

11-11-2025

## The Stress Parents Face When Their Autistic Child Turns 21

Everetta Joyce Irene Davis  
*Walden University*

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>



Part of the [Psychology Commons](#)

---

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact [ScholarWorks@waldenu.edu](mailto:ScholarWorks@waldenu.edu).

# Walden University

College of Allied Health

This is to certify that the doctoral dissertation by

Everetta J I Davis

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

Review Committee

Dr. Natalie Marr, Committee Chairperson, Psychology Faculty  
Dr. Mark Arcuri, Committee Member, Psychology Faculty

Chief Academic Officer and Provost  
Sue Subocz, Ph.D.

Walden University  
2025

Abstract

The Stress Parents Face When Their Autistic Child Turns 21

by

Everetta J I Davis

MS, Webster University, 2010

MA, University of Phoenix, 2005

BA, Mount Marty, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

November 9, 2025

## Abstract

This exploratory study examined the lived experiences of parents whose autistic children turned 21 and aged out school and services provided by the federally funded Free Appropriate Public Education (FAPE) program. Although researchers have conducted numerous studies on autism, limited research has focused specifically on the stress parents face when their autistic child turns 21 and loses access to FAPE. The purpose of this qualitative narrative inquiry was to gain a deeper understanding of the emotional, logistical, and systemic challenges these parents encountered during the transition out of high school. Family Systems Theory provided the conceptual framework for exploring these experiences. Five participants were recruited from autism-related social media groups. Data was collected through semi structured interviews via recorded Zoom sessions and analyzed by utilizing inductive and deductive coding approaches. The resulting themes revealed ongoing stress, uncertainty about the future, and significant service gaps after the loss of FAPE. Highlighting these real-life experiences helped fill a gap in research and brings needed attention to this underserved and often overlooked group of individuals. Findings from this study may promote positive social change by informing policymakers, service providers, and community organizations about ways that could better support autistic adults and their families during this critical transition.

The Stress Parents Face When Their Autistic Child Turns 21

by

Everetta J I Davis

MS, Webster University, 2010

MA, University of Phoenix, 2005

BA, Mount Marty, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

November 9, 2025

## Dedication

To my son Scotty who has been the inspiration for this study and my inspiration  
in all things!

## Acknowledgments

I would like to thank my husband William, my children, and Dr. Marr (my chair) and Dr. Arcuri (my committee), for helping me get through this!

## Table of Contents

List of Tables.....	v
Chapter 1: Introduction to the Study .....	1
Introduction.....	1
Background .....	2
Problem Statement.....	4
Purpose of the Study.....	6
Research Questions.....	6
Theoretical and/or Conceptual Framework for the Study.....	7
Nature of the Study.....	8
Definitions.....	9
Assumptions .....	11
Scope and Delimitations .....	11
Limitations .....	12
Significance.....	13
Summary .....	13
Chapter 2: Literature Review .....	15
Introduction.....	15
Literature Search Strategy.....	16
Theoretical Foundation.....	17
Literature Review .....	19
Overview of Autism.....	20

Autism and Transition.....	21
Federal Funding.....	23
State Funding.....	23
Various Treatments and Services for the ASD Individual in School .....	24
Medication and Treatment for Autistic Adults.....	24
ASD and Family Support.....	26
Parental Stress Associated With ASD Children.....	27
Transition and Parental Stress .....	28
ASD and Adult Services .....	32
Summary and Conclusions.....	34
Chapter 3: Research Method.....	37
Introduction.....	37
Research Design and Rationale .....	37
Role of the Researcher .....	39
Methodology .....	41
Participant Selection Logic.....	41
Instrumentation.....	44
Procedures for Recruitment, Participation, and Data Collection .....	45
Data Analysis Plan.....	46
Issues of Trustworthiness.....	47
Credibility.....	48
Transferability.....	49

Dependability.....	49
Confirmability.....	50
Inter- and Intra- Coder Reliability .....	51
Ethical Procedures .....	51
Summary .....	52
Chapter 4: Results.....	54
Introduction .....	54
Setting .....	54
Demographics.....	54
Data Collection.....	55
Data Analysis .....	56
Evidence of Trustworthiness.....	57
Results.....	60
Theme 1: Lack of Services and Support .....	60
Theme 2: Long Waitlists and Service Delays .....	60
Theme 3: Financial Strain .....	61
Theme 4: Family Support as a Lifeline.....	61
Theme 5: Lack of Awareness/Guidance and Structured Transition Planning .....	61
Theme 6: Frustration With State Programs.....	63
Theme 7: Emotional Toll and Caregiver Burden .....	63
Theme 8: Limited Vocational and Social Opportunities.....	64

Summary .....	66
Chapter 5: Discussion, Conclusions, and Recommendations .....	68
Introduction .....	68
Interpretation of the Findings .....	69
Theme 1: Lack of services and support.....	69
Theme 2: Long Waitlists and Service Delays .....	70
Theme 3: Financial Strain .....	70
Theme 4: Family Support as a Lifeline.....	71
Theme 5: Lack of Awareness, Guidance, and Structured Transition Planning .....	71
Theme 6: Emotional Toll and Caregiver Burden .....	72
Theme 7: Frustration With State Programs .....	72
Theme 8: Limited Vocational and Social Opportunities.....	73
Connection to Conceptual Framework.....	73
Limitations of the Study.....	74
Recommendations.....	75
Implications.....	77
Conclusion.....	78
References.....	80
Appendix A: Recruitment Flyer.....	94
Appendix B: Interview Questions .....	96
Appendix C: Interview Protocol .....	97

## List of Tables

Table 1. Facebook Groups Used for Participant Recruitment .....	43
Table 2. Demographic Questions .....	45
Table 3. Themes and Participant Endorsements .....	66

## Chapter 1: Introduction to the Study

### **Introduction**

Transitioning out of high school is stressful for most students and parents, and the additional stress of having an autistic child makes this an even more stressful time for parents. According to Cridland et al. (2014), there is little understanding and little focus on what parents of autistic children go through when their child turns 21 and ages out of services. These parents must learn how to navigate through eligibility requirements and services that are unfamiliar to them. Many autistic students attending high school receive services through the federally funded Free Appropriate Education (FAPE) program. This program ends when autistic and other special needs children turn 21. What this means for the autistic adult is that they will no longer be allowed to attend school, as well as lose access to FAPE funded programs that were provided from the school district. Parents face several issues when this happens, including finding adult daycare, occupational therapy, speech therapy, and work programs that the autistic adult had access to and participated in while in school. According to Lunskey et al. (2021), parents face a great deal of stress as they must now navigate a new landscape that involves finding care for an autistic adult that includes care during the day, suitable therapies for their specific areas of need, and an environment that provides the interaction that the autistic person had in the school system. In the school setting, a student with disabilities has access to classrooms, therapy, and an individualized education plan (IEP), which is specifically written for that child. In school, there is a lot of interaction with teachers, peer tutors, and other special needs students, all of which is difficult to replicate once the autistic adult leaves the school

setting. In addition to the change of aging out of school and losing access to FAPE programs and funding, parents discover that non-FAPE services vary from state to state based on eligibility, determination and funding. This means that in some states therapy services may not be provided to these newly graduated adults, even though they still have significant needs at this stage of development. Parents feel this stress in a different way because they must find these services all on their own, often without the backing or support of an entire school staff behind them.

### **Background**

Although there has been a plethora of research about autism there has been very limited research on the stress that parents experience when their autistic child turns 21. This lack of research reveals the minimal focus on the stress parents face when their autistic child does reach their 21<sup>st</sup> birthday. According to Curtiss et al. (2021), previous research has focused on the expectations that parents have for their children, but very few studies have focused on the experience of the parents and the stress they deal with as their child transitions out of the school system and loses access to school and other federal programs. Several studies have documented parents and caregivers struggles in providing quality care, finding services, and what happens when parents and caregivers pass away (Iadarola et al., 2019; Habayeb et al., 2022; Herrema et al., 2017), yet more data are needed to better understand the stress that parents face when they are thrown into having to be the subject matter expert on how to get services and support for their autistic child and to understand the challenges that parents face as their child is transitioned from FAPE benefits to eligibility requirements. According to Wong et al. (2020), the transition

out of school and then moving on to the next phase of an autistic adult's life is an ongoing process that has shifted from a shared responsibility of school and parents, to just the parents.

The lack of a formal guide or reference materials specifically pertaining to aiding parents in the transition process can be frustrating and stressful for parents. According to Thakkar (2018), it is difficult to create a roadmap for all parents of autistic children to follow because each autistic child is so unique. Thakkar (2018) utilized semi structured interviews from New Zealand and India to point out that disabled adults with high and complex needs (HCN), may not get the care they need due to more than one factor. These factors could be a lack of necessary skill sets or knowledge (of parents), lack of resources (space as numbers increase), lack of professionals in the area, and lack of finances, all of which create additional stress for the parents or caregivers.

Another factor that causes stress for parents of autistic children is the quality of care they will receive after they leave high school and lose not only FAPE benefits, but the interdisciplinary approach and quality of the coordinated care, communication, and support that the high school provided. Volkmar and Soloman (2023) pointed out that challenges for students with disabilities are often much greater than for students without disabilities. The authors pointed out that transition out of school, bullying, medical care, and insufficient support systems all affect the quality of care that the ASD adult receives after transition. While parents might find a space available in an adult care program it is often quite a shift from a high school community where there is usually more in-depth help and attention paid to the ASD student. Volkmar and Soloman pointed out that

research is extremely important because they found that there are specific categories that need to be identified and then clarified to ensure a more standardized process for transition. For example, the definition of needs and the clarification of ability to function. The authors pointed out other challenges that parents may face with their autistic adult, such as living independently or in a care facility if the parents are unable to take care of them or if the parents become unable to take care of them due to their age.

It is evident that ASD is growing in numbers (Dietz et al., 2020), and there does not appear to be clarity as to why there has not been a larger movement to create better transition plans when FAPE is no longer available. Additionally, there is not enough research addressing the stress that parents are facing related to their adult autistic children losing access to FAPE and more heavily relying on their parents. An exploratory study into understanding the stress that parents face when their autistic child turns 21 may lead to more than just addressing transition plans out of high school. This study could potentially lead to expanded services like extension of FAPE funding to ASD adults, and provision of a FAPE counselor or coordinator for ASD adults, as well as better medical care and family support programs which could be tailored to specifically assist parents during the transition period. By focusing on the parents' perceptions and experiences, this study could lead to suggestions that might enhance or improve support systems that would directly address the challenges that these parents face.

### **Problem Statement**

The increase in the prevalence of autism is rising. According to Dietz et al. (2020), it is estimated approximately 2% of the adult population of the United States have

autism. When the autistic or disabled person turns 21, they lose FAPE and are no longer allowed to attend school. There are a number of hurdles that parents of the ASD person face that cause stress and additional obstacles in the lives of the parents of these children. According to Marsack-Topolewski and Weisz (2020), the complexities of being a parent of a caregiver of an ASD adult create a multilayered effect on their mental wellbeing. Often parents or caregivers are faced with finding time, finances, and services, in communities where services are often nonexistent or overloaded.

Several studies have documented the rate of autism growth and the policy changes that have come about because of the prevalence of autism (Zeidan et al., 2022), but there is still additional research and data to be gathered to explore the stress that parents and caregivers face as they traverse the landscape of their autistic child becoming an adult. Zeidan et al. (2022) examined factors that related to the global impact of autism and the impact of geographic, ethnic, and socioeconomic factors around the world. While the research has shown that there have been gains in both policy and research, there continues to be a need to address unmet requirements for ASD adults and the information that will help parents provide their ASD children with proper care. With a decided disadvantage to overcome as the autistic child loses their FAPE benefits, it often falls to the parents to figure out the next steps. According to Bagatell et al. (2023), it is essential to understand the roles of these caregivers and their needs. The mental well-being of the parents is essential in order to better arm them with the ability to fill their roles, often as lifetime caregivers. Bagatell et al. (2023), conducted a qualitative study on the roles of caregivers of autistic adults and found that there were three main themes of the care they

were providing: managing daily living needs, obtaining services and support, and providing invisible support, which is much more complex than initially thought. The researchers also pointed out that the roles often change over time, and they are all complex and dynamic. The needs of the autistic adult in the present and the future can be taxing, so parents and caregivers need to ensure that their own needs are being met concerning their health and well-being.

### **Purpose of the Study**

The purpose of this qualitative study was to examine the stress parents face when their autistic child turned 21. Reviewing the in-depth stories from the parents of the autistic adult as they transition out of school and lose access to both the school and FAPE programs and services, helped fill the gaps in current research and brought focus to this problem, contributing and expanding information on the needs of these families. This study contributed to the field of psychology and provided insights that may positively impact the individuals involved, their communities, and institutions by informing training and future research. In addition, this study identified what may be needed in the future to further study this issue, which could result in more social change for special needs individuals and their families.

### **Research Questions**

The research questions (RQs) were as follows:

RQ1: What are the lived experiences of parents when their autistic child turns 21?

RQ2: What are parents' perceptions of the changes and/or reduction of services and resources when their autistic child turns 21?

### **Theoretical and/or Conceptual Framework for the Study**

A family systems theoretical framework was used to understand the experiences of parents whose autistic child turns 21 and loses FAPE funding and services, allowing themes to emerge which highlight stress of parents and obstacles they have faced during this transitional time. According to Cridland et al. (2014), data regarding families with ASD children/adults can often be limited because basic research designs do not address the complexity of the family system. The focus of this study was on the stress that parents experienced while trying to ensure that their child transitions away from FAPE services at age 21. A macroscopic approach allowed for the examination of how ASD families interact with their communities, their schools, and other families of ASD children/adults. This theory helps to flush out the stress parents are experiencing during this timeframe and conceptualizes the many sources of this stress, as well as provides a framework for how these macroscopic interactions influence how these parents deal with their stress. Roberts (2021) discussed the family systems theory in detail with regards to siblings of individuals with disabilities. Further exploration into family systems theory and how it could be utilized in relation to gaps can be explored when reading an article by Johnson and Ray (2016), where they pointed out that instead of focusing on one person, the family systems theory explores a more encompassing focus on the family unit and the problem that connects the family. This approach was well suited because of the complexity of the family unit and the ASD family member. This approach allowed me to shed light on the ASD family members and identify specific stressors and issues each family member

experiences making a connection with the ASD family member who affects everyone in the family unit.

### **Nature of the Study**

To address the RQs in this qualitative study, the specific research design included a narrative approach. According to Mertova (2020), using a narrative approach or narrative inquiry allows researchers to investigate unusual or unique experiences of people through their stories. This type of study also highlighted the culture that surrounds autistic adults, parents, and services that they can receive after they age out of FAPE. This approach allowed an opportunity to gather the parents' stories of their experiences. According to Leal (2023), narratives provide a way for us to understand the significance of a person's experiences. The author goes on to explain that the purpose is not to determine whether the narrative is true or false, but rather to focus on how the person telling the story relates the story they are telling, to their experience. When looking at how people view the world or how they view things that have happened to them, it is imperative to look at how they have been affected personally and understand their experiences through their stories.

The narrative approach allowed me to focus better on how the subjects in this study feel having an autistic child who has aged out of FAPE services has affected them personally. This included financial, emotional, or other personal impacts that have affected all the members of the family, including the autistic child, leading to stress for the parents and creating issues among the family. Utilizing a narrative approach provided a backdrop or tapestry that is relevant to the parents that autism has touched and how they

experience their children transitioning out of FAPE and into other programs. According to Matshaka (2024), one way to understand the world can be chosen through how research is conducted, for example utilizing narrative as a method of investigation can provide a deeper look into understanding how a particular person or group sees the world.

Participants were asked open-ended questions that explored the parents' experiences, their feelings, and the challenges that they faced when their ASD child turned 21. According to Karlsen et al. (2024), the narrative approach was useful in identifying themes and understanding experiences in relation to patients and their surroundings during their time in an intensive care unit. Utilizing a narrative approach in order to reveal how parents of autistic children experience and view the transition out of FAPE services was beneficial in capturing the parents' feelings and stories and identifying common themes as they emerged. The narrative approach allowed me to further explore these parents' perceptions of their stress following their adult children with autism aging out of FAPE.

### **Definitions**

*Autism spectrum disorder (ASD):* The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defined ASD as a neurodevelopmental disorder which is characterized by deficits in social interaction and often communication. ASD often has other symptoms which include stimming, repetitive behaviors, difficulty recognizing verbal and nonverbal cues, and being sensitive to smells, textures, and noise.

*Federal school funding:* Federal funding for schools can come in many forms and fall under different programs. Reilmann and Barber (2024), pointed out that key federal

funding comes from programs like Every Student Succeeds Act (ESSA), individuals on federal property which include military installations and tribal lands, Title IX, IDEA Part B which provides funding for students with disabilities, and IDEA Part C which provides funding for toddlers and infants. Finally, there is federal funding that provides school lunch and breakfast, broadband connectivity, and Medicaid funding.

*Free appropriate public education (FAPE):* FAPE requires all schools to provide an appropriate education at the public's expense to all students with disabilities. FAPE is defined in the Code of Federal Regulations (7 CFR 15b.22) to provide regular or special education as well as aids and services to meet the needs of disabled individuals based on their educational requirements.

*IDEA:* The Individuals with Disabilities Education Act (IDEA) was passed into law by Congress in 1975 and last reauthorized in 2004. The intent of IDEA is to support and meet the needs of individuals with disabilities in their education which currently serves close to 7 million children each year from age 3-21 (Center for Public Education, 2020).

*Individualized education plan:* The individualized education plan (IEP) is the foundation that is set in order to begin services for individuals with disabilities as the requirement for special education and/or services begins. The IEP is tailored to each student with disabilities by having clearly defined goals and objectives (Kurth et al., 2024).

*Intellectual disability:* According to Piotrowski and Houp (2024), an intellectual disability (ID) is when an individual is lacking in or has limitations in intellectual functioning as well as adaptive behavior.

*State school funding:* States fund their schools from three primary sources which include local, state, and federal government (Spurrier et al., 2023). Most revenue for public schools are supplied by local and state revenue streams which would include property taxes, but a small amount is provided from government resources which are then allocated by each state as they see fit.

### **Assumptions**

The purpose of this study was to gain a deeper understanding of the stress that parents experienced when their autistic child turned 21 and aged out of FAPE services. The main assumption was that parents of autistic children have more stress and face more obstacles when their child turns 21, compared to parents of non-autistic children. This assumption was important because it helped guide the research focus and questions asked during the interview process.

### **Scope and Delimitations**

The scope of this study focused on the perception of stress that parents experience when their autistic child turns 21 and transitioned out of school without the benefits of FAPE. This study was intended to address the lived experiences of parents whose children had already transitioned out of FAPE services, with particular focus on exploring those parents' areas of stress. The sample size was five individuals. This study was centered in a specific community within the same state.

### **Limitations**

This exploratory study had some limitations that could affect the findings and how they could be utilized overall. Generalizability may be limited due to the small sample size and the geographic focus on one region, which may not fully represent parents from other states, urban areas, or diverse backgrounds. The sample size lacks wide geographic diversity. In addition, there is a lack of heterogeneity in participant demographics, such as cultural background, income level, or access to resources, which may limit the application of this study to more varied or differing populations across the United States. Because access to resources varies so greatly in different states, or even in larger cities, caution should be taken when trying to generalize this study and its results to larger populations.

Another critical limitation was the potential for researcher bias, due to my personal connection to the topic. As a parent of a child with autism, I understood that my own personal experiences and emotions could potentially influence how I interpreted the data and how I interacted with participants. In order to address this limitation, I employed bracketing and reflexivity through the research process. According to Grajzel (2025), bracketing helps the researcher become aware of their own bias and experiences and helps to keep personal experiences and perspectives separate. Karcher et al. (2024) reported that reflexive journaling helps to highlight thoughts and feelings throughout the interview process and throughout the data analysis process. While these methods may not have completely eliminated bias, these methods ensured that I remained aware of any influence and worked to stay as objective and transparent as possible.

### **Significance**

This study is significant because social change is an important part of our learning environment at Walden. This study could be a building block for further study on the limitations of services for special needs communities and how this can create stress for the families of adults with autism. Students can use this study as a starting point to explore services for autistic individuals in their own communities and expand the research to examine local service availability and gaps. This also has the potential to create social change across many communities because this problem is widespread and is often overlooked. It is my hope that these findings will highlight this problem and help others recognize and understand the broader implications, bringing it into public awareness.

### **Summary**

According to the literature, there are many factors that are involved when an autistic child transitions out of high school. There are some gaps in research regarding the stress that parents experience and more research need to be conducted to fully explore this stressful time for parents and their adult autistic children. According to Cridland et al. (2014), there is an overall lack of understanding regarding this monumental transition for autistic children and their parents. There are several things to consider when exploring the stress that parents feel as their child transitions out of high school, including but not limited to a change in schedule and activities, the loss of FAPE funding, the difficulty in finding daycare, the difficulty in finding programs, and the difficulty in finding professional services that include medical and dental. According to Lunsky et al. (2021),

parents are traversing an entirely new landscape that involves finding all services on their own. Results of this study may benefit a variety of professionals not only in the school systems, but also within professional organizations. In Chapter 2, I reviewed articles that relate to this exploratory study and information on the conceptual framework for my study.

## Chapter 2: Literature Review

### **Introduction**

The aim of this study was to evaluate stress that parents feel when their child has to leave high school because they age out of the school system and corresponding FAPE services. This study focused on how parents experienced the entire transition away from high school, and the services that were lost, nonexistent, or wait listed. The objective of this study was to better understand the stress that parents face during this transition utilizing a family systems approach to better understand the lived experiences of parents, when the care and efforts have shifted from being shared with the school system to being the sole responsibility of the parent or parents. This study focused on the parent's experiences and stress this transition period creates that previous research has been lacking (see Curtiss et al., 2021).

Previous studies have explored autism in depth but have been limited in scope regarding the exploration of the stress that parents experience when their autistic child turns 21 and FAPE is discontinued. Research has also been conducted highlighting the struggle that parents of ASD children face when finding quality care but still lack focus on parent stress. This study addressed the identified gap in the research literature focusing on the stress that parents face when they must become subject matter experts in obtaining services, finding support, and finding suitable daycare or day programs for their ASD child who has transitioned out of the school systems and lost FAPE.

The sections that follow in this chapter begin with an explanation of the literature search strategy and a review of the theoretical and conceptual frameworks that guided

this study. The literature review also addresses key topics including the transition out of FAPE services, federal and state funding, available treatment and support services, family and sibling dynamics, and specific stressors experienced by parents of autistic adults. This chapter concludes with a summary of the current gaps in research and the relevance of this study pertaining to those gaps.

### **Literature Search Strategy**

To properly expand my search, I used the following keywords or terms: *autism, autism spectrum disorder, parenting, caregivers, parental stress, caregiver stress, autism stress, autism adult care, autism adult facilities, autism ageing, autism ageing out of the system, adult autism services, and free appropriate education (FAPE)*. While there were several articles that came up with the above word groupings, I had to keep refining my search strategies to find articles relating to the stress that parents faced when their child turned 21 and aged out of FAPE services and transitioned out of the school system. As I refined my search criteria adding on to my keywords and terms, I found that articles about parental stress and autistic adults searches led me to articles pertaining to perceived unmet parent and family needs which in turn helped me to focus on other keywords and terms such as transition planning and autism, as well as tying in FAPE with IDEA and individuals with disabilities and then adding transition plans or planning. This also allowed me to understand that there are significant gaps in the research detailing the stress that parents face when their autistic child turns 21. I utilized Walden University's library which led me to Thoreau, EBSCOhost, ProQuest, Psych ARTICLES, PsycINFO, ProQuest Dissertations and Walden University dissertations. My search consisted of a

timeline from 2019-2024 for current articles and an open timeline for context on articles that had been printed earlier. I ensured that the articles were peer reviewed and relevant utilizing my keywords, terms, and phrases mentioned above to flush out related information that helped to address the stress that parents felt when their autistic child turned 21. In addition, I found that there continues to be gaps in research that discuss the family support for their child's adult years. According to Schiltz et al. (2024), little is known about the support into adulthood, highlighting that formal support and professional services either shrink over time or are less likely to be available. Working to identify common themes within a plethora of articles utilizing my keywords and terms and then looking at references from those articles was beneficial in finding needed supportive articles for my exploratory study.

### **Theoretical Foundation**

To provide a thorough understanding of the experiences of parents who have a transitioning ASD child, I used a family systems approach to gain a better perspective on the lived experiences of these families. A family systems approach addresses the complexity of the family system and allows for a more in-depth exploration of the ASD family's lived experience (Cridland et al., 2014). The family systems approach is integral because it focuses on the whole family, how they interact, and how one thing can positively or negatively affect all the members of the family and aligns with the RQs of this study which asked about the lived experiences of parents when their autistic child turns 21, and the perceptions of the changes and/or reduction of services and resources when their autistic child turns 21. Johnson and Ray (2016) discussed how one issue or

problem within a family can have a ripple effect throughout the whole family and connect the family in a specific way relating to that specific issue.

The basic process of the family systems theory is that by looking at how family members interact, how they are connected, how they feel emotionally towards each other, and how they function within their family and outside their family with others, a better understanding can be gained. This approach provided a macroscopic look into how the ASD family member affects parents and siblings, and the feelings associated with living with an ASD individual (Roberts, 2021). Gaining this perspective into the whole family unit was imperative to examine the stress that parents feel, as it explored other children or other family members that were influenced and affected by the ASD child. Schmeer et al. (2021) discussed how having an autistic sibling affected the lives of the nonautistic sibling and the additional supports that are needed for the autistic sibling utilizing a family systems approach. Glidden et al. (2021) used family systems theory in order to better understand how an IDD child impacted parents and families. In depth analysis of how autism within a family causes stress, embarrassment, limitations, and the influence of autism on the family were explored. The family systems theory allows for a more in depth look at the transition of an ASD child out of FAPE services and school causing additional stress on the parents, including the differences of transitioning a non-autistic family member from high school with an autistic family member. The family systems theory helped me when examining the lived experiences of parents after their autistic child turned 21 as well as the parents' perceptions of the changes and/or reduction of services and resources when their autistic child turned 21.

## Literature Review

The basic tenants of the family systems approach are that by focusing on the interactions of the people within the family we can gain an understanding of how they are emotionally connected to each other and how problems or issues within the family can affect each member of the family. This study specifically looked at the parents of the ASD child and the stress they experienced when their ASD child turned 21 and transitioned out of school and out of FAPE services. By looking at the family unit, and how the parents and family members think, feel, and behave, a better understanding has been gleaned of the stress felt by the parents. For example, Roberts (2021) applied family systems to the family relationships of siblings of an ASD child and gained insight on how the siblings were affected by the ASD child. This study examined the stress, behaviors, and feelings of the siblings, and discussed how their feelings affected the family unit. In addition, Dantchev et al. (2023) pointed out that a family systems approach allows for the exploration and examination between and within the family which helps to understand the family unit as a whole. Johnson and Ray (2016) pointed out that instead of focusing on one person, a more in-depth look at the whole family unit and the problem that connects the family can provide insight into stress and family functioning as whole. By utilizing the family systems approach the complexity of the family was looked at providing more detail in stress factors that might not have been explored utilizing a different approach. In addition, family members will experience this phenomenon differently causing different behaviors from the parents and the family unit, as a whole. This was the focus of this study and how a family systems approach explores the

experiences of the whole family and the effect that has had on the parents who have an ASD child that has turned 21 and transitioned out of school and FAPE services.

### **Overview of Autism**

To better understand the lived experiences of parents who have an ASD child that has turned 21 and has transitioned out of school and FAPE services, this literature review began with researching how the ASD child is transitioned from a school setting utilizing FAPE to the full dependency on their parents to fulfill needs and requirements. To understand the transition of an ASD child this literature review starts with understanding what ASD is and how it can affect a child transitioning out of the school system. While there have been studies that highlight some success with the transition of the ASD individual the process is not utilized in all areas. According to Berg et al. (2023), the development of a framework of directives can be beneficial. According to Knudson (2024), there have been some successes with a transition planning program in Canada explaining that both students and educators feel that the program is beneficial, but it is still limited after graduation. While there have been some successes in transition planning and with some programs, there has been little progress made in adapting a lifelong program to help the ASD individual. ASD is a neurodevelopmental condition that is complex, it lasts a lifetime, and it is associated with repetitive movement and behaviors, communication and social challenges, sensory issues, and restrictive interests (Slaughter, 2024). A unique aspect of autism is that it is varied and complex, presenting differently from one individual to another in both severity and symptoms. While autism cannot be cured and does not go away, the characteristics of autism may change during different

developmental stages, which suggests that care and intervention strategies should commensurately continue to change throughout the lifetime of the ASD individual.

### **Autism and Transition**

According to Crasta et al. (2024), autistic adults process their surroundings differently than their neurotypical peers in attention, sensory processing, and social settings. This is particularly important to recognize during the transition from high school into adulthood. ASD individuals develop and react to their environments differently than typically developing individuals, according to Looden et al. (2022). Considering that ASD individuals react differently or may not understand the complex changes that are occurring as they transition out of school, the importance of maintaining sufficient support should be examined. The transition out of high school for an autistic adult has many challenges that may not be apparent to most of the population. According to Berg et al. (2023), there are approximately 50,000 ASD people leaving the high schools in the United States each year and a study consisting of 174 families explored their thoughts on how to make the transition better for the ASD individual and their families. The opinions of the families that participated in the study stated that it would be helpful to have the following: A roadmap of services, improve service access, fill gaps to address unmet needs, educate themselves and society about autism, and operate from a relationship-building paradigm with families. The importance of taking these steps could lead to better policy changes that could better assist with the transition process.

In addition to creating a better process through the transition from high school and the discontinuation of FAPE services, there are other considerations like the unmet needs

of the families of the ASD individual. According to Shanahan et al. (2021), there are factors such as a lack of planning, a loss of consistency in the lives of the ASD adults, and a lack of services for these autistic adults, which lead to additional stress and anxiety on the ASD adult and family members, reduction of support, and health issues. Because most of the focus of transition is on the non-ASD child, there is not a lot of support provided to the parents or the ASD individuals who are transitioning (Iadarola et al., 2019). What this means for the ASD individual and their families is that they now have to focus on finding not only the support system that the school once provided, but they have challenges that they will also face as the caregivers. Habayeb et al. (2022) pointed out that there is not enough research or prioritization on the transition process and how it affects the entire family, especially when the parents are unable to find providers for autistic adults during the day so that the parents can continue working. When dealing with these issues it is usually up to the parents to figure out the processes and procedures and it is an ongoing and continuous process (Wong et al., 2020).

Another aspect of the transition process for the ASD family is to define what it means for the ASD individual to be successful and for the family to feel a sense of accomplishment at the end of the transition process. According to Volkmar and Solomon (2023), the need to identify what will be the highest level of functioning for the ASD adult is important at the beginning of the transition process, in order to create a transition process for the individual.

## **Federal Funding**

Federal funds provide education for all students to include children with disabilities. In 1990 Public Law 94-142 was reauthorized as the Individuals with Disabilities Act (IDEA), which outlines provisions that satisfy FAPE (Scanlon et al., 2021). While appropriate may be open to interpretation, there is still federal funding and programs available for ASD individuals while in school (Scanlon et al., 2021). Because the educational guidelines are specifically for special needs individuals between the ages of three and twenty-one, all programs and the Individualized Education Plan end at that point including services that were provided. While there are other government or federally funded programs such as SSDI, SSI, Medicaid or Medicare, the expertise in navigating these services that the schools provided ends when the ASD individual ages out of the school system.

## **State Funding**

State funding varies from state to state and while federal funds are available to states which impact the ASD individual and their families differently, it is up to each state to determine how to administer those funds. States do have other programs that help the ASD individual through waivers, however the state programs are often not utilized properly, and states vary greatly in their use of funding like Medicaid which further complicates the provision of care for the ASD individual (Shea et al., 2021). While state programs and state funding are helpful to the ASD individual and their families, there needs to be a more focused evaluation on the programs to ensure that funding is being utilized correctly and providing the care that is needed. In addition, the wait lists for these

programs can take years, so an evaluation of the beneficiaries currently receiving funding should be considered in order to provide a more streamlined approach to triage individuals who require more care to receive funding faster than those who have only mild impairment and are able to work or effectively live on their own (Levine et al., 2024).

### **Various Treatments and Services for the ASD Individual in School**

Autism is complex and unique and treatments for autism are often as complex as autism itself. While there are many options available to treat the ASD individual the focus has been primarily on behavior, medication, and skills needed to reach their full potential. According to Lequia et al. (2023), there are several considerations when providing services to the autistic individual mainly focusing on educational interventions and behavioral interventions and utilizing medication as needed. When the ASD individual is in school, they will have an Individual Education Program (IEP), which provides services like speech therapy, occupational therapy, instruction, life skills, community experience, post school adult living objectives, and a transition plan (Lequia et al., 2023). All these school services provide a tailored plan for the ASD individual.

### **Medication and Treatment for Autistic Adults**

As ASD individuals transition out of high school, finding treatments can be difficult to manage and often parents are unable to find the services provided for their autistic adult. According to Stamer (2023), ABA therapy, despite its widespread clinical recognition for the treatment of autism, is often not provided for ASD individuals through insurance plans. While meeting the medical needs of ASD individuals in school can be

difficult, there are additional considerations when they become adults. According to Quiban et al. (2020), it can often be difficult to meet the medical and critical care needs of the ASD adult due to their physical size, their understanding of medical procedures, the need to have not only a primary care physician, but a psychiatrist and/or other medical professionals may be needed to provide the ASD adult's essential care. In general, it is common that a primary care physician can meet most of a patient's needs; however, the ASD adult has many other needs requiring specialized care to include dental care, which may be difficult to meet as they become adults (Lai et al., 2021). Many ASD adults when receiving dental care require them to be asleep during routine appointments like cleanings, cavity filling, and tooth extraction, creating a higher risk to the patient and additional costs which may cause additional paperwork or payments needed for treatment. According to Parry et al. (2021), dental treatment under general anesthesia is often an expectation for ASD adults and children.

In addition to dental care, there may be medication requirements for autistic children that must often be met by other specialists like psychiatrists, whom their general practitioner refers the ASD adult to because of the needs and requirements of behavior and medication. Medication can affect the ASD individual differently and they may not be able to tolerate procedures as well as non-ASD individuals, so extra care should be taken during medical and dental procedures. While selective serotonin reuptake inhibitors (SSRIs) are commonly prescribed to manage anxiety, there are side effects and often variables that should be examined carefully before administering any medication, which

is extremely important in the ASD individual due to a variety of reasons to include communication barriers, and medication tolerance (Rai et al., 2024).

### **ASD and Family Support**

Family support is crucial for the success of the ASD individual. Many autistic children's parents are unfamiliar with autism until their child is diagnosed, which sets a high learning curve for both the parents and the siblings of the ASD individual. When the ASD individual is younger, help is provided through early intervention services and there is more focus on family integration for appropriate interventions and support (Witwer et al., 2022). As the ASD individual gets older, they will need other support structures that family members need to be aware of and play a more active role in, for the development and assistance of the ASD individual. When an ASD individual becomes a teenager their bodies go through changes, they might become more aggressive, and they might begin to act out more than usual which requires additional support and understanding in the home (Brown et al., 2024). In addition, there are other considerations such as community activities, transportation, and ensuring that the ASD individual understands social protocols when out in public. Because siblings may be embarrassed by their autistic brother or sister, there should be additional support and communication within families about expectations and requirements when dealing with the ASD sibling. According to Perlman and Howe (2023), there are often positive and negative perceptions regarding the sibling relationship between the ASD siblings and their typically developing brothers or sisters, and the sibling relationship is bi-directional. The authors highlighted the relationship that siblings have with their ASD siblings and how it affects the family as a

whole. According to Siman-Tov and Sharabi (2023), sisters of ASD individuals showed a higher involvement, self-efficacy, and adjustment than brothers of the ASD individual. The authors also found that brothers compared to sisters showed a higher level of loneliness. These family dynamics create additional stress on the entire family unit and support structures for family members may not be readily available in many areas but often the ASD individual does influence career paths, relationships, and the quality of life of family members (Wright et al., 2024).

### **Parental Stress Associated With ASD Children**

The stress associated with raising an ASD individual varies in each home, however the stress that is associated with parents of an ASD child has higher levels of stress than parents of non-ASD children (Karnas, 2023). While there may be stress involved in raising non-ASD children, there are additional stressors that parents of ASD children face that are different due to requirements for care and support such as medical and dental requirements and coordination of services. According to Lai et al. (2021), when providing care for people with developmental disabilities there are individualized services for each person that must be taken into account. For example, the additional requirements of general anesthesia for basic dental work or specialist medical care. Another concern for parents of autistic children is their care during normal working hours, to allow parents to remain employed after the ASD adult's discontinuation of FAPE services. According to Mbamba and Ndemole (2021), single mothers of autistic children face greater challenges, such as stigmatization, being the only adult providing this more difficult care which requires more attention, and families can be judged or

rejected because autism is not understood. While this is true for all parents of autistic individuals' single parents often do not have a co-person with whom to share those burdens. Another issue that parents face which can cause stress is how to deal with siblings of the ASD child or adult. Siblings are often involved in the life of an ASD individual whether they want to be or not simply because of the high needs of the ASD individual. According to Siman-Tov and Sharabi (2023), siblings face challenges with adjustment, feelings of loneliness, and lack of resources. Parents of the ASD individual must consider many things as they traverse the landscape of everyday life, and as parents they must find ways to include all their children and remain cognizant of the needs and care of each child, those with ASD and without. Often the ASD individual will take precedence over other family members, in instances such as dinners out, movies, game nights, school plays, vacations, and other activities that must be planned around the ASD individual.

### **Transition and Parental Stress**

The stress of being a parent to any child can be analyzed by looking at the enormous changes that occur when children arrive in the home. According to Chen et al. (2024), there are numerous factors that are involved in stress during a child's lifetime which can stem from how a parent feels they are doing as a parent, how difficult it is, how the child changes through middle childhood, how conflicts are resolved, and behaviors which can all lead to stress as a parent. While stress may be considered part of normal patterns of parenting, there are additional stressors that are involved when special needs children are in the home. According to Rusu et al. (2024), stress among parents of

ASD children is well documented. When considering the stress that all parents face and the additional stress of having an ASD child in the home, it can be expected that stress among parents whose children are transitioning out of high school and out of FAPE services may affect them to a greater degree. The stress parents feel when they fully take over the care of their autistic child after FAPE services are discontinued can be compounded by basic requirements that differ simply because you have an ASD child. Stress has been well documented among parents of all children, and it is important to mention as well that stress for a single parent of an autistic child during transition out of school is compounded by doing this alone. While there is some mention of single versus dual parent households dealing with the transition of the ASD individual out of high school, the main focus is the parental stress whether it is a single or a dual parent household. While there it is acknowledged in many studies that additional stress is involved in raising an ASD individual, there are some similarities and differences as well for single parents compared to a dual parent household. According to Davy et al. (2024), there is often a give and take when it comes to raising an autistic child, often leading to a modification of the quality of life for the parents, being especially true for the single parent who does not have that in-house support that a nuclear family has. Stress can be related to several causes which include situational factors, maternal depression, social support, and child overall problems (Fang et al., 2024). While the authors did not focus on a single mechanism that caused stress for parents in their study the factors that do cause stress tend to include overall problems with a child and also point to stress that may be caused by an ASD child.

When an ASD child transitions out of high school there are many obstacles that parents must consider such as adult day care, whether continuing education should be pursued, or will the ASD individual be able to live on their own or live semi-independently. Some parents must consider the availability of services when living in underserved, remote, or rural areas. According to Wong et al. (2020), the transition out of school and moving on to the next phase of life for the ASD individual is usually left solely to the parents to navigate. While there are programs in schools to help with the transition process, it is a process that never ends and there are hidden challenges that must be faced constantly such as missing out on services, lack of caregivers, lack of medical personnel and specialty providers, and a lack of support (Wong et al., 2020). According to Han et al. (2023), there is also a stigma associated with autistic adults that may make it difficult to navigate care and facilities as well as focus on the positive aspects of the autistic adult which can make finding care, services, or facilities difficult and stressful for parents or caregivers. According to Habayeb et al. (2022), there are often a lack of medical providers for both ASD children and adults, which causes additional stress for parents as they try to navigate a new landscape of care for their now ASD adult. While these authors focused on results in Qatar, the United States has the same issues in rural settings and often the cities are overcrowded because of the sheer volume of ASD individuals leaving high school each year, which can all be stressful for the parents of the ASD adult. According to Berg et al. (2023) there are approximately 50,000 youths with ASD who are exiting the high schools each year that will utilize adult systems of care and many will remain dependent on their parents to provide them with day-to-day care and

find services that include medical, dental, and community involvement. Another factor that is not often considered is parental burnout which is often a result of parental roles and chronic parenting stress (Liu et al., 2024). Liu et al. (2024) also pointed out that very little is mentioned about parent connectivity to their autistic children and how parents can burn out because of stress and factors that require constant attention, care, and resilience of the parents of these adults.

While challenges are continuous during the transition stage there are further stressors for the parent with the ASD adult when parents consider what will happen when they can no longer care for their child, or defining what independence means for each ASD adult which could vary from being able to dress themselves and use the toilet, communicating, or even eventually marry and start families which would create new challenges (Volkmar & Solomon, 2023). While there has been some research on the stress that affects parents of autistic children little research has been conducted on the stress parents feel when they worry about the future of their autistic child highlighting what parents hope will happen for their autistic children and the future that they imagine (Well et al., 2024). The authors pointed out that while there is little research highlighting what parents' hope the future holds for their ASD adult, there are other stressors that parents continually face such as supported living and difficulty accessing resources. This combined with the stress of thinking about what the future holds for their ASD adults such as being engaged and having meaningful activities and relationships are just a few of the stressor's parents feel besides worry, love, and loss which were all themes shared by parents. Parents want what is best for their children whether they have autism or not,

but the worry associated with having an autistic child may often feel like more because ASD individuals are so unique in ways that cannot be mapped or targeted through traditional means. The stress that parents face in continuing the care of their ASD child as they transition out of high school cannot fully be measured because every ASD individual is unique and their care is also unique, making it difficult to find a consistent transition program for these individuals. According to Shanahan et al. (2021), parents, family members, and ASD individuals and/or ID individuals, have increased anxiety, degraded health (mental and physical), and reduced support because of a lack of planning, a lack of consistent programs, and a lack of available adult services. The authors point out that the lack of research, lack of support, and lack of resources are all contributing factors that lead to stress and anxiety in parents of and ASD child.

### **ASD and Adult Services**

The transition from school services to adult services for the ASD adult comes with several roadblocks, most notably the loss of FAPE and the loss of the expertise of the school staff that has been trained to navigate obstacles associated with care. With a growing number of ASD students transitioning out of school and losing FAPE funding, additional support is needed to help navigate available services for the ASD adult. When losing specific services that had been in place in school, parents may find it difficult to replace those services for their adult child for a variety of reasons. Berg et al. (2023) pointed out the struggle that parents or caregivers had in locating and coordinating services as well as getting access to those services. Parents and caregivers found that often when services were there, the wait lists for services could last for months (Schott et.

al., 2021). Many states have wait lists that vary in both length and requirements such as waivers and support services provided through Medicaid (Schott et. al., 2021). In addition to long waiting lists previous research has shown that there is a lack of continuity of care when ASD individuals transition into adulthood to include medical, dental, speech therapy, occupational therapy, and other support systems (Shanahan et al., 2021).

Marsack-Topolewski and Weisz (2020) pointed out in their phenomenological study that parents discussed eight services that were lacking after transitioning out of high school, which were case management, educational programs, employment and employment supports, physical/mental health care, housing, day programs or respite care, social life and recreation, and transportation. Parents of ASD adults may have difficulty finding specialized providers for medical and dental care which are integral to a well-rounded medical and dental programs for ASD adults (Lai et al., 2021). Many services were either unavailable, had long waiting lists, or they did not meet the needs of their ASD adult (Marsack-Topolewski & Weisz, 2020).

While there has not been a plethora of success stories of successful transitions out of high school and FAPE services, there are some innovative programs that show promise in the future. Considerations of both mental and physical health have been looked at and there have been programs that have worked towards meeting these needs. According to Pillay et al. (2022), successes can become more prevalent if there is more focus on educational and socially inclusive interventions and family support structures. In addition, Hart et al. (2022), mentioned that the Center for Autism Services and Transition (CAST), was involved in creating a more individualized high quality care system for

ASD adults. This program is located mainly in Ohio, Indiana, and West Virginia and has proven successful. According to Wong et al. (2022), a search for successful programs designed for cutting-edge autism care yielded results for some services located in the United States. Among the screened programs that were considered successful were the programs that had integrated care between community and clinical based services such as a hospital for special care in Connecticut which works to discover gaps in services in the communities it serves and works to develop new services to help fill those gaps. The authors mentioned that other successful programs were Pathway Community Hub, Penn Autism Clinic, and Neurobehavior (HOME). While these programs are relatively small and located in pockets around the country, there is hope that with more funding and shining a spotlight on these issues, that a more widespread and focused course of action might be identified moving forward.

### **Summary and Conclusions**

It is known that having an ASD child who turns 21 and ages out of the school system and FAPE services is a mammoth task that parents and caregivers must learn to adapt to while at the same time rise up and meet the challenges required to get quality care for their child. Parents of the ASD individual realize that having an ASD child will continue to affect the lives of everyone involved in their care and support during their lifetime, especially as they transition out of high school and lose FAPE services. While there has been some research into the stress of autism on parents and families it is apparent that parents of the autistic individual during a transition out of high school face a great deal of stress as they learn and discover that they must provide a new type of care

for their autistic child (Lunsky et al., 2021). While it is generally common for parents to support their non-ASD child throughout their lives, there is a different level of support and care that an ASD child requires that is unique and complex for each individual and according to Karnas (2023), both the stress levels of parents, their coping strategies, and their situations have not been looked at individually, but rather as a group. According to Marscak-Topolewski and Weisz (2020), parents felt that services were unobtainable, inaccessible, or inadequate, consistent with other studies and research. According to Knudson (2024), transition programs cannot mirror the programs received while in school and the responsibility falls to the parents to fill the gap that the schools provided while the ASD individual was enrolled. It is unknown whether some of the programs that have been researched would provide benefits to each state across the board, nor whether there will be a movement to utilize federal money to subsidize some of the smaller more successful programs that have been recognized. It is important to address this problem because there are now more ASD adults requiring care and services, and there has been a lack of focus on the effects this has on the family members, parents specifically, and how the family unit functions as a whole during this transition (Roberts, 2021).

This study directly addressed the gaps identified throughout literature by focusing specifically on the lived experiences of parents whose autistic children have aged out of FAPE services at the age of 21. While there has been previous research that has explored autism in a broad sense, and has sometimes examined parental stress, there are very few studies that have examined this unique transition point in depth in order to get a focused point of view of the parents. By using a narrative inquiry design grounded in family

systems theory, this study captures personal stories and the emotional impacts that can be or have been overlooked in broader studies. The findings from this exploratory study can contribute to the limited body of knowledge on the post-FAPE transition experiences of these parents. This exploratory study could inform practitioners and policy makers as well as support the development of resources and services that could better align with the real needs of families during this critical time.

## Chapter 3: Research Method

### **Introduction**

The purpose of this study was to explore and understand the lived experiences of parents who have an autistic child transitioning out of high school, and their experiences as they lose FAPE funding and learned to navigate an entirely new landscape of challenges. The potential benefits of this exploratory study might be an influx of information and data that could provide professionals not only an understanding of these experiences, but a course of action that might provide help and support to these autistic adults and their parents/families in the future. This chapter describes the research design and rationale; the role of the researcher; methodology-including participant selection, instrumentation, procedures for recruitment, participation, and procedures for data collection and analysis; issues of trustworthiness; and ethical procedures.

### **Research Design and Rationale**

Encompassed in the two RQs for this study, I explored the stress that parents face when their autistic child turned 21. I captured their personal stories and their perspectives about their journey as parents. This transition is significant, not only for the autistic child, but for the parents and the siblings because it highlights the end of a journey that began when the autistic child started school and ended with a transition into a completely different journey that the parents had to navigate on their own, often with little help. With this in mind my questions focused on those experiences and the parents' perception of this significant transitional time frame.

The first question I focused on was: What are the lived experiences of parents when their autistic child turns 21? The second question I focused on was: What are parents' perceptions of the changes and/or reduction of services and resources when their autistic child turns 21? In order to explore the lived experiences of these parents I used a family systems approach which addressed the complexity of the family system (see Cridland et al., 2014). In order to answer these questions, this study used a qualitative approach, specifically narrative inquiry, to focus on the lived experiences of parents during this transition. Narrative inquiry is a qualitative method that highlights the importance of gathering personal stories in order to better understand the meaning individuals assign to their experiences (Javadi & Kadkhodaei, 2022). This approach was appropriate for this study because it allowed for the collection of detailed, context-rich accounts directly from the parents, which helped to highlight the emotional and logistical challenges faced when their autistic child aged out of FAPE services at 21. In addition, a family systems approach was used in order to focus on the complexity of family dynamics during this major life transition (Cridland et al., 2014). The family system's perspective highlighted the emotional adjustments, relationship shifts, and broader impacts on the family unit. According to Wolpe et al. (2023), viewing the transition through a family systems lens brings attention to how the loss of services impacts both parents and siblings as they adapt to a new stage of life.

The family systems approach was integral because it could be focused on the whole family, the way they interact with each other, and how they feel about having an ASD individual in their home. This study allowed me to explore changes both mentally

and logistically that occurred within a household once an ASD individual leaves high school, and the perceptions of those changes. According to Johnson and Ray (2016), there are ripples from changes that may affect every member of the household especially when something like ASD connects an entire family.

### **Role of the Researcher**

My role as a researcher was to observe and participate as needed and remain honest and unbiased even though I do have a personal connection to this study. I am a mother of an autistic child who turned 21 and lost FAPE services. In addition, we lost speech therapy, occupational therapy, dental, and ABA therapy the day after he turned 21. The services were discontinued immediately the day after his 21<sup>st</sup> birthday and we had to explore sites, make cold calls to dentist offices, and travel over an hour to find an ABA therapist who would see adults. It was a huge change for our nonverbal autistic son, and it did cause us stress. In addition to finding services for him, we had to change our work schedules because we could not find a reasonable adult day care facility so my husband took on a swing/night shift so I could work days and our son would never be alone or with a caregiver who did not understand his needs. While I am personally connected to this topic, I did not let my experiences or bias influence me in this study. In order to address potential bias, I recognized my researcher positionality as both an insider (a parent of a child with autism) and a researcher. I managed my position carefully throughout all phases of the research process, including participant recruitment, interviews, transcription, coding, data analysis, and interpretation. Bracketing and reflexive journaling were used continuously to minimize bias, ensuring that participant

voices are represented authentically and that my personal experiences did not shape the findings.

I did not engage in any dual relationships with participants in this study. I did not recruit, interview, or collect data from individuals whom I knew personally or professionally. In order to maintain ethical standards and avoid potential bias, participants were recruited only from public groups that I did not have personal or social connections with, such as local autism support groups listed in Table 1. I screened participants during the prescreening process to ensure they were not individuals from my personal, professional, or social circles. This helped protect the integrity of the research and maintained a clear boundary between my role as a researcher and any personal affiliations. According to Weatherford and Mailtra (2019), research is often inspired by strong personal interests. While I find this to be true, I took steps to ensure that my own bias did not interfere with my data collection or interpretation of the data that I collected. One of the steps that I took to manage my own bias was bracketing. According to Grajzel (2025), bracketing helps the researcher separate and become self-aware of their own bias and experiences that could impact this study. I kept a journal in order to categorize my field notes, and I wrote down my own emotions throughout the process.

To further minimize bias throughout this process which included recruitment, data collection, transcription, coding, and analysis, I followed a structured and consistent protocol for each participant. During interviews, I refrained from sharing any of my own personal experiences or any of my own opinions. I used active listening and neutral prompts to elicit participant stories. During the transcription and coding phase, I

maintained an audit trail and used memo-writing to document analytic decisions and reflections. I regularly reviewed my reflexive journal entries to help me remain aware of potential bias and emotional responses. When I reviewed the results and wrote up the findings, I kept checking in with myself in order to make sure that I was not leaning too much on my own perspective and experiences. These steps helped me to stay focused on the participants' experiences instead of my own.

## **Methodology**

### **Participant Selection Logic**

I selected participants (parents) who had at least one ASD child who had reached the age of 21 and had transitioned out of high school and FAPE services. In addition, I ensured that the autistic adult was at least 21 years of age because FAPE will still cover speech and occupational therapy and sometimes ABA therapy until the age of 21. As such, I excluded speaking to parents with children under 21 for the purpose of this study. My focus was on adults over 21 who had transitioned out of high school so that I could better understand the experience and journey moving away from FAPE services. According to Dahal et al. (2025), utilizing purposeful sampling for participant selection compliments the narrative inquiry approach for this exploratory study. Purposeful sampling means that I only included those subjects that would further my research because they met the criteria that I was looking for. For example, I focused on families with autistic adults that were over 21 and who had transitioned out of high school, so I only chose to interview parents based on those criteria. Purposeful sampling can also be referred to as selective sampling. The narrative inquiry approach allows the researcher to

explore unique or unusual experiences by listening to people tell of their experiences in their own words. According to Leal (2023), the narrative approach can provide a better understanding of a person's life experiences, because that person will highlight the significance of their experiences, relaying information that is important to them or that has affected them. This helped me to understand how this transition affected them on a personal level. Dahal et al. (2025) explained that when using narrative research, the detailed experiences are more crucial than the number of participants. In addition, my selection criteria were transparent, and my participants quotes were used which adds transparency and rigor to this exploratory study.

In order to explore lived experiences I got a sampling of five families through social media as laid out in Table 1. Recruitment continued until narrative sufficiency was reached -- that is, when there were no new themes that emerged from the interviews and a full, detailed picture of the phenomenon had been captured (see Saunders et al., 2018). Because I live in a small community and saturation was reached with five participants, I was ok with the small sampling. I did not believe that new information would be forthcoming with a larger sampling. While I considered utilizing snowball sampling, I did not think that it fit with what I was trying to accomplish with my exploratory study. I preferred to find local participants in order to remain specific to the stress families experience in this particular location. I utilized social media (Facebook) in my recruitment and included my social media platform and the group (see Table 1), within this section.

**Table 1***Facebook Groups Used for Participant Recruitment*

Social media platform	Group
Facebook	Special Needs Families Hardin Co Connect
Facebook	Kentucky Parents of Autistic Children Support Group

The social media flyer was posted on two social media platforms in my area, and it contained my contact information, which included my phone number and email address. The flyer asked if they wanted to participate and if they did, they could contact me through the information that I provided in the flyer. Once participants reached out to me through phone or e-mail as stated in the flyer, I asked them my prescreening questions to determine their eligibility. The prescreening questions were as follows: Do you have an autistic child that is 21 or older?; Are you willing to participate in a study about the transition out of high school and the loss of FAPE services?. If they met the criteria, I reviewed the elements of the informed consent with them and sent them the consent form via e-mail, and they responded with “I consent” to me via e-mail as dictated by IRB. I then sent an e-mail to them with options for interview times. Once the participants replied with “I consent” and we set up an interview time I reminded them again that it would be recorded and let them know that they should be in a space where they had privacy and minimal interruptions.

## **Instrumentation**

I used observation sheets during interviews to note key nonverbal cues and/or contextual details. In order to ensure accurate data collection, I recorded each interview using both the Zoom conferencing platform and a DGFAN voice activated audio recorder. Because I used two technologies this means that I had a backup in case of technical difficulties. According to Dahal et al. (2025), as a researcher it is important to be an observer in the world of the participant. Because my RQs were open ended, I feel that having a recording device was crucial to ensuring I captured the entirety of the participants experiences. In addition, I was able to play back responses for clarification. While I had originally planned to use NVivo for transcription I was able to use a transcription software program to generate transcripts from zoom recordings. I then reviewed the transcripts for accuracy and organized them into Excel spreadsheets to support coding and theme development. I used the following questions for my demographic survey (see Table 2).

**Table 2***Demographic Questions*

Question	Response choice
What is your age?	Age in years
What is your gender?	Male, female, other, prefer not to answer.
What is your marital status?	Single, married, divorced, widowed
Who are the people that live in your house?	Spouse, autistic child, siblings, aunts, uncles, grandparents, other

The demographic survey was voluntary, and less than half the participants chose not to answer marital status and age. All demographic information collected was nonidentifiable and did not include names, addresses, or any personally identifying information. The purpose of the demographic survey was solely to describe the sample and support the credibility and transferability of the study findings.

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

I sought approval from the IRB at Walden University and once I got that approval, I began recruitment via social media (see Appendix A), on local autism sites. I was able to get sufficient responses, and I then conducted Zoom interviews that lasted between 0-30 minutes and used transcription software along with Excel spreadsheets to organize, display, and analyze my qualitative data. According to David et al. (2022), qualitative data analysis involves systematic organization and coding of data, which I

carried out by reviewing transcripts for accuracy, highlighting key words and phrases, and grouping them into categories that led to my theme development.

I reminded participants about my research to ensure that they were aware that I would be taking notes throughout the interview, and I asked them if they were comfortable, or if they had any questions. I ensured that I e-mailed out resources to everyone at the start. I ensured that they understood I was only there to gather information about their experiences. I did not conduct a pilot study, as the interview questions (see Appendix B) were based on research and supported by my conceptual framework and the existing literature. I used an interview protocol (see Appendix C) created by consulting dissertation examples.

### **Data Analysis Plan**

Once my data collection was complete, I used transcription software and reviewed and corrected the transcripts and then uploaded them into Excel so that I could analyze and code my data. I utilized coding, which included open coding, focused coding, identifying themes, and exploring themes. According to Coates et al. (2021), analyzing qualitative data is a step-by-step process which includes coding, finding themes and exploring themes. This allowed me to categorize and file specific information. I used a combination of inductive and deductive coding. According to Casula et al. (2021), deductive coding applies existing frameworks, and inductive coding allows new themes to emerge. Data were analyzed using thematic narrative analysis, which involved the following steps: (a) transcribing interviews verbatim, (b) reading transcripts for initial storylines and patterns, (c) coding data inductively and deductively, (d) identifying

themes across narratives, and (e) developing interpretive accounts of the transition experience (Coates et al., 2021).

Next was coding which followed the approach outlined by Braun and Clarke (2006), which included familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report. This systematic method allowed both inductive (emergent) and deductive (theory-driven) themes to be captured.

In order to maintain trustworthiness, I addressed any conflicting or contradictory stories that come up during the study. If a participant's experience was different from others, I included it in the final report in order to make sure that all voices and perspectives are represented (see Patton, 2015). Through this process, I was able to provide a detailed and authentic account of the lived experiences of parents whose autistic children have transitioned out of FAPE services at age 21.

According to Casula et al. (2021), the basics of inductive reasoning and deductive reasoning are that inductive reasoning develops a theory while deductive reasoning tests an existing theory. The themes that emerged from the participants' stories were used to see how well they align with family systems theory, and in addition they helped to explore new patterns that might suggest future research should look at other possible frameworks (see Ravitch & Carl, 2021).

### **Issues of Trustworthiness**

Trustworthiness is key for anyone conducting research. To strengthen and show transparency on the trustworthiness of my research, I employed strategies aimed at

enhancing credibility, transferability, dependability and confirmability.

### **Credibility**

According to Adler (2022), data, interpretation, method, and reflexivity are key components of ensuring that the researcher is honest and transparent in their findings. To help make sure my findings reflected what participants really meant, I used member checking. This meant that I shared a short summary of what I heard during the interview with each participant, and they let me know if it sounded accurate or if anything needed to be changed or clarified. Member checking helps build credibility because it gives the participants a chance to confirm or correct what they shared (Birt et al., 2016). According to Naeem et al. (2023), utilizing a combination of deductive and inductive coding allowed me to add trustworthiness and clarity to my research. According to Naeem et al., the thematic analysis process is considered systematic because it follows a specific approach that flows into steps. For example, Naeem et al. described in detail each step beginning with Step 1, which is transcription, familiarization with the data, and selection of quotations. This leads to the following steps, which are the selection of keywords in Step 2; coding, which is Step 3; theme development, which is Step 4; conceptualization through interpretation of keywords which is Step 5; and finally Step 6, which is development of conceptual model.

I began Step 1 by familiarizing myself with the data and the mediums that I used to collect my data, to ensure that I was familiar with Zoom recording and how to utilize the transcription program properly because I needed to ensure that I was pulling out the relevant parts of the transcripts. For Step 2, I ensured that I identified key words such as

stressful, difficult, fearful, tension, or the repetition of words. I followed the six R's (reading, recording, redefining, revisiting, refining, and relating), for keyword selection. Step 3 is coding, which is utilized for short phrases or key words such as "quit work" or "difficulty finding services" or "it was very stressful." In Step 3, both inductive and deductive reasoning were used and helped to solidify the trustworthiness of my findings. Step 4 was my theme development, which involved organizing codes, identifying patterns, and linking my data. Step 5 was where I interpreted my data, and finally Step 6 was the development of my conceptual model derived from the earlier steps in this analysis.

### **Transferability**

According to Adler (2022), transparency is essential to transferability which means that my research can be useful in other studies. Utilizing the six steps from above also adds to transparency and transferability. The information in my study could help provide relevancy to other parents, teachers, or researchers of autistic children who might be facing the same transition or perhaps different transitions in other areas. My study might prove useful in more rural or underserved communities, since participants were drawn from this environment in the course of this study. I provide detailed contextual information in the following chapters about participants and setting to allow readers to judge relevance to other contexts.

### **Dependability**

Dependability was obtained because I maintained a very detailed documentation process. I also maintained an audit trail, which includes chronological protocols,

codebooks, and analytic memos throughout the study. This process includes how coding was completed, any changes that I might determine necessary and my own personal reflections and notes as I go along. According to Nowell et al. (2017), in order to maintain dependability in qualitative research the researcher must ensure that interview procedures are consistent and do not vary from one participant to another. In addition, the interview process was structured with each participant receiving the same information.

### **Confirmability**

According to Adler (2022), confirmability in research refers to the degree in which findings are shaped by the participants and not shaped by researcher bias, motives, or personal perspectives or perceptions. One way to ensure confirmability is through reflexive journaling (Karcher et al., 2024), which I ensured to complete in my notes. By incorporating reflexive journaling, I was able to go back and ensure that I was holding myself accountable for any bias or even lack of self-awareness or perhaps find something that I missed. According to Karcher et al. (2024), reflexive journaling creates a more transparent research process by highlighting overlooked details as well as enhancing the objectivity of research. Reflexive journaling is a process where a researcher will either keep a journal or document their own thoughts throughout the research process which will allow the researcher to go through their notes and determine if there is any bias. According to Barrett et al. (2020), when researchers incorporate reflexivity into the research, they are ensuring both quality and integrity.

### **Inter- and Intra- Coder Reliability**

Coding involved both inductive and deductive approaches (Naeem et al., 2023), and it began with open coding leading to more focused coding which helped identify and develop my themes. I established the intra-coder reliability by coding transcripts multiple times over several days, which ensured that I was consistent. In order to ensure reliability, I coded transcripts multiple times over several days to ensure consistency. Given the sample size is small for this study. there was not a huge amount of data to sift through, and this was straight forward. This process improves transparency and trust in the coding process.

### **Ethical Procedures**

I completed human subject research training per Walden University IRB requirements. I ensured that if the participants become upset that I provided phone numbers to local mental health facilities as well as ensured they have contact information for the Helmwood Autism Support group (University of Louisville, n.d.), information for the Crisis Text Line (Crisis Text Line, n.d.), and a handout for the 988 national crisis hotline if needed.

I did not conduct interviews until I received IRB approval (approval number: 07-21-25-0175020), and I did not ask for participation before I received IRB approval. Once I got IRB approval, I sent out my digital flyer from Appendix A on autism social media sites, per Table 1. Before any interviews were conducted, I obtained both verbal and written informed consent from each participant. Participants first received the informed consent form via email to review, and they replied with “I consent.” I then reviewed the

informed consent with them verbally at the start of the interview and asked if they had any questions to ensure understanding and give participants another opportunity to ask questions before beginning. Participation was completely voluntary, and participants were able to decline to answer any question or withdraw from the study at any time without penalty. All data, including interview recordings, transcripts, and demographic information, will be securely stored on a password-protected computer. Identifying information was removed, and participants were assigned a code number to protect confidentiality. According to Walden University guidelines (Walden University, 2025), all data will be securely stored for a minimum of 5 years and then destroyed. Digital files will be permanently deleted, and any physical documents will be shredded after that period, following university policies and IRB regulations.

All participants were over the age of 18 (because they are parents of autistic children who are 21 or older), and I assured that all recordings, transcripts, and my research are on my computer which is password protected. I have provided all my raw data to my chair and committee and will provide it to the IRB members if requested.

I did not use actual names of participants within the transcripts, nor did I provide identifying information or contact information. All participants were identified with a number, and their numbers will be kept separate from their identifying information and my transcripts.

### **Summary**

The purpose of this study was to explore the lived experiences that parents of ASD individuals experience when their ASD child turns 21 and transitions out of high

school and loses access to FAPE funding and a support system that was in place for the entirety of their educational experience up until then. This chapter highlighted my recruitment strategies through social media, how my data were collected and analyzed utilizing Zoom recording and (Zoom Video Communications, Inc.), and accounts for how I addressed issues of trustworthiness in the application of the study and ensured I knew how to handle any ethical issues that might arise.

## Chapter 4: Results

### **Introduction**

The purpose of this qualitative exploratory study was to explore the stress that parents feel when their autistic child turns 21 and loses FAPE services and the autistic child transitions out of high school. I interviewed individuals who had an autistic child 21 or older and had transitioned out of high school. My goal was to explore and gain a more thorough understanding of these parents' experiences during this transition. In this chapter, I will discuss the results of my study, including the research setting, the participant demographics, data collection, data analysis, and evidence of trustworthiness.

### **Setting**

I completed all five interviews using Zoom online and I backed the interviews up with a separate recording. All interviews were conducted via audio only on Zoom. The interviews were conducted in my home office, which is enclosed with a door. In addition, I asked participants to conduct the interview in a quiet space, which was evident from the lack of noise during the interviews. There were no issues with the interview space or with Zoom. All interviews were completed in the same space utilizing the same equipment (my laptop and internet connection).

### **Demographics**

The demographic makeup of participants was determined by the inclusion criteria for this study. To participate, individuals had to be a parent or legal guardian of an autistic child who was 21 years of age or older and who had transitioned out of high school. A total of five parents participated in the study.

The parents who participated represented a range of experiences in terms of how long it had been since their child transitioned out of FAPE services. Some of the participants were still navigating the changes that occur when services end at age 21 because they were recent, while others reflected on their experiences that had taken place years earlier.

No additional demographic information such as race, ethnicity, socioeconomic status, or educational background was collected, as this was not necessary for answering the RQs. The primary focus remained on the lived experiences of these parents as their autistic child aged out of FAPE services and the stress this caused.

### **Data Collection**

The sample for this study consisted of five participants who met the inclusion criteria. Each participant was interviewed individually through Zoom. Interviews varied in time, with the average time lasting around 14 minutes. I followed the protocol outlined in Chapter 3, and there were no unusual circumstances that occurred during data collection. Participants were recruited through social media using a flyer that I created and submitted as part of my IRB application, which was approved prior to use.

Interviews were audio recorded through Zoom, and I used a secondary recording device as a backup to ensure no data was lost in case of technical issues. Before participating, each individual was emailed a consent form. To confirm consent, participants were asked to reply to the email with the statement, "I consent," per the instructions outlined by IRB. Only after this written confirmation was received did interviews take place.

### **Data Analysis**

Data analysis followed the procedures that I had outlined in Chapter 3, and it was consistent with a qualitative narrative inquiry design. Although I initially planned to use NVivo software (as stated in Chapter 3), I decided to complete my analysis using hand coding. I made this change because of the small sample size. The small sample size made hand coding more efficient and allowed, in my opinion, a more direct approach but still supported both rigor and transparency. I used Excel to organize transcripts and participant quotes as well as codes, which I added within the document. This helped me to easily identify themes. This decision by no means affected the analytic process, but I felt it was the best fit based on the scope and breadth of this study. This study still aligned with the systematic steps of the thematic analysis as outlined by Braun and Clarke (2006). Each interview was transcribed, and I read through each interview several times in order to better identify statements and key words. The first stage involved open coding, where I highlighted significant words and phrases as well as passages that spoke to the experience of the parents being interviewed. From there, I grouped the related words into broader categories that highlighted shared experiences or recurring themes.

I noticed overarching themes that represented the experiences of the parents, and I highlighted those and added them to an excel spreadsheet that incorporated exact quotes from the parents that were interviewed to better understand their experience from their own words. This process was repeated for each participant until there were no new ideas, or new themes or patterns that emerged from the data. This was an indication that saturation had been met or reached.

During my coding process, I identified specific codes such as stress, financial burden, long waitlists, family support, lack of guidance, and frustration with state programs. I was then able to organize the codes into my broader categories such as service barriers, emotional toll, and family coping. Then from this, I identified my eight themes: lack of services and support, long waitlists and services delays, financial strain, family support as a lifeline, lack of awareness/guidance, and structured transition planning, the frustration with state programs, emotional toll and caregiver burden, and finally limited vocational and social opportunities. One example would be that Participant 2 described, “We’re going on 22 next week, and we still don’t have services.” This statement reflected both lack of services and long waitlists and delays. Another example is when Participant 1 stated that “luckily we have a good family support system.” This reflects family support as a code and ties into the theme of family support as a lifeline. While there were some families that had more support from family members than others, the challenges remained the same with all the participants.

### **Evidence of Trustworthiness**

In this study it was important to establish trustworthiness to show that my findings were valid. The steps or components of trustworthiness are credibility, transferability, dependability, and confirmability. I have broken down these steps in the following manner.

Credibility was supported by using participants’ own words which were then input into an excel spreadsheet to better identify themes from each participants’ experiences. I ensured that I captured the participants words verbatim in order to

accurately reflect their experiences. In order to further strengthen the credibility of this exploratory study, I followed Braun and Clarke's (2006) systematic approach which includes familiarization with the data, generating the initial codes, identifying themes, reviewing those themes before defining and naming them, and finally producing the final report. According to Naeem et al. (2023), both inductive and deductive coding can be utilized in order to allow new themes to emerge while also connecting those findings to my conceptual framework. The steps that I followed are supported by Adler's (2022) recommendation that when conducting qualitative research you should be transparent in data collection, in interpretation, and reflexivity.

Transferability was supported through the findings. Although I only had five participants for this study, their experiences were highlighted by their personal stories. These findings included themes such as lack of services and support, long waitlists and service delays, financial strain, family support as a lifeline, lack of awareness and structured transition planning, frustration with state programs, caregiver burden, and limited vocational and social opportunities. I was able to present these shared themes with direct quotes which allow readers to see for themselves how these experiences may be connected with other contexts. According to Adler (2022), transparency is essential to transferability, and I supported transparency through the documentation of the research process which includes the recruitment, the consent, and the coding procedures. In addition, I utilized the six-step process that Naeem et al. (2023) described, which is transcription, familiarization, coding, theme development, interpretation, and conceptual modeling. This together helped to create a transparent analytic trail which further

shows the transferability of this exploratory study. I would also like to point out that this exploratory study could bring about social change in other similar locations.

Dependability was addressed because I remained consistent in my process and analysis. According to Nowell et al. (2017), in order to maintain dependability in qualitative research you need to ensure that the interview procedures are consistent and do not vary from one participant to the other. Participants were recruited and selected in the same way, without deviation from the criteria I set, and each participant was interviewed via Zoom. Each interview was recorded and transcribed in the same way and themes were developed through the same process. Each question was read to the interviewee the same way and I allowed participants to expand naturally with each question. While I had allowed for follow up questions to be asked through the consent from language, there were no follow-up questions that I felt were needed for this exploratory study.

Confirmability was established through my journaling and self-awareness of potential bias. According to Karcher et al. (2024), reflexive journaling creates a more transparent research process. This is done by highlighting overlooked details as well as enhancing the objectivity of the research. In my reflexive journal, I recorded my thoughts after each interview, allowing me to track or identify any biases as well as ensure that any perspectives or perceptions that I might have personally did not influence the research process. I ensured that my role was just one of the researcher in order to better understand the experiences of the parents. By utilizing reflexive journaling, it helped me stay in the

role of the researcher and keep focused on my goal of understanding the experiences of other parents.

## **Results**

The RQs for this exploratory study were as follows: What are the lived experiences of parents when their autistic child turns 21? What are parents' perceptions of the changes and/or reduction of services and resources when their autistic child turns 21? Based on the responses from the participants of this study, I identified a total of nine themes. While some of the themes do connect with each other, I decided to lay out all the themes for the purpose of this study.

### **Theme 1: Lack of Services and Support**

In this study all five participants consistently described the lack of services and support once their child turned 21 and transitioned out of high school. Participant 5 mentioned, "There ain't no help out here at all...for any special needs person." Participant 2 stated, "We're going on 22 next week, and we still don't have services." Participant 4 stated, "Overall...there's really nothing to offer my child...nothing. I have nothing, nothing." These accounts from the participants illustrate that they felt as if they had been left on their own to manage the care and find services for their child.

### **Theme 2: Long Waitlists and Service Delays**

In this study, more than half of the participants felt that if there were services there were extremely long wait lists, sometimes lasting several years. The participants felt that even when resources were there, they were not accessible in a timely manner. In addition, participants noted that accessibility was inhibited by services that were located a

distance away, necessitating long drives to and from services. This made it difficult for the parents to maintain the services for their child, especially if the parents were working.

### **Theme 3: Financial Strain**

In this study more than half of the participants frequently emphasized the financial burden of paying for out-of-pocket services, such as adult day care, health care, and therapy. Costs created a constant source of stress for the participants, especially when insurance did not cover costs. Participant 4 shared “I called 14 dentists in a row...finally found two...and they were nine months out. It cost me, they sued me. It was \$2,500...I didn’t even know I owed.” Participant 5 shared, “Insurance really don’t like to cover that. Most of its out of pocket.” Participant 1 stated, “Rally the only alternative was the adult daycare in Elizabethtown which of course, is very expensive. It’s about 80 bucks a day.” These examples highlight that financial strain was significant during the transition process.

### **Theme 4: Family Support as a Lifeline**

In addition to reporting the absence or scarcity of services and the financial burdens of out-of-pocket costs for many services, the theme of more than half of the participants needed to rely on family members to help fill these gaps arose. Participants highlighted this support as essential in order to maintain work and daily living.

### **Theme 5: Lack of Awareness/Guidance and Structured Transition Planning**

In this study, more than half of the participants reported that they felt there was little or no guidance from schools or outside agencies that might be able to help during or after the transition period. Participants felt that they were on their own after transitioning

out of high school and FAPE services. Many of the participants were unaware that there were resources until much later which delayed access to the services needed. There was a strong correlation among participants that their awareness of services was either absent, or it came much later after their child had already transitioned out of high school. For example, Participant 2 stated,

You need to start the transition process at age 16, so by age 21 you are in line for those services...they don't prepare you. They act like it's going to be a great transition; it's going to be an easy transition...and it is not.

In addition, Participant 3 stated,

I've been talking about transition since my son was in the ninth grade...but I don't think we did a good job...they kept asking me what I wanted to do. I'm not an educator...I wanted to know what my options were, but nobody guided me.

Overall, participants felt unprepared for the challenges of adulthood for their children, because there was no structured transition plan that addressed what would happen after their child turned 21 and lost FAPE services.

More than half the participants described a significant lack of guidance, planning, and awareness of services during the transition out of high school and FAPE services. Parents did express that they were left to figure things out on their own, and that they were often not aware of what services were available to them. Participant 2 stated, "You need to start the transition process at age 16, so by age 21 you are in line for those services...they don't prepare you. They act like it's going to be a great transition...and it is not." Participant 3 stated,

I've been talking about transition since my son was in the ninth grade...but I don't think we did a good job...they kept asking me what I wanted to do. I'm not an educator...I wanted to know what my options were, but nobody guided me.

This theme reflects that there was a deep frustration among the participants regarding the transition process. In addition, there were missed opportunities and missed services due to a lack of planning, a lack of a structured roadmap for services, and a lack of awareness of what was available.

#### **Theme 6: Frustration With State Programs**

All five participants expressed disappointment across the board with state programs that did not provide guidance or help after their child with autism transitioned out of high school. For example, Participant 5 stated,

I believe there are some of the people out there know the things they could tell you to help you, but it's like they don't want to help you. It's like if you ask for resources, it's almost like it's coming from their pocket.

Participants felt that state representatives led them to believe there were more state programs than there actually were.

#### **Theme 7: Emotional Toll and Caregiver Burden**

All five participants reported that they felt overwhelmed, exhausted, and even desperate when faced with the limited options they found for their children. For example, Participant 2 stated, "They don't give you an in-depth detail that it's going to be extremely hard and emotional." Participant 3 stated, "Theres a lot of anxiety, I can tell

you that...that's why I'm out here planting flowers...because I need to decompress...Its just, I need to get some rest and clear my mind." Finally Participant 4 stated,

It is stressful, I can honestly say, I don't know if I could even put a level of stress that I have...there's not a day that goes by that I don't worry about it at some point during the day.

The transition out of high school and loss of FAPE services placed a heavy emotional and sometimes physical burden on parents as they navigated through an unfamiliar landscape and their statements reflect that.

### **Theme 8: Limited Vocational and Social Opportunities**

More than half of the participants highlighted that there were very limited opportunities for employment, social interaction, or community involvement after their child turned 21 and their child transitioned out of high school and FAPE services. For example, Participant 3 stated,

We're not ready to meet the needs of this particular population...everything for elderly people or for kids that are younger, not 21 and above...my disappointment comes because...I don't think that we did a good job with trying to make sure out students can have positions.

Participant 1 stated, "I think we both were a little depressed. He missed his socialization, and you know, I missed being able to go out and about and do my job while he was at school. It was a very difficult time." Participant 4 stated,

I wanted to get him a kind of part-time job, but I can't get any kind of aid to go with him. So, the transition has been non-existent. It's just been from high school to my mother's house every day.

This reflects that there was a loss of structure that had been provided by the school and FAPE, and in addition it left the families concerned about quality of life and loss of routine and interpersonal interaction on a daily basis outside the family of origin.

While most of the participants' experiences were in line with the eight themes there were some outliers. For example, one parent described that they had found a dentist who continued to see her child into adulthood, which was not the norm for the rest of the participants who struggled or were still struggling to find dental care. Another parent discussed that her mother was the caregiver which made the transition better. This is consistent with the findings that other participants had to find alternate care, but it was a bit different because this participant had someone available immediately which made her child's transition less difficult. These discrepant cases did not obscure or take away from the accounts of the other participants and they did not diminish my overall findings, because they actually highlighted the lack of services, the lack of guidance, and the lack of opportunities. What these discrepant cases did was showcase the full range of participants' experiences.

A summary of the eight themes identified in this study, along with the participants who endorsed each theme, is presented in Table 3 .

**Table 3***Themes and Participant Endorsements*

Theme	Summary of theme	Participants endorsing theme
1. Lack of services and support	Parents reported no help available after age 21.	P1, P2, P4, P5
2. Long waitlists and services delays	Services had waitlists from months to years, disrupting care.	P1, P2, P3, P5
3. Financial strain	High out-of-pocket costs for adult programs/therapies.	P2, P3, P5
4. Family support as a lifeline	Grandparents/siblings filled service gaps.	P1, P4, P5
5. Lack of awareness/guidance and transition planning	Parents felt unprepared, unaware of resources.	P1, P2, P3, P5
6. Frustration with state programs	Misleading or inadequate program information from state reps.	P2, P4, P5
7. Emotional toll and caregiver burden	Parents are overwhelmed, exhausted, and anxious.	P1, P2, P3, P4, P5
8. limited vocational and social opportunities	Few jobs or social opportunities available post-21.	P2, P3, P4

*Note.* P = Participant.

### Summary

The goal of this chapter was to present the findings from this exploratory study. As shown in Table 3, each of the eight themes was supported by multiple participants, illustrating both shared experiences and individual variations in this monumental transition process. The experience of the participants showed that there was a consistent set of challenges that the parents had to overcome after their child transitioned out of high

school and FAPE services. The challenges they faced were lack of services, long wait times for those services that were available, financial strain, reliance on family members, a lack of transition and preparation for what would happen after transitioning out of high school and losing FAPE services, and caregiver burden coupled with limited opportunities. The eight themes that I highlighted are interconnected and show that there are systematic gaps while at the same time highlighting the emotional toll the participants faced after their child turned 21 and transitioned out of high school and FAPE services.

The findings in Chapter 4 showed that there were eight central themes that highlighted the lived experiences of parents as their autistic children turned 21 and transitioned out of high school and FAPE services. The eight themes discussed in this chapter highlight the lack of services and guidance, long waitlists, financial strain, reliance on family support, frustration with state programs, caregiver burden, and the limited opportunities available for autistic adults after they turn 21. While these findings do provide valuable insight into the challenges that these parents faced, they also highlight the gaps in services systems and transition planning that have contributed to the ongoing stress and uncertainty for families. In Chapter 5, I will interpret these findings and discuss the limitations of this study. In addition, I will offer recommendations for practice, policy, future research, and finally I will highlight the broader implication for positive social change.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this exploratory study was to use a qualitative narrative inquiry to explore the lived experiences of parents when their autistic child turned 21 and transitioned out of high school and FAPE services. I wanted to gain a better understanding of this transition based on these parents' experiences. This exploratory study examined parents' perceptions of this monumental change in their lives, the life of their child, and the impact on their families as a whole. The two RQs that were the guiding force behind this study were as follows: What are the lived experiences of parents when their autistic child turns 21? What are parents' perceptions of the changes and/or reduction of services and resources when their autistic child turns 21?

The participants included five parents whose autistic children had turned 21 and transitioned out of high school and FAPE services, and their interviews identified key themes that were present among all the participants. I identified eight themes that highlighted the experiences of these parents, including lack of services and support, long waitlists and services delays, financial strain, family support as a lifeline, lack of awareness/guidance and lack of structured transition planning, emotional toll and caregiver burden, frustration with state programs, and limited social and vocational opportunities. This chapter will discuss the interpretation of findings, the limitations of the study, recommendations, implications and my conclusion.

## **Interpretation of the Findings**

The purpose of this study was to explore the lived experiences of parents whose autistic child had turned 21 and transitioned out of high school and FAPE services. My goal was to find out what the parents' perceptions were regarding this transition process. I identified eight themes that helped to identify the difficulties and adjustments that parents had to make during this monumental transition. This section provides an interpretation of my findings and ties in with existing literature, my RQs, and my framework.

### **Theme 1: Lack of services and support**

Parents across the board reported that there were limited services available once their child turned 21 and transitioned out of high school and FAPE services. With the loss of these services and loss of the structured support of the school system, the parents reported in this study's interviews that they felt like they were left on their own to navigate this new chapter in their child's life. This finding aligns with earlier studies. According to Lunskey et al. (2021), parents face a great deal of stress when they have to navigate this new landscape of finding services, day programs, and suitable therapies. Anderson et al. (2018) also discussed service gaps and the end of support during this transition. According to Shanahan et al. (2021), this lack of services increases stressors for families and in addition the family must take on additional responsibilities, which include finding services, caregiver roles, and financial burdens.

**Theme 2: Long Waitlists and Service Delays**

Parents in this study consistently reported that services were difficult to find, and when they did find them there were often long waitlists that were detrimental to their child's well-being or quality of life. Parents expressed frustration with the lack of timely services and resulting disruption to their child's routine and quality of life. According to Anderson et al. (2018), the additional responsibilities that occur when services are disrupted for the autistic individual increases the strain to the parents and across the household. These results are consistent with previous research. According to Cridland et al. (2014), there is often little understanding of what parents go through when their child turns 21 and ages out of services.

**Theme 3: Financial Strain**

Parents described financial strain as an extremely challenging part of the transition process during their interviews in this study. The cited things such as the high cost of adult day programs, out of pocket medical expenses, and insurance that does not always cover therapies, as causes that left their families struggling to meet these new requirements. This is consistent with literature that highlights financial challenges once children are transitioned out of high school and FAPE services. According to Marscak-Topolewski and Weisz (2020), parents reported financial difficulties regarding adult daycare and complex funding systems for other services. Parents in this study described how the lack of affordable services intensified their stress.

**Theme 4: Family Support as a Lifeline**

Parents in this study consistently highlighted that support from family members has been essential in managing and navigating the changes after their child has transitioned out of high school and FAPE services. Parents described that they rely heavily on grandparents and siblings for both work and emotional support. This theme aligns with prior research documenting how families of autistic individuals rely heavily on family support. According to Marsack-Topolewski (2021), parents often use family support systems in the absence of formal systems. Schiltz et al. (2024) highlighted that family caregivers are significant in the care of autistic individuals from adolescence into adulthood. Parents of my exploratory study expressed that family support allowed them to continue to work and help meet the daily responsibilities of the autistic adult's care.

**Theme 5: Lack of Awareness, Guidance, and Structured Transition Planning**

Parents in my exploratory study described that they had a lack of awareness and guidance when it came to the transition process. Many reported that they received little information and were unaware of resources, sometimes learning years after their child had transitioned out of high school and FAPE services. Parents also expressed that transition planning either started too late or was not there for them, which they felt left them unprepared for the next steps in their child's and their lives. This finding is consistent with prior research which shows that families have reported that transition services were inefficient and that there was inadequate communication from the schools and state agencies which left them feeling unprepared to navigate this new chapter in their lives (Anderson et al., 2018; Shattuck et al., 2014).

**Theme 6: Emotional Toll and Caregiver Burden**

Parents in this study described that there has been an emotional toll and caregiver burden which has been a difficult aspect after their autistic child turned 21 and transitioned out of high school. Parents described that there was an abrupt halt to services, structure, and support which culminated in having to navigate finding programs, services, and support on their own. This added additional workloads for the parents such as finding medical care, finding or paying out for adult day programs, filling the gap for vocational and social opportunities, and working out a new schedule for themselves. This all contributed to additional stress that parents' experiences and contributed to both physical and emotional issues. All of the participants reported that they either felt overwhelmed, anxious, or worried as they tried to navigate this new landscape or chapter of their child's life. This finding connects to both RQs as families shared and expressed how the transition out of high school and FAPE services not only affected them but their child as well. This is consistent with existing literature that shows that when formal supports are taken away, parents will often have to assume additional roles, and this in turn heightens the stress and family dynamic and the overall well-being of the family (Lunksy, 2021; Marsack-Topolewski, 2021).

**Theme 7: Frustration With State Programs**

Parents in this exploratory study expressed deep frustration with state programs, describing them as unhelpful, misleading, inadequate, or nonexistent. Several parents mentioned that an unrealistic picture had been painted for them about the transition process and their child's future. This theme addresses my second question which asks

about the perceptions of the changes and/or reduction of services and resources when their autistic child turns 21. Instead of providing a stable net, parents felt that they were abandoned, and it caused them additional stress as they often felt there was a huge void and gap after transition. This finding is in line with prior research that shows that parents often experience heightened stress and a sense of isolation when formal supports end abruptly and leaves them to shoulder the responsibilities of caregiving all alone (Anderson et al., 2018; Marsack-Topolewski & Weisz, 2020).

### **Theme 8: Limited Vocational and Social Opportunities**

Parents in this exploratory study described that there was a sharp decline in their child's opportunities for vocational training, socialization, and employment after they turned 21 and transitioned out of high school. Parents in this study described there was an absence of opportunities for their autistic children and a lack of adult focused programs. Additionally, according to Shattuck et al. (2014), this finding is consistent with previous research discussing the limited postsecondary opportunities that are available.

### **Connection to Conceptual Framework**

The findings of this study align with family systems theory, which emphasizes that stressors that affect one member of the family can and do affect other members of the family like a ripple effect flowing across the entire family unit (see Cridland et al., 2014). The theme of lack of services and support as well as long waitlists and service delays show that routines were shifted among the participants, which created more responsibilities and disruption of schedules for the parents. The theme of financial strain showed that families had to depend on extended family or relatives, which highlights that

economic pressures can ripple throughout the family unit and connects to the theme family support as a lifeline, which highlights how parents had to rely on grandparents or other family members in order to address caregiving responsibilities. The theme lack of awareness, guidance, and structured transition planning highlights the parents' feelings of being unprepared and their inability to adjust to a monumental change at a rapid pace. The theme of emotional toll and caregiver burden highlights how the sudden change and loss of FAPE services magnified the stress and burden that the parents went through. The theme of frustration with state programs clearly demonstrated how inadequate and misleading the transition process was for the participants contributing to additional stress and affecting the family unit overall. Finally, the theme limited vocational and social opportunities highlighted that the lack of adult focused programs not only affected the autistic individual but also affected the family's long-term planning, their hope for the future of their autistic child, and their ability to imagine a better future later in life. These themes, when looked at together highlight the interconnectedness of family roles and the shared responsibilities illustrating how these themes ripple through the entire family unit.

### **Limitations of the Study**

This exploratory study had several limitations that should be acknowledged. First the sample size was small with only five parents, but the goal of this narrative inquiry was to capture or explore this phenomenon in depth starting with a small sampling and then hopefully heighten social awareness of this problem. Second, demographic information beyond the inclusion criteria was not collected. While this decision protected the privacy of the participants, there was an inability to capture or examine factors such

as race or socioeconomic status. Finally, all data were through self-reporting through interviews. As always, self-reporting responses could have been influenced by memory, interpretation, and social desirability. These limitations affect generalizability particularly when taking into account the demographic, which is focused on one region and the lack of a wide demographic diversity among the participants.

Another limitation that I mentioned in Chapter 1 was the potential for researcher bias, as I have a child with autism who turned 21 and aged out of FAPE services. In order to minimize risks, I used bracketing and reflexive journaling. This allowed me to go back and reflect on my own assumptions, to ensure that the analysis remained grounded in the participants' narratives and their experiences rather than my experiences. While these steps may not have eliminated all potential bias, they did enhance the transparency, the objectivity, and the credibility of this study. Despite these limitations, I feel that the findings provide valuable insights into the lived experiences of parents during their child's transition out of high school and FAPE services after they turn 21.

### **Recommendations**

Based on the findings from this exploratory study, it is recommended that practitioners and service providers begin transition earlier for families of individuals with Autism that will lose FAPE services upon completion of high school. Prior studies have also highlighted the importance of beginning transition discussion well before age 21 in order to help reduce stress and to improve success during this time (Anderson et al., 2018; Shattuck et al., 2014). It is additionally suggested there should be some provisions set in place that highlight what families will need to do to best support their child during

this transition out of high school, presented in a clear and concise manner which aligns with research about the lack of preparation during this time period (Lunsky et al., 2021). Parents in this study consistently reported that they felt unprepared, which suggests that schools, clinicians, and the community agencies involved in the transition process should take a look at having a more proactive role in the process.

Expanding vocational and social programs might also help to improve the quality of life of the autistic adults and help to reduce caregiver burden. According to Schiltz et al. (2024), when there is inadequate planning during transition periods leaves the parents feeling more stress and increases a reliance on informal caregiving systems. The loss of the structured based system from school which provided consistent schedules, vocational opportunities, and socialization all end after the child leaves the school. According to Marsack-Topolewski and Weisz (2020), the burden of filling this void falls to the family members.

In addition, there should be a focus on policy change. At the policy level, state agencies could better address the lengthy waitlists and the service shortages that were expressed by the parents' interview during this study. In addition, this study points to a possible need for increased funding measures for Medicaid waivers, adult day programs (with transportation), and specialized services in healthcare therapies, which parents in this study reported are currently falling to them to pay. Research has shown that these issues and inequities in programs add financial strain as well as stress (Lunsky et al., 2021). Policies could also be implemented that would help ensure that better communication with families occur so families will be notified in a timely manner what

the available supports and services are, with clear, concise, and transparent communication for transition planning. According to Shanahan et al. (2021), a critical component of this transition planning process is to ensure that there is indeed that component of communication with families that needs to take place, and the author also specifies that it should be in a clear, concise, and timely manner.

Finally, additional research could include a larger and more diverse population to explore how demographic factors shape the experiences of the parents. As pointed out by Keller (2020) and Frost (2024), using a family systems perspective can help highlight the effects of the transition out of high school and how it affects the parents and rest of the household. Future studies could also examine the perspective of the whole family, the school systems, and state agencies to gain a better understanding of the full process and where there may be breakdowns between these parties. Longitudinal research could capture how families navigate services over time, highlighting patterns of how they adapted and how they remained resilient during the process, which in turn could influence a feedback loop towards what adjustments can be made sooner in the transition process for autistic adults aging out of high school and FAPE services.

### **Implications**

The findings of this exploratory study carry several implications for practice, for policy, and for future research. The practice piece would be that professionals such as school staff, clinicians, and service providers could begin transition planning at a much earlier date and provide families clearer and more concise guidance while being completely transparent. As it relates to policy, the findings of this study suggest that state

agencies could step in and address issues like long waiting lists for post-high school services, funding gaps and financial burdens on families, and service shortages. The results of this study indicated that future research could be conducted with larger and more diverse sampling, to broaden the perspectives gathered from family members and could include the caregivers that are helping out the parents. In addition, this study supports Walden University's mission of promoting positive social change by allowing these parents to be heard about the challenges they experience during the monumental time of transition from high school and out of FAPE services once their child turns 21 and influencing how we can better support these adults through this transition. The changes that could be implemented by highlighting the unmet needs and systemic barriers that are faced during the transition time frame could create more opportunities for autistic adults and their families and help alleviate the stress that parents feel during and after the transition period.

### **Conclusion**

The purpose of this exploratory study was to explore the lived experiences of parents when their autistic child turned 21 and aged out of high school and FAPE services. I wanted to explore the experiences of these parents, to learn more about how the change in services and resources impacted the overall stress for these parents during this time. Through my narrative inquiry with five parents, I found that eight themes emerged, and while some of the themes do overlap, I felt that highlighting them individually better explored all the aspects of what these parents reported during their interviews. These themes reflected the challenges that parents indicated they had faced

during this transition period with their adult autistic child, including limited services, long waitlists, financial strain, reliance on family members for support, lack of guidance and structured planning, caregiver burden, frustration with state programs, and limited social and vocational opportunities.

The interpretation of these findings showed that parents face significant systemic barriers during this transition period which include gaps in services, transition planning, and state programs that left families feeling unsupported. In addition, the study highlighted the added emotional burden that parents felt during this monumental transition time. These experiences do support existing literature while helping to identify gaps in services, transition planning, and state programs that leave the parents feeling alone and stressed during this time.

Finally, this study highlights the resilience of these families, and the interviews provided an insight into the experiences of the parents and the stress those parents reported they felt when their child turned 21 and transitioned out of high school and lost FAPE services. By highlighting the voices of these parents, this study adds a meaningful perspective to the work that could be done to improve the transition process and promote positive social change for autistic individuals transitioning from high school and FAPE services into the next phase of their care.

## References

- 988 Suicide & Crisis Lifeline. (n.d). Help yourself, help others. <https://988lifeline.org>
- Adler, R. H. (2022). Trustworthiness in qualitative research. *Journal of Human Lactation*, 38(4), 598–602. <https://doi.org/10.1177/08903344221116620>
- Anderson, C., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics*, 141(Suppl 4), S300-S306. <https://doi.org/10.1542/peds.2016-4300G>
- Bagatell, N., Lamarche, E., & Klinger, L. (2023). Roles of caregivers of autistic adults: A qualitative study. *American Journal of Occupational Therapy*, 77(2). Article 7702205010 <https://doi.org/10.5014/ajot.2023.050117>
- Berg, K. A., Ishler, K. J., Lytle, S., Kaplan, R., Wang, F., Olgac, T., Miner, S., Edguer, M. N., & Biegel, D. E. (2023). “Don’t promise something you can’t deliver:” Caregivers’ advice for improving services to adolescents and young adults with autism. *Autism Research & Treatment*, 1–13. <https://doi.org/10.1155/2023/6597554>
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13), 1802–1811. <https://doi.org/10.1177/1049732316654870>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

- Brown, C. E., Quetsch, L. B., Aloia, L. S., & Kanne, S. M. (2024). Predictors of aggression, disruptive behavior, and anger dysregulation in youths with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, *54*(4), 1264–1280. <https://doi.org/10.1007/s10803-022-05876-6>
- Casula, M., Rangarajan, N., & Shields, P. (2021). The potential of working hypotheses for deductive exploratory research. *Quality & Quantity*, *55*(5), 1703–1725. <https://doi.org/10.1007/s11135-020-01072-9>
- Center for Public Education, (2020). Number of Students Served by IDEA (IDEA Fact Sheet #1)
- Chen, T., Xie, R., Yang, Q., Li, W., & Ding, W. (2024). Parents' perception of children's behaviors, self-compassion, and parenting stress: Actor–partner interdependence model. *Journal of Family Psychology*, *38*(1), 143–153. <https://doi.org/10.1037/fam0001270>
- Coates, W. C., Jordan, J., Clarke, S., & Pensa, C. (2021). A practical guide for conducting qualitative research in medical education: Part 2—Coding and thematic analysis. *AEM Education and Training*, *5*(4), e10645. <https://doi.org/10.1002/aet2.10645>
- Crasta, J. E., Green, O. J., Gavin, W.J., & Davies, P. L. (2024). The relationship between attention, sensory processing, and social responsiveness among adults on the autism spectrum. *Journal of Autism and Developmental Disorders*, *54*(8), 2972–2986. <https://doi.org/10.1007/s10803-023-06019-1>
- Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism

- spectrum disorder research: A review of the utility of family systems approaches. *Autism*, 18(3), 213–222. <https://doi.org/10.1177/1362361312472261>
- Curtiss, S. L., Lee, G. K., Chun, J., Lee, H., Kuo, H. J., & Ami-Narh, D. (2021). Autistic young adults', parents', and practitioners' expectations of the transition to adulthood. *Career Development and Transition for Exceptional Individuals*, 44(3), 174–185. <https://doi.org/10.1177/2165143420967662>
- Dahal, N., Neupane, B. P., Pant, B. P., Dhakal, R. K., Giri, D. R., Ghimire, P. R., & Bhandari, L. P. (2025). Participant selection procedures in qualitative research: experiences and some points for consideration. *Frontiers in Research Metrics & Analytics*, 1–13. <https://doi.org/10.3389/frma.2024.1512747>
- Dantchev, S., Zemp, M., & Wolke, D. (2023). Child hyperactivity, mother–child negativity, and sibling dyad negativity: A transactional family systems approach. *Journal of Family Psychology*, 38(1), 82–91–91. <https://doi.org/10.1037/fam0001090>
- Davy, G., Barbaro, J., Unwin, K., & Dissanayake, C. (2024). Leisure, employment, community participation, and quality of life in primary caregivers of autistic children: A qualitative study. *Journal of Autism and Developmental Disorders*, 54(7), 2591–2603. <https://doi.org/10.1007/s10803-023-05992-x>
- Dietz, P. M., Rose, C. E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 50(12), 4258–4266. <https://doi.org/10.1007/s10803-020-04494-4>

- Fang, Y., Luo, J., Boele, M., Windhorst, D., van Grieken, A., & Raat, H. (2024). Parent, child, and situational factors associated with parenting stress: A systematic review. *European Child & Adolescent Psychiatry, 33*(6), 1687–1705.  
<https://doi.org/10.1007/s00787-022-02027-1>
- Frost, R. T. (2024). Making sense of human life: Murray Bowen’s determined effort toward family systems theory. *Family Systems: A Journal of Natural Systems Thinking in Psychiatry & the Sciences, 19*(1), 87–92.
- Glidden, L. M., Floyd, F. J., Hastings, R. P., & Mailick, M. R. (2021). Family impact and adjustment across the lifespan: Parents of children with intellectual and developmental disabilities. In L. M. Glidden, F. J. Floyd, R. P. Hastings, & M. R. Mailick (Eds.), *APA handbook of intellectual and developmental disabilities: Clinical and educational implications: Prevention, intervention, and treatment* (Vol. 2, pp. 213–246). American Psychological Association.  
<https://doi.org/10.1037/0000195-009>
- Mertova, P. (2020). *Using narrative inquiry as a research method : An introduction to critical event narrative analysis in research, teaching and professional practice* (L. Webster, Ed.; 2nd ed.). Routledge.
- Grajzel, K. (2025). Meditation in qualitative research for bracketing and beyond. *International Journal of Qualitative Methods, 1*–10.  
<https://doi.org/10.1177/16094069241312826>
- Habayeb, S., Al-Harashseh, S., Ratto, A., Verbalis, A., Pugliese, C., Nadwodny, N., Al-Meer, F., & El-Akoum, M. (2022). Meeting the needs of autistic adults in Qatar:

- Stakeholder perspectives on gaps in services and priorities for future programming. *Autism*, 26(1), 88–100.
- Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). Development of stigma-related support for autistic adults: Insights from the autism community. *Autism*, 27(6), 1676–1689. <https://doi.org/10.1177/13623613221143590>
- Hart, L. C., Saha, H., Lawrence, S., Friedman, S., Irwin, P., & Hanks, C. (2022). Implementation and evolution of a primary care-based program for adolescents and young adults on the autism spectrum. *Journal of Autism and Developmental Disorders*, 52(7), 2924–2933. <https://doi.org/10.1007/s10803-021-05171-w>
- Helmwood Autism Support Group. (n.d.). University of Louisville. <https://www.louisville.edu/helmwoodautism/about>
- Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Brief report: What happens when I can no longer support my autistic relative? Worries about the future for family members of autistic adults. *Journal of Autism and Developmental Disorders*, 47(11), 3659–3668. <https://doi.org/10.1007/s10803-017-3254-6>
- Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: a focus on under-represented families. *International Journal of Developmental Disabilities*, 65(1), 20–30. <https://doi-org.ezp.waldenulibrary.org/10.1080/20473869.2017.1347228>
- Johnson, B. E., & Ray, W. A. (2016). Family systems theory. In C. L. Shehan (Ed.), *The Wiley Blackwell encyclopedia of family studies* (pp. 1–5). Wiley.

<https://doi.org/10.1002/9781119085621.wbefs130>

- Karcher, K., McCuaig, J., & King-Hill, S. (2024). (Self-) reflection / reflexivity in sensitive, qualitative research: A scoping review. *International Journal of Qualitative Methods*, 23, 1–13.
- Karlsen, M.-M. W., Heyn, L. G., & Heggdal, K. (2024). Being a patient in the intensive care unit: A narrative approach to understanding patients' experiences of being awake and on mechanical ventilation. *International Journal of Qualitative Studies on Health & Well-Being*, 19(1), 1–13.
- <https://doi.org/10.1080/17482631.2024.2322174>
- Karnas, M. (2023). What coping strategies do parents of children with autism use to cope with stress? *International Journal on Social and Education Sciences*, 5(3), 722–735.
- Keller, M. N. (2020). Bowen theory: A systems model for family research. In M. N. Keller & R. J. Noone (Eds.), *Handbook of Bowen family systems theory and research methods: A systems model for family research*. (pp. 49–61). Routledge/Taylor & Francis Group. <https://doi.org/10.4324/9781351103282-5>
- Knudson, S. (2024). Transition planning and perceptions of support in an autism spectrum disorder resource program. *Preventing School Failure*, 68(3), 220–230.
- <https://doi.org/10.1080/1045988X.2023.2207482>
- Kurth, J. A., Lockman Turner, E., Gerasimova, D., Hicks, T. A., Zagona, A., Lansey, K., Mansouri, M. C., Jameson, J. M., & Loyless, R. (2024). Quality of IEPs for students with complex support needs: Is there alignment across IEP components?

*Exceptionality* 32(2), 109–124. <https://doi.org/10.1080/09362835.2024.2389079>

Lai, J., Luo, O. D., Klag, M., & Shikako-Thomas, K. (2021). Caregiver perceptions of care of a medical-dental community clinic for adults with autism and intellectual disabilities: Implementing a program evaluation. *Journal of Intellectual & Developmental Disability*, 46(4), 306–318.

<https://doi.org/10.3109/13668250.2020.1865684>

Leal, P. (2023). Emily is an egg: An example of a narrative analysis approach to the antecedents of critical language teacher cognition. *TESL-EJ*, 27(2).

Lequia, J. L., Vincent, L. B., Lyons, G. L., Asmus, J. M., & Carter, E. W. (2023). Individualized education programs of high school students with significant disabilities. *Education and Training in Autism and Developmental Disabilities*, 58(1), 22–35.

Levine, A. A., Cole, M. B., Michals, A. L., Wang, N., & Rubenstein, E. (2024).

Inequities in Medicaid home- and community-based services waiver enrollment among people with intellectual and/or developmental disabilities: A nationwide claims-based analysis. *Disability and Health Journal*, 17(2) 101676.

<https://doi.org/10.1016/j.dhjo.2024.101676>

Liu, S., Zhang, L., Yi, J., Liu, S., Li, D., Wu, D., & Yin, H. (2024). The relationship between parenting stress and parental burnout among Chinese parents of children with ASD: A moderated mediation model. *Journal of Autism and Developmental Disorders*, 54(4), 1527–1537. <https://doi.org/10.1007/s10803-022-05854-y>

Looden, T., Floris, D. L., Llera, A., Chauvin, R. J., Charman, T., Banaschewski, T.,

- Murphy, D., Marquand, A. F., Buitelaar, J. K., & Beckmann, C. F. (2022). Patterns of connectome variability in autism across five functional activation tasks: findings from the LEAP project. *Molecular Autism*, *13*(1), Article 53. <https://doi.org/10.1186/s13229-022-00529-y>
- Lunsky, Y., Albaum, C., Baskin, A., Hastings, R. P., Hutton, S., Steel, L., Wang, W., & Weiss, J. (2021). Group virtual mindfulness-based intervention for parents of autistic adolescents and adults. *Journal of Autism and Developmental Disorders*, *51*(11), 3959–3969. <https://doi.org/10.1007/s10803-020-04835-3>
- Marsack-Topolewski, C. N. (2021). Parental caregivers' use of support networks for adults with autism by educational status. *Journal of Family Social Work*, *24*(2), 81–97. <https://doi.org/10.1080/10522158.2020.1777239>
- Marsack-Topolewski, C. N., & Weisz, A. N. (2020). Parents' perceptions of access to services for their adult children diagnosed with autism spectrum disorder. *Families in Society*, *101*(2), 190–204. <https://doi.org/10.1177/1044389419881273>
- Matshaka, C. (2024). Narratives as a gateway to transitional justice: reflections on research methodology. *Acta Academica*, *56*(1), 103–120. <https://doi.org/10.38140/aa.v56i1.8010>
- Mbamba, C. R., & Ndemole, I. K. (2021). “I paused my life”: Experiences of single mothers caring for their autistic children in Ghana. *Journal of Social Service Research*, *47*(5), 659–669. <https://doi.org/10.1080/01488376.2021.1875966>
- Naeem, M., Ozuem, W., Howell, K., & Ranfagni, S. (2023). A step-by-step process of thematic analysis to develop a conceptual model in qualitative research.

*International Journal of Qualitative Methods*, 1–18.

<https://doi.org/10.1177/16094069231205789>

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis:

Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13.

Parry, J. A., Brosnan, S., Newton, J. T., Linehan, C., & Ryan, C. (2021). Brief report:

Analysis of dental treatment provided under general anesthesia for children and young adults with autistic spectrum disorder and identification of challenges for dental services. *Journal of Autism and Developmental Disorders*, 51(12), 4698–4703. <https://doi.org/10.1007/s10803-021-04898-w>

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4<sup>th</sup> ed.). SAGE Publications.

Perlman, J., & Howe, N. (2023). Mothers' perceptions of the sibling relationship when one child has autism spectrum disorder. *Journal of Child & Family Studies*, 32(3), 965–976. <https://doi.org/10.1007/s10826-022-02495-8>

Pillay, Y., Brownlow, C., & March, S. (2022). Transition approaches for autistic young adults: A case series study. *PLOS ONE*, 17(5), Article e0267942.

<https://doi.org/10.1371/journal.pone.0267942>

Piotrowski, N. A., & Houp, K. H. (2024). Intellectual disability. *Salem Press*

*Encyclopedia of Health*.

Quiban, C., Brooks, R., & Armstrong, D. (2020). Caring for adult patients with autism in the critical care setting. *Critical Care Nursing Quarterly*, 43(1), 58–67.

- Rai, D., Webb, D., Lewis, A., Cotton, L., Norris, J. E., Alexander, R., Baldwin, D. S., Brugha, T., Cochrane, M., Del Piccolo, M. C., Glasson, E. J., Hatch, K. K., Kessler, D., Langdon, P. E., Leonard, H., MacNeill, S. J., Mills, N., Morales, M. V., Morgan, Z., ... Wiles, N. (2024). Sertraline for anxiety in adults with a diagnosis of autism (STRATA): study protocol for a pragmatic, multicentre, double-blind, placebo-controlled randomised controlled trial. *Trials*, 25(1), Article 37. <https://doi.org/10.1186/s13063-023-07847-3>
- Ravitch, S. M., & Carl, N. M. (2021). *Qualitative research: Bridging the conceptual, theoretical, and methodological* (3rd ed.). SAGE Publications.
- Reilmann, C., & Barber, H. P. (2024). The SBO's Guide to Maximizing Federal Funding for Public School Districts: Tips for not only securing federal funds, but also optimizing their impact on student success. *School Business Affairs*, 90(3), 15–16.
- Roberts, C. (2021). A review of the literature on siblings of individuals with severe intellectual disabilities. *International Review of Research in Developmental Disabilities*, 60, 153-188. <https://doi.org/10.1016/bs.irrdd.2021.08.005>
- Rusu, D. M., Stevanovic, D., & Enea, V. (2024). Affiliate stigma and parental stress among parents of children with autism spectrum disorder: The mediating role of shame. *Focus on Autism and Other Developmental Disabilities*, 39(2), 127–135. <https://doi.org/10.1177/10883576231221751>
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlan, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52, 1893–1907.

<https://doi.org/10.1007/s11135-017-0574-8>

Scanlon, D., Calhoun, M. B., & Berkeley, S. (2021). Making FAPE appropriate now for students with learning disabilities. *Learning Disabilities Research & Practice*, 36(4), 287–294. <https://doi.org/10.1111/ldrp.12262>

Schiltz, H. K., Clarke, E., Rosen, N., De La Rosa, S. G., Masjedi, N., Christopher, K., & Lord, C. (2024). A longitudinal mixed-methods characterization of family support from adolescence to young adulthood in autism and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 54(9), 3225–3241. <https://doi.org/10.1007/s10803-023-06070-y>

Schmeer, A., Harris, V.W., Forthun, L., Valcante, G., & Visconti, B. (2021). Through the eyes of a child: Sibling perspectives on having a sibling diagnosed with autism. *Research in Developmental Disabilities*, 119, Article 104066. <https://doi.org/10.1016/j.ridd.2021.104066>

Schott, W., Nonnemacher, S., & Shea, L. (2021). Service use and unmet needs among adults with autism awaiting home- and community-based Medicaid services. *Journal of Autism and Developmental Disorders*, 51(4), 1188–1200. <https://doi.org/10.1007/s10803-020-04593-2>

Shanahan, P., Ollis, L., Balla, K., Patel, R., & Long, K. (2021). Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition. *Health & Social Care in the Community*, 29(5), 1429–1438. <https://doi.org/10.1111/hsc.13198>

Shea, L. L., Koffer Miller, K.H., Verstreate, K., Tao, S., & Mandell, D. (2021). States'

- use of Medicaid to meet the needs of autistic individuals. *Health Services Research, 56*(6), 1207–1214. <https://doi.org/10.1111/1475-6773.13671>
- Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., Trani, J. F., & Anderson, K. A. (2014). Services for adults with an autism spectrum disorder: A systems perspective. *Autism Research and Treatment, 2014*, Article 924182. <https://doi.org/10.1155/2014/924182>
- Siman-Tov, A., & Sharabi, A. (2023). Differences between typically-developing brothers & sisters with developmental disabilities. *Journal of Child & Family Studies, 32*(5), 1559–1570. <https://doi.org/10.1007/s10826-023-02574-4>
- Slaughter, V. (2024). Autism. *Salem Press Encyclopedia of Health*.
- Spurrier, A., O’Keefe, B., & Schiess, J. (2023). *How are public schools funded? Splitting the bill: A Bellwether series on education finance equity* (No. 2). Bellwether [https://bellwether.org/wp-content/uploads/2023/10/splittingthebill\\_2\\_Bellwether\\_October2023.pdf](https://bellwether.org/wp-content/uploads/2023/10/splittingthebill_2_Bellwether_October2023.pdf)
- Stamer, C. M. (2023). Federal mental health parity rules eroding traditional health plan limits on ABA and other behavioral treatments for autism. *TortSource, 25*(4), 1–15.
- Thakkar, H. (2018). “It’s like me leaving a manual of me behind”: Parents talk about succession planning of long-term care and support for their disabled adult children with high and complex needs. *Aotearoa New Zealand Social Work Review, 30*(2), 3–15. <https://doi.org/10.11157/anzswj-vol30iss2id506>
- Volkmar, F. R., & Solomon, C. (2023). Youth with autism spectrum disorder and the

- transition to adulthood. In L. J. Crockett, G. Carlo, & J. E. Schulenberg (Eds.), *APA handbook of adolescent and young adult development* (pp. 457–468). American Psychological Association. <https://doi.org/10.1037/0000298-028>
- Walden University. (2025). *University guidelines for data retention and destruction*.
- Weatherford, J., & Maitra, D. (2019). How online students approach bracketing: A survey research study. *Educational Research: Theory and Practice, 30*(2), 91–102.
- Witwer, A. N., Walton, K., & Held, M. K. (2022). Taking an evidence-based child- and family-centered perspective on early autism intervention. *Clinical Psychology: Science and Practice, 29*(4), 420–422. <https://doi.org/10.1037/cps0000122>
- Wolpe, S. M., Johnson, A. R., & Kim, S. (2023). Navigating the transition to adulthood: Insights from caregivers of autistic individuals. *Journal of Autism & Developmental Disorders, 54*(11), 8966–8980. <https://doi.org/10.1007/s10803-023-06196-z>
- Wong, V., Pham, M., Godfrey, K., & Milstein, A. (2022). Distilling innovative US autism care programs that address widely perceived unmet patient and family needs. *Autism, 26*(1), 281–286. <https://doi.org/10.1177/13623613211027999>
- Wong, V., Ruble, L., & Brown, L. (2020). “We are mama and papa bears”: A qualitative study of parents’ adaptation process during transition to adulthood. *Research in Autism Spectrum Disorders, 79*, Article 101671. <https://doi.org/10.1016/j.rasd.2020.101671>
- Wright, B. M., Benigno, J. P., McCarthy, J. W., & Chabot, J. (2024). “They change our

lives more than we change them”: Young adults’ perspectives on relationships with autistic siblings. *International Journal of Disability, Development & Education*, 71(3), 389–402. <https://doi.org/10.1080/1034912X.2022.2095361>

Zeidan, J., Fombonne, E., Scolah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778–790. <https://doi.org/10.1002/aur.2696>

## Appendix A: Recruitment Flyer

**Zoom interview: I am seeking participants who have adults over the age of 21 with**

**Autism**



There is a new study called “The Stress Parents Face When Their Autistic Child Turns 21: An Exploratory Study”, which could help mental health professionals and schools better prepare parents for the transition from the high school environment to parent focused care. For this study, you are invited to describe your experiences with your autistic child and how this has impacted you.

About the study:

- One 30-60 minutes online interview
  - Zoom interview, which will be audio recorded
- Possible short phone call follow up (if needed for clarification)

Volunteers must meet these requirements:

- Parent of an autistic adult who has transitioned out of high school and is over the age of 21
- Your autistic child (over age 21) received FAPE services
- Read, speak, and understand English to respond to this post, please contact Everetta Davis at [telephone number redacted], or email [address redacted].

This survey is part of the doctoral study for Everetta Davis, a Ph.D. student at Walden University. Interviews will take place during [Date timeframe to be entered after IRB approval].

Please use the listed contact information to let me know of your interest.

## Appendix B: Interview Questions

1. What was it like for you once your child turned 21 and had to leave high school?
2. What was your experience in finding services for your child after your child turned 21?
3. Can you describe your experience in finding other comparable services such as Speech therapy, occupational therapy, and Applied Behavior Analysis (ABA) therapy for your child?
4. What was your experience in finding care such as dental care for your child after they turned 21?
5. What has been your experience with finding day care or day programs and transportation to those programs for your child?
6. Overall how would you describe the transition process out of high school and other services?
7. Can you describe how state programs did or did not help you feel prepared when your child left high school?

## Appendix C: Interview Protocol

*(This interview protocol was developed based on prior research and literature aligned with the Family Systems Theory conceptual framework, and no pilot study will be conducted).*

### **Interview Protocol**

#### **Title:**

The Experiences of Parents Following the Transition Out of High School for Autistic Children at Age 21

**Interviewer:** [Your Name]

**Date:** [Insert Date]

**Location:** [e.g., Zoom, in-person]

**Participant ID:** [e.g., P01]

#### **Introduction (Scripted)**

“Thank you so much for taking the time to participate in this study. I’m interested in learning about your experiences as a parent whose autistic child transitioned out of high school FAPE services when they turned 21. I’d like to hear your personal story and how you feel about the transition process and what that process has been like for you and your family. This interview is completely confidential, and you may skip any question or stop at any time. With your permission, I will be recording the interview which is necessary for me so that I can be accurate when I transcribe this interview on paper. Do you have any questions before we begin?”

**Demographic Information**

1. Age of your child now?
2. Relationship to child (e.g., mother, father, legal guardian)?
3. What types of services did your child receive in high school (e.g., IEP, speech therapy, ABA)?
4. What services, if any, does your child currently receive?

**Interview Questions**

1. What was it like for you once your child turned 21 and had to leave high school?
2. What was your experience in finding services for your child after your child turned 21?
3. Can you describe your experience in finding other comparable services such as Speech therapy, occupational therapy, and Applied Behavior Analysis (ABA) therapy for your child?
4. What was your experience in finding care such as dental care for your child after they turned 21?
5. What has been your experience with finding day care or day programs and transportation to those programs for your child?
6. Overall, how would you describe the transition process out of high school and other services?

7. Can you describe how state programs did or did not help you feel prepared when your child left high school?

**Wrap-Up / Closing**

“Thank you again for sharing your experiences with me. I appreciate you doing this and I want you to know that your story is incredibly valuable. Your experience will contribute to a greater understanding of what families go through during this major transition. If you think of anything else you’d like to share later on, or if I have any follow-up questions, would it be okay to contact you again?”