- Exploring Postsecondary options- Student reactions to programs
- Important features of a postsecondary program- Extra curricular
- Important features of a postsecondary program- Vocational
- Expectations for the PSE experience
- Important features of a postsecondary program- Location
- Important features of a postsecondary program- Life Skills
- Important features of a postsecondary program- Academics
- Important features of a postsecondary program- maturity of the program
- Experiences with vocational training during PSE
- Experiences at other PSE programs

Experiences and impacts of postsecondary education

- Impact of postsecondary education- Social relationships
- Impact of postsecondary education- Independence
- Impact of postsecondary education- Personal growth
- Impact of postsecondary education- Employment

- Impact of postsecondary education- Life Skills
- Descriptions of employment post PSE
- Referring the program
- Surpassing expectations
- Positive descriptions of PSE Experience
- Suggestions for program changes or additions
- Opinions or experiences of inclusion in typical University life
- Transition out of PSE

Uncertainty about the future post PSE

- Current concerns for the future- Romance
- Current concerns for the future- What happens when we're gone
- Continuing supports needed by graduate
- Current expectations or hopes for the future
- Current concerns for the future- Finances
- Current concerns for the future- Employment
- Current concerns for the future- Health
- Current concerns for the future- Misc.
- Alumni Community and Supports
- Societal challenges

Parenting

- Advice for other parents
- Approach to or experience of parenting
- Comparisons to siblings
- Approach to or experience of parenting- Advocacy

Characteristics of the child/adult child

- Challenges related to disability
- Strengths of the student
- Disability identity
- Emotional challenges
- Self-determination
- Social Challenges

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Curriculum Vitae

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