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# Occupational Therapy Intervention for Project Search Interns With Autism Spectrum Disorder: Potential for Improved Transition Outcomes

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OCCUPATIONAL THERAPY INTERVENTION FOR PROJECT SEARCH INTERNS  
WITH AUTISM SPECTRUM DISORDER:  
POTENTIAL FOR IMPROVED TRANSITION OUTCOMES

Presented in Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Occupational Therapy

Eastern Kentucky University  
College of Health Sciences  
Department of Occupational Science and Occupational Therapy

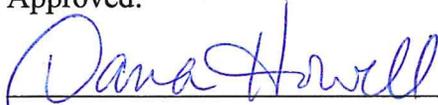
Jessie L. Bricker  
2018

**EASTERN KENTUCKY UNIVERSITY  
COLLEGE OF HEALTH SCIENCES  
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL  
THERAPY**

Certification

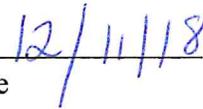
We hereby certify that this Capstone project, submitted by Jessie Bricker, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

Approved:



Dana Howell, PhD, OTD, OTR/L, FAOTA  
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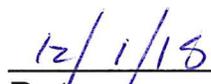
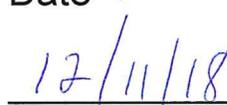


EASTERN KENTUCKY UNIVERSITY  
COLLEGE OF HEALTH SCIENCES  
DEPARTMENT OF OCCUPATIONAL SCIENCE AND  
OCCUPATIONAL THERAPY

This project, written by Jessie Bricker under direction of Doris Pierce, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

CAPSTONE COMMITTEE

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Committee Member	Date

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## Executive Summary

**Background.** As the prevalence of autism spectrum disorders (ASD) continues to rise, the individual and societal costs associated with disconnected adults with ASD in our communities also continues to rise. Thus, it has become vitally important to address the needs of adults with ASD as they transition from secondary education into the work world. Project SEARCH, an internationally recognized service delivery model, has one of the best success rates in assisting individuals with disabilities in attaining competitive employment in the community; yet, even in this program model, individuals with ASD have comparatively lower success rates in sustaining meaningful employment than individuals in other disability categories.

**Purpose.** The purpose of this action research study was to explore the needs of individuals with high functioning autism spectrum disorder (HFASD) within the Project SEARCH program from their own perspectives, and to utilize the knowledge gained to examine the potential for occupational therapy interventions within the Project SEARCH program aimed specifically towards improving employment outcomes for interns with HFASD.

**Method.** Utilizing ethnographic qualitative methodology within an action research framework, the study examined the experiences of three interns with HFASD at various points within the Project SEARCH program, as well as the experiences of their support staff, mentors, coworkers, and employers. Data collected from initial phases of the project was analyzed using open coding procedures, and then used to plan and implement occupational therapy interventions, before gathering qualitative data regarding the value of the occupational therapy interventions implemented.

**Results.** Thematic analysis first two phases of the project seemed to suggest that the needs of interns with HFASD were distinctly different than the needs of interns within other disability categories. Further, the current service delivery model, which focuses primarily on job skill development, was ineffective in addressing some of the unique differences noted for interns with HFASD, specifically environmental modifications and adaptations, addressing sociocultural differences in the workplace and basic psychological needs to support self-determined behavior (Deci & Ryan, 2001).

**Theoretical Framework.** Utilizing a Person, Environment, Occupational Performance (PEOP) framework (Baum, Christiansen, & Bass-Haugen, 2015), the investigator collaborated with stakeholders to utilize the information gathered in initial data collection phases to implement specific educational, consultative, and direct occupational therapy interventions to specifically address the needs of interns with HFASD as a cultural difference, and to promote autonomy, perceived competence, and relatedness within the context of work (Deci & Ryan, 2001).

**Conclusions.** Initial findings during suggested that while specific occupational therapy interventions that included direct treatment and consultation with stakeholders were reported as effective and valued among stakeholders and interns, education and training services alone were not felt to be effective in addressing the needs of interns with HFASD. The findings suggest there may be a unique and valuable role for occupational therapists to play within the Project SEARCH model in addressing the unique needs of interns with HFASD.

## Acknowledgements

First, I would like to express my utmost gratitude to the Project SEARCH intern participants who allowed me a glimpse into their lives during a very tumultuous time. This project could not have been completed without their wholehearted support and willingness to share their stories.

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To Dennis Cleary, thank you for always being open to having your brain picked by a novice researcher.

Last, but certainly not least, I want to thank my family. Words cannot adequately express the love and support they have shown me over the last two years. Jeff, thank you for being my constant encouragement, personal assistant, housekeeper, handyman, cook, and nanny. I could not have done this without you. To my sons James and Noel, and to my daughter, Annabel, thank you for your unending patience, hugs, and smiles - you will never know how much I needed them. I love you guys.

And to my son, Sean, I dedicate this work to you, and to the young man you will become. I have learned far more from you than I will ever learn from a book. Thank you for helping me to understand that when it comes to becoming who you want to be, working hard is not nearly as important as being accepted for who you already are. I love you, and I hope you are proud of me.

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DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY**

**CERTIFICATION OF AUTHORSHIP**

Submitted to (Faculty Mentor's Name):     Doris Pierce, PhD    

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Title of Submission:     Occupational Therapy for Project SEARCH Interns with Autism

Spectrum Disorder:     Potential form Improved Transition Outcomes    

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*Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.*

*Jessie Bricker, MS, OTRK*

Student's Signature: \_\_\_\_\_

Date of Submission:     11-27-18

# Table of Contents

<b>Background</b> .....	1
Outcomes in HFASD .....	2
Role of Occupational Therapy .....	4
A Window for Change .....	5
Project SEARCH.....	6
Problem Identification.....	7
Capstone Project Purpose.....	7
Theoretical Underpinnings .....	8
Project Significance.....	9
Summary .....	11
<b>Review of the Literature</b> .....	12
Characteristics of High Functioning Autism Spectrum Disorder (HFASD).....	12
Post-Secondary Outcomes.....	14
The Importance of Employment for Quality of Life.....	16
The Lived Experience of Adults with ASD .....	17
Demand-Side Perspectives .....	21
Current Interventions for Work Transition .....	23
The Role of Occupational Therapy for Transition to Adulthood.....	26
<b>Methods</b> .....	27
Setting.....	27
Project Design .....	29
Intern Participants .....	33
Stakeholder Participants .....	36
Data Collection Techniques .....	38
Ethical Considerations.....	41
Rigor in Data Collection .....	42
Planning and Implementation Phases.....	47
<b>Results</b> .....	51
Early Findings: Personal Accounts .....	51

Thematic Analysis.....	63
Intrinsic Factors.....	63
Extrinsic Factors.....	85
Goodness of Fit .....	96
Acceptance .....	118
Advocacy.....	136
Occupational Therapy Role.....	156
Cultural Differences .....	173
Psychological Needs for Self-Determination.....	189
<b>Discussion.....</b>	<b>196</b>
Overview of Findings.....	196
Distinctly Different: The Culture of HFASD.....	197
Bridging the Cultural Divide.....	201
Goodness of Fit .....	204
Occupational Therapy and SDT in Project SEARCH.....	211
Role of Occupational Therapy .....	213
Recommendations for Future Directions .....	214
Conclusion and Future Implications for Research .....	215
Limitations .....	216
Future Research.....	216
<b>References.....</b>	<b>218</b>
<b>Appendix A .....</b>	<b>231</b>
<b>Appendix B .....</b>	<b>237</b>
<b>Appendix C .....</b>	<b>244</b>

## **Background**

Autism is on the rise worldwide. The estimated prevalence rate of autism spectrum disorders (ASD) in the US has reached an all-time high of 1 in 59 (Centers for Disease Control [CDC], 2018). The data gathered by the CDC (2016) estimates that nearly half of those diagnosed with autism have “high functioning” ASD; or ASD with average or above average intelligence (HFASD). Though research and program efforts have primarily focused on diagnosis, early intervention, and etiology of the condition, there is heightened awareness that autistic children are predominantly growing up without the supports they need to become successful adults (Shattuck, Wagner, Naredorf, Sterzing, & Hensley, 2011). In the United States, approximately 50,000 individuals with ASD either graduate from high school or age out of education-based services each year, with nearly half a million individuals with ASD expected to enter their young adult years over the next decade (Roux, Rast, Anderson, & Shattuck, 2017).

The transition from high school into young adulthood is widely known as a pivotal time in development for all individuals. Failure to achieve independence, self-sufficiency, and autonomy in making life choices after the first few years following high school can have a long-standing, detrimental impact on health, well-being, and further neurological development (Arnett, 2000; Hogan & Astone, 1986; Rutter, 1989; Shattuck et al., 2011). Attaining competitive employment while doing meaningful work can also be an important factor in life satisfaction for all individuals. The relationship between quality of life and employment is complex; but undoubtedly, an individual’s well-being is related to social engagement, supportive relationships, a sense of meaning and purpose, and financial resources to meet one’s needs (CDC, 2016). Many individuals with ASD desire to achieve the same milestones of adulthood as

their, “neurotypical” peers: interesting work, meaningful relationships with others, and financial independence (Howlin, Moss, Savage, & Rutter, 2013).

### **Outcomes in HFASD**

Current research indicates that average employment rates for autistic adults, regardless of intellectual ability, ranges between 4.1 and 11.8% (Taylor & Seltzer, 2011). Further, young adults with HFASD have been shown to have a lower college matriculation rate, are dramatically underemployed, and have a higher rate of unemployment than individuals in any other disability category (Chen, Leader, Sung, & Leahy, 2015; Roux et al., 2017; Wehman, Schall, Carr, Targett, West, & Cifu, 2014). One study, utilizing data from the National Longitudinal Transition Study-2 (NLTS-2), found that nearly 40% of individuals with ASD become disconnected after high school, failing to make the transition to post-secondary education or work between late adolescence and their early 20s, compared to only 8% of individuals with other educational eligibility categories, such as learning disability, emotional disturbance, or speech-language impairment (Roux, Shattuck, Rast, Rava, & Anderson, 2015). Young adults with autism who have attended college continue to have persistent employment problems, and longitudinal data has shown that employment issues linger far beyond the typical “failure to launch” after high school (Howlin, 2013; Wehman et al., 2014).

Despite having average or above average intellectual capacity, those with HFASD are particularly vulnerable during the transition to adulthood. A variety of factors are contributing to the challenges this group faces in making a successful transition to adult life. The literature highlights the general insufficiency of current secondary education transition planning services in preparing adolescents with a wide range of disabilities for adult life (Eismann et al., 2015; Newman et al., 2011; Wehman, 2013). This lack of effective transition planning can be even

more pronounced for adolescents with HFASD, as many are likely not receiving necessary targeted, occupation-based transition services in high school as part of their transition plan, and experience decreased self-determination as a result (Wehman et al., 2014). Additionally, many adult workers with HFASD experience additional social pressures due to appearing “neurotypical” in work and social settings, but not meeting the expectations of supervisors and coworkers (Ghaziuddin, Ghaziuddin, & Greden, 2002; Sterling et al., 2007). Simultaneously, individuals with HFASD may experience decreased access to individualized, high-quality transition support services (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012; Shattuck et al, 2011; Taylor & Seltzer, 2011).

The many factors contributing to difficulty with transitioning into adulthood may lead to poor quality of life for individuals with HFASD, and increased comorbidity of mental health disorders. There is some research that finds depression to be a common comorbid condition to ASD, especially for high functioning autistic adolescents and adults (Ghaziuddin, Ghaziuddin, & Greden, 2002; Hirvikoski et al., 2016; Sterling et al., 2008). A recent study published in *Pediatrics* found prevalence of depression in autistic adolescents at a rate of 20%, compared to a rate of 8-12% in neurotypical adolescents (Greenlee, Mosley, Shui, Veenstra-Vanderweele & Gotham, 2016). An Australian study examining the work experiences of individuals with high functioning autism spectrum disorder (HFASD) found 68% of the participants were being treated for anxiety or depression, and 75% were not receiving any workplace support (Baldwin, Costley, & Warren, 2014). A few studies have even pointed to increased prevalence of suicidal ideation and suicidal attempts in individuals with HFASD, at least in part due to comorbid depression and experiences of social rejection and isolation, though no systematic, controlled studies aimed at

identifying the suicide rate in the autism population have been performed to date (Ghaziuddin et al., 2002; Hirvikoski et al., 2016; Richa et al., 2014).

### **Role of Occupational Therapy**

Occupational therapists have unique value in assisting individuals during times of transition; yet occupational therapy practitioners continue to have an extremely limited role in providing transition services to adolescents and adults (Capo, 2001; Eismann et al., 2017; Mankey, 2011). Research on current occupational therapy practice patterns in the education setting suggests that occupational therapy services taper off as children receiving these services mature into adolescence and adulthood, in spite of increased occupational demands experienced by adolescents as they transition into new work roles, living situations, and social networks (Chiang et al., 2012; Cleary, Persch, & Spencer, 2015; Eismann et al., 2017; Kardos & White, 2006; Mankey, 2011). The recent study by Eismann and colleagues (2017), using the NLTS-2 data, found that only 7.5% of all students with disabilities eligible for special education services receive occupational therapy services during the transition years. Though ASD was noted to be one of the top three eligibility categories treated by occupational therapists in secondary education, respondents receiving occupational therapy services reported moderate levels of disability overall, indicating that many individuals with HFASD who may be eligible for occupation-based transition support, are not receiving occupational therapy services (2017).

Furthermore, the existing practice patterns of occupational therapists working with children and youth in education settings often do not incorporate occupation-based assessment and treatment. Past studies have found that in most cases, evaluation in pediatric settings were almost entirely focused on assessing body structure and function, despite the therapists' self-reported use of client-centered, occupation-based practices (Kardos & White, 2006; Rodger,

Brown, & Brown, 2005). This finding is particularly problematic when considering the complex nature of environmental and contextual influences on occupational performance, as individuals with ASD transition to the workplace. (Baldwin et al., 2014; Brooke et al., 2018; Gal, Landes, & Katz, 2015).

### **A Window for Change**

The culmination of several recent legislative changes has created a great need for occupational therapists to be involved in transition planning for young adults with disabilities, as they age into adulthood. The mandate to provide transition services from school to adult life was first established in 1990 (Pub. L. 101-476), with the Individuals with Disabilities Education Act (IDEA). This legislation was followed by more recent legislation that strongly emphasizes the need for occupational therapists to be involved in transition planning in order to address transition to adulthood as a critical time for occupation-based intervention, task modification, and adaptation. The IDEA 2004 (Pub. L. 108-446) emphasizes measuring functional performance as well as academic progress in IEP goals, while the Workforce Innovation and Opportunity Act of 2014 (Pub. L. 113-128), mandates states to spend 15% of their Title I vocational rehabilitation budget on secondary education transition services. In addition, the more recent 2014 consent decree between the US Department of Justice and the State of Rhode Island mandates states to phase out sheltered workshops and seek competitive, community based employment opportunities for individuals with disabilities. Thus, the need for occupational therapy to address transition needs in secondary education has never been so great (Cleary, Persch, & Spencer, 2015; Eismann et al., 2017).

## **Project SEARCH**

Few programs have been successful in addressing the transition needs of young adults with ASD as they transition to work. One such organization, the Project SEARCH Program (<http://www.projectsearch.us/>), is a unique, international service delivery model that utilizes an effective business-immersion work training program to help students transition into competitive employment opportunities. A key feature of this program is its use of the natural work setting to train future employees in real world skills (Wehman et al., 2013). Although Project SEARCH has established a 70-100% success rate for competitive employment for many of its interns, those on the autism spectrum have the lowest outcome scores across the nation's Project SEARCH sites (E. Falk, personal communication, July 13, 2017). Existing autism-specific Project SEARCH sites, which exclusively focus on meeting the needs of interns with ASD, emphasize the importance of intensive social and communication training, intensive training in job skills, use of visual supports, and routine and structure within the workplace (Wehman et al., 2014).

Yet, at its recent Annual Conference, Project SEARCH presented data that indicates the majority of their interns on the autism spectrum are being placed in jobs such as dishwashing and janitorial work; positions that tend to be a poor fit for the collective strengths known to be common within this group (E. Rhiele, personal communication, July 31, 2018). Incidentally, the Project SEARCH model does not typically involve occupational therapy practitioners. Occupational therapists possess skills vital to the Project SEARCH methodology for successful transition to work services, such as task analysis, environmental modification, and understanding of the individualized value of a specific occupation may hold within an individual's life

(American Occupational Therapy Association, 2014; Cleary, Persch, & Spencer, 2015; D. Cleary, personal communication, July 24, 2017).

### **Problem Identification**

Individuals with ASD are not well-supported in the workforce. As a society, there is a great cost associated with such a large population of occupationally marginalized individuals. Disconnection from satisfying work opportunities not only results in decreased quality of life for adults with ASD; but strips the workforce of being able to benefit from their creative ingenuity and dependability. Employers are likely to find significant advantages in hiring individuals with ASD, as their different cognitive skills lend assets such as reliability, attention to detail, focus on work output, and memory capacity for large amounts of information (Hendricks, 2010). Even the studies with the most positive employment outcomes for adults with ASD only claim an employment rate of around 50% (Chiang, Cheung, Li, & Tsai, 2013; Farley et al., 2009; Gotham et al., 2015). Additionally, there is significant financial burden associated with supporting individuals with ASD throughout their lifespan. The total estimated societal economic burden for autism in the United States alone is expected to approach \$461 billion by the year 2025, if the trends in increased prevalence of the condition continue (Leigh & Du, 2015). Knapp and colleagues (2009) found that approximately 36% of the total costs of autism are related to loss of employment and subsequent costs to family members over the adult lifespan.

### **Capstone Project Purpose**

The purpose of this capstone project is to address the apparent disparity in employment outcomes for individuals with HFASD within the Project SEARCH program, an internationally-recognized program with well-established efficacy in transitioning individuals with disabilities to successful employment, by considering the experiences of individuals with HFASD in planning

occupation-based interventions within the Project SEARCH program. The objectives of this action research project are to:

- describe factors that could contribute to relatively poorer outcomes for interns with ASD, from the intern's point of view;
- explore the potential for occupational therapy collaboration and consultation with stakeholders within the existing Project SEARCH model for individuals with HFASD;
- and utilize the data gathered within the action research process to make recommendations to improve employment outcomes for interns with HFASD.

### **Theoretical Underpinnings**

Community-based action research aims to create new programs or enhance the quality of existing programs by considering multiple outcomes that honor and preserve the needs of all individuals involved (Stringer, 2007). To begin such a project with a theoretical perspective related to the nature of the project would potentially discount the perspectives of the individuals the project aims to serve, and disregards the potential meaning the project might possess for community stakeholders. For this reason, an interpretive research orientation using action research methodology was selected as a means to emphasize the assumption that knowledge can be gained from the daily lived experiences of those the research aims to serve (Stringer, 2007). This is particularly important for studies pertaining to the needs of young adults with ASD, as the first-person perspective of these individuals is essential to effective interventions and strikingly absent from the current literature (Roux, Shattuck, Rast, Rava, & Anderson, 2015).

Action research can be viewed through the lens of postmodern perceptions of knowledge, in that knowledge about human behavior cannot be reduced to a set of testable "truths," but

inevitably results from the investigator's own inherent cultural and social biases in interpreting the social context (Stringer, 2007). Action research methodology addresses this inherent bias by incorporating understanding of multiple perspectives, cultures, and viewpoints to create a new, mutually understood perspective, in order to formulate solutions to complex social problems. Action research is culturally sensitive, as it authenticates the cultural perspectives of others, particularly marginalized groups (Denzin, 1997; Stringer 2007). This is an important consideration in addressing the issues of young adults with HFASD, as their perception of social rules implicit to specific social contexts is often dramatically different and could be considered a cultural difference of its own. Deconstructing social meaning from the perspective of an individual on the autism spectrum lends validity to the process of discovering new ways to meet the challenges of occupational performance in a "neurotypical" social world.

Action research can be an essential tool in conveying issues in a light that is meaningful not only to the Project SEARCH staff and mentors, but also to potential employers and the individuals receiving training through Project SEARCH, known as "interns." Potential solutions that are developed from the action research process can tip the balance of power in favor of a person with ASD, promoting occupational justice and reducing the likelihood of further marginalizing the autistic young adult as they navigate their social world.

### **Project Significance**

Though action research projects often seek to resolve identified problems specific to the context in which they are conducted, the knowledge gained from this research may be applicable within other Project SEARCH sites, as the model has been standardized across its locations internationally. Findings may also be useful to occupational therapists serving adolescents and young adults in settings beyond Project SEARCH. Further, this work intends to acknowledge

the important contributions made by individuals who are served by the project itself. Conveying this lived experience in a format that is meaningful to program planners and interns alike creates opportunities for meaningful change that facilitates occupational justice within the program, and serves to empower individuals with autism. Reducing social and occupational injustice for young adults with HFASD will not only improve quality of life indicators for this population, but could also lead to reduced rates of mental illness and improved productivity, thus lowering the costs of having autism for both individuals and society.

This project also has significance to the field of occupational therapy. Since the inception of occupational therapy, the profession has advocated for the power of *doing*; that is, to improve one's health and well-being through everyday engagement and participation in life (Peters, 2011). Though occupational therapy has been a mainstay in medically-based health care for decades, occupational therapy practitioners as a whole have struggled to maximize their potential within the landscape of interventionists in education, community, and work settings.

In 2018, the American Occupational Therapy Association (AOTA) revived the call for forward-thinking healthcare in a variety of settings with Vision 2025 (AOTA, 2018). This new vision statement charges occupational therapy practitioners with a responsibility to grow the profession's influence in population-based areas of practice (AOTA). Further, one of the guideposts within this new vision calls for occupational therapy practitioners to be leaders in our contribution to influencing complex systems, policies, and procedures in ways that improve quality of life and well-being for all people (AOTA). This project provides an illustration of how occupational therapy practice can embrace Vision 2025, since it highlights strategies for impacting the experiences of adults with HFASD through collaboration and leadership within a complex system of organizations.

## Summary

This capstone work will explore the impact of embedding occupational therapy assessment and intervention strategies into the Project SEARCH approach, through the perspectives of the Project SEARCH interns with HFASD and stakeholders in the Project SEARCH program, in order to improve the work-related outcomes of young adults with HFASD.

Project SEARCH is a viable, widely-accepted and effective model for assisting young adults with disabilities into successful and satisfying employment, incorporating blended funding streams, employment matching strategies, follow-up services, and community awareness initiatives ([www.projectsearch.org](http://www.projectsearch.org)). As one of few internationally recognized programs supporting young adult transitions, this program is ideally suited to expand to meet the needs of autistic individuals in a more targeted way that honors their cultural differences and capitalizes on their strengths. Though occupational therapy is not typically a core component of the Project SEARCH model, occupational therapists are uniquely trained to address the individual's capacity for adaptation and to create opportunities to build self-efficacy and occupational identity through community and work participation. Occupational therapy fully leverages the power of occupation to improve health, well-being, and quality of life, regardless of a diagnosis or condition, by striving to increase clients' self-reliance, social participation, and productivity within the client's natural context (Baum & Law, 1997; Clark, 1998; Coster, 1997; Fisher, 1998; Fisher, 2013; Jackson, Carlson, Mandel, Zemke, & Clark, 1998). Individuals with HFASD require unique training, environmental adaptations and task modifications in order to support their ability to attain and maintain employment. This action research project was designed to

consider their perspectives and to create solutions that will lead to improved opportunities for work and community participation.

### **Review of the Literature**

As much of an individual's life is spent as an adult, research related to autism in the adult stages of life is critically important (Roux et al., 2017). Yet, only 1% of all autism-related funded research is dedicated to the study of autism into adulthood (Roux et al., 2017). There is a paucity of information regarding the level of support individuals with ASD might need as they age into adulthood, and little is known about which interventions are effective for adults on the autism spectrum (Roux et al., 2015). Multiple studies have emphasized the need for further research to begin to address the specific needs of our growing population of individuals with ASD as they transition into their adult years (Howlin & Magiati, 2017; Howlin & Moss, 2012; Leigh & Du, 2015; Roux et al., 2015). As a whole, the existing literature represents a wide range, in both characteristics of its samples, as well as descriptions of outcomes. As a result, the research is relatively weak in terms of its ability to produce consistent results regarding factors that influence success in employment, ability to achieve appropriate levels of employment or supports, or what those supports should look like (Howlin & Magiati, 2017). In addition, very few studies incorporate the perspective of autistic adults when identifying barriers to work performance or job satisfaction, which may lead to the development of intervention and support strategies that are ultimately ineffective or irrelevant for adults on the autism spectrum (Chown et al., 2017; Robertson, 2009).

### **Characteristics of High Functioning Autism Spectrum Disorder (HFASD)**

Autism is not a disorder of childhood. It is a lifelong neurodevelopmental condition in which challenges with social cognition, communication and intense interests or repetitive

behaviors can significantly disrupt an individual's ability to participate in the community, and live independently (Roux et al., 2017). The condition of ASD itself does not cause a shorter life expectancy than what is expected in the typical population. High-functioning autism spectrum disorder (HFASD) is a neurodevelopmental difference in which an individual experiences autistic traits such as social cognition challenges, communication difficulty, and highly preferred interests or repetitive behaviors, but without intellectual impairment (Baron-Cohen, Skinner, Martin, & Clubley, 2001). A young adult in today's society diagnosed with high functioning autism spectrum disorder (HFASD) would likely have been diagnosed using the nomenclature listed in the *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Edition* (DSM-IV-TR; American Psychiatric Association [APA], 1994). Under DSM -IV criteria, an individual with HFASD would likely carry a label of Asperger Syndrome or pervasive developmental delay, not otherwise specified (PDD-NOS), which would indicate significant impairment in social, adaptive, and communication skills; with evidence of restricted, repetitive behaviors, but without evidence of impaired language or intellect (APA, 1994).

Jaarsma and Welin (2012) offer a thorough history of theoretical perspectives surrounding the idea of autism as a natural human variant, rather than a disorder. The authors assert that though individuals with more significant impairments from autism symptoms and intellectual dysfunction should be treated as a disabling condition, higher functioning individuals on the spectrum can be seen as members of their own subculture, sharing an alternate experience of the world. Jaarsma and Welin highlight the damaging effects of society's view of HFASD as a mental health disorder, as the pathology often overshadows the unique strengths of this population. Several studies have pointed to the many positive qualities autistic employees bring to the workplace, including reliability, honesty, intense focus, accuracy, attention to detail, time

management, innovative problem solving, visual pattern recognition, and ability to remember and manipulate large amounts of information (Cassidy, 2018; Gal et al., 2015; Hedley, Wilmot, Spoor, & Dissanayake, 2017; Hendricks, 2010; Hillier et al., 2007).

Employers have begun to acknowledge the advantages of hiring employees with HFASD, as well. According to Austin and Pisano (2017), the prominent tech company, Hewlett-Packard Enterprises (HPE) began strategically recruiting and hiring autistic programmers in 2015 in order to leverage a competitive advantage in innovation. Preliminary research conducted by HPE on their campaign for targeting neurodiversity in the workforce indicated a 30% increase in productivity in teams that included autistic members, compared to teams without autistic members (Austin & Pisano, 2017). Numerous other companies have followed suit, hoping to gain skilled workers who can help them think creatively for the future (Austin & Pisano, 2017; Cassidy, 2018; Hedley et al., 2017). The concerted effort to bring more neurodiversity into the workforce often involves a complete reconsideration of interviewing and hiring practices, as traditional human resource practices are almost universally geared to seek out a well-rounded individual with skills in communication, teamwork, and initiation; a process that often systematically eliminates autistic applicants during the interview process (Austin & Pisano, 2017),

### **Post-Secondary Outcomes**

The *National Autism Indicators Report* from the A. J. Drexel Autism Institute (2015) utilized data from the last wave of data collection on the National Longitudinal Transition Study 2 (NLTS-2), completed in 2009, to examine outcomes such as employment, living arrangements, social participation, and self-reported safety and satisfaction for individuals with ASD between the ages of 21 and 25 (Roux et al., 2015). The authors found that 37% of young adults with ASD

became disconnected after high school; eighty-one percent of young adults surveyed reported they had never lived independently, 42% had never had a job since finishing high school, and 68% had no postsecondary education. Even more surprising was that a full 26% of surveyed individuals reported receiving no therapeutic services whatsoever after finishing high school, confirming the anecdotal “services cliff” that many parents raising children with ASD report experiencing, once their child is no longer eligible for education-based services.

A study by Taylor and Seltzer (2011) compared the occupational patterns of those with HFASD to individuals with ASD and intellectual disability (ID) for 66 individuals with ASD in the five years after they finished high school. The authors found that 25% of the individuals with ASD but without ID fell in the “no day activity” category, indicating they had no regular daily activity as part of their daily occupational patterns. Additionally, this study found that only 18% of the ASD group without ID were getting any vocational support services, compared to 86% of the ASD with ID group. Individuals with HFASD were even less likely than those with intellectual impairment to have any gainful employment or community participation, and were at higher risk for disconnectedness in the five years following high school. The authors conclude the evidence in their study speaks to the lack of support services for individuals with ASD without ID that would allow them to develop meaningful careers.

More commonly, individuals with ASD are largely underemployed. A study using the NTLS-2 data set by Chiang and colleagues (2013) attempted to identify factors associated with participation in employment for young adults with autism post-high school. A retrospective analysis of 830 participating secondary school students, collected between 2001 and 2007, was performed using pre-determined independent variables deemed likely to influence participation in employment: family characteristics, student characteristics, and transition planning services

(Chiang et al., 2013). The authors found 56% of the students in the study had participated in post-secondary employment, with the top five occupation types identified as material recording and scheduling, (36.3%), record clerks (12.9%), building cleaning and pest control (8.5%), retail sales (5.2%) and other production occupations (5.1%). Mean hourly wage was lower than the minimum wage in 2007, the year the data was collected (Chiang et al., 2013). Though this study reports relatively high employment rates for individuals with ASD, it also highlights the occupational disparity regarding socioeconomic status for individuals with ASD, as they are at risk of under-employment in low paying positions pertaining to menial work. Some studies have taken a strengths-based approach to characteristics of ASD and work; one study involving employed adults with ASD examined the impact of preferred interests on social and work function, finding that the majority of surveyed participants reported being employed in positions that involved their preferred interests (Koenig & Williams, 2017). In fact, 62% of the adults with ASD surveyed reported feeling their preferred interests helped more than hindered their daily life (2017).

### **The Importance of Employment for Quality of Life**

Quality of life has become a key indicator of health for individuals as well as populations in recent years, and is an important topic of interest with respect to the US healthcare system ([www.healthypeople.gov](http://www.healthypeople.gov); [www.cdc.gov/hrqol/wellbeing.htm](http://www.cdc.gov/hrqol/wellbeing.htm)). Well-being and quality of life are widely recognized as constructs that consider an individual's self-perceived satisfaction with their physical health, social connectedness, and productivity, as well as their social and physical environment ([www.cdc.gov/hrqol/wellbeing.htm](http://www.cdc.gov/hrqol/wellbeing.htm)). When examining factors related to quality of life for individuals with autism, it is important to recognize that although the literature frequently isolates factors such as living arrangement, community mobility, income level, education level,

social relationships or employment, as these discrete variables are all interconnected in an individual's life (Roux et al., 2015). Employment outcomes are a key variable to consider in terms of overall health and quality of life, because income from paid employment is often a determining factor in access to care, opportunities for community and social involvement, independent mobility, and standard of living. As a result, lack of employment or underemployment can impact an individual's satisfaction with life on a variety of levels. Satisfaction with employment is particularly predictive of quality of life for individuals with ASD (Burgess & Gutstein, 2007). This may be because individuals with autism often are less motivated by money, and more motivated by preferred interests and purpose in their work.

During the transition into adulthood, factors such as increased awareness of challenges and limitations, bullying or experiencing social stigma, and loneliness; complicated by poor social, problem solving, and coping skills, have been identified as contributing to depression within the HFASD population (Sterling, et al., 2007). Further, many individuals lose access to critical support services offered through the educational system at the time they transition into adulthood, creating additional stress for the individual already struggling with social and communication issues at a time marked by significant disruption in routine (Shattuck et al., 2011). All of these factors can contribute to decreased quality of life for individuals with autism.

### **The Lived Experience of Adults with ASD**

There is a striking gap within the current literature regarding the lived experiences of individuals with ASD as they make the school to work transition. By their very nature, autistic individuals see the world differently from their neurotypical counterparts. Thus, the first-hand voice of young adults with ASD is an essential component to understanding their perceptions of their own quality of life and job satisfaction (Baldwin et al., 2014; Jaarsma & Welin, 2012;

Johnson & Joshi, 2016; Pfeiffer, Braun, Kinnealey, Matczaka, & Polatajko, 2017; Robertson, 2009). However, self-advocates with ASD are speaking out in increasingly larger numbers. A paradigm shift away from a deficit-based perspective of ASD to a model that acknowledges ASD as a natural variant in cognition appears to be developing in some facets of the literature (Austin & Pisano, 2017; Chown et al., 2017; Koenig & Williams, 2017; Jaarsma & Welin, 2012; Robertson, 2009).

Chown and his colleagues propose that researchers consider the epistemological and ethical repercussions of neglecting to involve individuals with ASD in research about ASD (2017). “Research in autism involving autistic co-researchers produces outcomes that could not have been achieved if autism research undertaken by non-autistic scholars does not benefit from autistic perspectives on the subject matter of their investigations” (Chown, et al., p. 722). Chown and his colleagues follow elegant descriptions of collaborative research benefits with a detailed framework that outlines key elements for research, maintaining the integrity of data pertaining to individuals with different cognition, upholding their values and beliefs as individuals, respecting them as equal members of the human race, and empowering them to enhance our knowledge of ASD with the personal insights, perspectives, and cognitive processes inherent to their neurological type. The researchers advocate for participatory and emancipatory research methodologies, which are aimed at affecting change through shifting perspectives and evolving systems of care, as an essential component to producing meaningful and positive change for individuals with ASD.

One study that aimed to collect first hand perceptions from individuals with HFASD used data from 255 autistic individuals who had completed surveys on the Interactive Autism Network, an internet-based registry in North America for individuals with ASD and their

families (Gotham et al., 2015). Of the sample who responded to the survey in Gotham and colleagues's study, only 11% had been diagnosed with autism in early childhood, thus they likely represented a more mildly affected group. Nearly half (47%) of the respondents who self-reported stated they held a job, and only half of those worked full time. Approximately 72% of the employed respondents reported they wished to work more hours, but had been unable to attain them. Of those self-reporting respondents who were unemployed, 41% reported wanting to work but being unable to secure employment. Sixty percent of the unemployed participants in the sample reported finding the work setting to be too challenging, 29% feared it would disrupt their public benefits. A full 47% of the respondents reported facing workplace discrimination.

In the study by Gotham and colleagues (2015), 80% of the respondents in the self-responding group described having special abilities or positive traits they attributed to ASD, such as intense focus, honesty, creativity, good memory, and sense of justice. However, 45% of self-respondents disclosed that intense interests occasionally impeded their ability to be successful in work or relationships. The data discussed within this study clearly emphasizes that even those on the milder end of the autism spectrum may benefit from therapeutic and support services that promote success in the workplace.

An Australian study by Baldwin and colleagues (2014) examined the work experiences of individuals with high functioning autism spectrum disorder (HFASD) by surveying 130 individuals, with a mean age of 35, most having at least some education beyond high school. Of these, 68% reported being treated for anxiety or depression, and 76% expressed frequent worry or anxiety. Nearly three quarters of the respondents reported they did not receive any workplace support related to ASD. Sixty-six percent of all respondents reported a desire for more support at work. Respondents indicated a need for accessing workplace counseling, being recognized,

and greater respect from others. Respondents in more skilled jobs were much more likely to associate their work with self-actualization, but also more likely to have stress and difficulty maintaining health and well-being at work. Respondents who were underemployed consistently reported boredom and lack of intellectual stimulation as the worst parts of their job. The findings reported by Baldwin and colleagues (2014) emphasize the detrimental impact that underemployment may have for individuals on the spectrum, and speaks to the need for increased accommodations and supports, even for individuals who may be employed in more highly skilled work.

A smaller, qualitative study examining transition experiences for young adults with Asperger Syndrome (AS) identified sensory differences, particularly noise, as a barrier in the workplace (Giarelli, Ruttenberg, & Segal, 2013). In this thematic analysis, authors conducted semi structured interviews with 14 young adults with AS. Identified barriers to transitioning into adulthood reported by the participants included limited attention span and focus, anxiety, and mood instability. Giarelli and colleagues (2013) also noted sensory differences as a barrier; namely increased noise. Identified bridges, or facilitators of transition included flexible individualized schedules, additional instruction or orientation to a novel task, and preparation of others, which was a category that included the efforts of employers, teachers and others to understand the issues in AS and educate themselves on ways to be more accommodating. Most participants were able to identify their own strengths and weaknesses. The participants articulated the value of mentorship in terms of modeling appropriate behavior, assisting with work related problems, and accepting them for who they are. The findings in the study by Giarelli and colleagues (2013) highlight the importance of acceptance, and note that effort on the

behalf of peers and administrators to understand and accept the individual with AS is a significant facilitator to workplace success.

A recent study examined a strengths-based approach to considering the impact of preferred interests on social and work function in adults with ASD (Koenig & Williams, 2017). The researchers surveyed 80 individuals with ASD who answered questions about their own perceptions of highly preferred interests and the impact of their interests on daily life, and found that 62% of the respondents felt that their interests helped more than hindered their function. Further, the majority of respondents (n = 69) reported being currently employed in positions that involved their areas of preferred interest (2017). This study emphasizes the importance of considering the important perspectives of individuals with autism in considering appropriate supports or interventions to support their success.

### **Demand-Side Perspectives**

A study performed by Ameri and colleagues earlier this year involved an interesting field experiment, in which over 6,000 false resumes are sent to accounting firms with open positions for hire. This study examined the call back rates for three separate groups: non-disabled applicants, applicants that disclose a spinal cord injury, and applicants who disclose having Asperger Disorder. The authors deliberately chose accounting jobs, as neither of these conditions would hinder someone's ability to perform in the job role, and in fact, Asperger's Disorder may be an asset in an accounting position. Ameri and colleagues (2018) found that significantly fewer of the applications indicating a disability were given an interview, and that applications indicating experience in the field and disability were even less likely to be called back, indicating that simply ensuring individuals with disabilities have the appropriate skillset is not enough to combat stigma in hiring practices. Incidentally, no significant differences were

found in call back rates between the two disability groups. Smaller businesses who are not covered under ADA were more likely to reject applications where disability was disclosed, indicating that ADA may be providing some protection within larger agencies, and at least is not deterring hiring individuals with disabilities. This study was helpful in that it emphasizes the significant influence bias can have on hiring practices, and points to the importance of helping individuals learn to self-advocate in work settings.

Another recent study by Hedley and colleagues (2018) explores the effect hiring autistic workers can have on work teams and administrators. This study described effects of the Dandelion Program, a joint initiative between Australian Department of Human Services and Hewlett-Packard Enterprises to support adults with ASD at work. In this study, eleven trainees with autism and 17 other stakeholders, such as coworkers and family members participated in focus groups aimed at exploring their experiences. Close support from supervisors and trainers, environmental modifications to reduce sensory overstimulation, and assistance with navigating social expectations were identified as enablers. Barriers included individual factors, such as anxiety, and unpredictable changes in work routine or structure, such as difficulty with the network going down. Supervisors and support staff identified positive outcomes in changing workplace culture, pride in assisting trainees in their transition, and a sense of collaborative partnership and team achievement with successful transitions. The trainees' work quality and dedication to work were noted by coworkers and supervisors alike, which also positively influenced the department culture.

Though the study by Hedley and colleagues (2018) highlights the positive work culture changes seen with neurodiverse hiring and onboarding procedures, other studies have called to light the stigmatizing experiences some autistic workers have had, and how this might impact

their willingness to disclose their ASD to administrators or coworkers (Johnson & Joshi, 2016). The study by Johnson & Joshi examines results from two separate studies, one utilizing surveys the other utilizing interviews, to examine the experience of stigma and the decision about whether or not to disclose a disability to an employer, to perceived work discrimination and age at time of diagnoses. Those who were diagnosed with ASD earlier in life were found to be more likely to disclose, have a lower perceived sense of stigma in the workplace, and were more likely to access accommodations for issues related to ASD or take positions with fewer social demands. Overwhelmingly, respondents chose not to disclose their ASD diagnosis publicly, as they felt it opened the door for more stigmatizing experiences at work, was an invasion of their privacy, and made them feel as if all of their behaviors and life decisions were being scrutinized by their coworkers.

### **Current Interventions for Work Transition**

A 2010 study by Hendricks published in the *Journal of Vocational Rehabilitation* sought to review the existing literature on employment in adults with autism in an effort to articulate best practices to support individuals with ASD in postsecondary employment within natural community settings. Hendricks highlights the impact of decreased interpersonal skills, decreased performance due to stress or anxiety in the workplace, and employer misinterpretation of behavior as common barriers to employment and employment satisfaction. Evidence is cited for interventions that involve supervisor and co-worker training, on the job training with gradually faded job coaching support, workplace environment modifications, clearly defined work roles and tasks, and ongoing long-term vocational counseling services. The author concludes that the existing literature provides a wide array of topics with few solid conclusions in any area.

One of the most promising work transition programs for individuals with disabilities is the Project SEARCH model, which currently boasts an average employment rate of over 70% for its interns, who are between the ages of 18 and 35, with a variety of disabilities (Rutkowski, Daston, Van Kuiken, & Riehle, 2006). Project SEARCH is an internationally recognized service delivery model with sites in nearly every state in the US, as well as several other countries. Unique features of the Project SEARCH model include immersion in the workplace setting; braided funding streams from private businesses, the education system, vocational rehabilitation, and community based services; and specific training in employability, life skills, and independent health behaviors (Rutkowski et al., 2006). Project SEARCH follows their interns' progress and offers intermittent employment support and consultation for a full five years after graduation. In the last few years, Project SEARCH has begun to pilot ASD-specific sites across the country to address the unique needs of the ASD population they serve, but thus far has not developed an organization-wide process for how to support individuals with ASD (personal communication, E. Falk. July 13, 2017).

A study by Wehman and colleagues (2014) examined the effectiveness of modifications to the Project SEARCH intensive internship model that meet the needs of individuals with ASD for three separate cohorts (academic years 2009-2012) compared to a control group receiving traditional transition services from their local school district. Key elements of the existing Project SEARCH model were retained, and included business-based internships and workplace immersion (2014). The ASD-specific elements embedded into the model included regular consultation with a behavior analyst, specialized structure and schedules within each internship experience, explicit instruction in social and behavioral expectations, use of visual supports, use of self-monitoring reinforcement systems, intensive social skills training through role play and

behavioral practice, and the use of applied behavioral analysis techniques in training. The authors found that 87.5% of the participants in the autism-specific Project SEARCH program attained competitive employment, compared to 6.25% of the control group; this rate was maintained at three months post finishing the internship. While these results are encouraging, the study does not examine the effect of the modifications made to the Project SEARCH model to support individuals with ASD compared to the traditional Project SEARCH model. Interestingly, none of the specific modifications to the Project SEARCH model addressed leveraging strengths, interests, or individual self-determination, important elements of job satisfaction that are repetitively stated in the literature that describes the experiences of adults with ASD in the workplace (Gotham et al., 2015; Koenig & Williams, 2017; Müller, Schuler, & Yates, 2008).

A follow up study by Wehman and his colleagues (2017) expands the original study to a five-year period examining the effects of an ASD-specific Project SEARCH model compared to traditional transition services within the education system. This study further examines the effects of the autism-specific Project SEARCH program by measuring employment retention post-graduation. Forty-nine students with ASD and cognitive impairment were enrolled in the study, with 31 participants in the treatment group and 18 in the control group. In addition to the previously described program modifications, the intervention in this study included a “customized employment” strategy to match job tasks most suitable to the strengths of the interns with ASD. Supported employment was also offered outside of the classroom supports in four phases: job seeker profile, job development, job site training, and long term supports. The treatment group attained community based employment at a rate of 74.2% (Wheman et al.). Of those who attained employment, 87.1% had maintained employment at the 12-month follow up.

Among all employed participants, there was no significant difference between groups for wages earned. This study is limited by small sample size and lack of detail in ASD specific intervention and supports, but is initially encouraging and a great demonstration of the lasting effect of the Project SEARCH program model.

### **The Role of Occupational Therapy for Transition to Adulthood**

Occupational therapists have a unique and valuable role to play in the health, well-being, and quality of life of many individuals, groups, and populations (Pizzi & Richards, 2017). In 2011, the American Occupational Therapy Association (AOTA) named transitions for older youths an area of emerging practice for occupational therapists. However, occupational therapists continue to have a limited role in helping to plan and execute transition-focused services for adolescents and young adults (Kardos & White, 2006; Mankey, 2011; Summers, 2015). The transition from adolescence to adulthood for individuals with ASD can be particularly difficult. Thus, it becomes even more important for occupational therapists to realize the important role they can play in facilitating purpose, role fulfillment, and life satisfaction for young adults with ASD. In occupational therapy practice, the occupation serves as a medium for achieving improved satisfaction with engagement in daily occupations, performance in work roles, and adaptation to changing circumstances; and is simultaneously the end result of such interventions, culminating in the client's enduring, active engagement in their everyday life (Baum & Law, 1997; Clark, 1993; Fisher, 1998; Gray, 1998; Trombly, 1995).

Capo provides an illustrative look at the literature in a commentary that provides guidelines for the role of the occupational therapist in employment for individuals with ASD. Capo utilizes a series of case studies from the literature to provide examples of occupational therapy involvement in assisting individuals with ASD in attaining and maintaining gainful

employment. Capo emphasizes that successful programs for employing individuals with ASD include highly structured curricula that focus on skills, interests, and abilities of the individual, matching these with job opportunities in the community that are a good fit for the individual. She concludes occupational therapists are uniquely trained to not only address work skills, but to evaluate and provide support within the social context of the work environment, while considering the individual and their specific motivation for vocational engagement (2001). Occupational therapists are able to develop jobs, as well as perform job placement and training for the employee and the employer and coworkers (2001).

## **Methods**

### **Setting**

The Project SEARCH Program is an internationally recognized, trademarked program model dedicated solely to assisting individuals with disabilities between the ages of 18 and 33 with attaining and maintaining gainful, competitive employment. The Project SEARCH model began in 1996 at Cincinnati Children's Hospital, and has since grown to over 400 sites in 40 states within the US; and additional sites in Canada, England, Scotland, Wales, Ireland, and the Netherlands ([www.projectsearch.us](http://www.projectsearch.us)).

In 2016, Project SEARCH partnered with St. Bernard's Medical Center and ACCESS, Inc., to start the first Project SEARCH site in Jonesboro, Arkansas; becoming the fifth Project SEARCH site in the state of Arkansas. At the time of this study, the St. Bernard's location is the only Project SEARCH site in the Northeast Arkansas Region. Interns complete three 10-week rotations located throughout the St. Bernard's Medical Center campus during the 9-month program. The first intern class of eight young adults with disabilities graduated from the program in May of 2018. A second class of nine interns began the program in August of 2018.

Interns are engaged in the Project SEARCH Program five days a week for the duration of their 9-month internship. The first hour of the day is spent in the training room with the program coordinator and two skills trainers, in which explicit instruction and training is provided on a variety of work-related skills, such as role playing interpersonal interactions or preparing for new job duties, and instruction on other life skills, such as positive health behaviors or public transportation. The interns then “go to work,” spending approximately five hours immersed in a work setting, working alongside the department’s paid staff, with periodic monitoring from the job coaches and/or program coordinator. The day typically concludes with either individual or group debrief sessions in the training room with the skills trainers and coordinator. Interns are typically assigned to a coworker within their department who serves as a mentor and point of contact should the intern experience any difficulty. Each 10-week internship experience is selected by thorough assessment of the intern’s specific strengths and needs for job skill acquisition, as well as a brief interest inventory. The internships available to the St. Bernard’s Project SEARCH Program include entry-level positions in grounds-keeping, housekeeping, laundry, nursing, imaging center, central supply, sterile surgical supply, lab, hospice, quality control, nutrition services, and the Health and Wellness Center Café.

The principal investigator for this study, an occupational therapist with over 15 years of clinical experience working with children, adolescents, and young adults with ASD, used action research methodology to discover issues and barriers experienced by interns with HFASD, through observation and intern interview. Occupational therapists are uniquely skilled to not only examine the specific strengths and challenges of an individual, but to also consider the skills and abilities of an individual within the context of occupation. Thus, the data gathered from the lived experiences of interns, as well as a variety of stakeholders involved with the Program, were

used to plan and execute occupational therapy interventions for the interns. Occupational therapy interventions focused on best practice implementation of the tenets of occupational therapy practice: client centered care, occupation-based intervention, and empowerment of individuals with different abilities to create meaning in daily occupations (Baum & Law, 1997; Clark, 1993; Coster, 1997; Fisher, 1998; Fisher, 2013; Gray, 1998; Jackson, Carlson, Mandel, Zemke, & Clark, 1998; Trombly, 1995). Additionally, the researcher considered the complex network of stakeholders involved in facilitating successful employment opportunities for interns with HFASD, collaborating on supportive interventions that would promote success in their roles.

Occupational therapy interventions were client-centered, based on the specific needs of each intern and data gathered from stakeholders. Intervention activities included evaluation of the interns, analysis of the job tasks assigned within the internship, and evaluation of the various contextual factors inherent to the internship or potential job, in addition to individual strategies for skill development and remediation, environmental adaptation, or task modification. The occupational therapist implemented these interventions through a variety of means, including direct interactions, consultation with the interns, staff, and potential employers on site with the intern as they participate in their internship and training, staff education and training, and advocacy. Additionally, education and training for key stakeholders in the Project SEARCH Program was performed as a form of occupational therapy intervention.

### **Project Design**

In order to understand how occupational therapists can assist interns with autism spectrum disorders participating in the Project SEARCH Program, a community-based, action research design was selected to analyze the perspectives of interns, staff, and potential employers involved in the Project SEARCH Program. This design also allows for both direct observation

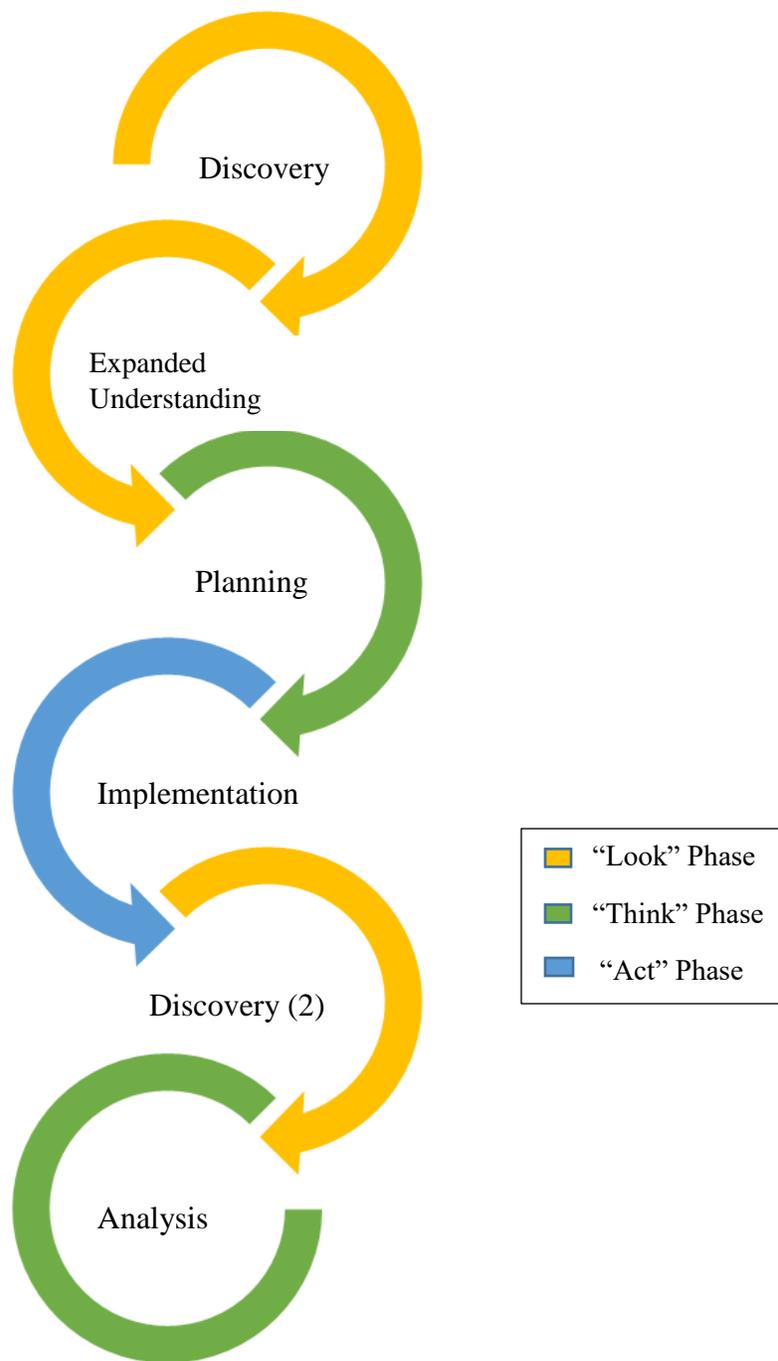
of the interns and stakeholders as they participate in the Program, and trials of potential occupational therapy interventions to support them. The features of the current study align with the action research methodology described by Stringer (2007), in that the primary source of information is ethnographic in nature, and collected through direct observations and interviews with key stakeholders for the purpose of synthesizing viewpoints and creating solutions that directly affect change in the delivery of the Project SEARCH model to positively impact outcomes for participants with HFASD.

The action research study involved a series of stages designed specifically to utilize qualitative data to make changes to the Project SEARCH Model through the addition of occupational therapy services. Figure 1 depicts a model for understanding the phases of this action research study, which can be conceptualized in sequential cycles, each subsequent stage building on the information gathered in the stages before it.

This approach lent itself to an in-depth exploration of the complexity that exists within the transition to the work world. “Investigation of the social and behavioral worlds cannot be operationalized in scientific terms because the phenomena to be tested lack the stability required by traditional scientific method” (Stringer, 2007, p. 193). Thus, in order to generate knowledge of the issues surrounding employability of individuals with HFASD within the Project SEARCH model, an integrative research design is required to impart the perspectives of both the interns and the work cultures in which they must thrive. Action research can provide a bridge between knowledge and practice in a way that empowers groups to make real and lasting change; a much needed strategy in this particular case. HFASD can be considered a culture unto itself, the voice of which is vitally important in the process of arriving at solutions to address employment needs. Qualitative research can also be a valuable way to examine the impact that a particular

environment impacts an individual or group of people (Colorafi & Evans, 2016). Environmental factors are an essential consideration of this work, as environmental barriers can be a significant factor in successful employment outcomes for individuals with HFASD (Hendricks, 2010).

**Figure 1. Action Research Methodology Implemented in Phases**



**Figure 1.** Conceptual model for action research methodology executed in phases (Stringer, 2007). Qualitative data is gathered to guide occupational therapy interventions, with subsequent data gathering to analyze the effectiveness and evolve programming in order to enhance outcomes.

## **Intern Participants**

Intern participants in this study were limited to interns at least 18 years of age with a primary diagnosis of ASD and without comorbid intellectual impairment. Participants were selected via purposive sampling from interns already accepted into the first and second intern cohorts of the St. Bernard's Medical Center Project SEARCH Program. By selecting participants without influencing the application and acceptance process, interns participating in this study are representative of interns meeting the qualifications for participation in the Project SEARCH Model. The participant group was limited to three participants in order to allow for in-depth study of each intern's experiences within the Project SEARCH Program. As it was important for the principal investigator to collaborate with the Project SEARCH staff in this work, recommendations for interns to recruit into the study were solicited from the Project SEARCH site coordinator. Diagnoses were confirmed through a review of the Project SEARCH records, which contained referral information and a psychological report from the vocational rehabilitation office.

Informed consent was obtained from each participant. Alias names have been assigned to each intern in order to protect their identity, while enhancing the readability of the following descriptions. The consent process was conducted during separate face to face meetings with each intern. The researcher reviewed details of the study and consent process with each intern, using the intern's preferred mode of obtaining the information; two of the interns preferred having the consent documents read aloud to them, while one intern preferred to read it himself. The researcher responded to questions or concerns during the initial consent process. Intern participants were reminded at each meeting of their ability to ask questions at any time, to refuse

to answer questions if they wished to; and to decline participation at any time in order to encourage autonomy in the consent process.

Adaptations to typical consent processes were as follows. The first participant recruited for the study was her own legal guardian and provided consent to participate with the assistance of the Project SEARCH Coordinator as an advocate; however, she did not have the expressive language ability to participate in the face to face interviews, thus her participation was discontinued as a case study after attempting the first interview. An additional intern was recruited to take her place in the study. An assent process with parent permission was utilized for one intern participant, as she was over the age of 18 but was not her own legal guardian. All participants were notified of their right to discontinue participation at any point during the study.

Table 1 (below) describes the intern participants included in the study, and the phase of the Project SEARCH program in which they were engaged at the time of consent. All participating interns had obtained their driver's licenses and had graduated from high school at least one year prior to admission into the Project SEARCH program. All three interns also reported negative experiences regarding their prior employment in the community as a primary reason for their involvement in Project SEARCH. All three interns were eligible for an Individualized Education Plan during their high school years. Only Justin had received supported employment through the state's vocational rehabilitation program prior to his participation in Project SEARCH. Mary's high school records included borderline IQ scores; however, the reporting psychologist discounted the reliability of the scores, given that Mary's academic performance was at grade level. During the course of the study, all three of the interns were employed or engaged in internship experiences at St. Bernard's Medical Center.

Table 1

*Intern Case Demographic Information*

<i>Case</i>	<i>“Cassie”</i>	<i>“Mary”</i>	<i>“Alex”</i>	<i>“Justin”</i>
<i>Gender</i>	Female	Female	Male	Male
<i>Age</i>	21	21	22	20
<i>Race/Ethnicity</i>	Appalachian	Caucasian	Asian	Caucasian
<i>Primary Diagnosis</i>	Autism	Autism	Autism	Autism
<i>Secondary Diagnosis</i>	Seizure Disorder	None	Anxiety Disorder	Anxiety Disorder
<i>Guardian Status</i>	Self	Parent	Self	Self
<i>Program Status</i>	Graduate	Graduate	Graduate	Intern
<i>Employment</i>	Job Searching	Part-time	Full-time	First rotation
<i>Consent Date</i>	5-7-18*	5-30-18	6-7-18	8-29-18

*Note.* The first intern consented in the study (Cassie) was dropped from participation after the first interview was attempted, due to difficulty with expressive communication. She was replaced by the second intern consented into the study.

The general sequence of intern experience in Project Search includes initial evaluation and placement, rotation through 2-3 different internship experiences, and transitioning to the work setting with follow-up services for a period of five years after graduation from the program. Entry into the research project was staggered to allow for examination of how the intern experiences the Project SEARCH Program at the end of the internship rotations and during the transition to competitive employment, as well as during the internship itself. Observations of the

interns as they participated in the Program were conducted throughout the course of the study. Interns were formally interviewed about their experiences at least twice during their Project SEARCH experience; one prior to any program delivery changes, and one after implementation of program changes using occupational therapy interventions. Additionally, reports, evaluations, and other records collected at intake and throughout the interns' participation in Project SEARCH were utilized in order to gain information about each intern's performance and progress in the program. For the readers' ease, all three cases will be referred to as "interns" throughout the following descriptions, even though they may have transitioned to permanent employment prior to or during the course of this study.

### **Stakeholder Participants**

In addition to understanding the perspective of interns with HFASD within the Project SEARCH Program, information regarding the perspectives and culture of various stakeholders within the St. Bernard's Project SEARCH Program was obtained. As the Project SEARCH Program combines services from several agencies, and eventually transitions interns out into the community, it is important to understand the expectations, experiences, and perspectives of the individuals involved in facilitating a successful transition for the intern with HFASD.

Purposive sampling was also utilized to recruit stakeholder participants. By selecting stakeholder participants that interacted directly or indirectly with the intern participants, the stakeholder data lent information that is relevant to the experiences of stakeholders that regularly interact with individuals with ASD throughout Project SEARCH sites (Stringer, 2007). Stakeholder participants who joined the study included the Project SEARCH Site Coordinator and both full-time Project SEARCH skills trainers. The trainers are contracted to implement the Project SEARCH program by an outside agency that operates statewide services for children and

adults with disabilities. Stakeholder participants also included two internship mentors and three department supervisors at St. Bernard's Medical Center. Additionally, steering committee members from various key partnering agencies agreed to be stakeholder participants, including representatives from human resources, training, vocational rehab, a transition consultant from a local special education cooperative, and administrators from the vendor agency implementing Project SEARCH.

Originally, the study protocol entailed interviewing each stakeholder individually at least twice during the course of the study. However, due to limitations in the stakeholders' schedules, primary stakeholders, or those involved directly with interns, were interviewed at least once prior to intervention, and then provided with additional avenues to offer feedback to the principal investigator post-intervention if a second interview was not feasible. Stakeholders provided additional information via impromptu conversations, emails, and phone when issues pertinent to the study arose. Secondary stakeholders, or those who did not have direct interaction with the interns but held other roles in program implementation, were provided two formal opportunities to provide comments; once during a strategic planning meeting midway through the study, and once during a post-intervention focus group. Both of these opportunities occurred during regularly scheduled steering committee meetings for the convenience of stakeholders, since scheduling individual interviews was not feasible for these participants. Again, alias names were assigned to primary stakeholders as needed in order to protect participant identity while preserving ease of readability of narrative descriptions. Table 2 provides a summary description of the primary stakeholder participants.

Table 2

*Summary of Primary Stakeholder Participant Alias and Role by Case*

Intern Case	Stakeholder Role	Primary Stakeholder Alias
Intern 1: Mary	Project SEARCH Site Coordinator	Jane
	Skills Trainer	Kay
	Department Supervisor	Cory
Intern 2: Alex	Project SEARCH Site Coordinator	Jane
	Skills Trainer	Chris
	Department Manager	John
	Department Shift Supervisor	Jerry
	Internship Mentor/Coworker	Dory
Intern 3: Justin	Project SEARCH Site Coordinator	Jane
	Skills Trainer	Chris
	Internship Mentor	Lindsay

**Data Collection Techniques**

Multiple forms of data were collected during the course of this study. For the Discovery and Expanded Understanding phases of data gathering (Figure 1, Table 3), records, interviews, and field notes from observations of interns and stakeholders were the primary forms of data gathered. Data gathered in the second Discovery phase (Figure 1, Table 3) consisted primarily of post intervention interviews, informal conversations and communications with stakeholders

and interns, and journal reflections by the principal investigator. Table 3 provides general descriptions of each phase of the project with an outline of the type and number of data sources for each phase as they specifically pertained to each intern case. A comprehensive timeline of all of the study activities as they were accomplished can be found in Appendix A. Each activity is color-coded to indicate the phase of action research it represents by case.

Descriptive qualitative techniques of ethnography and minimally structured interviews were the primary forms of data gathered in this study. Field notes were collected from all observations. Field notes were then transcribed into a digital format, and de-identified for coding and analysis. Interviews followed a semi-structured format that allowed the participant to take the researcher on a “grand tour” of their experiences (Stringer, 2007). Audio recordings of all interviews were collected, transcribed verbatim, and analyzed for themes, pivotal or meaningful events, and other experiences. De-identification of participants occurred during the transcription process, in which alias names were utilized. Names of specific locations or businesses were either omitted or included in a generic form, in order to prevent indirect identification of participants. Interns and other stakeholders engaged in the activities being observed were given the opportunity to participate in debriefing after observations, and to review the raw data and analyses collected from observations.

Table 3

*Description and Timeline for Research Phase Implementation*

Phase	Description	Intern	Total Sources	Phase Initiation
Discovery	Observations of interns as they participate in training through the Project SEARCH Program. Minimally structured interviews with interns.	1	8	5/30/18
		2	7	6/15/18
		3	8	9/12/18
Expanding Understanding	Minimally structured interviews with, staff, and potential employers; triangulation with literature review.	1	13	6/15/18
		2	13	6/16/18
		3	5	10/17/18
Planning	Analysis and synthesis of gathered data; planning OT interventions specific to the intern based on gathered data.	1		9/12/18
		2		9/12/18
		3		10/17/18
OT Intervention Implementation	Implementation of specific interventions to address specific barriers revealed in the first two phases of the study. PI will reflect on the progress of interns as well as the experience of implementing OT services with in the Program.	1		9/19/18
		2		9/19/18
		3		10/18/18
Discovery (2)	Observations and interviews with interns, staff, and potential employers regarding the OT interventions implemented in the previous phase. Triangulation with current literature.	1	5	10/29/18
		2	4	10/29/18
		3	9	10/29/18
Analysis	Analysis and synthesis of gathered data in order to produce proposal and recommendations for changes to the Project SEARCH Program for interns with HFASD.	1		11/7/18
		2		11/7/18
		3		11/7/18

**Table 3.** Description of phases through the action research process for this study, with timeline for staggering participants through the data collection, intervention and analysis process. Phases are color coded to align with the representation in Figure 1 that illustrates the “Look,” “Think,” “Act” components of action research (Stringer, 2007). Source totals specific to each case are listed in the data gathering phases to illustrate distribution of data from interns’ experiences. Sources that contributed to more than one case description are included more than once.

## **Ethical Considerations**

In order to effectively and accurately represent the perspectives of the interns with autism involved in this study, all data collection involving interns was conducted utilizing best practices in inclusive research for people on the autism spectrum (Cooperative Research Centre for Living with Autism, 2016). Specifically, the principal investigator waited to initiate any formal data collection with each intern until rapport could be established with the intern. The principal investigator provided her email address and cell phone number to intern participants so that they could email or text to communicate about appointments, feedback or other comments or concerns. Communication and environmental preferences were taken into consideration during interviews, and all interns were offered assistance from an advocate of their choosing if they wished to have someone present for interviews or observations. Scheduled beginning and end times for meetings or observations were strictly adhered to, and if changes in the schedule were necessary, at least 24 hours' notice was given to participants.

Interns were also given the opportunity to participate in member checking a variety of ways, including reviewing notes and transcripts, talking with the principal investigator about the information gathered, or listening to audio recordings of their own interviews. Intervention materials were provided to interns in advance of any reflection or feedback interviews in order to allow for the intern to process the information at his or her own pace. Interns were offered breaks or to discontinue the conversation, if needed, during all interviews, and informal conversations. Observations were performed at non-peak hours to reduce over-stimulation, and were reduced or canceled if requested by the intern.

In addition to records, interviews, and observations, the principal investigator engaged in journaling throughout all phases of the study, in order to reflect on the information gathered and

record reflections and annotations of observations, interviews and meetings with stakeholders. Journal entries were also transcribed into a digital format, and de-identified for coding and analysis. All raw data recorded by the principal investigator was maintained by the principal investigator and stored in a locked file. A running record of each observation or encounter with participants in the study was maintained throughout the study, including a log of journal entries included in the data analysis (Appendix A).

### **Rigor in Data Collection**

Several elements of rigor consistent with action research methodology were incorporated into the study design to ensure that the inquiry process minimized chances for superficial or biased reporting (Stringer, 2007). The principal investigator's relationship with the Project SEARCH Program began as a steering committee member in April of 2017, almost a year prior to the initiation of the study. This allowed the principal investigator to develop a relationship with stakeholders and interns involved in the Program as the site was being established, and enhanced the overall depth of information gathered. Prolonged engagement continued throughout the course of the study, as the principal investigator donated one day per week to the Project SEARCH site as an occupational therapy consultant for a period of seven months, allowing for regular conversations and feedback from participants, both formal and informal, with interns as well as stakeholders. It should be noted that the researcher has extensive experience with autism on a personal and a professional level. The researcher's personal reflection on her own bias was included as a source of data, and can be found in Appendix B.

Persistent observation was also implemented, as both intern and stakeholder participants were encouraged to be cognizant of events, issues and contexts relevant to the study over several months. Both interns and stakeholders readily agreed to this, and interview data was particularly

robust with their personal observations and reflections on the significance of the events described. Data gathered through the interview process was triangulated with data from observational field notes, past records, intern journal reflections, and investigator reflections in order to clarify meaning, and to delineate perspectives owned by particular members of the participant groups.

Due to its braided funding stream and immersive intervention framework, Project SEARCH has a multi-faceted service delivery model comprised of many different stakeholders who may have varied education levels, backgrounds, perspectives and interests within the program. For example, stakeholders may include direct interventionists, program administrators, or vocational rehabilitation counselors; as well as demand-side stakeholders, such as employers, supervisors and coworkers. Understanding each of these perspectives is essential to developing effective collaboration and planning interventions that will meet the needs of interns without becoming burdensome to any single group of stakeholders. To the extent feasible within the timeframe of the study, diverse case analysis was employed in order to include representation from all relevant stakeholder groups within the data. Inclusion of all stakeholder groups allows the investigator to recruit stakeholders from as many different roles within the program as possible, in order to capture all of the potentially varied perspectives of the many stakeholders engaged in the Project SEARCH Program (Stringer, 2007). Two of the stakeholders originally recruited for the study (one parent and one employer in the community) were unable to participate due to unforeseen personal life events that made scheduling interviews unfeasible; thus those two groups are not represented in this report.

Consistent with the action research design, analysis included member checking, in which participants are able to review the collected data, such as interview transcripts or field notes from

observations, in order to clarify their perspectives or expand on the information provided (Stringer, 2007). Member checking was performed in a variety of ways, according to participant's preferences, including audio recordings of interviews, verbatim transcripts of interviews, written notes regarding observations, and specific clarifying questions asked by the principal investigator. Full transparency was used throughout the project to encourage participants to review findings and clarify any misrepresentation. Participants confirmed the accuracy of their representation in the information they reviewed by providing confirmation or clarification via email or verbally in direct conversations with the principal investigator. To date, the participants involved in this study have voiced their affirmation that the information reported here is dependable and accurate. The confirmability of the data is clearly apparent, as all forms of data gathered throughout the project have been filed and stored.

### **Data Coding and Analysis**

Data collected throughout the study was coded for primary and secondary themes using an open coding procedure, with HyperRESEARCH, a qualitative coding software program (Creswell & Creswell, 2018). A total of five primary codes and 35 secondary codes were utilized during this phase of data analysis. Preliminary data analysis, primarily from the Discovery and Expanded Understanding phases of the first two case studies, was performed during the Planning Phase. The purpose of this phase of data analysis was to provide early data to primary and secondary stakeholders, in order to facilitate identification of issues related to success in the Project SEARCH Program for interns with HFASD. The data was then triangulated with current literature and presented to stakeholders, who collaborated with the principal investigator on a strategic action plan to address the identified issues with occupational therapy service implementation.

In the second phase of data analysis, the principal investigator's reflections during the Planning and Implementation phases were coded, along with data collected from the third case study and post-intervention data collection during the Discovery 2 phase. Once data was coded for primary and secondary themes, further comprehensive analysis of all of the data collected was performed through memo-ing on the primary themes identified during the coding process (Saldaña, 2016). During analysis, the original five primary codes persisted, and were identified as primary themes within the data. A sixth primary theme related to the role of occupational therapy emerged during the second phase of data analysis. A total of 35 secondary themes were identified from the 40 codes utilized in the first and second phases of data analysis. Table 4 provides an overview of the primary and secondary themes identified in the cumulative data analysis that occurred after the Implementation phase.

Memos generated through the analysis process were then further analyzed for overarching themes that were threaded throughout the data. A second review of the literature was performed in order to triangulate findings from second phase of data analysis with the current research. In addition to collecting and coding qualitative data regarding the experiences of interns with HFASD, perspectives from stakeholders were then analyzed, synthesized for main themes or problems, and triangulated with the literature in order to better understand the origins of the perspectives of stakeholders. Secondary themes in Table 4 are highlighted according to how the data contributed to the two overarching themes.

Table 4

*Overview of Primary and Secondary Emerging Themes Second Data Analysis Phase*

Primary Theme	Secondary Themes
Extrinsic Factors	Cultural Context Social Context Physical Context Temporal context
Intrinsic Factors	Unique Strengths Unique Challenges Motivation Anxiety Self-Awareness
Goodness of Fit	Person – Task Person – Environment Job Satisfaction Value Added
Acceptance	Attitudinal Barriers/Facilitators Getting a foot in the door Knowledge about ASD Systems barriers Behavioral expectations Equal and Valued Communication Perceived Inadequacy
Advocacy	Stakeholder Advocates Disclosing disability Attitudinal barriers Leveraging resources

Primary Theme	Secondary Themes
Advocacy	Interpreting
	Self-Advocacy
	Decision-making
	Initiating
Occupational Therapy Role	Occupational therapy consultant
	Occupational therapy direct interventionist
	Supervisor perspectives
	Effectiveness of occupational therapy intervention
	Future steps
	Need for occupational therapy in Project SEARCH

*Note:* Primary and secondary themes emerged during the first phase of data analysis, prior to implementation of occupational therapy interventions and persisted into the second phase of data analysis, with the exception of the occupational therapy role primary theme, which emerged after the implementation phase during the second phase of data analysis. Two overarching themes also emerged in the data: Cultural Differences (contributing secondary themes highlighted green) and Psychological Needs for Self-Determination (contributing secondary highlighted in orange).

### **Planning and Implementation Phases**

In addition to categorizing and coding multiple forms of data, subsequent phases of the study involved the analysis of key experiences conveyed by the participants. A framework for understanding and communicating the outcomes of the initial stages of this study was developed in collaboration with stakeholders in the form of a concept map (Figure 2). This allowed all stakeholder participants to have voice in clarifying the key issues from their own perspectives, while providing a practical focus for potential occupational therapy interventions aimed at improving the outcomes of the Project SEARCH Program delivery model for interns with HFASD (Stringer, 2007).

Figure 2

*Strategic Planning Meeting Concept Map*

The concept map was utilized to collaborate with stakeholders in developing a SWOT Analysis of the Project SEARCH site's ability to meet the needs of interns with HFASD (Appendix C). The SWOT Analysis is a common method for examining the strengths, weaknesses, opportunities, and threats related to an organization's ability to achieve a specific objective. The purpose of conducting the SWOT Analysis was to clarify an action plan for changes to the existing Project SEARCH service delivery model that leverage strengths and opportunities for enhancing services specifically for interns with HFASD, while mitigating risks associated with weaknesses and threats to the program's success in achieving better outcomes for this population (Humphrey, 2005). The SWOT Analysis process facilitated collaboration with

stakeholders in generating an action plan that guided the interventions used in the implementation phase of the project (see Appendix C). During the strategic planning phase, data gathered during collaboration with stakeholders was used to outline the content and format for a variety of educational tools and a plan for implementation of a series of trainings for specific groups of stakeholders was designed. Trainings led by occupational therapists were overwhelmingly recommended by stakeholders as a way to address the primary issues outlined by the stakeholder group. Key groups identified for the training intervention included parents, Project SEARCH skills trainers and program coordinators (at the state level), vocational rehabilitation counselors, hospital departmental supervisors for existing internship rotations, and interns in the Project SEARCH program. Table 5 provides a detailed breakdown of the content and timeline for trainings offered by the principal investigator during the Implementation phase.

Table 5

*Implementation Phase Training Timeline and Content*

Stakeholder Group	Date	Length of Training	Format	Content
Parents (local, open to public)	10-15-18	45 minutes	Face-to-face	Awareness of strengths Strategies for promoting independence
Project SEARCH Staff (statewide)	10-19-15	45 minutes	Skype presentation	Characteristics of ASD Goodness of Fit Autonomy support Culture clash OT Role
Vocational Rehabilitation Counselors (local)	10-30-18	45 minutes	Face-to-face	Characteristics of ASD Goodness of fit Assistive technology OT Role
Project SEARCH Interns Cohort 2 (local)	10-31-18	45 minutes	Face-to-face	Goal setting Making an action plan
Departmental Supervisors (local – hospital)	11-7-18	60 minutes	Face-to-face	Characteristics of ASD Goodness of fit Workplace culture Project SEARCH services OT Role

As occupational therapy interventions were implemented, the qualitative phase of the study resumed in the form of a second discovery phase and data was again collected from interns and stakeholders in response to the addition of specific occupational therapy services. Although the proposed timeline included a completely staggered format for each of the three cases, the end phases overlapped considerably for each of the three cases, primarily due to constraints in the program schedule and availability of stakeholders. Thus, the second discovery phase was initiated for all three intern cases simultaneously (see Table 3).

## **Results**

A total of 61 separate sources of data were collected throughout the course of the study; 19 sets of field notes from direct observations completed by the researcher, 16 interviews of interns and stakeholders, 3 record reviews of case information, and 24 journal reflections authored by the principal investigator. Early data gathering from the first two phases of the project allowed for in-depth observation and recording of first-hand accounts from the three interns with HFASD participating in the study, as well as the primary stakeholders who interact with them in the work setting on a regular basis. Data analysis occurred in two phases; the first of these was within the Planning phase, in preparation for sharing preliminary findings with stakeholder participants during a strategic planning meeting, which occurred on September 19, 2018. The second phase of data analysis occurred after the intervention implementation stage, and allowed for more comprehensive analysis of the accumulated data; both prior to and post intervention.

### **Early Findings: Personal Accounts**

Consistent with an action research approach, early data collection results from the Discovery phase of the project are presented first as a series of personal accounts from three

intern perspectives. The practice of story-telling allows each intern's voice to be heard, capturing the richness of their lived experiences in their own language and perspective (Stringer, 2007).

This also prevents significant details regarding each individual's lived reality from being lost in the process of data aggregation (Stringer).

### **Mary**

I started the Project SEARCH program last year. My mom and my sister both work at the hospital, so I thought it would be cool to work there, too. When I first started the program, I was frustrated because the pizza place where I worked had cut my hours back majorly. I was only getting one hour a week. I don't really know why, because I'm a hard worker. It was a boring job, anyway. They wouldn't let me make pizzas anymore, so I was just rolling up silverware and putting it out in these bins for the waitresses. We had to describe ourselves on this one worksheet at Project SEARCH. I said I am silly, confident, excited, organized, timely and outgoing! Project SEARCH has been good. The best part was when Jane and Kay helped me study for my driver's license test. I have my license now and I can drive myself to work. Someday, I want to have my own car and my own apartment. The thing I am always most afraid about is not doing good work. But, I think I mostly do a good job, because I am a really hard worker.

My first rotation at the hospital was in the nursing unit, 2 North. I really liked my mentor there. She was super-nice and always told me I did good. I also liked doing the data entry stuff for them, but it was kind of hard because they wanted me to answer the phones and do call lights and stuff. I didn't really like it. Kay was always up there, too, and she would help me figure out what to do. But after a while, I moved to laundry. Laundry was a hot place to work, but it was fun, too. I worked on the clean side and

folded towels and washcloths and baby clothes. And, I learned how to work the big ironing machine for the sheets. I liked all the people I worked with in laundry, they were nice. After that, I did a rotation in the imaging department and I got to sit behind the desk. People were so rude down there, you would not believe the stuff they would say to me! It was pretty funny. Kay was constantly down there with me though, and I hated to be watched all the time. She would never let me work by myself down there.

Right before graduation, I got a job at a store for home decorations doing stocking and stuff. I like it there but I don't like having to work on the weekends all the time. I go in and do stocking with these big carts and put stuff from the back onto the shelves. I don't know why there's always so much stuff, they always had us putting out stuff that was already on the shelves. Nobody ever cared how you get the stuff to fit on the shelves as long as it got out onto the floor, but Kay would always make me follow the instruction sheets. The managers never cared, though. This one time, one of the cashiers didn't show up for work and they put me on the register... I had only done the register a couple times before that, and not by myself. So, I texted Kay to see if she wanted to do it with me. She said yes. We were super-busy that day, it made me so tired. The line just kept going and going, and Kay would get mad at me because I didn't tell the next person to come up to the register. I was so glad when that day was over!

I wasn't getting enough hours at the store, so Jane helped me keep looking for another job. I went to an interview at a department store in the mall, and I did it all by myself, I did really good. There wasn't even any questions, the managers just watched a bunch of us put together this plastic block thing. It was a lot like the teamwork things we used to do in the training room, so I already knew how to do it. They called us back to

the back office one at a time and told us if we got the job, and I did. I don't know why they never called me back to start working there, but they didn't. So then, I got a job in the nutrition department at the hospital. The job I applied for was hostess, but they had me start on the tray line. I liked the tray line. The other girls were really nice, and they had me put the rolls on the trays, if the patient ordered one on their ticket. I only messed up one tray, but other people messed up trays, too. Somebody would check them before they went on the carts, just in case we missed something.

I went on vacation after they trained me on the tray line, and when I got back, the department switched everything up - we don't even do that anymore. The manager put me in utility – that's dishroom. Because now, people call in and they print out the receipts and then they fill the order on the receipt, it's completely different. It's all call in, people just order the tray and call it in, and then the starter people fill the orders. You have to read everything off the receipt to make sure it prints out. It's not as fast as it used to be. Nobody works together anymore, everybody's just everywhere. I don't think they will go back to the old way, though, because they got new carts to bring up for the people that deliver them.

So, I just don't really like my position I'm in. I thought I did, but I don't. I don't like being in there by myself. I have to do all of the dishroom work. I have to, like, push them, I have to catch them. I have to do all of that by myself. It just gets lonely in there, it's the same every day. I'm in there by myself sometimes. Every day. It's stressful because I never get out on time. The other night we got out at 8:40, and I'm supposed to leave at 8:00. They told me to stay late so they could show me how to drain the dish machine...nobody's ever taught me how to turn it off so I had to watch them do that.

Jane was gonna make me some directions so I can remember how to do it, but what I really want is not to be on dishroom anymore. I was going to ask my boss if I could try doing the hosting- the hosting position. But I don't know if they have enough people for dishes. I went with this girl I work with one time up to do the hosting job. It was good. I got to talk to patients. In each room you help them fix their wheelie tray and check their name on the ticket and their allergies. It was a little bit hard to learn but I'm getting used to it. The hardest part was dressing out for the isolation rooms and all that stuff. Because some patients are in isolation and we have to dress out, put the gown on, the gloves on, just to bring the tray in, and then you take it all back off. I couldn't get mine tied in the back but the girl I was working with helped me.

I don't want to tell my boss I don't like my job because I don't want her to get mad at me, but If I was on hosting I would get to talk to people. Because I really don't talk to anybody in there when I'm by myself. I'm fast on dishes, but man, I would really like some help. It is so gross, because I always spill stuff on my feet and on my shoes and spill stuff on my shirt and my pants. I smell like food all the time. The smell is so bad, and I sweat because it's really hot back there. And the hairnet always makes me mess up my hair. One day I tried to work for a whole eight hours back there, and it killed me...I went home and told my mom I am never doing that again! She said I would be better as a hostess, and I think I would too, because I told her I would like it a lot better. I need to get more hours though, because I just got engaged to my boyfriend. If I get to do the hostess job and I get more hours, I will probably quit the home decorating store.

(Interviews, Mary, August 22, 2018; September 19, 2018)

**Alex**

I graduated from Project SEARCH last May, and now I work full time in Central Supply at the hospital. It's a pretty good job, definitely better than my old job. In Central Supply, I probably get a little bit more freedom compared to what I used to. Because used to, you know, used to when I worked at the grocery store, it was much more difficult and it wasn't (pause) it just didn't make me feel welcome and here it's making me feel a little bit more welcome and, um, I know that, if something goes wrong, they got zero tolerance for it and I think this will be a little bit more (pause) I think this will be more fair. I guess compared to my last job. At the grocery store, they had rules. Only the thing was, the manager could kind of make up rules. Some of those I thought wasn't necessary, some of them I think were, but, like, I would take a break. Our breaks were 15 minutes or so, I think. And I would take a break at, you know, 20 minutes 'til and my managers told me, you know, that we couldn't do that and I had somebody who was there, a coworker said, "I think they made that rule up, because they hadn't told me not to do that." And I'm like, "Okay." Here, they're pretty straightforward about what they expect. Basically, the grocery store was just a position where, you know, you start at the bottom, and you're not going to move. All of the union rules still applied to me, but I was not eligible to get their benefits because I wasn't there full time. I didn't want to work full time there, because I knew it was just going to make me (pause) add more pressure, and you know, I wasn't going to like it, basically.

I was a porter at the grocery store. That meant I had to walk out half the parking lot, grab the trash, and then walk back in. It was scary at night, but I had to get over that pretty quickly. It actually made me feel a little better because I knew, "Okay, the rush is

over and everybody's gone.” I cleaned the bathrooms and pushed the carts some, but I really mostly enjoyed pushing carts and helping up front than I did cleaning. The porter job was harder than my job now because, well, you know they told me, the floor has to be this wet, or the bathrooms have to be this clean. I guess it was just trying to make everybody happy, best I could. Everybody’s standard of a clean bathroom was different. Their view was different than what I was trying to do, basically. In this job, as long as you get what the machine says is full then you're fine, basically.

When I first came to Project SEARCH, I had no idea what I wanted to do, I just knew I didn’t want to stay at the grocery store, I wanted more than a cleaner job. When I was at the grocery store, I didn’t have the right mindset. I knew that after my day at Project SEARCH I gotta go back to what I’m facing. And I just felt terrible. I was arrogant, tired and, um, worried, you know, just worried about me at the moment of what I was going to face a few hours later. I felt terrible and I kind of showed it at Project SEARCH. And Kay kind of got onto me, and I was like, “Well, I just need to straighten up.” I came in after work to tell Kay that I just didn’t really have a good night at work, and all I was thinking about was me, and not really thinking about everybody else. I kind of had some bad behavior, but it was kind of hard to straighten up when I realized, I gotta go back, you know, from feeling good at Project SEARCH to feeling terrible at the grocery store. When I really didn’t want to do that. So, I kind of got a little dramatic when I realized what I did. I feel like my behavior wasn't a very good example and I didn't want to be a bad example in front of them and I wanted to quit. I gave Kay my badge back, and they're like, "No, you're not quitting." So I didn’t quit, but the point was I didn't want my bad behavior to be a bad example for everybody else. So I knew that

wasn't acceptable. So, I've kind of overcome some things. I guess I've learned about respecting other people and just having patience. Because I'm not very patient.

Basically, I've just learned more about how to behave in a workplace.

The hardest part of my job now is just getting along with coworkers. But other than that, it's not so bad. At lunch, you know, it's just teasing. We're all just kidding about it. Most of the time I just need to learn if I don't understand something, I just need to keep my mouth shut. Basically, I just try to ignore whatever they're saying, if I don't understand it. I just try to keep my nose or ears out of whatever they are saying. I really don't want to go into the details of that because (pause) well, there is this certain person down there, I'm not going to say names to be nice, but she was like, just wanted me to apologize to her and she said something about her, you know, something about I said something to her kid, and I'm like, "Well, and my first thing is if you're talking about a second ago, you know, I did not, you know, specifically say anything. But if you're talking about weeks ago, that was weeks. Look, if I did say it, I'm deeply sorry for that." I feel bad about it. To be honest, I don't really remember what she was talking about. Then she was like, "Well, I ain't going to put up with your pity," you know, "blah, blah blah and blankety blank." And I'm like, "Okay." I had a sincere voice, but she just didn't take it, basically. Then I was like, "Okay, I think I'll remember that." I'll be like, "Okay, I'll remember that if you try to apologize." So she doesn't really talk to me anymore, but I'm not going any farther than that. Usually the best thing to protect yourself, you know, in that situation, just don't say anything, basically. (Interview, Alex, August 31, 2018).

**Justin**

Before I came to Project SEARCH, I used to work at this one restaurant. You know, when I first started working there, they had some really nice people. The real problem was, that management was not the best there at the time. You know, when I was there, I guess I would always expect the owner to be there. But, as I learned, the owner is not always going to be there. It's more of a manager deal and stuff like that. And one of the managers gave me a rough time, a very picky person. And, you know, and if I can compare Project SEARCH to my old job, this is actually a lot better. It really opened my eyes to see, you know, that there's actually good management and good people being in an area, because I took the restaurant job as a bad experience and I just didn't want to work anymore. I was ready to give up. They gave me a really rough time and I was pretty criticized by one of the managers. Every day I would hope, "Oh, it better be Grace, not Donna." Those were two different managers. It was just really stressful. It was more helpful when the owner was there. He was very nice, and understanding. And, he knew my disability because we had talked about it during the interview. But, he was never really there.

When I started at the restaurant I didn't really take criticism well. That is still something I struggle with, I cannot take criticism or it's just going to- I just want to shut down and quit, you know. And so to control my anger, I decided to shut down. That way I don't make anything a hostile work environment. You know, I just, it doesn't seem very professional. So I guess there was just a lot of miscommunication. I don't really remember on what happened. I think it could have been that Donna was just being ugly to me for, for God knows what. She was frustrating the crap out of me. I mean like... she

would add onto my job list. And, you know, and at that time I didn't, I didn't really have a list. You know, I was always, I was doing the same thing until, you know, like until a certain time and then that was when I was cleaning the bathrooms, like the men's and women's restroom and changing all that stuff. She wasn't really mad at me, it was more like... she was very clean-freaked. She talked about like scrubbing the bottom of the toilets when they were like already clean. You know, and then she would complain about the bathroom stalls. I would have to put like some- some kind of- some kind of spray that makes it shine like shine spray like chrome spray on a car. And so- and then she would come and she would, she would always come and inspect my work. It was every day. Honestly I just (pause) I just think she really piled on me.

The one thing that I got that was good out of my old job was that I really wanted to run a restaurant. You see, um, on top of the surgical field, I want to be a restaurant owner because I, you know, part of my goals is I want to help, like, you know, also help special needs children actually get a real job kind of like me because they don't deserve to go what I've went through with Donna, you know? You know, they deserve the modifications and honestly to me it's not fair to them that sometimes they don't have jobs because they can't handle their emotions and a lot of these people now like at Bills or, Burger King....they refuse to give them modification and, you know, and it's just that kind of thing that I think deserves to be put on notice when it comes to a restaurant, you know? And- and just work in general, you know. People (pause) and I'm not saying that all the people in my restaurant are going to be special needs people. That'd just be, that'd be pretty kind of ridiculous, but uh (pause) what I've learned is that people need help sometimes. This is the United States. I mean, we all need a work life, regardless.

And so, I saw Project SEARCH as a golden opportunity to figure out, you know, what I want to do with my life, just what are these modifications going to help me in the future. And that's when I'm just like, "Yes." You know, this is a program that can be helpful. Right now, I am working in the ICU. So the ICU is pretty nice. I've seen about two cardiac arrest already. I just stood there, I wasn't in panic or anything. I wasn't like, "Oh no, please don't die," or anything, you know, because I kind of had faith in them when I watched it. It was just very (pause) it's very inspiring to watch, you know, because when people go through pain like that, you want to do everything to help them, you know? So, this rotation in the ICU, it's used a lot of things that I want to do too, and it's a combination I think. Uh, there's cleaning, there's stocking, there's watching how nurses take care of people, you know, to me it's all in one package right now, I don't know how greatly overwhelming that is. It's just (pause) it's just great.

I am a little shy and, you know, and uh, I guess they treat me really well down there. They are so laid back and they, you know, they're just- they're just so nice, and they're not picky, you know? You do what you want to do in whatever order you want to do it, it's just, it's a flexible work environment. You know, but uh, there are so many nurses that work there sometimes and most of the patients need rest. So a good part of the time they'll play on their phones but they'll also pay attention to like the sounds and the alarms and all that stuff. I mean they are really good at multitasking their stuff. Like they can play on their phone and hear a sound. They put the phone right down, the patient comes first. I think that is what they're really good on. For me, I think time (pause) time, you know, just that's probably one of the biggest things I have trouble with when it comes to work is everything has to be there at a certain amount of time and it has

to be done this quickly and stuff. But with ICU you kind of get to choose how you want to do things, you know, and that's, that's something that I really like is that I get to kind of choose how to use my time, you know. I can't really, I can't really just do it all in one time, you know? It's got to be broken down.

I think a lot about my future and it makes me stressed out. It's very hard. And I think that's what killed me on the inside is, before coming into this program that I feel like that everything is just going to be screwed now that I don't have all my friends with me, I don't have anyone that partners with me, and all that stuff. I think it's hard for people to keep in touch after high school. But you know, I just kind of learned after a while that they're in the same shoes. Some of these people are in the same shoes as I am and graduated the same year as I did, you know? I want to go to college but, you know, it also depends on my mental life, I feel like my mental life kind of comes before like physical goals. I guess part of it is, thinking about marriage or where my finances are and all that stuff is kind of (pause) all that stuff kind of weighs on you before college. And so, uh, you kind of want to figure out what you're gonna do. You know, if you want to get married at a certain age, and if it doesn't happen, you're just going to break down, you know, it's not going to work out for you. It feels like- you feel like it's the end of the world because, oh, your girlfriend or your boyfriend decided that it was a good idea to marry a little early. I honestly feel disappointed that things cannot be a little easier, in that aspect. It just seems like in order to be happy you have to have money for something. Almost everything that you want to be happy for, you got to have money for something. (Interview, Justin, October 3, 2018)

## **Thematic Analysis**

Data from both data collection phases was coded for primary and secondary themes with coding software support, as described in Methods. Through this process, five major themes emerged from the first phase of data analysis, which occurred during the Planning phase: Intrinsic Factors, Extrinsic Factors, Goodness of Fit, Acceptance, and Advocacy (Table 4). The five themes continued to be prevalent in the second phase of data collection, however, an additional theme emerged from analysis of the data collected after the Implementation phase of the study: the role of occupational therapy. Finally, two overarching themes appeared with great frequency: Cultural Differences and Psychological Needs for Self-Determination (Deci & Ryan, 2001). The two overarching themes were threaded throughout all forms of data, and were prevalent in both the intern and stakeholder comments (Table 4).

## **Intrinsic Factors**

Intrinsic factors are factors that are inherent to the individual. These factors can be unchangeable characteristics, such as demographics, gender, or life experiences; but can also include factors such as motivation, thoughts, or attitudes, which might change over time (Baum, Christiansen, & Bass, 2015). Intrinsic factors are important because they form the individual's personal narrative, and lend insight into the intern's perspective (Baum et al, 2015). Intrinsic factors were mentioned by both interns and stakeholders as characteristics unique to interns with HFASD that influence the intern's performance and satisfaction in the Project SEARCH program. The subthemes described below outline the common features of these intrinsic factors.

**Anxiety.** Two of the interns who participated in the study expressed feelings of intense anxiety, and were receiving treatment for anxiety disorders at the time of the study. They

provided rich descriptions of their lived experiences with anxiety. Justin expresses his anxiety about failing to meet expectations, and the pressure he feels to be successfully employed:

Justin: You feel like it's the end of the world because... your girlfriend or your boyfriend decided that it was a good idea to marry a little early, you know...

PI: So you feel like the expectation can set you up for failure?

Justin: Expectations. Yes. Some expectations that are (pause) that you cherish and have more goals for. Those are probably what also kills people when it comes to being homeless and all that stuff. (pause) I honestly feel disappointed that things cannot be a little easier, I guess, you know, in that aspect. Because everything now just seems in order to be happy you have to have money for something. Almost everything that you want to be happy for, you got to have money for something. (Interview, October 3, 2018)

Justin's written reflections also revealed his anxiety about meeting expectations. He stated, "Sometimes I feel like I am in this alone when I'm really not and I feel like I'm under too much pressure because of that. Might like a little help so I don't mess up things" (September 17, 2018). In another reflection, Justin stated, "I mostly go all over the place and will sometimes stress myself on figuring out what I need to do" (September 23, 2018).

Alex described his anxiety in anticipating having to return to a job he was unhappy in.

I knew it was just going to make me- add more pressure and, you know, I wasn't going to like it basically... They told me, you know, the floor has to be this wet or the bathrooms have to be this clean. I guess it was just trying to make everybody happy, best I could. Everybody's standard of a clean bathroom was different. Different- their view was

different than what I was trying to do basically...When I was at [the grocery store], I came in [to Project SEARCH], and I didn't have the right mindset. I was just like, oh, you know, I knew after I- this was over like, oh, I gotta go back to what I'm facing...You know, and I just felt terrible. Terrible....[In Project SEARCH] I learned about respecting others, having patience ...I had some bad behavior, I was worried. (Interview, Alex, August 31, 2018)

Mary did not personally express feelings of anxiety, but her support staff and supervisors picked up on signs that she was feeling anxiety about not performing well, or feeling overwhelmed. At times, she would seek to please others, but overall tended to mask her feelings of anxiety until she reached her breaking point. Kay, Mary's skills trainer reflected on Mary's behavior in her position at the home decorating store, noting how Mary showed signs of anxiety.

All of a sudden, you look up and you've got 15 people tapping their fingers, like, "Let's go!" She had no concept of how to get them through the line - once she finished with someone, she would flip her ponytail and run her hands through her hair, and I'm inside like dying... I'm going, (cheerful voice) "Okay, we can help the next person!" (whispers) "Mary, you have to tell them," and she says, "Oh, okay," but then the next person finished [and no change]. It was like she was de-escalating... I think maybe in her mind because that was (pause) it was really overwhelming. (Interview, Kay, June 15, 2018)

Support staff, coworkers and supervisors also reported being aware of subtle signs of anxiety in the interns while they were engaged in work activities. Alex's mentor, Dory, noted that Alex often gets frustrated because he wants to do it right, to be perfect – this seems to be related to his anxiety. Dory stated, "We're teaching him slowly, that we all make mistakes" (Investigator Reflection, September 12, 2018). Jerry, the shift lead in Alex's department also

notes subtle signs of Alex's frustration. "You have to know [Alex] to know he is unhappy... You can see his frustration in his face. He deals with his anxiety, [he] gets a little antsy" (Interview, Jerry, September 12, 2018).

Jane also notes Justin's frustration in his body language. After observing him during orientation in the ICU department, she stated, "Justin looked like he was freaking out on the inside – [he] had shut down, [he] wasn't attending or taking notes" (Conversation, Jane, September 12, 2018). Justin also appeared to have a glazed over expression during observations of him in the ICU over the first week of his rotation, as well as during orientation in the sterile supply unit in preparation for his second rotation. Chris, Justin's skills trainer, interpreted these subtle signs as a cue that Justin needed emotional support.

I can usually tell [Justin is anxious] because he sighs. He- his face might turn a little red. He'll become quiet. A lot of the times when he is stressed, he actually wants to- he'll become quiet but I can feel like he's wanting me to talk to him. (Interview, Chris, October 17, 2018)

Interns expressed strategies they use to mask anxiety and frustration in the workplace in order to meet perceived behavioral expectations. Justin stated, "You know, and so to control my anger I decided to shut down, you know, that's- that way I don't make anything a hostile work environment. You know, I just- it doesn't seem very professional (Interview, Justin, October 3, 2018). Alex expressed similar self-protection strategies.

Like I know when they're teasing me. But if they're having a bad day and they're just blurting out some random stuff I'm thinking, "Okay," you know, "just kind of walk.

They won't do it if I go to walk.” Yeah, walk quietly away. Yeah. (Interview, Alex, August 31, 2018)

**Unique challenges.** A theme of challenges unique to interns with HFASD emerged in the comments. Comments coded under this subtheme related to the specific issues interns with ASD seemed to struggle with that were different from issues characteristic of other interns in the program who do not have a diagnosis of ASD. Comments included behaviors that were atypical for the expectations of the setting, differences in communication styles, rule-bound logic, and emotional reactivity. Very few issues related to motor or sensory function that are characteristic of individuals with HFASD were commented upon. Issues that resulted in awkward social situations were most commonly noted.

Cassie had a specific routine that she did. Um, she didn't like change. That's at work, at home, just in her regular routine....We did have to work with them [interns with autism], not necessarily because they were being rude or whatever, but in the workplace we did have to work on - you know, “you may [want to] say it this way instead of being so blunt to make sure that you're not upsetting a customer, or that they don't take what you're saying the wrong way.” (Interview, Chris, May 30, 2018)

It was the social interaction for the most part - any task that has social interaction [Mary] had to initiate...it was just really difficult....She's [Mary's] stocking and opening boxes, shelving...you almost have to be completely blunt like harshly blunt for her to understand when you're giving her direction. (Interview, Kay, June 15, 2018)

I think the biggest struggle for those that had autism was, I mean it's the social aspect of... I don't know if you call it social, but, communication. The communication. Maybe

understanding or not understanding what to do, knowing those social bubble boundaries when you've got your personal space issues...they don't take the visual cues or facial expression cues from people. (Interview, Jane, July 13, 2018)

Interns provided personal descriptions of unique challenges they face. Justin was particularly articulate in describing his unique challenges.

The fact- the real problem was, is that management was not the best there at the time and, you know, when I was there, you know, I guess I would always expect the owner to be there. But, you know, as I learned, the owner is not always going to be there. It's more of a manager deal and stuff like that. (Interview, Justin, October 3, 2018)

Well, for a while I felt like thinking about my personal stuff kept me from doing my checklist or made it hard for me to talk to people at work...I've never been very good at setting goals because I don't really know how to write them. I get frustrated when I never meet a goal, so then I end up just not working on anything ....Well, [for example] I might tell her [my girlfriend] that I have a lot of sensory reactions; that I get overwhelmed, but she doesn't really understand what I mean. She thinks I don't care or I don't want to do things. (Interview, Justin, November 7, 2018)

Skills trainers and coworkers also noted unique challenges that created moments of social or interpersonal miscommunication. Dory, Alex's mentor, described how Alex's tendency to get overly focused on the task caused him to miss social cues. She described pausing to call something to his attention, more as a reminder than instruction. Dory felt Alex knows what he should do, but can't always divert his attention to thinking about other people, rather than solely focusing on the task at hand. John, Alex's manager in central supply, described a moment when

Alex was offended and embarrassed by an unfamiliar staff member from another department because he misread a joking remark and took her statement seriously:

[The nurse] has some little cards and everything, and was talking about learning CPR. Alex said, “Well I learned CPR in Boy Scouts, and I didn't like it.” And the nurse said, “Well you just weren't put with the right boy during the mouth to mouth!” (Chuckles) She was just kidding, but Alex really got offended by that, and I caught him after the meeting, and I said, “She was joking, you know that, right?” And Alex said, “You know that can be (pause) That can be offensive.” [Then I said,] “But you know she was just joking, right?” He's like, “Well I didn't know.” (Interview, John, June 18, 2018)

Alex was able to perceive that his coworkers were used to the chiding remarks, and they took it on as a mission to “teach” Alex to “cut up” like everyone else. However, when Alex attempted to use the same communication style as his peers, he was misunderstood. John relates an incident in which this caused significant interpersonal conflict between Alex and a coworker.

The incident Monday happened when a coworker who is relatively new to the department came in on her day off to get her paycheck. She had her son with her, who has a stuttering problem. Alex made a comment about the stuttering. The coworker was taken aback by his comment, but tried to make light of the situation, “Oh, well, we're working with him on it.” Alex stated, “Oh, well he's probably stubborn and hard-headed, just like his mom.” (Conversation, John, August 29, 2018)

Later, Alex described his perspective, and explained he was attempting to joke around with the coworker, just as another coworker had done moments before:

Alex: Basically, what really happened was Jerry was just teasing with her kid and he was like (pause) he said something, "Well I'll put you work!" And he's like, "No," and then I mutter under my breath, then I kind of mutter under my breath, "Just like his mother." And she comes around and she got her (pause) she looked like she was steamed and she was like, "Don't say that to my kid!" and I'm like, "Okay."

PI: Jerry was there when it happened?

Alex: Yeah, Jerry was, he was there... or he probably knew what happened better than I did, basically. (Interview, Alex, August 31, 2018)

When Alex was confronted by the coworker about it, the issue no longer seemed relevant to him. When he attempted to apologize anyway, Alex could not understand why the coworker was upset about the interaction:

Alex: I thought she was talking about some high school kid she was annoyed with or somebody, and I'm like, "Oh, well," and said it, and she's like, "Oh [expletive]." Then someone told me, like, "Oh, well, that was bad."

PI: Did you remember the whole thing?

Alex: It just sounded like she was talking about somebody, somebody, you know, else. I'm thinking, well... To be honest, I don't really remember what she was talking about. But I went and apologized to her and then she was like, "Well, I ain't going to put up with your pity." You know, blah, blah blah and blankety blank. And I'm like, "Okay."

PI: Wow. So it was kind of not a good apology then.

Alex: Well I had a sincere voice, but she just didn't take it basically. Like I was like, "Okay, I think I'll remember that. I'll be like "Okay, I'll remember that if you try to apologize."

PI: Does she talk to you at work now?

Alex: No. And I just try to avoid her. (Interview, Alex, August 31, 2018)

In reflection, the differences in perspectives between the coworker and Alex were apparent, but Alex had considerable difficulty in communicating his perspective. He used his preferred interest in history to describe his perspective.

Alex: Basically what I meant by, you know, by not saying a word, reminded me of this famous feud between Jackson and Quincy and, you know, how Quincy said things that were true and now Jackson thinks they weren't. And that's what I'm trying to avoid. I'm trying to say things that are true and trying really not to say things that aren't, basically.

PI: So, what you said when you were joking around, was it something that you believe was true?

Alex: Just a little- just a little bit because... I mean the way I saw her first come in, she looked like she didn't really want to be at work today, you know, and I'm like, "What's the deal?" You know?

PI: I'm sorry it happened like that.

Alex: Yeah, well it's fine just (pause) well to me it's just part of it [working].

(Interview, Alex, August 31, 2018)

Alex also struggled with concrete thinking around procedures and policies:

One of the biggest things with him is he seems to have a little trouble thinking outside the box. If things go wrong upstairs, something was in the wrong place, it really- you can tell it really frustrates him and he has to stop and think about, "Okay, what do I need to do to

fix this?" I mean, you can see it clicking in his head. It's like, "This is not right and I didn't do this, so what do I do?" (Interview, Dory, September 12, 2018)

Justin's rule-bound logic often served as an impetus for conflict he experienced in his rotation when things were not going the way he thought they should:

Sometimes I've heard him blame staff. I've heard him blame Project Search staff. But I know...when he says things like that, I know that it's a defense mechanism because he's not going to place the blame on himself and he feels like if something's not going the way that it should or the way that he needs it to go for himself, that it has to be someone's fault. (Interview, Chris, October 17, 2018)

Justin's active avoidance of others in his physical space was also apparent to his internship mentor, Lindsay.

But like, if he's in the middle of stocking something, and then people come into that area, I feel like he kind of shies away from that. But, he always comes back to it. But if he has to talk to someone that he doesn't know or he bumps into someone, he kind of automatically just shuts himself down from that. (Interview, Lindsay, October 31, 2018)

**Unique strengths.** Stakeholders commented often on the intrinsic qualities that are unique to individuals with HFASD that can be strengths in the work environment, and described how these strengths are assets in the work setting. Many of these comments related to the ability to focus, accuracy, detail-orientation, organization, and rapid rate of learning. Kay stated, "[Interns with autism are] very detail-oriented, I would say. [They] followed a list fairly well. Visually, if there was a list, for them to follow, either words or pictures, typically, they could follow that very well" (Interview, Kay, June 15, 2018). Mentors commented on specific traits of

interns with HFASD. “You know, [Alex] he’s naturally gifted in numbers” (Interview, Dory, September 12, 2018). “You know, [Justin] is just so smart and he catches on to everything so fast” (Interview, Lindsay, October 31, 2018). Dependability, loyalty, and respect for rules, processes and procedures were also noted to be particular strengths. Interns were also observed to display specific traits that helped them to excel at work: “[Cassie] works diligently and never stops to talk, or sits for a break. She stops only once to get a sip of water from a water bottle, and goes directly back to work” (Investigator Field Notes, May 10, 2018). Alex exhibited several positive traits that set him apart from his coworkers in central supply.

We start everybody at a low level and gradually work up. Some advance more than others, you know, faster than others, but [Alex] did quite well with it. He has an excellent memory. Once you told him something and then followed to make sure he had it accurate, he had it.... [Alex] has really good focus. He has extremely good focus. I mean, in fact they- several of our colleagues in other departments have said, "Boy that young man sure does go." He just- he knows what he's going to do and he goes and he takes care of it. (Interview, Jerry, September 12, 2018)

Alex never uses cheat sheets, visual cues, or extra notes on his clip board. He has his ID [number] memorized and knows the passcodes to access restricted areas of the hospital, such as surgery and ICU. He never loses his place when counting out inventory, and prepares ahead for the route he plans to take. (Investigator Field Notes, June 13, 2018)

At times, even communication style was found to be an asset for interns with HFASD.

But I have found that because they don't get offended by me asking the question.

Whereas a lot of people, I feel like, take things personally if you question them or they

feel attacked or they feel like you're invading some kind of personal privacy. But if I am blunt and direct and ask direct questions from those that have autism, it doesn't offend them and they can give you a straight answer. (Interview, Jane, July 13, 2018)

Interns generally had few comments regarding their own strengths, and had more difficulty articulating strengths without direct questions or prompting. After being presented with information about strengths in individuals with HFASD, Justin stated, “Yes, I do that. I’m very good with details...I can see the whole picture, but I also get really focused on the details” (Interview, Justin, November 7, 2018). When prompted to consider her strengths in her work role, Mary described herself this way: “Because I'm probably a hard worker... Yeah, I work really hard when I think about it” (Interview, Mary, September 19, 2018).

**Self-awareness.** Self-awareness was a major sub-theme in the area of intrinsic factors. Self-awareness refers to the intern’s ability to know about themselves; to identify their strengths, weaknesses, capacity for new situations or roles, and needs in terms of support or resources. It also refers to the intern’s ability to judge their own progress or performance. Self-awareness was noted to be a focus of many of the training sessions for interns in Project SEARCH, particularly during the orientation phase of the program, when interns are preparing to work in their first rotation.

I know we had to ask just, just as a learning experience for ourselves and them, we had asked that at the beginning of the internship program, “What is your disability?” And we learned that most of them did not even recognize that they had a disability. They didn’t know that there was any disability there, which I think is great, in a certain sense (laughs) but is not great in another sense, because I think it’s good to define something, and then work on it, and grow from it, grow from there. (Interview, Chris, May 30, 2018)

I think they knew what [autism] was and that they had one [type of autism] kind of, but I don't think they were aware of what it- what it was even called or what were their characteristics, what is their- what is the makeup of this disability? And so we did a ton of education on that and I think it helped. (Interview, Jane, July 13, 2018)

Interns most frequently articulated their specific preferences. “I cleaned the bathrooms and pushed the carts some, but I really mostly enjoyed pushing carts and helping up front than I did cleaning” (Interview, Alex, August 31, 2018). In records from his initial interview, Alex had stated, “I just want to discover what is out there – I work at grocery store but I want more than a cleaner job [janitorial work] (June 18, 2018). Justin felt he had learned something about what he wanted in a career: “The one thing that I got that was good out of [my old job] was that I really wanted to run a restaurant” (Interview, Justin, October 3, 2018).

Though Mary could articulate her preferences when asked specific questions, did not often volunteer information about her preferences unless she was having a negative experience.

PI: What don't you like about your job?

Mary: Being there by myself. (Interview, Mary, August 22, 2018)

Mary: I'd rather work like probably mornings instead of nights.

PI: Do you could get here that early? You'd have to leave your house at like 6:30 or something.

Mary: Yeah. I'd rather do mornings than do like four to nine. (Interview, Mary, September 19, 2018).

Interns were generally more focused on their challenges or areas of weaknesses than their strengths. Interns typically articulated a need or an issue without recognizing a specific solution

or resource to address the issue. Alex stated, “I've kind of overcome some things...I guess respecting other people and just having (pause) I guess just having patience, I guess. Because I'm not very patient” (Interview, Alex, August 31, 2018). Justin echoes similar negative comments about himself.

I didn't really take criticism well working there when I started. And I (pause) and that is still something I struggle with. I cannot take criticism or it's just going to (pause) I just want to shut down and quit, you know? (Interview, Justin, October 3, 2018)

I always feel like I need my mom to speak for me, like when I go to the doctor...I'm just afraid I will say something wrong or forget to ask something, and it will mess up my medications. (Interview, Justin, November 7, 2018)

Justin seemed to adopt comments he had heard others make about him as part of his own self-concept. He made the following remarks in his daily personal reflections: “Sometimes I have a mean resting face because of how stressed I am as a person and sometimes it's seeable at work” (Personal reflection, Justin, September 23, 2018). “I've noticed that I'm sometimes a little too quiet when I'm working because I'm pretty focused on the current task at hand” (Personal reflection, Justin, October 1, 2018). Jane reported that she felt maybe Justin had been told by someone else that he is being taken advantage of. Jane's impression was that Justin was confused about whether or not he actually was being taken advantage of. His difficulty with reading others made Justin reliant on the interpretation of others, which added to his insecurity.

Comments related to recognizing and error or mistake frequently included comments related to emotional reactivity:

Alex: I kind of got a little dramatic and realized what I did... you know, I almost quit and they're like, "No, you're not quitting."

PI: You almost quit Project SEARCH?

Alex: I feel like my behavior wasn't a very good example and I didn't want to be a bad example in front of them and I wanted to quit. (Interview, Alex, August 31, 2018)

Alex's tendency towards emotional reactivity continued even after he graduated from Project SEARCH and took full-time work. "I knew it was wrong but I didn't want to apologize, I'm just not going to talk to her anymore" (Interview, Alex, August 31, 2018).

Though interns could usually identify their preferences and weaknesses, they were not often able to articulate their capacity to do something they had never done before.

Mary: They start the silverware and like the pepper and stuff and then scoot it down. You have to get all the plates from the top of the- that little - top shelf thing. And they grab it with the receipt and then they stick it on the tray and then they put it in one of the carts for the hostess to bring up.

PI: Okay. Did you like that job? Do you think you could do that?

Mary: It was kind of fun at first.

Jane: What's the host position do?

Mary: It's like they deliver them.

Jane: Okay. Deliver the trays to the rooms?

Mary: Yeah.

Jane: Have you ever done that before? Or you've seen it?

Mary: Well I've seen them do it, but I haven't done it by myself yet. (Interview, Mary, August 22, 2018)

PI: Did you know, coming in, "I really want to do this kind of work," like what you're doing now?

Alex: Not really. I had no idea. (Interview, Alex, August 31, 2018)

Interns also had some trouble articulating their strengths, progress, or judging their own performance. It was particularly challenging for interns to consider the expectations of a specific position, and judge whether or not they possessed those skills. In general, interns tended to underestimate their performance and progress compared to the comments from stakeholders. These examples illustrate Justin's difficulty with self-awareness. "I feel anxiously curious about my job. I think I did a good job stocking paper in the printers the correct way" (Personal reflection, Justin, September 12, 2018). "The hardest interview questions I had were: 'What are your strengths?' and, 'What are your weaknesses?'" (Personal reflection, Justin, September 5, 2018).

[Justin] couldn't tell me specific ways he could tell on his own what his performance on the job is like. He rated himself a 4/5 at first, then a 4/10. He doesn't seem to have a point of reference for how to tell what is expected of him, and is trying to read others' body language to figure it out. (Investigator reflection, October 3, 2018)

Interns frequently judged their own performance based on their preference for a specific role or task, instead of a true judgement of ability. For example, Mary struggled with this when she was prompted to gauge her ability to perform a new role at work.

PI: Which job do you feel like you're better at?

Mary: Hosting....And [my mom] agrees with me, she thinks I should be a hostess, so.

PI: Why does she think you ought to be hostess?

Mary: Because I told her about how fun it is and I don't get dirty and she thinks it's the best thing. (Interview, Mary, September 19, 2018)

Even with further probing, Mary had difficulty judging how well-suited she is for the hostess position. Though she knows she works hard, she could not give specific examples of her hard work.

PI: How do you think she's going to judge whether or not [being a hostess] it's a good fit? What is- what do you think she's looking for?

Mary: Mm, she already knows I work hard, so. (Interview, Mary, September 19, 2018)

Though Alex learned his position faster than anyone else in his department, he still did not feel confident about his job performance a few months into working as a full time technician in central supply.

PI: How long did it take for you to learn that job [stocking]? Were you still learning it when you started your third rotation?

Alex: Yes ma'am. Still learning it. (Interview, Alex, August 31, 2018)

Justin required support from his skills trainer, Chris, to see that running out of work was a sign of how efficient he was, and not a failure of his or on the part of the department:

And I would have to tell him that's actually (pause) I said, "It is, that is a problem that we don't want to have, but it's actually a positive thing because you're getting your work done." I said, "You're doing your job so well that they're running out of things for you to do. So we can continue working on making sure that you have tasks and things that you can work on in the department." And so I feel like now, he's starting to really understand that it's not his fault. (Interview, Chris, October 17, 2018)

**Motivation.** Motivation for work was frequently in the coded data from interns, stakeholders and field notes from observations. Decreased motivation tended to negatively impact job performance, while increased motivation was usually described in the context of increased performance, or better attitude. Feeling important or needed led to increased motivation. Justin stated, "That's the great thing about being in the ICU is that you get to see how nurses take care of people, and I really like taking care of people, if I can" (Interview, October 3, 2018).

Mary was also given the opportunity by her direct her supervisor to scan and enter patient information... no problem. And that was great, she loved it, and you could tell she was very proud of herself because she blew through that, no problem....And then [Mary] went to imaging and she was really excited about that because, you know, sitting behind a computer, you feel important. (Interview, Kay, June 13, 2018)

Increased feelings of being accepted were also associated with comments of increased positivity and performance, which seemed to be outward behaviors that skills trainers related to motivation for tasks. Kay commented, "[Mary] seemed more confident, or more relaxed, Socially open to communicating with her co-worker, so her participation I would say was better

is in that type of environment [laundry]” (Interview, Kay, June 13, 2018). Alex’s coworkers started to notice a big difference in Alex’s work performance and demeanor when he started to relax and feel accepted by the group. Once he started to feel comfortable, his learning accelerated.

I think the thing [Alex] was always the most upset about was that he didn't want to be treated different. He brought that up several times. He wanted to do the work and he had the capability, but people see him as someone who is disabled who can [only] sweep the floors. If he hadn't kept working to improve that [perception], we would have lost out on a fantastic employee. (Interview, John, June 18, 2018)

Physical environmental factors also impacted motivation for work. Jane’s awareness of how these factors influenced motivation evolved through the course of the study.

So we found out- I thought it was about the cleaning, she didn't want to clean. But in reality, it's not that she didn't want to clean, it was the fit of the place. She didn't like the grocery store, but she likes the mall. (Interview, Jane, July 13, 2018)

He is struggling and it looked as though he had no self-initiation. He had no drive to work or be there. It almost looked - it looked like he was going to be lazy. It looked like he, um, we thought he was too good to do work, you know, he had an attitude about him. When in reality, you came in, um, first, you know, we worked on the environment. (Interview, Jane, October 29, 2018)

Unexpected changes at work tended to be associated with behaviors that indicated decreased motivation. Mary's performance in particular, was observed to wax and wane with her level of motivation.

Jane: Did you stay because someone asked you to stay or you just stayed...

Mary: They asked me to stay late.

Jane: Okay. But you know as far as at least that you can get paid for that because you didn't clock out until 8:40, right?

Mary: Yeah. (looks out window) (Interview, Mary, August 22, 2018)

Justin experienced lack of motivation when he did not have the opportunity to act autonomously, which contributed to a feeling of decreased control.

So, I had to go to the department head of the quality department to see if, you know, if there was anything else that he [Justin] could input. So that he wouldn't be done so early. And, the head of the department did have more surveys that he could input and whenever I brought that to Justin, I noticed that he was very, like, "Oh, whoa, whoa, whoa, let's slow down." He became very hesitant to take anything else on. (Interview, Chris, October 17, 2018)

Money was not as motivating as enjoying the work itself, though when interns realized they had a need for money, increased rate of pay or being assigned more work hours became a more motivating factor:

PI: How are things going at the store? Do you like it there better?

Mary: Yeah, I got a 10 cent raise per hour. Now I make \$9.25 at Home Goods. Before I only made \$9.15.

PI: What's the best part about working at Home Goods?

Mary: I like making better money! (Smiles)

PI: What do you do with the money you make? Are you saving up for something?

Mary: No, not really. I usually use it for eating out and I spend most of it on my boyfriend. (Smiles) I don't really worry about what I get paid, I just worry about my, my job duty....

PI: If you did have bills to pay right now, like if you had your own apartment and stuff like that...

Mary: Then I would worry about it.

PI: Would it be as important that you like your job? Or would you be more concerned about how much you make?

Mary: Uh, more concerned [about what I make] probably. (Interview, Mary, September 19, 2018)

Once prompted to talk about her recent engagement, Mary then commented on increased motivation for working more hours:

Mary: [My fiancé] thinks- he thinks it's a good idea for me to go full time.

PI: Yeah? What do you think?

Mary: I think it is. (Interview, Mary, September 19, 2018)

Mary's supervisor in the nutrition department commented that after she became engaged, she took the initiative to ask for more hours at work:

I think she wasn't too excited about it at first, working the eight-hour shift. But she did it and she did okay...and then she told us she was needing to get more hours. She stopped me and said, "I need to get more hours." (Interview, Cory, September 25, 2018)

Project SEARCH committee members and staff, as well as vocational rehabilitation counselors identified lack of motivation with money as an obstacle. Many related concerns about parents' knowledge of how to teach their adolescent and adult children with HFASD about money.

Parents...complained of Amazon packages showing up on the doorstep when their children began to earn money, usually for video games and other items. They expressed concern over letting them have control over any of their own money, so many parents are just holding on to the interns' earnings. (Field notes, Jenna, September 19, 2018)

When interns with HFASD were motivated for the work, they demonstrated the ability to "rise to the challenge," performing beyond the expectations of others. John, Alex's department manager reflected on his observations of Alex's motivation for the role in central supply. John stated, "[Alex] actually came in on that [holiday week] break and learned [the technician position in central supply], and actually worked from 7:30 am to 4 pm every day" (June 18, 2018). John talked to Alex during the interview process about whether or not he thought he would be able to work a weekend shift by himself, a rite of passage for technicians, once they have completed their training.

So we first talked about during the job interview that [working alone on weekend rotation] was one of the things that we always plan for when they're fully trained, because they're on their own... "You know, you don't have that cushion, somebody there to back

you up. You have to be able to do the job.” And [Alex] said, “Once I learn the job I can do that.” (Interview, John, June 18, 2018)

### **Extrinsic Factors**

Extrinsic factors are characteristics of the environment that influence occupational performance and participation in work. Coded data from intern interviews, stakeholder interviews, field notes and reflections contained 714 comments related to extrinsic factors, the second most frequently coded theme after Acceptance. Comments described a variety of environmental characteristics, some enabling and others as contextual barriers within the built environment, social environment, cultural norms, and temporal context.

**Cultural context.** Within the primary theme of extrinsic factors, characteristics of the cultural context comprised the largest subtheme. Cultural norms and views that were perceived as barriers to performance and participation were commented on far more frequently than cultural factors that were perceived as enabling the interns’ success. Cultural barriers and facilitators were noted in a wide range of systems, including family systems, work systems, support service systems, and society as a whole. The cultural barriers described were usually related to “hidden” or “implied” rules or expectations that were based in sociocultural norms that may not be immediately perceived by interns with HFASD. Kay, Mary’s skills trainer, describes the contradiction between the store manager’s expectations, and the corporate expectations for the store, and how this impact’s Mary’s ability to learn her job tasks.

But, because there at that particular store they really don't care, as long as you get it out on the shelf (pause) I mean, that's their goal because they have another one [truck] coming in, and another one coming, so no one there has really emphasized to her the way

it's supposed to be done... Until corporate shows up, and then it hits them all at once.

(Interview, Kay, June 15, 2018)

Jane describes the culture of the hospital's internship rotations.

I've noticed that the hospital, like when there's new employees, I feel like it's kind of, "sink or swim". You're supposed to just jump into your role and like observe what's going on and just start working in all lot of the departments and then they're all different roles, different jobs, you know. And there's not a lot of training. (Interview, July 13, 2018)

Jane also articulates the problem of "hidden rules" created by the conflict in messaging regarding "acceptable behavior."

For me, it does bother me because you go anywhere in any of these, any job I see just about at the hospital, people are a lot more relaxed than our expectations of our interns. They have Cokes, they have their phones, they have sidebar conversations with each other for 20 minutes. They, um, you know. It's that way everywhere you go. (Interview, October 29, 2018)

Many "hidden rules" seemed to exist within the nutrition department. Mary took a position in nutrition shortly after graduation from Project SEARCH, and both Mary and the program coordinator, Jane, misunderstood the position Mary had been hired for, due to system changes within the department that shifted the structure of roles within the department.

Jane: When you started, did they give you the impression that everybody sort of circulates through the jobs? Like, you're going to be in dishes for a while...

Mary: No. I applied for the hostess job. I really don't know who or how they decide who does what. (Interview, Mary, August 22, 2018)

Mary's supervisor relayed a different perspective.

PI: And then when you guys made that switch over, then she was more dish room after that?

Cory: Yes. Yes. That was her position that she was hired for, [it] was dish room, but since we didn't have a dish room at the time she was hired, [we] kind of just kind of trained her on the tray line. (Interview, Cory, September 25, 2018)

The program coordinator, Jane, had yet another perspective. Jane reported that Mary did believe that she was interviewed for a hostess position, but the head of the department decided to put her in utility for a, "trial run" to, "see how she does" (Investigator Reflection, October 31, 2018).

Cory, Mary's supervisor in the nutrition department, describes her management style, and how she chooses to respond to employees. Her selective attention to employees is based on her rule of how she prefers employees communicate with her. Mary eventually navigated this situation herself, and started texting Cory to ask if she could rotate in to roles other than the dish room.

But I have a lot of employees, not just [Mary], they will not come tell me that they're unsatisfied. They will tell their friend. They expect their friend to come tell me or coworker. I've got one [employee] now, someone keeps telling me, "She can't do that shift, she's not going to come in." I said, "Well, she needs to come talk to me. I'm the only one that can change her schedule. If I don't know what's going on, I can't fix it. And for three days she's seen me and has not told me she has an issue about her schedule.

But she is telling other people that she can't come in because of those hours. (Interview, Cory, September 25, 2018)

Other cultural barriers were related to societal expectations and attitudinal barriers, some of which were stigmatizing to interns with HFASD.

The supervisor didn't really want to consider a hostess role for Mary because of the safety and cleanliness risk and the level of autonomy required. She had not "earned" this by demonstrating her independence in other areas. Interestingly, this fits more into Mary's description of the department, but seems only to apply to her. (Investigator reflection, September 25, 2018)

That was one of the things that we told [Program Coordinator] right before we hired [Alex], he's got to be able to do the work and same functions that everyone else does and he does. So no, we did not change anything. (Interview, John, June 18, 2018)

If [the department] wanted someone lower functioning and cute – which is what they wanted anyway – it would be perfect. They could poke their heads in rooms and just stay "hi." (Conversation, Jane, September 12, 2018)

And that's kind of for everyone... you're either at, "you've got to do this," or, "it doesn't really matter, you're cute and sweet, and we're just going to let you do whatever you want to do because you have a diagnosis." So, I mean, it's like right there. Very few mentors and very few managers are like, you know... "We're going to take the time and we're going to do this right, and we have expectations of you." (Interview, Kay, June 15, 2018)

**Social context.** In addition to cultural barriers, social barriers were also commented on by both Project SEARCH staff and departmental supervisors. Lack of understanding about how to communicate effectively with interns with HFASD was identified as a major reason for the social and communication breakdown.

[Internship mentors] don't know how to check for understanding as well. [Project SEARCH staff] have found it really, really difficult, because a lot of the expectations. It's almost like [the department expects] you just pick up and start following [directions] and that's not the case. It's not that easy... Whether it be someone with Down's syndrome or someone with maybe a speech disorder [or something] of that nature, it is more commonly understood that they are an intern with Project SEARCH, and they seem to be helped [by mentors and coworkers] more frequently. Those that had autism, struggled more. (pause) Well, I don't think that they struggled as much, the people in the department struggled with understanding how to help them and understanding how to guide them, talk to them and kind of mentor those individuals because they didn't really know, they didn't know how to... They don't- they don't know how to break down a task and they don't use the right kind of communication and language to teach someone [with autism]. (Interview, Jane, July 13, 2018)

That was pretty much the only conversation we had with the staff - just not to take it out on the intern if there's issues. To come to me [the department manager] or to come to their supervisor, and we'll work through it if we can work through it if we can't then, well, we'll just deal with it. (Interview, John, June 18, 2018)

My team leader's sitting right there but they're not saying anything to them. I don't know if it was I'm scared to say something, "I'm scared to tell this person to put a hair net on,"

or what it is. But we've been working with them too on getting more proactive and taking care of things instead of me having to come out of my office and say, "Hey, can you put a hair net on?" When that's something you should have been easily able to just say, "Hey, you need to put a hair net on." Or, "You need to put gloves on if you're touching that." (Interview, Cory, September 25, 2018)

At times, support or explicit instruction to assist with social barriers was delivered in a way that was socially isolating to the intern with HFASD. Alex reflects on a time when Kay, his skills trainer corrected him, in comparison to a similar situation in which Chris, the other skills trainer, offered corrective feedback. Alex stated, "She was more private, thankfully. But it was the reason I was a little embarrassed was because, you know, he had to [correct me] in front of everybody" (Interview, Alex, August 31, 2018). Once Mary finished the Project SEARCH program and became employed, she became resistant to corrective feedback from skills trainers, due to the impact on her perceived acceptance at work. "Generally, Mary does not like getting on the job support from the skills trainers or others outside of her workplace. She feels embarrassed by this" (Investigator reflection, September 19, 2018).

Many facilitating factors in the social context were related to explicit instruction on social expectations or supports put in place to serve as reminders.

The bathroom doors are unmarked, and are in amongst other small rooms, such as storage and janitorial closets. Jane explains that the bathrooms are unmarked on purpose so that if patients or families wander around, they don't use bathrooms designated for staff. (Field notes, November 7, 2018)

I think it's very visual. I think, in my experience, that the individuals with autism that I've helped teach, for the most part, they're all very visual learners. So...you have to kind of know your individual to know what they will understand, what they will get out of how you can break down tasks. So, I think a big part of my job is really to observe these individuals and to help them process specific tasks, specific things in their own terms, in their own language, in their own visual way.... But I kind of wish that I could sit down and say, "This individual, when he says this, this is what he means." (Interview, Chris, May 30, 2018)

Some comments on enabling factors in the social context related to support from a coworker in bridging the social gap with other peers. "[His coworkers] tell me about how much they like working with Alex, and how they are determined to teach him to tell jokes" (Investigator reflection, June 13, 2018). Justin's mentor acted as a buffer between Justin and less accepting nurses in the ICU. "...some of our nurses are just so cut and dry, and will go say whatever, so I try to, be like, 'you have to be sensitive about this'" (Interview, Lindsay, October 31, 2018). Dory, Alex's mentor explained specific strategies she used to help Alex avoid frustration and anxiety.

If I see it, I just say, "Alex, just think about it now. Whether you're the one that did this or someone else did it, just think a minute. The main goal is here to correct it. Whoever done it, that's really not important in- right at this moment. Just take care of the problem at hand and then we'll sort it out and figure out who done what." ...I've tried to make it a point where if I've got to get by [Alex], I'll make a big deal of it, you know, jokingly. And I'll say, "Oh, excuse me, oh excuse me." ...By the same token, it's getting him into his head, it's okay to have a little fun while you're working because we have such a

routine...to make things work smoothly here that you got to have a little fun with it, you know, to enjoy your job. (Interview, Dory, September 12, 2018)

Social supports also came in the form of coworkers who communicated their “tricks of the trade.” In this example, Justin is paired with a new employee in sterile supply as he prepares for his next rotation.

The new employee...talked slowly through each step. He used mnemonic devices to remember the labels of specific tools: “Mayo makes you fat, so the Mayo scissors have the fat handles.” He also encouraged Justin that he could take his time as he learns the kits, and that he could go as slowly as he needed to in order to be accurate. (Investigator reflection, November 7, 2018)

**Physical context.** Physical barriers were encountered with some work environments, though these comments represent a relatively low proportion of all comments related to extrinsic factors. In this example, Mary explained the complexity of the hostess position she is learning.

Because some patients are in isolation and we have to dress out, put the gown on, the gloves on [to bring their tray in]... And then you take it off after we get done....You have to always use hand soap every time you come out.... We have to tell them their name and their date of birth. We have to check it on the receipt. The receipt that they get and make sure that it's right. (Interview, Mary, September 19, 2018)

Lindsay, Justin’s mentor in ICU, described the tight physical space the staff are required to work within:

We bump into people, we don’t even notice, we just keep going...People just work around you and you just keep going. There’s always someone in my personal bubble... I

don't even have a personal bubble at work! People are just there. (Interview, Lindsay, October 31, 2018)

Jane describes the confusion she felt when orienting Justin to the ICU at the beginning of his rotation, due to the department's lack of structured organization.

I wanted to ask, "What does, 'clean and organize equipment' mean?" Nothing is labelled correctly. How will we know where things go? Where is the linen chute? Where are the dirty linen bags? (Field notes, September 12, 2018)

Enabling physical supports were often in the form of visual supports that assisted the intern in navigating the environment, recalling information, or executing a specific sequence of tasks, but also reflected a degree of autonomy in how a job role could be performed. Dory describes the freedom that Alex can have within finding his own systems for completing his job duties in central supply:

And the beauty of that is, too, is once we've gone through training... ..and you find that you develop your own style and as long as you get the job done correctly, you can use your style...And it's right, it's correct. (Interview, Dory, September 12, 2018)

Comments regarding physical barriers were almost always embedded in socio-cultural context, as the intern often felt they were not meeting the behavioral expectation when they needed more support for the physical aspects of their role. During the intervention phase, Kay requested consultation on addressing physical barriers for an intern in laundry. She notes,

He also speaks negatively about other accommodations that have been attempted: social stories, playing games with learning work tasks (like races to speed up his productivity) and visual supports, like a taped line on the floor to mark where he is supposed to stand

when working in the laundry department. I think he has perceived the support strategies as demeaning. (Investigator reflection, October 24, 2018)

Some supports recommended by program staff simply weren't adhered to, depending on how they were perceived by the intern:

Mary did better with scripts than any other support. When she is scripted and prepped, she is great. (Interview, Kay, June 15, 2018)

I observed Mary stocking. There are visual reminder cards about protocols for displaying items on shelves, but Mary does not reference any of them as she works. (Field notes, June 20, 2018)

The process of deciding [whether or not bins needed stock] seems difficult for him [Justin]. As he takes several moments to examine them [the bins], he seems to hesitate to fill them. He doesn't use our agreed upon cue to look for the bottom of the bin as an indicator if it needs refilling. (Field notes, September 18, 2018)

**Temporal context.** Temporal factors mentioned in the data were related to the pace of work and expectations of when work would end. These seemed to be a barrier to performance and participation when they were changed, or poorly communicated. Chris, Justin's skills trainer, finds that he needs to give explicit direction to Justin about breaks, so that Justin does not become stressed that he cannot take a break.

He expresses a need for just sit for a break to breathe. And I told him that's okay as long as it's not, you know, as long as you're not just sitting and doing nothing for a long period of time. If you need to grab some water, go to the restroom, sit down and breathe for a minute. Um, so he may take a short break. (Interview, Chris, October 17, 2018)

When Justin masters his tasks in the ICU, he begins to finish his task list before his shift is over. Chris describes Justin's difficulty in understanding why he could not simply leave for the day.

Well the only answer that I ever (pause) the only answer that he ever gave me was to go home early. And I explained to him when you're at a job and you have a shift that's eight to three and you are done with what you need to do, you can't just go home if you're done at two. (Interview, Chris, October 17, 2018)

In this conversation, Mary is upset because she unexpectedly had to stay late at work to learn how to operate a piece of equipment. Getting paid for the additional time was not motivating to Mary, and did not make up for the stress caused by the sudden schedule change.

Mary: We were- had to learn how to turn off the whole dish machine and drain it. But nobody's ever taught me how to turn it off and...

Jane: Was last night the first time you were supposed to do that by yourself? Or that you had to do that? Or was that something that you had done- that somebody's done before?

Mary: ...they never told me how to- I'd never done it by myself before.

Jane: Yeah. That is stressful.

Mary: Yeah.

Jane: Did you stay because someone asked you to stay or you just stayed...

Mary: They asked me to stay late.

Jane: Okay. But you know as far as at least that you can get paid for that because you didn't clock out until 8:40, right?

Mary: Yeah. (stares out window) (Interview, Mary, August 22, 2018)

Interns with a tendency towards detail-orientation often found work environments that valued high productivity difficult to work in.

She [Cassie] folds towels systematically, checking them for spots and stains. The checking process she uses seems much more thorough than the process used by her peers. She finds a soiled towel about once every three towels she folds; much more than anyone else. (Field notes, May 10, 2018)

The intern's pace of folding picks up briefly when the team lead is standing nearby folding, but the increase in pace isn't sustained after he steps away. (Field notes, October 24, 2018)

I feel like in other settings...this will be our fourth... the one where it was so highly fast paced, and they needed [Mary] to get it right and be independent, and they didn't necessarily have the time to learn her or be personable with her, it was almost like she was just kind of a like, defiant teenager, and not doing what they wanted her to do. (Interview, Kay, June 15, 2018)

But, if it was a fast-paced job, we'd have to really maybe, uh, work with [interns with HFASD] on keeping that detail-oriented nature but maybe speeding up a little bit. (Interview, Chris, May 30, 2018)

### **Goodness of Fit**

The idea of goodness of fit between the intern and the work position was also a frequently mentioned theme across all of the data collected. Comments related to this theme describe how a match, or "good fit" between the intern, their work responsibilities, and the context of the work environment influence the work experiences, from the perspectives of interns

as well as stakeholders. Four sub-themes emerged related to goodness of fit. Two of the subthemes, person-environment fit and person-task fit provide detailed descriptions of the ways to think about what factors create a “good fit” for the intern. Two more subthemes emerged as ways to characterize the outcomes of a “good fit;” job satisfaction as a product of goodness of fit from the perspective of the intern, and value added as a product of goodness of fit from the employer’s perspective.

**Person-environment fit.** Goodness of fit comments were most often related to aspects of person-environment fit. Comments coded in this subtheme focused on the relationship or interaction between an intern’s individual characteristics and specific aspects of the physical, social, cultural, or temporal environment. Changes within the social environment, specific to a job or job role, were identified as a factor that influenced the intern’s performance and attitude in the work setting. “In certain environments their [interns with HFASD] disabilities might be more noticeable. I think it just really depends on where they are, who they’re with, even” (Interview, Chris, May 30, 2018).

Now with strangers, I think Alex struggles a little bit still with the interaction, but since he knows us, and he's kind of gotten [used to] our personalities... You know that we would kind of cut up down there, he goes along with it. But I think he still struggles on the floor. I’ve seen it once or twice where he has had awkward interactions with people he’s not familiar with. (Interview, John, June 18, 2018)

Putting somebody, say with autism, up there in that role of being the customer service representative, um, you could do it to prove a point or have a culture shift or whatnot, but is it what's best fit for everyone? The job, individual and the customer? I guess you kind

of have to look at what's best fit for everything. Um, and it might not be. You might want to give them the opportunity but it might not be what's best fit [for either one].

(Interview, Kay, June 15, 2018)

Mary felt isolated in her utility station in the nutrition department, and sought out peer interaction. Her supervisor, Cory, noted that her productivity decreased dramatically when Mary felt isolated.

I guess when she was supposed to be in the dish room she'd come out here instead to talk. But I understand, I guess she gets lonely in there because I think she was in there by herself that one day, so she would just come out here and talk and they would try to redirect her to tell her, "Hey, you need to go back in there." She didn't want to go back in there so she just continued to stay there and talk. (Interview, Cory, September 25, 2018)

The social and cultural structure of the work setting also influenced the intern's motivation for working. All three of the interns expressed willingness or preference in work environments based on social aspects of the work environment.

PI: Is there anything about your job now that's really hard? Or challenging for you?

Alex: I guess just- I guess getting along with, you know, workers. But other than that... most of the time it's just blurting something our loud or, you know, talking to yourself usually. Usually down there. But, other than that it's- it's- it's not so bad. At lunch, you know, it's just teasing. (Interview, Alex, August 31, 2018)

Alex compared his experience in central supply to his rotation through the quality assurance department, associating social interaction with his preference for the work itself, stating, "It [data entry] was boring work, I never talked to anyone" (Interview, August 31, 2018). Justin

articulated his desire for emotional support from his supervisors. Here, he describes a manager he enjoyed working for during his time working in the restaurant.

Now Beth was a really good manager. She cared about our mental aspect. You know, she cared about how we were feeling, you know, and you know and I think that is a good example of a good manager is to care about someone's well-being, plus their work ethic. It's very important to have that because these managers don't know what people go through in life, you know. And it's good to- it's actually good to care, you know. And so I was always looking forward to Beth coming to work. (Interview, Justin, October 3, 2018)

During Justin's rotation in the ICU, an occupational therapy consulting session was held with the Project SEARCH program coordinator, Jane, and the nursing director for the ICU. Specific recommendations for improving the social and emotional support for Justin on the rotation were given to the nursing director. Subsequently, the nursing director reinforced to her staff that they needed to be especially welcoming to him. Data collected in later phases of the project documented the impact of this change:

Staff on the unit have gone out of their way to greet him and socialize briefly with him as they can, even though this is uncharacteristic of their work culture. This has definitely helped him feel more welcome and is a preference of his in a work setting to be validated; however I think this change will be fleeting if it is not continually reinforced by the ICU director. (Investigator reflection, October 17, 2018)

Physical and temporal environmental characteristics were also identified as factors in the interns' occupational performance:

So if there were changes in the work day, if there was...a week maybe that we weren't at work and we were doing different activities, you could see that they maybe become fatigued with what we were doing, different than their regular schedule. (Interview, Chris, May 30, 2018)

Interns were able to recognize specific physical characteristics of the environment and identify whether or not they were a good fit. Here, Jane describes a conversation with Cassie, marveling at Cassie's ability to recognize for herself which work environment would be the best for her, even though the two positions she was considering had nearly identical job responsibilities.

[The job is] the exact same. I mean it's a cart, you're cleaning, you're wiping and you're sweeping or mopping your bathrooms. It's the exact same job. Almost the function to the T is the same. But she adamantly hated it, would not- and refused to - work at the grocery store, but she is excited and loves the thought about working at the mall. And so I just, I started kind of grilling [her] like, "Do you like the mall because of this? Do you like it because there was birds in there..." and she likes the fact that there's birds in there. Um, so I think it's just, it was just a better fit. She felt better there. So it wasn't about cleaning. (Interview, Jane, July 13, 2018)

Mary described the environmental characteristics of the dish washing job that she hated.

PI: Tell me about your dishwashing job. Is there something about it that you like?

Mary: I just like pushing them in there and then going to catch them on the other side. I don't like dumping them... Because every time I put the cup on the carting thing, whatever you call it, and I move it, the freakin' top of the table, there's like food in there and it like splashes on the... It's gross.

PI: Do you go home smelling like food?

Mary: I smell like nasty food every night I go home... Because I always spill stuff on my feet and on my shoes and spill stuff on my shirt and my pants.

PI: Has it ever been so bad that you couldn't continue working?

Mary: Yeah the smell sometimes.

PI: Like that it makes you like slow down or like have to stop and go rinse yourself off?

Mary: [nods] And I sweat because it's really hot back there. (Interview, Mary, September 19, 2018)

Chris relayed a conversation with Justin, describing how he felt about the pace of work in his current rotation in the ICU:

I asked him about how he felt about this experience right now in his department for right now. And he explained it, um, he said, "Do you know, like a meter on a car, your car can either be too cold or too hot and it needs to be in the middle." And I said, "Yes." And he said, "My old job was too hot and I feel like this is not all the way down, but it's in the middle of being...It's almost too cold for me." He said, "I need something that's in the middle to help my anxiety." (Interview, Chris, October 17, 2018)

Goodness of fit with the physical environment also tended to influence confidence and behavior at work. For example, being able to discover new ways to navigate the hospital added appeal to Alex's position in central supply.

He likes to play the odds on which elevator might be faster, so he often takes different routes through the hospital, to see which one will be fastest. I remembered that Alex has an affinity towards maps and locations, and I thought it was interesting he had found a

way to work his interest into the routine of his day... He smiles all day. (Field notes, June 13, 2018)

Conversely, the close quarters in the ICU caused discomfort for Justin:

He moves slowly but does a thorough job. He goes back over some areas more than needed. He bumps into another staff, "Oh, excuse me," the staff member smiles quickly, and keeps moving. Justin seems to feel awkward, "Sometimes it gets really wound up over here." (Field notes, September 18, 2018)

Emphasizing environmental considerations for occupational therapy intervention created positive changes for interns. In later phases of data collection, Cory changed Mary's work hours after occupational therapy consultation regarding environmental characteristics of Mary's job, and how those impact her performance. Cory comments on the positive impact changing Mary's work hours made on her attitude and work performance.

Her focus has been much better on the morning shift. I am so glad you told me that she prefers mornings. That has made such a big difference for her. (Conversation, November 7, 2018)

Considering issues related to goodness of fit was an important part of the Project SEARCH Program for all interns, including interns with HFASD. However, program staff have historically addressed person-task fit more than person-environment fit. As the study progressed, comments related to person-environment fit became more prevalent in the data. Earlier data regarding fit was more related to person-task fit.

You're observing them for nine months to see their biggest strengths and weaknesses and then at the end of the program it's like, then you'd have to look at what's best to fit. So I

guess you can kind of say the whole program is about finding their fit...It was a lot of stress, a lot of kind of misunderstandings because we did have an intern that it was just causing trouble amongst the departments. And so we tried changing the environment...it kind of ended up not being the environment, it ended up being kind of the intern and their just ability and demeanor. (Interview, Jane, July 13, 2018)

Though Jane recognized the need for person-environment fit, modifications to the environment were left to the discretion of the supervisor or employer. After a negative experience with an intern in central supply, Jane felt a responsibility to assign an intern who was already a “good fit” for the work environment, rather than advocating for accommodations, in order to keep good relationships with the department.

We changed some social things about him where he gained skills, but because you're not working in an environment that you're going to be working in long-term, you can't change or mold some of their [the department's] things [environmental characteristics] until you get them [interns] into what they're going to be doing long-term...And then I asked [what the department needed], I basically selected one of our interns that was good with fast paced work environments. (Interview, Jane, July 13, 2018)

Conversely, when an employer was more amenable to accommodations and initiated making them, Jane perceived the opportunity as a “good fit.”

And it turned out that, the supervisor there has worked with someone with autism before and she made these lists for them and she told us that she knew that um, if things were overwhelming that they only need a few at a time and then they can add on tasks. I mean, it was a very good fit for everyone. (Interview, Jane, July 13, 2018)

Though the support staff expressed confidence with creating and adapting work activities, they felt less confident about their ability to create changes in the work environment that better fit the intern's needs. The program coordinator, Jane, desired more training and consultation from the OT after the intervention phase:

[Skills trainers] would've [liked to have] had more time to spend listening to you with you and discussing things because so many things that they deal with daily are they look at it as behavioral and I think you gave them another perspective, talking about changing the work environment to help them better, instead of changing the intern or changing the student or changing the person, let's work on changing our environment. (Interview, October 29, 2018)

**Person-task fit.** A good fit between the intern and the job responsibilities and tasks was highly valued by both Project SEARCH support staff and departmental supervisors in the hospital. This sub-theme came up frequently in the data. Skills trainers and the program coordinator acknowledge the importance of person-task fit in creating a positive experience for both the intern and the employer, particularly since the ultimate aim of the program is to enable the intern to function independently in the workplace.

The whole point of a job and somebody being in that role is, you're supposed to be really good at your role, I think. I think that you can learn to be good in a role, but my perspective is, you know, you hire someone for a role, they should fit the role. (Interview, Jane, July 13, 2018)

[Supervisors] needed Mary to get it right and be independent, and they didn't necessarily have the time to learn her or be personable with her. It was almost like she was just kind

of a like, defiant teenager, and not doing what they wanted her to do. That was my perception of how they were interpreting her behavior. That she was defiant or lazy, when really it was a processing issue. (Interview, Kay, June 15, 2018)

Employers and department supervisors expressed the importance of person-task fit, as well:

Because obviously, it's not a good fit for a position, we just don't want to put that applicant through the stress of the job. They're probably going to struggle. (Interview, John, June 18, 2018)

When a position was clearly a good match for the intern's skill set, supervisors were quick to point out the unique characteristics or skills the intern possessed for the role. Here, John describes Alex's talent for working in central supply.

You know, his attention to detail is amazing. He is very task-oriented; once he learns that job he really focuses on that. We have so many supplies and you have to look at the number of the supplies. There's a number on every item and his attention to detail is just amazing. You know, if we have a backorder issue or we have to sub out supply, he will catch it, where everybody else will not. (Interview, John, June 18, 2018)

Mary's position in nutrition was not a good fit between her personality, skills and the demands of the job. However, her supervisor articulates the way she infers Mary's abilities onto other roles within the department in order to determine where she might have the best person-task fit.

It's an independence thing, that's the only thing that worries me. She would be by herself doing that [hostess role] if I put her in that spot full time. And with some of the forgetfulness, like things that (pause) I don't want to put patients at harm due to risk of germs and things like that. She can do the dish room job, she does that. I think, maybe

it's not her favorite thing to do, so. But I know the tray line, she- she was excellent with that when I worked with her. She was- she was just great. She got everything, she kept everything in line. So, that's where I hopefully see her moving forward. (Interview, Cory, September 25, 2018)

Poor person-task fit seemed to cause feelings of insecurity for interns. Kay describes what she has observed with Mary and the other interns with HFASD she has worked with:

[Customers might say,] "Why are you having someone with autism who might have difficulty [with] eye contact and verbalizing things, taking my order or helping me in customer service if that's what they struggle with?" It devalues [the intern] because they are capable...but it does go back to the goodness of fit because they might not be comfortable doing that. They might not know how to identify they're not comfortable doing it. They'll try, but I do think it would heighten their anxiety. I do think it would cause emotional stress. They might just not know how to express that. (Interview, June 15, 2018)

Kay describes the accommodations she implemented with Mary.

She had a notebook that she carried that department and she laid out these scripts all around her so that she could see, you know, what was being asked of her, what was appropriate to say to them. So after a while, she caught on pretty well in that department. In other departments where it was not as structured, and the task was not repetitive, and there was a lot of problem solving she appeared to be I don't want to say lazy, but needy, because she wasn't able to figure out how to or initiate what was being what was asked of her. (Interview, Kay, June 15, 2018)

**Job satisfaction.** The intern's level of job satisfaction seemed to be related to goodness of fit. Most commonly, job satisfaction was mentioned in relationship to a good match between the intern and the social context of the work environment. All three interns who participated in the study articulated the desire for social interaction and acceptance with their peer group at work; however, lack of social interaction was associated with decreased job satisfaction:

It was so great, there was this guy I think he was about in his maybe thirties or forties and he was a very great guy, on spare time he would come and help me in the dish room when I needed help. He was probably one of my personal favorites there. (Interview, Justin, October 3, 2018)

PI: What would be better about the hostess job, do you think?

Mary: Mm, just communicating with people.

PI: More social interaction?

Mary: Yeah...Because I really don't talk to anybody in there when I'm by myself... It's just I'm in there by myself all the time and it gets a little bit lonely. And stressful.

(Interview, Mary, September 19, 2018)

Skills trainers and internship mentors also noted how social acceptance impacted the intern's job satisfaction:

If this were a longer term employment opportunity for Justin, I think the lack of social interaction would eventually make the job less satisfying for him. (Interview, Chris, October 17, 2018)

[Coworkers in laundry] loved Mary. They knew about her personal life. She opened up about her boyfriend what she was doing for the weekend. You know, it was it was

almost like family down there to her and so... That she was very successful at....she would help with loading the carts, and so her, her mentor at that time would tell her, "I need x amount of sheets on the cart going to 2 North," or, "I need this many towels..." she just be-bopped through there, with that ponytail slinging, and you could tell, there was like, a confidence in her stride, she felt good.

[Alex is] doing well...He's getting better all the time. Again, I think the key for him, too, is the fact that he feels that now he's accepted. He feels like, "Okay, I'm part of this team now." You know, "I belong here. People accept me for who I am."

Cultural factors that related to decreased job satisfaction were primarily related to a mismatch between the intern's perception of ambiguous expectations from others and the unspoken cultural norms of the setting, or "hidden rules." More structured environments with clearly communicated expectations were associated with increased job satisfaction. Here, Alex explains why his job in the central supply department is so much more satisfying than his previous job:

[At the grocery store] They had rules. Only the thing was, the manager could kind of make up rules. Some of those I thought wasn't necessary, some of them I think were, but...Like I would take a break. Our breaks were 15 minutes or I think. And I would take a break at, you know, 20 minutes 'til [the hour] and my managers told me, you know, that we couldn't do that and somebody who was there said, "I think they made that rule up because they hadn't told me not to do that." [In central supply] They're pretty straightforward about what they expect...In training they go through orientation here and that pretty much gives you an idea of what the rules are. That way you don't walk in, you know, and realize, "Oh, I wasn't supposed to do that." (Interview, August 31, 2018)

Alex expressed his misunderstanding of the “rules” as an issue of honesty. The most important issue for him in terms of satisfaction with work culture was related to feeling supervisors and coworkers were dishonest, indicating a poor fit between his rule-based logic and the subjectivity of his work environment.

PI: If you were there [back at the grocery store], what would you say is really important to you?

Alex: Um, oh I guess honesty. Because usually honesty... Honesty works usually the best (pause) usually the best policy.

Justin related a similar experience, commenting that his decreased work satisfaction was related to a sense of unfairness, indicating a poor fit between his sense of justice and the unequal expectations from different managers who were responsible for supervising him.

One of the managers gave me a rough time, a very picky person. And, you know, and if I can compare this to my last job, [Project SEARCH] is actually a lot better. It really opened my eyes to see that there's actually good management and good people [at work]... because I took that as a bad experience and I just didn't want to work anymore... Because it was, they gave me a really rough time and I was pretty criticized by one of the managers. (Interview, Justin, October 3, 2018)

Feeling unfairly treated stemmed from ambiguous expectations from one of the managers in his previous work experience:

[The manager] talked about like scrubbing the bottom of the toilets when they were like, already clean. You know, and she would complain about the bathroom stalls. I would have to put like some- some kind of- some kind of spray that makes it shine like shine

spray like chrome spray on a car. And then she would come and she would, she would always come and evaluate the bathrooms... She would always inspect my work. It was every day...I just think she really piled on me. (Interview, Justin, October 3, 2018)

Job satisfaction related to cultural fit seemed to be related to a match between the level of support the intern expected, and the typical level of support provided in the workplace. Chris gives an example of how a mismatch in expectations of support can cause dissatisfaction for the intern:

[Justin] would do what he's supposed to be doing [at work]. But without emotional support he would be so dissatisfied and he wouldn't outwardly express that at work. He would get done with his shift and then be so dissatisfied with what he just did...internally, he would be ripping himself apart. (Interview, Chris, October 17, 2018)

Goodness of fit with the sensory aspects of the built environment was also commonly articulated as a factor in job satisfaction. Alex reflects on his internship rotation doing data entry for the quality assurance department. He recognizes that the lack of movement in the position caused him to dislike the work.

Alex: What I should've done was kind of got used to, uh, what I'm doing now [walking around the hospital] and then go upstairs. That way it wouldn't, I guess, you know, be so bad. You know, so, I guess. You get too still [doing data entry].

PI: If you had something where you were moving around more first, maybe then you would have not felt like you needed to quit, you think?

Alex: Well like, and I feel like everything was so quiet and, you know, slow...

(Interview, Alex, August 31, 2018)

Mary contemplated quitting her position in nutrition when it seemed she was going to have to stay in the dish room:

PI: So what will you do if you have to keep working in dishwashing?

Mary: (silent, long pause... makes a grimace)

PI: Would you look for another job?

Mary: Yeah, probably.

PI: How are things going at Home Goods? Do you like it there better?

Mary: Yeah...I like it better there.

PI: Is that because you get to talk to people?

Mary: Yeah, it's more social. And I don't smell like food all the time.

The manager in the nutrition department required Mary to work a full shift, "to see if she could handle it" before a move to a different role would be considered for her. Mary describes her experience working a full shift in the dish room, which intensified her dissatisfaction for the role.

Mary: Uh, yeah. I tried the dish room 12 to 8:30.

PI: Whoa.

Mary: Yeah. It killed me.

PI: That was a long day.

Mary: It killed me.

PI: What'd you do when you got home?

Mary: I, I just relaxed, took my shoes off then said to my mom, "I'm not doing it again."

Person-task fit issues were associated with feelings of competence and feeling valued in the workplace, which impacted job satisfaction.

They [interns with HFASD] all seem to want to be needed, liked. They want to feel proud of what they're doing. I think that they want to be challenged and they don't see themselves as being challenged sometimes. That's what they want and they desire is- is to, um, to be challenged and needed and wanted and I guess it's kind of a thing that we all want, you know... (Interview, Jane, October 29, 2018)

One intern was struggling with too much down time between tasks due to a variable workload. Justin said he felt like the gaps in his schedule are “a waste of time.” Justin’s vocational counselor told Justin this was an indicator of Justin’s strong work ethic, but he downplayed the specific need Justin has for structure in his work setting. When his job responsibilities were adjusted to include data entry in addition to his stocking and cleaning responsibilities, Justin reported a significant increase in job satisfaction.

So far the ICU is very, very enjoyable and it’s a job I definitely enjoy. It does have its ups and downs but overall I can see myself working in my current department. I also would love to work with the patient surveys that I do before I go to the ICU. They are both really laid back jobs and I really enjoy that in a job. (Personal reflection, Justin, September 27, 2018)

Having choices in how to solve problems in task completion or taking on additional responsibilities also added to job satisfaction for interns with HFASD. When Justin chose to add patient transport to his list of tasks to fill his extra time, his job satisfaction increased, and so did his flexibility. His mentor, Lindsay, noticed this change in his affect and his ability to be more flexible with his tasks.

I think it's good to have that, like, "Hey, can I pull you from this, and you come help me do this, and you can come back to that." So I think that's good. I really like that he's able to do that. And I think HE likes being able to do that...

Two interns reported being aware that low job satisfaction was apparent in their attitudes and behaviors at work. Alex reflected on when he realized that his low job satisfaction with his job at the grocery store was impacting his behavior.

I felt terrible and I kind of showed it at Project Search and they kind of got on to me. The skills trainers kind of got on to me and I was like, "Okay, I just need to straighten up." But it was kind of hard to straighten up when I realized I gotta go back, you know, from- I'm going from feeling good to going back to feeling, you know, terrible [at the grocery store]. When I really didn't want to do that.... In other words, I came in and I was pretty arrogant... Arrogant, tired and, um, worried, you know, just worried about me at the moment of what I was going to face a few hours later [going back to work]. (Interview, Alex, August 31, 2018)

Justin also realized his low job satisfaction at the restaurant had impacted the way his coworkers saw him, creating even more of a mismatch between Justin and his social environment.

I guess there was just a lot of miscommunication. I don't really remember on what happened....People miscommunicated me there [at work], they saw me as mostly frustrated. (Interview, Justin, October 3, 2018)

Mary did not report self-awareness of how decreased satisfaction with her job in the dish room affected her behavior, but her supervisor, Cory, related an incident in which Mary became

so distraught at work that she nearly walked out. The evening shift lead, unsure of how to resolve the issue, contacted Mary's mother to come in and intervene.

I know she got really frustrated a few weeks ago. Uh, I think they had to call her mom down here. She was ready to quit. And [Mary's mother] kind of talked to her and told her, you know, "No, you're not going to quit." Something about the dish room. I think she didn't want to be in there. I don't know if it got too overwhelming? Sometimes they can throw a lot in there and if there's one person in there you do get kind of frustrated. (Interview, Cory, September 25, 2018)

After the intervention phase, the importance of job satisfaction as an outcome for interns with HFASD became more apparent to the Project SEARCH staff. They expressed a need to incorporate this into their intervention strategy:

They have to intrinsically be motivated to make any kind of change or to learn the job or to have the desire to do more and I think that opened up our eyes to, you know, cultivating their motivation to be there and to do it. And in order to find their motivation, you've got to look at what drives them, what pleases them, what makes them happy, what, do they need out of the job? Not just what does the job need out of them. I think that's the big thing. (Interview, Jane, October 29, 2018)

This shift represents a conflicting paradigm to the directive, skills-based format of the traditional Project SEARCH program. Here, Jane reflects on the need for the Project SEARCH program to take a different approach to work readiness for interns with HFASD, considering the need to promote internal motivation to achieve goodness of fit for the intern.

The sense was [from state-level leadership] that you don't need to get that personal [considering the intern's opinions] because you are trying to get them work ready and, that opens the door for something bad... I don't agree, you don't need to [ignore the intern's perspectives].... If I'm being honest...that's not a good practice for this situation. Because I think it is way more than just teaching them work ready skills and I think that being able to interview them, being able to honor their likes and needs and desires and opinions, goes into how they are going to fit in in this specific work environment. I think it goes into how they're going to react to their mentors, to their supervisors, to their coworkers and I think you've got to get to know that individual on different levels in order to identify what work environment fits for them. (Interview, Jane, October 29, 2018)

**Value added.** One of the primary aims of Project SEARCH is to provide meaningful work experiences to individuals with disabilities that add value to the employer or business. Value added was a theme that appeared as a positive outcome from the employer's perspective, when the intrinsic characteristics of the intern with HFASD were a good fit for their work position and context. Both supervisors and coworkers described the value they saw in having interns with HFASD in the workplace, when goodness of fit was achieved. Reflecting on Mary's strengths, Cory stated, "[Mary's] got a great positive attitude. And that does help, I think, when you've got kind of a stressful, time sensitive [work environment]...to have somebody who's smiling and friendly" (Interview, Cory, September 25, 2018). Other supervisors and mentors noticed strengths in their interns and the value they added to their respective departments.

Let me say this: I feel like Alex could be a long-term employee....Like I said, the amount of work that...these young men do. You have no idea how hard it is to find employees

like that...if I could have three or four like him, I would do it in a heartbeat. He is never calling in sick, he is never late, if you need anything he's coming in... (Interview, John, June 18, 2018)

So I will be finishing up for the day, emptying the shelves in the front area here by receiving. And [Alex will] already have all the shutdown stuff done. Nobody had to say a thing to him. He's got the trash pulled, he's got the cardboard carts emptied, he's sweeping...Nobody asked him [to do those tasks]. (Interview, Dory, September 12, 2018)

[Justin] is always cleaning something! Always! And we are not very tidy as nurses (laughs). I'm not gonna lie to you, we get caught up in other things... So it's really helpful, sometimes our counters get so cluttered we don't have any room to mix meds or do anything and he just comes behind us, like he's our little mother hen and picks up after us... (Interview, Lindsay, October 31, 2018)

[Justin's coworker] came up to me and said that- he said obviously not everyone in the department gets to stop and slow down very much. But he said, as a compliment, most of the time he didn't even realize Justin was there. He said, "That sounds bad maybe, but it's really a compliment because Justin is very respectful of giving everyone their space and letting them move about the units like they need to." But he can tell that [Justin's] been there because everything is so, everything is stocked. Everything's really nice and organized. And he said before Justin did that it was not. No one was doing that. (Interview, Chris, October 17, 2018)

[The intern] learned each kit after assembling it only once. He remembers each tool by the details of its specific traits, and has memorized dozens of surgical tools based on their visual attributes. His department finds his memory and detail orientation to be invaluable. (Field notes, November 7, 2018)

The demand-side perception of value added was often related to the Project SEARCH support staff's effort to meet the intern's needs without disrupting existing occupational patterns in the workplace:

The bathroom doors are unmarked, and are in amongst other small rooms, such as storage and janitorial closets. Jane explains that the bathrooms are unmarked on purpose so that if patients or families wander around, they don't use bathrooms designated for staff. He still hesitates, so Jane opens the door for him and checks to see if it is the bathroom. She comments that she will mark the doors with the Project SEARCH logo so that he will be able to identify the bathrooms without breaking the hospital's policy. (Field notes, November 7, 2018)

At times, environmental modifications resulted in universal design everyone in the workplace can benefit from, increasing the perception of value added. For example, during an occupational therapy consultation with Mary's supervisor, Jane offers to come in and place additional labels and signage in the nutrition department stock room so that Mary will consistently fill her empty stock on the tray line. Cory, the supervisor states:

That would be really great. All of my staff struggle with finding things in the storage room. They could be back there forever, I usually have to leave my office and go find it for them. (Conversation, November 7, 2018)

## Acceptance

Acceptance in the workplace was the most commonly coded theme throughout the data collected. Acceptance was a theme recognized throughout the data, but was particularly prevalent in both intern and stakeholder comments during the first two phases of data collection. Within the larger theme of acceptance, comments seemed to be related to general community or societal acceptance, as well as a more specific “fitting in” level of acceptance within the workplace. Comments about community-level acceptance were often related to the perceived attitudes of business owners and employers.

**Getting a Foot in the Door.** Stakeholders frequently commented on a general unwilling nature to give interns with HFASD opportunities in the community. Lack of awareness of the program and lack of knowledge about ASD were noted as barriers to gaining acceptance, as was perceived lack of time for being able to adequately support an employee with HFASD. John stated, “It is hard [to accommodate interns with HFASD] because everyone’s schedule is filled up, no one has time to stop and give extra time” (Interview, June 18, 2018). Dory commented on biased reactions towards interns with HFASD from other coworkers. “You know, I don't guess it matters where you're at, you run into people that just aren't willing to give people a chance. And we kind of ran into that here” (Interview, September 12, 2018). Jane spoke about the resistance she felt trying to secure internships. “Some places do not want [Project SEARCH] in there” (Interview, July 13, 2018).

One of the interns in the program wasn’t able to find a position in her area of interest, decorating cakes:

After two meetings with the department and store manager, they ultimately decided the intern did not have the expressive language ability to communicate with customers, and would not [consider her for] hire for the bakery. Even with an AT (assistive technology) device for communication, the store felt customers would become easily frustrated and it would impact the quality of service. (Conversation, Jane, May 29, 2018)

Another intern encountered trouble accessing accommodations for her interview.

An HR officer eventually came to start the interview...He looked put out, and told us that we would have to wait in the lobby, and that no one except candidates was allowed in the interview. Jane told Mary she would probably have to go into the interview alone, and Mary's whole face turned red. (Field notes, May 30, 2018)

**Attitudinal Barriers and Facilitators.** Whether or not interns with HFASD felt accepted as employees in community businesses or departments within the hospital seemed to be impacted by the perspectives and attitudes of key individuals within the respective organizations, as well as the management style and culture of the workplace. In some situations, interns with HFASD encountered low expectations for their performance. "I think understand so much more than sometimes people give them credit for" (Interview, Jane, October 29, 2018). Kay stated, "It's frustrating when the expectation is so low that there's no accountability" (Field notes, August 29, 2018). Kay described how low expectations impacted Mary during one of her internship rotations.

Her direct supervisor wanted Project SEARCH there, and [she] praised her and loved on her and doted on her. I mean so much, to the point where Mary couldn't ...wouldn't, be independent of her. She really sought her out and encouraged her...almost like a

grandmother. And so, we really had to encourage Mary to leave her alone and let her do her job, and Mary follow the list. That was very difficult, because she just wouldn't initiate. (Interview, June 15, 2018)

Conversely, interns felt more accepted and more confident when they were held to the same expectations of others. Alex compared his new job after Project SEARCH with his old job:

Because used to, you know, used to when I worked at [the grocery store], it was much more difficult and it wasn't (pause) it just didn't make me feel welcome and here it's making me feel a little bit more welcome. (Interview, Alex, August 31, 2018)

His supervisor understood that he wanted equal treatment in a position:

That was one of the things I stressed to [Program Coordinator] before we decided we were taking interns. I feel like to be fair to him, you know, we hold everybody to the same standard. That was one of his frustrations he worked at [the grocery store] prior to this... they would make him sweep the floors. He didn't want to get the floors clean, he wanted to do more. He didn't feel like he was held to the same standard as everyone else and he can do it. (Interview, John, June 18, 2018)

Supervisors and coworkers who assisted interns by bridging misunderstandings or communication gaps also facilitated a greater sense of acceptance. For example, Kay picked up on Mary's discomfort about getting on-site support during follow along visits, and responded by using social cues and strategies that would not draw extra attention to her at work. During observations of Alex at work, his coworker also sensed his anxiety about an error with a machine, and jumped in to help.

Alex looked up at one of his coworkers and then back at the machine, but didn't say anything. The coworker immediately came over and checked to see what the problem was. She noted he was sent for supplies for an item that was already stocked, and the error had been in the inventory. (Field notes, June 13, 2018)

Dory relayed a story about a miscommunication Alex had with a new coworker in his department. The mentor's ability to re-frame Alex's intention for the coworker helped to smooth over a wrong first impression:

He was wanting to move in the direction that they were blocking the aisle...he just kind of blew through. And they were like, "Well, you didn't say excuse me." And he just didn't pay any attention to it because he knew what he was after. I said, "Don't get all, you know, bent out. He's just wired that way. We're training him a little bit on the more social end of those things." And so, you know, once they really thought about it, kind of stepped away from the offense... (Interview, Dory, September 12, 2018)

Skills trainers also frequently tried to bridge communication gaps, not only by re-training the intern, but trying to interpret the intern's actions to clarify for coworkers the intention behind the intern's actions.

I would expect if I missed something and my coworker or boss saw that... I wouldn't necessarily want them to do it for me, I would expect someone to say, "Hey, did you do this?" I would go do it. And I think that that would be something that would be really helpful, is just to have that communication with them, and not feel like their off limits or something. And so I was talking with his boss earlier and I told him, "it's perfectly fine for his coworkers to, you know, if they see him miss something, it's perfectly fine to say,

‘Hey, can you change this toilet paper out,’ or, ‘can you restock that?’ and he would be happy to do it, he just didn’t know. (Interview, Chris, May 30, 2018)

**Knowledge about HFASD.** Prior knowledge of ASD seemed to be a factor in the confidence level of coworkers and supervisors working with interns with HFASD.

Those that had autism struggled more...well, I don't think that they struggled as much, the people in the department struggled with understanding how to help them and understanding how to guide them, talk to them and kind of mentor those individuals because they didn't really know, they didn't know how to. (Interview, Jane, July 13, 2018)

Fear of mishandling a conflict was mentioned by several supervisors. Coworkers and supervisors expressed concerns that they might offend or “set off” an intern with HFASD by correcting their work performance. Cory stated, “So if Mary does have an issue, it'd be nice to kind of have some background on how things are handled with her and redirecting her to something different” (Interview, September 25, 2018). Cory elaborated by explaining her shift leads had some trepidation about how to coach or correct Mary.

PI: You can say, "Hey, I watched you touch your face six times. Change your gloves...."

They're not going to feel like you hate them.

Cory: Yeah. And I think some of [Mary’s coworkers] were scared of that.

Several internship mentors in the hospital reported having personal experiences with HFASD that helped them to navigate ways of acclimating interns within their departments.

And it turned out that the supervisor there has worked with someone with autism before and she made these lists for them and she told us that she knew that if things were

overwhelming that they only need a few at a time and then they can add on tasks.

(Interview, Jane, July 31, 2018)

Now I'm biased, because my son deals with what Alex deals with. And so I kind of already have an idea of how to go about explaining things to try to make it work best for Alex. (Interview, Dory, September 12, 2018)

**Systems Barriers.** Project SEARCH program expectations and procedures seemed to impact feelings of acceptance, as well. Interns and stakeholders commented on a mismatch between advocating for equal treatment, but feeling that the instruction strategies might set interns up for different expectations and different work behaviors than their peers.

...you walk into an environment that already has a working standard and you're trying to make someone be what that [is] that's already existing... [We thought], "Oh well, they don't need the interaction because they don't seem to desire it." So it's like we at first were looking for [placements] that (pause) we wanted to put them in a place where they were off on their own. (Interview, Jane, October 29, 2018)

Jane also commented on the discrepancy between rules for the interns in the Project SEARCH Program and the work culture, and how this might specifically impact interns with HFASD who are less flexible in how they perceive policy and procedure. She commented, "I just think Project SEARCH is big on teaching policy, procedures, and expectations, they wouldn't want the interns to think that they could get around [the rules] if they complained.

Data collected after the implementation phase further highlighted areas where the system of instruction may impact the intern's ability to find acceptance amongst coworkers.

Kay and Jane both stated that all of the day's training up to that point [prior to the OT presentation] had been in almost an entirely different direction; it was focused on how to deal with behaviors in the workplace...Many of the interns the PS staff struggle to work with the most are on the autism spectrum, but the approach they discussed using was a behavioral system involving "de-merits." (Investigator reflection, October 31, 2018)

And we're teaching them to work with all these limits or to, you know, you're teaching them what you say are skills but then in reality, a lot of people don't work on work in the same. They don't do these skills that we're teaching them. Like you're teaching them the skills to be a coworker...or, you're teaching them skills to be compliant. (Interview, Jane, October 29, 2018)

**Behavioral expectations.** Coworkers and supervisors commented on a variety of factors that provided insight on their expectations of interns. These comments were often conveyed in tandem with statements about how well the intern "fit in" with peers. In work settings where stakeholders felt the intern was capable of the same level of work performance as their peers, coworkers and supervisors expressed feelings of acceptance.

And so we will be more protective of him, but also try to tell the staff that, you know, Alex is one of us. He can do everything that we can do... so it works both ways... he can do the job as well and better and some others that are down there. (Interview, John, June 18, 2018)

We've all made our mistakes here. Not one of us can go through a day without doing one, you know, a little bit here and there. Um, and so he's, like you said, now that he's

getting more comfortable with us, he's learning that we've accepted him for him.

(Interview, Dory, September 12, 2018)

Many comments made by stakeholders indicated that they expected interns to follow the cultural norms of what they considered to be an, “easy to get along with” employee. When interns were able to do this, they were positively regarded by their supervisors and coworkers.

While Alex is pulling the cart in to unload it, a staff member on the floor pulls me aside and asks if I am with Alex. I nod. He stopped me to tell me that Alex is the nicest guy, and awesome to work with. Always smiling, and always greets me when he sees me.

“He just wanted me to know that”, he says excitedly. (Field notes, June 13, 2018)

Joan checks the plates as they are done and matches them with the tickets. She periodically calls back errors that need to be fixed. Mary continues sliding plates down, takes corrected plates to Joan. Joan asks for another roll after checking one of the trays. She calls out, “this one wanted two [rolls].” Mary takes the plate from her, “Oh, sorry, I didn’t see that.” Joan smiles, “it’s ok!” Joan pats me, “I love her!” she says quietly to me. (Field notes, July 13, 2018)

When interns had difficulty with demonstrating politeness or common courtesy, some coworkers were less accepting. A mentor relays a recent conversation with a coworker regarding Justin’s interactions on the nursing unit:

Okay, well, it’s like... one thing someone said to me the other day, she was like, “He doesn’t really talk to me that much.” And I said, “Well, he really doesn’t talk to me that much, either. Then she was like, “So I’ll ask him how he’s doing, and he’ll just be like, ‘good’ and just turn around and walk away.” (Interview, Lindsay, October 31, 2018)

Justin reflected on his trouble with social interaction in the workplace, aware of how others perceived him, but not able to articulate why or what to do about it. He commented, “I think people miscommunicated me there with that because they would always tend to see me as frustrated and stuff like that” (Interview, October 3, 2018).

Coworkers and supervisors also responded positively towards interns who exhibited good teamwork in the workplace:

Alex stops loading his cart midway to clear empty boxes from the shelves, as there are quite a few. A coworker sees him and says, “Oh, Alex, you don’t have to do that right now.” Alex replies, “Well, I’ve already got the Medline order pulled and I’m waiting for my second one [to come on the printer].” (Field notes, June 13, 2018)

However, when interns were less considerate of team members, coworkers exhibited subtle signs they were not happy with the intern. Interns with HFASD were frequently unreceptive to the subtle nonverbal cues that signaled trouble with a coworker. In one observation, a coworker at the home decorating store becomes disgruntled with Mary because of her disregard for her teammates, when she accidentally spills furniture polish but doesn’t clean it up or communicate about it.

As Mary stocks a nearby shelf in the same aisle, the coworker asks her if she knew about the spot. Mary says yes, she knew about the spot, and that it was dusting fluid that spilled on the floor. She had attempted to clean it up with a paper towel and thought she had fixed it. The coworker cautioned her that someone could fall, and she needs to check for slick spots next time before she leaves the aisle. Mary simply said, “okay”...The coworker is blunt about it...and is somewhat rude and demeaning in the tone of voice she

uses, clearly irritated with Mary... Mary acts as if it never happened. When I asked [Mary] about being corrected, Mary didn't seem to take the interaction that way at all, and stated, "Well, I cleaned it up." (Field notes, June 20, 2018)

**Equal and valued.** Just as coworkers and supervisors had expectations that influenced their acceptance of the intern, the interns also had expectations of their coworkers and supervisors that influenced their perspective on how accepted they felt in the workplace. Regardless of their role or whether they were interns or employees, the individuals with HFASD expected for others to see them as valuable members of a team, equal to their coworkers. Justin was particularly adept at articulating a need to be seen as an equal. Chris stated, "Justin told me he 'feels weak' when he has to ask for something to do or request help" (Interview, October 17, 2018). In a written reflection, Justin stated, "It's not easy for me to feel valued but one of the only things that makes me feel valued is when I'm complimented on the job I'm doing or just complimented in general" (Personal reflection, October 12, 2018)

Stakeholders also frequently made comments acknowledging the intern's perceived value as an important factor. In her frustration with the nursing rotations, she stated, "I would fail down there [if I were the intern], I would feel totally inferior" (Conversation, September 12, 2018).

John stated that Alex's main frustration in his past position at the grocery store was underemployment. He felt he was not in a job he could be proud of because it was demeaning work, and that he was capable of more. Similarly, Justin felt like he wasn't valued as a member of the team. He felt like he was just "piled on" and didn't get a break. Kay remarked how Mary 'felt important' in imaging because she was able to sit at a desk with a computer (Investigator reflections, June 15, 2018; June 18, 2018; October 3, 2018).

**Communication.** The communication style within the work setting also influenced the intern's sense of belonging in the work environment. Generally, interns reported an expectation that directions would be clearly communicated, and that evaluation of their performance would be objective. When interns were unsure of the performance expectations, they felt a sense of unfair treatment, as though there were "different rules" that applied only to them. Alex stated,

At [my old job] they had rules. Only the thing was, the manager could kind of make up rules. Some of those I thought wasn't necessary, some of them I think were... So in training [in my new job] they go through orientation here and that pretty much gives you an idea of what the rules are. That way you don't walk in, you know, and realize, "Oh, I wasn't supposed to do that" (Interview, August 31, 2018).

Justin: She would always inspect my work. It was every day.

PI: Did she do that to other employees or just you?

Justin: I feel like I was a main target... (Interview, Justin, October 3, 2018)

Interns also expressed a very literal understanding of resolving conflict, in that they had an expectation that if they apologized in some way, the apology should "reset" their relationships in the department, as if the conflict had never occurred. Alex perceived the communication style in his department to be one of a light-hearted, teasing nature. After attempting to tease a coworker and accidentally offending her, Alex expressed his frustration about not being immediately forgiven.

I went and apologized to her and then she was like, "Well, I ain't going to put up with your pity" you know, blah, blah blah and blankety blank. And I'm like, "Okay...." I had a sincere voice, but she just didn't take it basically. Like I was like, "Okay, I think I'll

remember that. I'll be like, "Okay, I'll remember that if you try to apologize..."

(Interview, Alex, August 31, 2018)

Interns felt more accepted when coworkers and supervisors gave consistent and objective feedback about performance, without emotion, and privately. Justin stated,

I didn't really take criticism well working there when I started. And I (pause) and that is still something I struggle with is I cannot take criticism or it's just going to (pause) I just want to shut down and quit, you know. (Interview, Justin, October 3, 2018)

Alex articulated the importance of getting constructive feedback privately, as embarrassment can cause him significant anxiety.

PI: If John was going to talk to you about [a performance issue]...how would he talk to you about it?

Alex: Usually in private.

PI: Yeah. Do you think that's important?

Alex: Yes.

PI: ... what would you say is really important to you [in communication]?

Alex: Um, oh I guess honesty. Because usually honesty...Honesty works usually the best. Usually the best policy. (Interview, Alex, August 31, 2018)

When department leadership fostered this type of communication, interns felt that the work environment was more, "fair." Alex commented,

Because used to, you know, used to when I worked [at the grocery store], it was much more difficult and it wasn't (pause) it just didn't make me feel welcome and here it's making me feel a little bit more welcome and, um, I know that if something goes wrong,

they got zero tolerance for it and I think this will be a little bit more (pause) I think this will be more, I guess, more fair. I guess compared to my last job. (Interview, Alex, August 31, 2018)

The culture of his current workplace values the clear, performance-driven communication. The shift lead stated,

It can be something as basic as, "Hey, you know, when you get a second, can you go correct this? I see it's..." You know? You're not attacking them, you're saying, "Look, I think we've got a situation here, would you please fix it?" And just keep moving...zero drama. (Interview, Jerry, September 12, 2018)

Alex's coworker, Dory, related an uncomfortable conversation over lunch, in which he got into a disagreement with another coworker about the existence of angels. Dory stated,

And so we just basically had to say, "Okay, you know, we respect your opinion on that. We also have our opinions and it's okay to disagree with each other, but just respectfully." And so I could see the wheels turning with him. And then he come back to me later he said, "Look, I didn't mean to upset anybody." And I said, "You didn't upset anybody. As long as you acknowledge that it's okay to disagree with people and still respect them." And he said, "Okay." I said, "We're good?" He says, "Yeah, we're good." (Interview, Dory, September 12, 2018)

Dory's clear, objective feedback helped Alex to learn from the situation without having an emotional reaction. In some departments, coworkers were more ambivalent to the intern, and gave vague and inconsistent feedback. The lack of clarity on when to have conversations with coworkers or a consistent person to ask questions of led to feelings of insecurity for Justin:

During the rotation so far it's been a little difficult to communicate because almost everyone in ICU is busy and I believe the best way to communicate in the ICU is through text, writing, and/or email. Communicating this way is easier because I feel like they are better off reading what I have to say instead of explaining it to them while they're busy taking care of patients. (Personal reflection, Justin, September 20, 2018)

Justin experienced similar anxiety in his previous job, before coming into Project SEARCH.

Justin associates the insecurity he feels with a sense of unfairness.

At a place like [my old job] there just wasn't a lot of help. There was a lot of do it on your own kind of thing. Once they got done training you, you were on your own. And, you know, and people- certain people who have disabilities like myself, deserve to have a life ahead of them and they deserve to fulfill in a career like- like a restaurant or anything they want to achieve. (Interview, Justin, October 3, 2018)

**Perceived Inadequacy.** Interns and stakeholders commented on the interns' feelings of inadequacy and how perceived inadequacy impacted their interactions with coworkers. Most frequently, interns struggled with holding themselves to a high performance standard, which limited their ability to initiate communication with peers, or feel a part of the teams where they worked. Justin related to Jane that he feels insufficient most of the time. He tries to do everything perfect in relationships with others, but often feels taken advantage of. "I always feel helpless and insecure" and "I feel like I have to do better always." (Field notes, October 31, 2018). Justin stated, "I know in another department I can do better at talking to coworkers. I have run out of things in my head to talk about, and I don't want to make them talk to me..." (Field notes, November 7, 2018).

...I also need to have more self confidence in myself and learn not to be told by my mentor what I need to do next because sometimes they have to deal with the patients and do not have time to explain everything on what is required of me. (Personal reflection, Justin, September 17, 2018)

Frequently, Alex and Justin expressed internalized expectations of themselves that were not communicated to them by their skills trainers or supervisors, but seemed to be based in their own assumptions that they were inadequately performing their roles, without considering others might feel the same way. During an intervention session, Justin is explaining why he rated himself with a low score for his personal goal of being more responsible and focused.

PI: Do you think you really aren't responsible or focused? Can other people tell?

Justin: Well, I don't really know. I am thinking about other personal things in my head.

PI: Well, let me tell you a secret. Everybody does that.

Justin: They do?

PI: Yes! Especially if the job doesn't really require you to think too hard about what you are doing.

Mary expressed feeling ashamed to receive on the job support from occupational therapy or her skills trainers, sensing it might separate her from her peers.

PI: Would you prefer people not to come and watch you at work? Or do you...

Mary: Yeah.

PI: Why? Does it bug you?

Mary: A little bit.

PI: What bugs you about it?

Mary: I don't know...

PI: Is it kind of like embarrassing in some ways? Or is it more like...people are wondering why?

Mary: People are just wondering.

Interns commented on specific self-protection behaviors they would resort to when feeling inferior or on the outside of a peer group at work. These self-protection mechanisms indicated that interns valued “fitting in” over getting a job done correctly, or sharing their real feelings about something. Alex relates his need to protect his feelings over fitting in:

PI: How important is it for you to have friends at work would you say? Like in the bigger scheme of life, is it important to you or not important to you?

Alex: Um, important, but you don't need to let your (pause) kind of don't need to let your guard down, you know?...Yeah because the best thing is, you know, not to, you know, not to say (pause) usually the best thing to protect yourself, you know, in that situation, you know, don't say anything basically. (Interview, Alex, August 31, 2018)

Justin explained his tendency to overwork himself in order to fit in:

I've noticed in my life that I have trouble asserting myself comfortably towards people. I guess I try to impress everyone by saying yes when sometimes I mean no because I'm afraid of the person's reaction to the word “no.” So sometimes I would stress myself in order to make everyone not all unhappy with me. (Personal reflection, Justin, October 9, 2018)

Mary also demonstrated a need to please others. Kay, Mary's skills trainer, relates an incident where Mary disregarded the department policy on showing identification to access records because a customer got angry with her:

The woman did not have ID, and normally when they come in in scrubs, it was explained to us, as long as they had the name tag on that identified them, you know, we were fine, but that particular woman came in wearing dress clothes that day, with just like a shirt on that had their logo, no name tag, and she was already mad. And Mary was going to do whatever it took to make her happy, and so I had to step up and ask the department mentor, "I need you to make sure that this person is who she says she is." (Interview, Kay, May 30, 2018)

Skills trainers and mentors commented that feelings of inferiority were a barrier to feeling accepted. Chris, Justin's skills trainer, noted that Justin is afraid to solve his own problems when he is working in the ICU:

He requires a lot of talking through. So he had- he might have 10 ideas internally, but he needs me to give him permission and say, "I want to hear your ideas." I feel like he doesn't have confidence in- he doesn't have confidence that what he is going to bring to the table is going to work maybe. Or that it's a good idea necessarily. Or he may even be scared that what he's going to say will come off the wrong way. (Interview, Chris, October 17, 2018)

Chris also commented on Justin's reluctance to take responsibility, stating that Justin was often afraid to admit a mistake at work:

I wanted to understand what he was doing and why he had to (pause) what he was redoing, and once he kind of agreed...he had made a mistake, I just was like, "Okay." And I didn't make it a big [deal]. He didn't seem like he was stressed out or anything about it. He just seemed that he didn't want to discuss it...[He thinks,] "Because if I take the blame it's over for me." (Interview, Chris, October 17, 2018)

Alex also struggled with making mistakes in his position in Central Supply, but seemed to overcome feelings of inferiority related to making a mistake with support from his supervisor and coworkers. The manager of his department, John, describes an incident in which Alex made an error filling one of the Pyxis machines.

Perfect example, on Friday afternoon, I got a call from one of the floors, and we had some wrong IV fluids stocked in one of machines. I pulled the report. Alex filled it, so I had to pull Alex from what he was doing. "Buddy, you placed the wrong fluids." And I could tell he kind of took it hard on himself. He never said anything he just said, 'I'm sorry I got distracted' but just his body language, you know: sighing, shoulders drop...you can tell by the look on his face he was frustrated. You know, he was actually in the middle of break when we found out. That's kind of our standard when someone makes a mistake. You know, we don't do it for punitive reasons but we have to go out and see what caused the issue so that it doesn't happen again. And it is a little hard... I could tell it made him really upset but you know, the staff is the same way with a smaller sibling almost... (Interview, John, June 18, 2018)

Alex benefitted from his coworkers explicitly stating how they felt about making mistakes at work.

Dory: You know, okay if somebody did a situation and they didn't notice it, say something to them but don't flog them with it. You know, and don't go behind their back and...

Jerry: No, just point it out and let them take care of it and go about your day.

Dory: Yeah, point it out and fix it. (Interview, Dory and Jerry, September 12, 2018)

Dory pointed out her own mistakes to Alex, in order to show him that everyone in the department is fallible:

We have these long boxes of needles, some of them look identical. They'll be a different gauge or whatever, but they'll be identical boxes and all. And I had taken the needles that would go on one aisle and put them on a separate aisle. Well, when I come in, Pam said, "Uh, by the way, I need to show you something." And so we walked down there and she showed me and I said, "Ah! Okay." Because we initial the boxes so we know who's put things out in different areas. And I said, "Whoops!" Well, a little later that day, Alex did something and I said, "That's okay, Miss Pam got me about needles." And he turns around and he looks at me and I said, "Yeah, I put something on the wrong spot and she got me." And he just kind of laughed and then it was okay... (Interview, Dory, September 12, 2018)

## **Advocacy**

Advocacy was also a prominent theme in the data. Comments related to advocacy described advocacy in a variety of forms, and how advocacy might play a role in the success of the interns and workers with HFASD in Project SEARCH. Data related to advocacy was present in all phases of the study, including interviews, written first-hand accounts from interns, and

field notes from observations; as well as coded data from the researcher's reflections on observations and interviews and related experiences.

**Stakeholder advocates.** Comments related to stakeholders acting as advocates for the young adult worker with HFASD were noted frequently in the data. Stakeholders tended to act as advocates in a variety of ways, including fostering self-advocacy skills within the autistic worker, as well as in their interactions with coworkers, workplace personnel, and the public. Skills trainers and the program coordinator frequently commented on the interns' lack of self-awareness and knowledge of autism as barriers in learning self-advocacy skills. Jane remarked, "I think what the parents desire isn't always what the interns desire. Or the interns aren't made aware that they have a choice to, you know, to do what is best for them" (Interview, July 13, 2018).

I don't think they were aware of what it- what it was even called or what were their characteristics, what is their- what is the makeup of this disability? And so we did a ton of education on that, and I think it helped. Especially the ones with autism. I like drawing it out, you know, you, right now you see these social situations happening as either black or white, right or wrong, and you're having a hard time understanding that things aren't black and white. (Interview, Jane, July 13, 2018)

As the program coordinator and skills trainers work with the interns and they graduate into employment, they reported assessing and monitoring self-advocacy in the workplace.

Justin internalizes his frustrations a lot but then doesn't know how to problem-solve outward, you know. He's required a lot of, um, help in finding solutions to problems. (Interview, Chris, October 17, 2018)

Very, very seldom did anything ever arise that was an issue, but [Mary] was good about turning around and asking the department peer, “can you help me,” or, “this person needs this,” so she did learn to interact and [Mary and her mentor] had a good close relationship. (Interview, Kay, May 30, 2018).

Kay commented on a situation that raised her awareness of Mary’s struggle with self-advocacy:

She called me one day at 3:30 while she was at work, and said, “Hey, I’m getting to be on the register, you wanna come up here with me?” Like... “that’ll be fun!” (laughs) And so I (pause) I don’t know if it’s that she wants me to hang out with her, or if that was her way of saying, “I’m drowning, come help me!” So I said, “let me wrap up here and I’ll be there.” So I went. (Interview, Kay, May 30, 2018)

After occupational therapy consulting was implemented with Chris regarding Justin’s decreased self-advocacy skills, Chris begun focusing on supporting Justin’s autonomy as a way to encourage self-advocacy:

Recently, it’s been a lot of me going up and I do observe [Justin], but also I have been brainstorming with him to figure out, you know, “If we finished all these tasks, we finish your checklist, what do you do? Do you see anything [you can do]?” Because I want him to feel like he has control over (pause) I don’t know if control is the best word. But I want him to feel like he’s got to say so in what tasks he evaluates, because he seems to have input a lot. (Interview, Chris, October 17, 2018)

The program coordinator and skills trainers also engaged in assisting interns with autism to gain more independence and autonomy as young adults, as a way of assisting them from being limited by low expectations or lack of freedom in choice:

There's two that we helped get their driver's license and they both succeeded. One it has successfully helped because she does drive to work. She does work an evening shift, she works four to 8:00 PM... that was really helpful because it did allow, you know, one young lady complete independence from her mom, which she needed. And so now she is able to drive to work. (Interview, Jane, July 13, 2018)

**Disclosing disability.** The Project SEARCH staff voiced concern over disclosing disability the intern's disability to the department where the intern would be working, and even to potential employers. This was particularly evident in interviews with skills trainers and the Project SEARCH program coordinator, as the first graduating class of interns was embarking on their first paid employment opportunities. Generally, the Project SEARCH staff felt conflicted that to disclose would undermine the intern's autonomy and right to privacy, and may make it difficult for them to be accepted in the workplace. However, they recognize how failing to disclose may limit the extent to which they can advocate for the workers' rights. Kay's comment highlights the social impact of disclosure.

I'm still torn... do we disclose? Do you educate people about [Mary] disability? Or do you continue to let them think of her as an equal peer, you know what I mean? ....And so, you're torn, because here, they respect [Mary] as a peer on the one aspect, and they you know, have expectations of what a typical peer would do, and she has that respect on that personal level, but when it gets down to it, she's struggling, and she can't keep up. So, at some point, you have to pull them aside and say, "this is what she has, you know, this is where she struggles" and hope that they understand. (Interview, Kay, May 30, 2018)

You know, we don't want to disclose their disability. It's sad that we have to expose so much of their personality, you know...they don't want that, yet I think that that helped so much of the interns if they are- if we are able to disclose the disability, disclose the personality characteristics and traits that they need help with, or that they are really strong in, and that also can help guide their job ....We kind of joked sometimes we wish we could just hang a sign around their neck that says, "I have autism..." to do it for just some kind of awareness. You don't want somebody to ever have to wear a sign around (pause) I mean, that's not what I mean by it... But it's like you almost want it to make their life better. (Interview, Jane, July 13, 2018)

Jane, the Project SEARCH program coordinator, reflected on the guilt she experienced after disclosing Justin's disability to his department, after she felt he received a chilly reception from his coworkers on his first day of the rotation.

I felt like I had to stop everything and introduce the staff to him, but then I felt bad. I'm basically announcing his disability to the unit, like, "Everyone say 'Hi' to Justin... you guys need to help him..." and then no one really said anything. (Field notes, September 12, 2018)

The marketing coordinator for the Project SEARCH programs in the state, attempted to bolster the staff's confidence with disclosing details about the intern's strengths and challenges by putting Project SEARCH services in the context of the Americans with Disability Act (ADA) accommodations structure.

Project SEARCH support should be seen as part of the accommodations and modifications, and should be a "selling point" to potential employers. If they aren't open

to the possibility [of support that is faded over time], we don't want them [as potential employers].... [In the interview] I don't speak for them [the intern], but I do disclose strengths and challenges. I leave it to the intern to disclose their diagnosis if they choose to. (Field notes, June 27, 2018)

Supervisors and coworkers also had differing opinions on the issue of disability disclosure. Here, John, the department manager for central supply, strongly advocates for disclosure as a way to increase understanding and communication between the worker and their supervisors and coworkers.

It depends on where you work at obviously, but I think it's very important to disclose if you have any kind of disability. That's human nature. People are more than willing to help if people know there's an issue. People aren't willing to help if people don't know there's an issue. If people are not be willing to help [employees with disabilities] may not be able to overcome that, so [disclosing disability] is very important. (Interview, John, June 18, 2018)

In contrast, Justin's mentor, Lindsay, in the ICU recognizes the culture of her department might be less accepting, and she is more conflicted about whether or not disclosure is beneficial to the intern.

So, I can see both sides of that. I can see how it would be helpful if people knew, so they knew how to approach it, and how to react in a situation, but at the same time, I see how if they knew, they might be overly ridiculous about it... I don't know how else to say that...Like, they might walk up there, and talk to him like he's not smart. Some people

don't realize that autism's not like, they can't learn... it's just a social... so it's... I don't know. I see both sides of that. (Interview, Lindsay, October 31, 2018)

On an individual level, however, Lindsay recognizes how disclosure would have helped her to develop rapport and interact effectively with Justin.

If someone had told me exactly, maybe not everyone, but for me, like, if I had known in the beginning what was going on with him, I would have like, ok, so this is how I need to, "whatever"...So in the beginning, before I realized it, I would always be like, "Hey Justin," and have my hand on him, and then I always kind of noticed, afterwards, he would be like, "uh." So then I was like, "Okay, no more touching!" So then I feel like if I had known that in the beginning, I would have started out just talking and not touching him. (Interview, Lindsay, October 31, 2018)

**Attitudinal barriers.** Though benefits to disclosing disability were apparent in the remarks, trepidation about disclosure was often related to perceptions of attitudinal barriers that could limit opportunities for interns with autism. Attitudinal barriers of family members were recognized by stakeholders as a problem in earlier phases of data collection.

You know, I think what I've learned from this, is these families want their individuals, their children...to still have a kind of a crutch in life...I think that parents have such a fear of them losing benefits, but I think if they would just devote themselves to working...you can lose a job but there's always another one out there. (Interview, Jane, July 13, 2018)

The idea of disability is primarily built on years of school professionals, doctors, and therapists telling us what is "wrong" with our children, and how they will "treat" it. But

when the issues linger after so many years of intervention, parents have a tendency to expect less from their “disabled” child. (Investigator reflection, October 15, 2018)

Stakeholders also commented on experiencing attitudinal barriers from coworkers and employers:

[Jane] went to greet the store manager, introduced herself, and explained why we were there [to support Mary during her interview]. He looked put out, and told us that we would have to wait in the lobby, and that no one except candidates were allowed in the interview. (Field notes, May 30, 2018)

Because sometimes people just like, when I tell them who [Justin] is, and why he’s there, they are just like...Well, most of the time, they’re like, “well, that’s a really cool thing,” and then they’re like, “Oh, I had no idea he was autistic, or that he was part of a program that works with people like that.” (Interview, Lindsay, October 31, 2018)

In the second phase of data collection, after occupational therapy intervention, stakeholders reported taking more action on addressing attitudinal barriers as a form of advocacy. Addressing the bias in other stakeholders often involved assertive statements, strength-based comments about the intern with HFASD, and educating others about the intern and the support available to them. Jane relays a conversation with Cassie’s parents. “They [Cassie’s parents] were all excited [we placed her in a job]. They said, “You couldn’t find something with the computer? I was like, “No, but she wants to do this. This is her choice” (Interview, Jane, July 31, 2018). Regarding another intern with HFASD’s experience in a poor-fit internship, Jane stated,

I was very, almost hostile towards them [the department] because I felt like they didn't support him enough. I did have a team meeting with all of their [the hospital department's] employees and we discussed disability awareness, we discussed what our program is, and I think that helped the support level by having a full understanding.

(Interview, July 31, 2018).

In response to a coworker in central supply complaining about Alex, Jerry commented:

I've actually said, "Well you let me know when you get to this person's [talent] level and we'll talk more. (Interview, Jerry, September 12, 2018)

**Leveraging resources.** Stakeholders also reported advocating on behalf of the intern with autism by attempting to leverage resources that would provide more opportunities for the intern, including financial resources, social capital, and community support. Here, Jane comments on several ways she leverages resources in her role as the program coordinator.

I feel like a lot of my role, too, is, um, making sure everybody knows how thankful I am. I feel like I do a lot of politicking....So not having any kind of transportation, I think hurts it [opportunities for work]. Because we've talked about that. How if the state, could somehow fund some sort of transportation...that would be really useful...There are all kinds of random options out there [for funding]. You know, I think that's kind of where a hole can be, too, is making sure that the families truly know what is, you know, what is, what could be offered to them.....We're having a benefits counselor come to our orientation that can kind of tell them about how much money they can make and up to so many hours they can work. (Interview, Jane, July 31, 2018)

Social capital, in particular, was noted to be an important factor in the success of the Project SEARCH site to secure desirable work opportunities for the interns. Many of the Project SEARCH staff members and steering committee members commented on leveraging social capital to promote specific interns, as well as the program as a whole. When Mary had difficulty with performing multiple tasks at the home decorating store, Kay leveraged her friendships with the managers of the store. “I have offered, I’m friends with both of the managers, and I have said, “If you want to put them on the register, call me and I will be right there, we can do this” (Interview, Kay, May 30, 2018). Jane felt her social connections were inadequate to assist interns in gaining access to more meaningful job opportunities. “Sometimes the interns’ opportunities for employment are limited because I don’t have enough social connections here” (Conversation, Jane, May 7, 2018). One steering committee member stated, “Social capital still drives the [Project SEARCH] program, how do we brand Project SEARCH to the community?” (Field notes, August 29, 2018).

Erica, the marketing coordinator, seemed to endorse the idea that social capital gained Project SEARCH sites a better variety in job opportunities:

[Finding better job opportunities for interns] can be a door to door processes, or online applications. Sometimes it’s more about the political or social capital of the coordinator. First impressions are important, it’s the nature of people and how they are. (Field notes, June 27, 20018)

**Interpreting.** A prevalent subtheme in the data related to stakeholder advocates pertained to specific strategies intended to create a bridge between the intern’s expectations and the expectation of family members, coworkers, and supervisors, in order to promote better use of accommodations, expand understanding and promote acceptance and equality. The descriptions

of these strategies can be likened to the stakeholder advocate acting as an interpreter to reconcile differing points of view, learning and teaching strategies, or patterns of thought. Jane felt this was a significant part of her role as the coordinator.

We have to just ask a lot of questions because we've found that people that work there don't know how to break down a task. And so we're, they- they don't- they don't know how to break down a task and they don't use the right kind of communication and language to teach...Let's communicate better on how our program works. I don't think she understood either how our program works well enough. So we had a meeting, we went over the program, what we could do differently on both ends....So trying to almost teach departments how to, um, how they need [to onboard an intern with HFASD] we've actually changed a lot of the departments on how they would teach a new employee their job. (Interview, Jane, July 31, 2018)

Mentors and skills trainers also acted as interpreters at times. “Well, and like I’ve said... some of our nurses are just so cut and dry, and will go say whatever, so I try to, be like, “you have to be sensitive about [Justin’s behavior]” (Interview, Lindsay, October 31, 2018). Kay expressed her understanding of Mary’s behavior this way: “Others may perceive [Mary’s] behavior as defiant or like a ‘lazy teenager’ but really she just can’t process... she doesn’t comprehend, but she’s afraid to ask for help” (Interview, Kay, May 30, 2018). Dory and Jerry, Alex’s coworkers in central supply, related a situation in which a new employee was complaining about her social interactions with Alex, who was hired full time in the department. The two veteran coworkers acted as advocates on his behalf to bridge the misunderstanding:

Dory: Sometimes you just got to put it right out there. I think there are situations where people are so afraid of offending somebody...

Jerry: and again, the key is respect. You can put something to somebody without attacking them that makes them think....

Dory: It's a long, hard road because we have a- an immature person who's working in our department right now that we're having to go over and over this with them... (Interview, Dory and Jerry, September 12, 2018)

**Self-advocacy.** Self-advocacy, the ability for interns with HFASD to advocate for themselves in the workplace, was described in several different forms, including voicing preference, making independent decisions, being assertive, and asking for help. Interns most frequently voiced personal preferences to the Project SEARCH support staff, both during their internship and after they had graduated from the program. Most of these incidences were elicited or prompted, through specific questions asked of the intern to better understand their preferences:

We've got her [Cassie] a job, but she did not want to work at [the grocery store] as a cleaning person. But she does want to work at the mall as a cleaning person. So we found out (pause) I thought it was about the cleaning, she didn't want to clean. But in reality, it's not that she didn't want to clean, it was the fit of the place. She didn't like the grocery store, but she likes the mall.

Here, Alex voices preference for the ability to make his own decisions about work tasks:

PI: What do you like the best about your job?

Alex: Well, probably, I probably get more, um, I guess a little bit more freedom compared to what I used to.

Justin talks about specific work tasks he hopes to have in future employment after Project SEARCH. "Don't get me wrong, I do like to clean, but I also want to deal with people in my

future too, you know. If I could have both, that would be awesome” (Interview, Justin, October 3, 2018).

Mary was hired in the nutrition department of the hospital after graduating from Project SEARCH. Though she thought she was applying for a hostess position, she was assigned to dishwashing. She reported to the program coordinator (PC) during a follow along visit she was struggling in her dishwashing position, and was considering whether or not she should express her disappointment to her supervisor:

Mary: I just don't really like my position I'm in...

Jane: You don't like the job?

Mary: I thought I did, but I don't.

Jane: What don't you like about your job?

Mary: Being there by myself.

Jane: Okay. So, you don't have many coworkers in the dish room when you're in there?

Mary: No.

Jane: It's just you?

Mary: Mm-hmm.

Jane: And then...

Mary: I have to, like, push them [the dishes], I have to catch them. I have to do all of that by myself.

Jane: Okay. Is it that it gets lonely? Or it's hard and you need help?

Mary: It just gets lonely in there... I was going to ask if I could try doing the hosting, the hosting position. But I don't know if they have enough people.

Jane: To help with dishes?

Mary: Yeah.

In order to voice her own values in terms of work satisfaction, Mary needed specific questioning:

PI: How important is it for you to like your job versus get paid more money or work better, more convenient hours or other things that are good about jobs?

Mary: Mm, it's important to me.

PI: More important than what you get paid, would you say?

Mary: Yeah.

PI: Yeah? So if they offered you full time, you'd do it.

Mary: I would take it for the hostess part.

Eventually, the intern's mother intervened, leveraging her own social capital to advocate for her daughter to be considered for a hostess position that had recently become open. Mary describes her mother's advocacy on her behalf as essential to having the opportunity to try a different role.

Mary: I think my mom (pause) I think my mom already applied for it, I don't know.

PI: Okay. Do you think if your mom hadn't like reached out to her first, how do you think that conversation would have gone?

Mary: Probably not the way I wanted it to.

PI: Really? Why?

Mary: I don't know. Because I'd rather just do that than be...[pauses]

PI: Do you think you would have talked to [your supervisor]?

Mary: Yeah. I would've said something.

PI: Okay. But you don't think she would have agreed?

Mary: Probably not. She probably would've kept me back in the dish room the whole time.

PI: Why do you think so?

Mary: I don't know. Because we're always like, short [staffed].

PI: So, you think the reason that she's letting you do this is because she knows your mom?

Mary: [pause]

PI: Or do you think it's really because you're a hard worker?

Mary: Because I'm probably a hard worker. And I told her I'd just rather do that than be in there.

PI: Okay. Which job do you feel like you're better at?

Mary: Hosting.

After trying out the hostess position, Mary was able to ask her supervisor, Cory, about switching roles more permanently, but did not elaborate on her request to explain her preference:

[Mary] hasn't really talked to me about anything other than, you know, she just texted me and asked me could she do it. And that's really the only, the length of the conversation we had was her wanting to do it. (Interview, Cory, September 25, 2018)

When Mary was asked about the conversation, she had difficulty connecting her voiced preference with what she should tell her supervisor, in order to advocate for herself:

PI: So did you tell her, "I thought this [hostess position] is the job I was going to have?"

Mary: Yeah.

PI: What did she say about that?

Mary: She said we can switch it up a little bit. She told me this week a few more times then she said we'll go from there after.

PI: Okay. And so how many times have you done it [the hostess position] now?

Mary: Like twice.

PI: Okay. And what's different about it? Like better? Definitely a better situation?

Mary: I don't have to cover my scrubs. And my shirt and stuff.

PI: Okay. And so it doesn't smell as bad?

Mary: Mm-hmm. (shakes head)

PI: Okay. Do you get to talk to people?

Mary: Patients, I do.

PI: Yeah? And how's that?

Mary: I like it.

As Mary became more comfortable with her role, she was more vocal about her preferences, but still only to the principal investigator and her support staff:

Mary: I'd rather work like probably mornings instead of nights.

PI: Yeah. you think you could get here that early? That- you'd have to leave your house at like 6:30 or something.

Mary: Yeah. I'd rather do mornings than do like four to nine.

Mary's need for a different shift influenced her attitude, motivation and performance, but she may not have ever realized the impact the later hours were having on her without specific interview questions that highlighted this. Even after this conversation, Mary did not take the initiative to ask for different work hours; she relied on others to advocate for her. The change in work hours to improve focus and performance was suggested to Cory during an OT consultation:

Cory would've liked to have had Mary on an earlier shift, so when I suggested that Mary would prefer that too and would be open to changing, the change was made almost immediately. (Investigator reflection, September 25, 2018)

Interns also tended to make statements about accommodations they desired or preferences, but without a specific request, requiring the support staff or supervisor to interpret the meaning behind their statements:

[An intern with HFASD in sterile supply] told me that the other staff were using the computers at work stations to Google the equipment, but he never asked me if he could do that, too... I didn't even think about letting him take his iPad down there. (Field notes, Jane, November 7, 2018)

Justin tries to communicate how he perceives his coworkers have different rules than he does in his internship, but never requests to be able to use his phone on breaks or "down time" on the unit.

So a good- about a good part of the time they'll play on their phones and, uh, but you know though, but they'll also pay attention to like the sounds and the alarms and all that stuff, you know? And...I mean they are really good at multitasking their stuff. Like they can play on their phone and hear a sound. They put the phone right down, the patient comes first. Patient comes before the cell phone, you know...A lot of good things happen in the ICU. (Interview, Justin, October 3, 2018)

**Decision making.** All three interns exhibited the ability to make decisions about their work roles and tasks when given the opportunity to do so, however, comments from stakeholders

and reflections indicated that interns with HFASD were more likely to make decisions when interacting with Project SEARCH support staff than with supervisors in the department.

I asked him, "What do you evaluate in your department that you think you might be able to help with?" And he said, "I guess pushing beds." I said, "That would be a great idea. I'll check on that for you." (Interview, Chris, October 17, 2018)

Justin hesitates to finish taking trash out of patient rooms. He turns to me and says, "Sometimes I feel like I shouldn't go into some patient rooms if they are full of people, so I just wait." (Field notes, September 18, 2018)

Well, I thought about working up here [nutrition department], but then when I got hooked to, you know, stock, I thought, "Okay, this is a little bit better." You know, going from, I guess from working at- going from working at [the department store to the grocery store]... You know, they were stores. And then I thought, "Okay, this can't be bad." (Interview, Alex, August 31, 2018).

Making decisions about which job to keep was closely tied to Mary's comfort within her work role after she had spent extensive time in both positions:

Jane: Mary is feeling so much more confident in her position at the hospital that she quit her stocking position at [the home decorating store], which was not an ideal fit for her.

Cory: I think she is ready to move up to a full 40 hours with us. (Field notes, November 7, 2018)

**Initiating.** Initiating conversations with supervisors or coworkers to request help or assert needs was frequently commented on in reference to the intern's perceived level of

acceptance within the workplace. Interns commented on how feeling inadequate impacted their ability to self-advocate, reporting self-protection mechanisms they used to maintain the behavioral expectations of the workplace, even when they were experiencing difficulty. Justin stated, “You know, when, (pause) like I was saying with my old job, if someone yells at me, I just want to give up. If someone gets too picky, I just want to give up” (Interview, Justin, October 3, 2018).

PI: *When you say it’s stressful, what are you thinking about? When you’re just back there, doing the dish thing...*

Mary: [I’m thinking], “*Man, I wish I had some help.*” (Interview, Mary, September 19, 2018)

Well, at first I guess this is funny, I mean, to think about it. I guess the first I should have done was go down there, you know, walk around and then sit down. Because at first, had a job up in Quality [Assurance Department] and I was sitting half- the whole day, and I was kind of just really trying to find something to do. (Interview, Alex, August 31, 2018)

I’ve noticed in my life that I have trouble asserting myself comfortably towards people. I guess I try to impress everyone by saying yes when sometimes I mean no because I’m afraid of the person’s reaction to the word, “no.” So sometimes I would stress myself in order to make everyone not all unhappy with me. (Personal reflection, Justin, October 9, 2018).

Support staff, mentors, and supervisors also noticed a relationship between feeling accepted, initiating requests or asserting needs. Dory, Alex’s mentor stated, “But anyway, yes, [Alex is]

taking the initiative now. And it's, I think, all about being accepted and comfortable” (Interview, Dory, September 12, 2018). Chris commented,

There are some coworkers in [Justin’s] department that he has become more familiar with. He will address them and ask them if I'm not there ...And that's the part [feeling inadequate] that he's [Justin’s] good at hiding. Unless you prod to say, "Hey, how are you feeling?" and he trusts you. (Interview, October 17, 2018).

[Mary] did laundry the second half of the first rotation... that is a very supported, repetitive environment. So you're with the same group every day and she thrived like she was one of them. They loved her they knew about her personal life. She opened up about her boyfriend what she was doing for the weekend - you know, it was it was almost like family down there to her and so... That she was very successful at. She moved from just doing the folding the laundry and being repetitive over to the press machine, repetitive to over to the press machine which is a very...hard skill. I helped out on it a little, and you look at it and you think “oh, it’s easy” but it’s really hard. You really have to be in-sync with your two other coworkers. (Interview, Kay, May 30, 2018)

Mary described her conversation with Jane, the Project SEARCH program coordinator, after she felt comfortable enough in her job role that she no longer desired direct follow along support from the skills trainers. She requested that Jane stop visiting her while she was working, but was concerned that Jane would be unhappy with her. Mary relayed her conversation with Jane about having support with a skills trainer at work. “I said, ‘I'm not trying to be rude but...’ [Jane] said, ‘I know you're not trying to be rude.’ She's not mad about it” (Interview, Mary, September 19, 2018). Only one intern participant mentioned disclosing his disability.

Justin reported being most comfortable at work when the owner of the shop was present, because the owner was aware of his disability:

[The restaurant owner] was, he was very nice, very... he was very understanding, you know. And he, he knew my disability because we had talked about it during the interview...we kind of had to discuss it through the job interview.

### **Occupational Therapy Role**

Though data that centered on the idea of the occupational therapist's role within the Project SEARCH model was present in the journal reflections from the principal investigator throughout the study, relatively few comments were made by interns or stakeholders regarding the role of occupational therapy prior to the Planning phase of the study. Proportionally, the frequency of comments made by stakeholders in the post-intervention Discovery phase that indicated a role for occupational therapy increased substantially, warranting consideration of the role of occupational therapy as a theme emerging after the Implementation phase. Subthemes within the occupational therapy role emerged as descriptors of the ways in which occupational therapy practitioners could intervene, the effectiveness of occupational therapy interventions, and the need for continuing occupational therapy intervention for interns with HFASD within the Project SEARCH model.

**Occupational Therapy Consultant.** Consultative occupational therapy services were implemented with all three intern participants, with two of the interns transitioning to full-time employment at the hospital during the course of the project. It was noted that the interns mentally made a shift into perceived independence once they became employed full-time, and were no longer receptive follow along visits from Project SEARCH staff or the principal investigator. Thus, most of the consultation services occurred with participants during the time

they were still interns in the program, or during the first few weeks of their employment after graduation.

Consultant-level occupational therapy services were the most frequently coded type of occupational therapy intervention strategy in the data. Consulting was described on a large, organizational or systems level in some of the comments. Comments about consulting were often related to observing and assessing issues of goodness of fit:

We talked about whether or not we could directly compare jobs without the [Vocational Fit Assessment (VFA)] profile, and plan to ask about this at [the annual] conference. Jane would like to have VFA results by the employment planning meeting (EPM) to guide placement decisions. (Field notes, June 27, 2018)

Project SEARCH skills trainers are on the front lines of on the job coaching and training once the intern graduates, and may not be skilled in this [occupational analysis] process. Likewise, skills trainers may have limited time or knowledge to be able to isolate specific issues within a set of positions, making it difficult to evaluate a specific intern's ability to take responsibilities from a coworker...Occupational therapists could potentially work as liaisons between the employer and the instructor to perform skilled occupational analysis and to make recommendations for accommodations according to newly carved positions, in consideration of the context as a whole. (Investigator reflection, August 4, 2018)

Other comments described the role of the occupational therapist in addressing the needs of specific interns, reducing barriers, making recommendations for accommodations, or in reframing the stakeholder's perspective regarding a specific problem or behavior. "[Cassie's] opportunities had been dramatically limited by her inability to communicate with others. I

assisted Jane with making a referral to the vocational rehab department for an AT evaluation” (Investigator reflection, May 29, 2018). Jane commented on the advantage of occupational therapy in reducing barriers, as well.

At the very beginning [of Justin’s first rotation], I think we all - I was stressed, and it was a situation where I walked into an environment and I felt like this environment is not supportive, this environment, it's not clear what we need to do.... It looked like he...we thought he was “too good” to do work, you know, he had an attitude about him. When in reality, you [principal investigator] came in, first, you know, we worked on the environment... (Interview, Jane, October 29, 2018).

After the researcher consulted with Mary’s supervisor, Cory, about issues impacting her work performance and motivation, she stated,

And that's helpful to know because I didn't know a lot of these things. So I found out a lot of new things I didn't know. (Interview, Cory, September 25, 2018)

**Occupational therapy direct interventionist.** One of the most challenging aspects to supporting interns with HFASD who graduated from Project SEARCH was their reluctance about seeking any support once they became “employees.” Often, the graduate participants were reluctant to even have their skills trainer come into work for regular check-ins, called “follow along visits” which are designed to support graduates for the first five years of employment. Interns expressed a lack of interest in meeting or being observed at work, concerned that it might impact their ability to be accepted by coworkers. Thus, direct intervention within the work setting was not implemented once the interns graduated.

Mary: Yeah. I told Jane and them that. That I really don't like...when you come down here that much anymore. I said, "I'm not trying to be rude but..." and she said, "I know you're not trying to be rude." She's not mad about it...

PI: ... if there's ever anything that you need help with, they just want to know for sure that you know, like if you had a problem, you'd know what to do.

Mary: Yeah.

On rare occasions, the graduated interns with autism were receptive to working with the principal investigator away from the work setting. This tended to occur during scheduled meetings that were intended to be interviews, and not treatment; however the conversation became more intervention focused when the intern graduate expressed a desire to have help with an issue. In the following conversation, Alex demonstrates this reluctance, as he is trying to make the transition to full independence. He eventually expresses his point of view about a negative interaction with a coworker, in response to an offer of help as the conversation was closing. The principal investigator attempts to re-frame the event by relating it to another experience, in which the intern himself felt embarrassed. This encourages him to take another perspective, but he exhibits a defensive reaction.

PI: Is there anything that you think I can help you with?

Alex: Um, probably not right now. Probably not right now.

PI: Well, if you think of anything you can let me know. One of the things that I'm doing as part of this project is figuring out if there are things that occupational therapists can do to help support people when they have kind of like interactions like what you just described. So, if you ever needed to ask someone like, what something means, or kind of process what happened in interaction, you can let me know. That's stuff I can help with.

Alex: Basically what I meant by, you know, by not saying a word, reminded me of this famous feud between Jackson and Quincy and, you know, how Quincy said things that were true and now Jackson thinks they weren't. And that's what I'm trying to avoid. I'm trying to say things that are true and trying really not to say things that aren't [true] basically....

PI: Yeah, so, when you're really honest with people, right? Sometimes, they don't want to be honest with themselves, right? Or be honest with their coworkers about it. And do you think that's what kind of caused the...

Alex: Yeah, I think so. A little bit.

PI: So, when you said what you said, it was like too- maybe too honest for what she wanted to have said out loud?

Alex: Probably.

PI: You remember...that time Kay said to you, "You look like you don't want to be here," right? "You're worried about your old job, you're in a bad mood,"... whatever she said, right? When she said that, how did you feel?

Alex: Yeah. Thought that was- that was...[hesitates]

PI: So it didn't make you feel embarrassed?

Alex: A little bit. In front of the class basically....

PI: Right. So, almost in a way, you felt the way this other coworker might've felt a little bit. So you kind of have experienced that before. I think that's the hardest part is remembering those kinds of experiences, and that helps to train us not to call people out. But I think that's just something that comes with experience. So now that you've had that experience at work, do you think you'll do something different next time?

Alex: A little bit better? Yeah, more like, keep my mouth shut.

Direct, individualized occupational therapy interventions could be implemented with the third intern participant in the study, when necessary. This was more readily accepted by the intern, as the intern understood his role as more of a trainee, someone who was still learning. After touring the department and talking with Justin about problems he has encountered, and teaching him strategies for working through problem solving, he demonstrates the ability to find more efficient ways to work:

When Justin goes to get items to restock from the Pyxis, he leaves his binder with notes on the counter, and goes into the next room to the Pyxis machine. He enters his ID, but can't remember the name of the item to search. He goes back to his binder, returns to the Pyxis. He then forgets how many he was going to pull out. He goes back to the binder again, but this time, brings it into the closet with him, to have his notes right in front of him. Justin hesitates, trying to decide which is the correct item [to stock], as many have similar names. "I need to go back and check something," he states. He goes back to the bins and grabs one of each item he plans to stock from the bins, and brings them to the Pyxis machine so he has examples...this was a great strategy, and he did it completely independently, without becoming distressed. (Field notes, September 18, 2018)

Justin's skills trainer, Chris, comments on the change that has occurred in him since focusing more on autonomy support with occupational therapy services:

He's gotten really good about if there's a change and there's- he doesn't have work to do, he'll- he'll shoot me a text and say, "Hey, I'm out. I ran out of my tasks, they don't need me for transportation right now. Do I need to do anything differently?" So he's become

really good about instead of appearing stressed out or just waiting on something, he's become at least more proactive about letting me know... (Interview, Chris, October 17, 2018)

Other methods of intervention were requested specifically by Project SEARCH staff and other stakeholders, such as providing training and education for coworkers, creating visual aids, and direct individual or group interventions for evaluation and goal setting instruction. The researcher, “put together recommendations for his visual support to assist with ease of locating items, as Justin has difficulty with visual scanning” (Investigator reflection, September 18, 2018). After an education session was held for skills trainers all over the state, “Jane had the idea of putting a reminder card together [for staff] that could be worn under their badge, and include communication tips with a checklist of what [strategies] to consider” (Investigator reflection, October 31, 2018). Additional requests included more training specific to interns with ASD, but delivered in the training room to avoid singling out interns with ASD.

Jane requested I lead a goal-setting session with the interns while skills trainers observe, because she is having difficulty talking to them about how to support decision making and problem solving skills. I showed her the CO-OP strategy to as one idea for how to instruct interns... (Investigator reflection, October 31, 2018)

**Supervisor perspectives.** Department supervisors and coworkers made the fewest comments pertaining to the role of occupational therapy, even during times when feedback was solicited. Department mentors and supervisors tended to have a more vague understanding of how occupational therapy could benefit interns working in their departments, but did articulate an observable change after occupational therapy presence in their departments and occupational therapy-led training opportunities. John stated, “I appreciate you, and I appreciate Project

SEARCH. It's been a truly amazing program. I've been really shocked [by the culture change], and not just this department but the whole entire hospital” (Interview, June 18, 2018).

Department supervisors and mentors were generally receptive to training.

The group was generally quiet after the presentation, without much feedback in terms of information they benefitted from. They did comment on how many of the issues brought up in the presentation resonated with their own experiences with individuals with autism. They were generally receptive to additional training for coworkers, but did not seem as engaged with questions regarding...specific ways they feel like the information could benefit their department. (Investigator reflection, November 7, 2018)

Some supervisors indirectly noted how the occupational therapy services helped to streamline communication and specifically address the work performance issues in their department. Cory stated, “Mary’s [behavior and performance is] much better on the morning shift, I am so glad you told me that she prefers mornings. That has made such a big difference for her. (Conversation, Cory, November 7, 2018)

After working with Chris and Justin on increasing Justin’s problem solving skills, Lindsay, Justin’s mentor noted a change in the ICU based on an idea Justin had to communicate he was available to transport patients in his down time:

[Justin and Chris] were doing this thing where [Justin] could hang a sign if he could help transfer... so if someone needed help, they would know he was there...They would say, “Oh Justin’s here, I need to go down here, and I need an extra person because I have all this equipment that has to go down with us...it is really helpful when you have two different IV poles... (Interview, Lindsay, October 31, 2018)

**Effectiveness of occupational therapy services.** During the second discovery phase of the project, stakeholders commented about numerous benefits they saw that were the direct result of occupational therapy education, consultation, and direct intervention. These included new ways of thinking, different strategies for evaluating and solving problems, and greater awareness and consideration for the autonomy of the individual. Stakeholders described a change in the way they themselves understood interns with autism, and ways they had seen this change in thought process affect their intervention style, the way they advocate for interns, and the way they educate others about the interns' needs.

Many of the points they made and resources they provided [during the parent training] were on-target with the ideas I had highlighted. Janine even brought a self-determination checklist for parents to use when trying to understand their child's needs in this area. This was quite a change from the beginning of the program, when most of our conversations revolved around skill acquisition... (Investigator reflection, October 15, 2018)

I think I mean if I'm being honest... I think [Project SEARCH for interns with HFASD] is way more than just teaching them work ready skills and I think that being able to interview them, being able to honor their likes and needs and desires and opinions, goes into how they are going to fit in in this specific work environment. I think it goes into how they're going to react to their mentors, to their supervisors, to their coworkers and I think you've got to get to know that individual on different levels in order to identify what work environment fits for them....And a lot of times, what we do with Project SEARCH is you try to tell them, I guess sometimes you would try to tell them what to do, tell them who to be, how to act as a typical coworker instead of fostering those (pause)

kind of empowering them to be an individual and to make their own choices...I think that, um, it [training presentation] brings such strong awareness to small details about autism that people don't see, I guess don't understand or don't know regularly....And, um, I think we're learning with what you've [researcher] taught us to give them the opportunity to make their own choices, learn from their choices. They seem happier when they're able to... choose what to do or to choose their job or to choose even the skills that they need to work on. (Interview, Jane, October 29, 2018)

Justin was able to share his perspectives on the effectiveness of the training designed for department supervisors within the hospital. He was moved and empowered by having a tool to share about his unique skills and needs, both in terms of his work and professional life. After the presentation, Justin was quiet for a moment.... He almost cried, and said to the researcher,

Well, I am just really amazed by this power point presentation...I never really knew that stuff. I mean, I never really had an explanation but I think this could really help me explain it. Could I have a copy? I really want to show this to my girlfriend. I just, I really need her to know this stuff about me. (crying) It just really warms my heart to see this, because, I just think it will not only help everyone here and in Project SEARCH to understand [HFASD], but it is definitely going to help me, personally. (Interview, Justin, November 7, 2018)

After being involved in educational and consultative occupational therapy services, skills trainers in particular exhibited a significant change in their approach to interns with HFASD. After one intern had an aggressive reaction to being told to stop talking under his breath, the skills trainer did not immediately try to eliminate the behavior, but first tried to understand its function.

Kay had decided not to attempt to train him out of the auditory self stim. Instead she took data on his productivity when he was allowed to self-stim, and when he was told not to. Trying to suppress the scripting resulted in half the productivity! (Investigator reflection, October 24, 2018)

Chris, the other skills trainer, demonstrated a change in his perspective on specific issues and behaviors with his interns with HFASD early on in the study, simply through participating in discussions and interviews. “Jane reports his change in perspective towards the interns has overflowed into a change in his behavior, and this has created more growth for his interns, and better awareness for his employers” (Investigator reflection, June 25, 2018). Even so, skills trainers rarely felt empowered to address attitudinal barriers that made behaviors like auditory self-stimulation “unacceptable” in the work environment.

The solution never seems to be to address the culture of the work environment to be more accepting of such a difference. Especially in an environment like laundry, it would not be disruptive for him to talk quietly to himself while he works. I wonder why this is so frowned upon. (Investigator reflection, October 24, 2018)

Stakeholders and interns commented on ways they have seen occupational therapy services change the Project SEARCH experience for interns with HFASD.

I feel like we've been more successful having [occupational therapy] this year. I mean having you [principal investigator] come in and basically train us, train and talk with the departments, and you interviewing and discussing the different things with the intern has really, really opened our eyes to looking at things in a different light, to...making changes. (Interview, Jane, October 29, 2018)

So I think when he started it was more- when [Justin] started in the units it was more hectic and not very many people acknowledged him being there. But now I've even seen several of [his coworkers], I hear them every day, almost when I go in there, 'Hey, how's it going?' They'll stop and pat him on the back or, you know, address him. So, that's definitely changed. (Interview, Chris, October 17, 2018)

**Future steps.** Feedback received from stakeholders indicated the initial intervention phase of the project, which consisted of a 45-60 minute training addressing goodness of fit, environmental modifications, and autonomy support, was beneficial. However, Project SEARCH staff at sites elsewhere in the state who received only training without consultation did not feel the training alone was adequate in supporting them for meeting the needs of interns with HFASD. During the training debrief, Chris stated, "It seemed like many of the sites were having more behavioral issues, but were only trying to address them from the skills training standpoint" (Investigator reflection, October 24, 2018).

I would say it was the best training that we've been offered. And that was...that was told to us by other employees as well...It was completely things that they hadn't thought about and it was, um, they felt like it was like a breath of fresh air thinking we can do things differently...they would've [liked to have] had more time to spend listening to you [principal investigator]...and discussing things because so many things that they deal with daily. They look at it as behavioral, and I think you gave them another perspective.... After [the training], a lot of conversation went into, "Let's look at instead of trying to change that person because they are who they are, how do we structure their environment? How do we identify what their needs and wants are to better place them?" And kind of just utilizing that.... I think our skills trainers...focus so heavily on going in

early, finding tasks, creating the task, being knowledgeable about the task and then you're just going to teach them those tasks. When in reality, what needs to be worked on are the social skills, communication skills, problem solving skills. It's all of those like softer skills and I don't (pause) I don't know that they've been provided enough [training].

(Interview, Jane, October 29, 2018)

[Project SEARCH staff] appreciated how successful utilizing a more holistic approach has been, particularly in listening to the experiences of the client, and trying to understand their actions from the perspective of the intern themselves. (Field notes, October 24, 2018)

Project SEARCH staff and vocational rehabilitation staff who partner with Project SEARCH requested additional materials to support the training content that would help them consider the ideas in their everyday work.

[Summary points and handouts] will help, I think, because for our work culture we get into the mode of... you forget. You know you have these tools, you know you have this information about these individuals [interns with HFASD], but I think it's our problem sometimes because we get in the heat of the moment in working on something with them that we forget the tools we need or need to remember in order to help them reflect on what needs to be done. (Interview, Jane, October 29, 2018)

During the second discovery phase, Project SEARCH staff voiced concerns about having a strategy or plan to continue using some of the strategies they had begun implementing during the project.

You have really changed the way we address issues [for interns with HFASD]. You taught it, modeled it several times, we have seen that it works, and we believe in it, but we need a plan to follow in order to continue to do it. (Interview, Jane, October 24, 2018)

**Need for occupational therapy in Project SEARCH.** From the beginning of the project, The Project SEARCH support staff at the site, state-level administration of the program, and national leadership in Project SEARCH were generally receptive to the idea of a project focused on OT involvement in the program model. “[Project SEARCH leadership] ...seems very supportive of occupational therapy in the Project SEARCH model, and is particularly concerned with the success of interns with HFASD, a growing population they are serving” (Investigator reflection, April 23, 2018). Stakeholders participating in the steering committees were also interested in occupational therapy services. Erica stated, “An occupational therapist is heading up our parent advisory board [in another part of the state] and had offered some information about occupational performance. That’s an interesting idea, could you send me some information about that [PEO Model]?”

I provided some information on the Vocational Fit Assessment [to the steering committee] and what it provides. None of the sites state-wide are...using this tool consistently. The vice president of human resources for the hospital looked surprised that we had access to such a tool, and thought it sounded great. (Investigator reflection, August 19, 2018)

Stakeholders involved in the program also noted the need for different processes. When asked about barriers to additional referrals for AT and other support services, Shayne

commented, “This is how we’ve always done it. We see it over and over, [interns falling through the cracks] it happens all the time” (Field notes, August 19, 2018)

Stakeholders who attended a strategic planning meeting during the Planning Phase identified a need for more training that would specifically address attitudinal barriers towards interns with HFASD. Erica commented, “I think the training should be sensitive to anyone, as anyone could have a disability. We shouldn’t make assumptions about attitudes or behaviors” (Investigator reflection, September 19, 2018).

I provided an update on the progress of my project, sharing some preliminary findings from the first two phases of the data collection. I introduced the idea of goodness of fit, self-advocacy and culture clash as some barriers identified early on. Culture clash was particularly intriguing to the group, and was discussed at length, along with community attitudes about hiring people with disabilities in general....Overwhelming comments that one of the first priorities for the parent advisory council should be some education around the importance of [social] connectedness through work, to encourage investment in the program and in getting interns there....The overall objectives of training were to create a culture of acceptance of differences, how to handle communication conflicts, and how to handle accommodations. (Investigator reflection, September 19, 2018)

Prior to the Planning stage of the project, the researcher offered a break-out training at the 12<sup>th</sup> Annual Project SEARCH Conference in Savannah, Georgia. Ideas around HFASD culture were presented to an audience primarily made up of skills trainers and vocational counselors.

... direct care staff from all over the country were intrigued by the idea of searching for aspirational development opportunities for interns with HFASD. They also found the

idea of HFASD as a culture difference interesting. I really had no idea how many people would attend... I ended up packing the room with a whopping 91 people, more than any of the other breakout sessions. Some people were even turned away due to the fire code limit for the room.... Many in the audience were nodding as I spoke about consideration of environmental qualities, social, cultural, and temporal factors that can influence the experience of disability. The information appeared to be very well-received.

(Investigator reflection, August 1, 2018)

During and after the Implementation phase, the need for occupational therapy services was also frequently mentioned. Stakeholders recognized a lack of knowledge base, inadequate training, and need for a paradigm shift to lead to a different process for interns with HFASD.

...the strategies I have employed as I've worked with Project SEARCH interns and staff have illuminated some basic needs and core strategies, but ultimately, have involved a level of skilled service specific to OT, due to the complexity of the analysis.

(Investigator reflection, October 31, 2018)

That's just it – we've identified we definitely need a consult. We aren't trained to do this, we don't have the same knowledge [as an occupational therapist]... We just aren't equipped to know how to do that, we aren't equipped to know what accommodations would be needed, or how to advocate for ADA.....but what do we do FIRST? Do we look at how we presented the task? How do we problem solve? Coordinate or strategize with the supervisor? ...No, I don't think we're skilled enough. We all walked away from that presentation and said, "I think we need either an occupational therapist or even maybe...like a licensed therapist to work with these individuals [interns with ASD] because they have so many mental health needs as well"... I don't think that any of us are

equipped to see the type of skills training that needs to go on that an occupational therapist would see. (Interview, Jane, October 31, 2018)

While the researcher was observing orientation to Justin's next rotation and consulting with Jane on modifications, Justin expressed the need for occupational therapy services within the Program, unsolicited from the researcher.

Justin: That was your idea, wasn't it?

PI: Which idea? About bringing the iPad stand? Yes. Why?

Justin: I can usually tell when something is your idea. It's good you come over to give [Project SEARCH staff] advice.

PI: You think so? Why?

Justin: Well, I just think maybe they need a little help, sometimes. (Field notes, November 7, 2018)

A few administrative stakeholders within Project SEARCH expressed some concerns related to utilizing occupational therapy services within the program. Jane summarized these concerns, as they were related to her in a post-intervention conversation at the state-level training.

And so I suggested to the other skills trainers and coordinators that you might want to talk to your interns a little more...you might want to value why they don't want to do something or why they do want to do something...instead of just having them a compliance expectation. And my supervisor said, "No, you don't need to do that. You don't need to get that personal, um, because you are trying to get them work ready and,

um, that opens the door for something bad." When I made that suggestion to the group it was shot down...

Jane was asked to describe what she thought the resistance to supporting the intern's autonomy was related to:

Jane: That I'm losing authority over them. That it's too...It becomes more of a...

PI: It validates their perspective is right?

Jane: Yes. I think they're trying to prevent, they're trying to prevent things that could be looked at as misbehavior or, not following (pause) it's setup like a rule, not following rules. When in reality if you give them, I think if you give them something where they could mess up on, I think it gives us an opportunity...it's also a way to foster...time management skills.

### **Cultural Differences**

From a behavioral perspective, culture can be defined as a set of complex elements that result in learned and accepted ways of behaving that are specific to a group (Gupta, 2016).

Analysis of memos detailing thematic elements in coded data revealed an overarching theme of cultural differences between individuals with HFASD and "neurotypical" individuals without a diagnosis of ASD. Numerous events and interactions described in the comments from interns and stakeholders highlighted the fundamental differences in values, beliefs, patterns of thinking that contribute to differences in behavior between individuals with HFASD and those without ASD.

**Cultural differences in intrinsic factors.** Themes in the coded data represent ideas about the unique characteristics of individuals with HFASD, and how those characteristics might result in cognitive and behavioral differences when compared to the majority of people.

Behavioral differences stemming from rule-bound logic, or difficulty with perceiving the thoughts and feelings of others were prominent in the coded data. For example, in this observation of Justin, his patterns of behavior when taking out trash followed his “rule” about how to maintain cleanliness. Justin emptied two trash cans, stopped, and put on hand sanitizer over his gloves.

PI: Why did you put on the sanitizer?

Justin: I feel like my gloves are dirty.

PI: Well, should you clean the gloves, or just get new ones?

Justin: Probably just put on new ones.

Justin seemed to operate off of a paradigm of “blame” when something wasn’t going well... He expressed repeatedly to his skills trainer a need to assign fault. In the beginning of the internship, Justin tended to blame himself when things did not go the way they thought they should. This would create situations in which Justin would become overwhelmed or “shut down” when he was at work. ”So to control my anger I decided to shut down, you know, that's-that way I don't make anything a hostile work environment. You know, I just- it doesn't seem very professional” (Interview, October 3, 2018). After occupational therapy intervention and consultation with his skills trainer, however, Justin became more aware of his own strengths and was less likely to blame himself in every circumstance. However, if he did not fault himself, he still had a tendency to assign blame to someone else, which was often perceived as “complaining”. Here, Chris describes Justin’s tendency to assign fault.

Sometimes I've heard [Justin] blame staff, but...when he says things like that, I know that it's a defense mechanism because...he's not going to place the blame on himself and he

feels like if something's not going the way that it should or the way that he needs it to go for himself, that it has to be someone's fault. (Interview, Chris, October 17, 2018)

In the post-intervention data, Jane, the program coordinator, also demonstrates an increased realization of how Justin's behavior can be understood by understanding Justin's paradigm. By understanding his perspective and thought pattern, she interpreted his behavior differently.

Justin went to volunteer with, the nuns and there was multiple other interns and skills trainer there. The job was that they were to rake leaves into the piles. Justin didn't, didn't do anything. He didn't grab a rake. He kind of walked around and was kind of telling people what to do. He seemed to complain a little bit but it appeared to the skills trainer that he didn't work, [that] "he didn't want to, he was being rude, he was being disrespectful," and those are all things that were being told to me, and I kept thinking, "there has to be a reason that he didn't"... I went and just talked to him. "How did the day go?" It kind of came out that, um, in his mind he felt like it should have been done differently. Everybody was raking small piles, [and] he was trying to tell them if they would rake it into one big pile, it would make it easier for cleanup. So I think in his reasoning skills, he didn't understand how they were doing it or why they were doing it. ... And he just continually, I would say kind of "rock-brained" on how it could be done differently... (Interview, Jane, October 31, 2018)

Alex also demonstrated rigid thinking patterns that led to tense interactions with coworkers. Shortly after starting in central supply, Alex was focused on his productivity and accuracy as he mastered his job, but he did not intuitively see his role as a support staff person to the medical professionals in the hospital. John describes how this prompted more explicit instruction and "rules" to be formed around his position:

Alex was so dedicated to his job, he was trying to put away supplies - you know, our priority is going to be the patients. If a physician or nurse needs something [while we are working] we log out [of the Pyxis machine], then we let the nurse or the physician get what they need, take care of the patient, and we finish our job. Alex was kind of dead set on it. He was like, "I've got to get this machine loaded, y'all won't have supplies if I don't get this machine loaded!" And so, I had to try to explain to him, "You know we're here to support them. If they need something, we have to get out of the way." (Interview, John, June 18, 2018)

Both Alex and Justin expressed feeling "picked on" or that supervisors were overly critical when expectations for work performance were not made explicitly clear.

[Justin and Alex] became dissatisfied with their work situations when their supervisors gave them more work to do that wasn't on their original list, even though the reason for the addition was that they had finished all of their tasks.

The same cultural differences in HFASD that might create challenging interactions or work patterns, were also related to comments about extraordinary talent for a specific role. Rigid or rule-bound thought patterns were reflected as an asset when it came to memory, dedication to a work task, and detail-oriented performance. "But you know, sometimes we find the intern [with HFASD] learns [work tasks] quicker than we [skills trainers] do" (Interview, Chris, May 30, 2018). Jerry stated,

I noticed that Alex pretty much takes ownership of whatever area he's given and that's a big plus for anybody... But yeah, Alex can really converse on a fair amount of topics like that because he does pay attention. In fact, he pays attention to a lot of things I didn't

realize a person his age would necessarily be looking at. (Interview, Jerry, September 12, 2018)

Difficulty interpreting the facial expressions, body language, and verbal communication of from supervisors and coworkers made it difficult for interns to become self-aware, and contributed to feelings of anxiety and perceived inadequacy. Mary also vocalized this insecurity, in her statements about being a hard worker, but not having real examples that allowed her to see herself this way. Likewise, Justin had difficulty forming an opinion about his performance without getting verbal feedback from someone else.

When I asked [Justin] why he needed another opinion he said, “Well, I just like to take at least two opinions and put them together” ...to get consensus on a particular performance issue or feedback.... which adds to his insecurity.

Alex’s manager clearly felt Alex was one of their best employees, and had mastered his role in central supply.

It's usually 6 to 8 weeks to learn the job... but [Alex] actually had the job down within about 3 to 4 weeks. I can't say enough about how detailed he is and how perfect is for this job and it's just amazing all the stuff he catches even that I would miss. (Interview, John, June 18, 2018).

However, Alex was not aware of his own exceptional performance:

PI: So tell me about like how long did it take for you to learn that job? Were you still learning it when you started your third rotation?

Alex: Yes ma'am. Still learning it.

**Differences in values.** Notable differences in the values expressed by interns with autism, compared to cultural norms. Cultural norms across work environments were similar, in that coworkers in those departments tended to value productivity, politeness, and a pleasant or “easy going” demeanor. However, these expectations were not always explicitly or clearly communicated to the intern. One hospital staff person commented, “Alex is the nicest guy, and awesome to work with. He’s always smiling, and always greets me when he sees me” (Field notes, June 13, 2018). Chris reflected on a compliment about Justin, stating Justin’s “[coworker] said that he appreciated [Justin] a lot and that anytime he did see Justin, Justin was very polite and, you know, sociable” (Interview, October 17, 2018).

Mary’s easy going nature and positivity are great to have in the department. The work can be stressful, and many times they are putting out fires. She has brought the morale of the department up since starting there. (Investigator reflection, September 25, 2018)

It seemed consistent between departments that there was a process of approval related to whether or not the coworkers deemed the intern as “one of us,” or, a member of their work culture, somewhat based on whether or not the intern was able to exhibit the values of politeness, or sociability. “Mary is just like everyone else here [in nutrition]” (Interview, Cory, September 25, 2018). “Now that he's getting more comfortable with us, [Alex] is learning that we've accepted him for him” (Interview, Dory, September 19, 2018).

Justin had not quite received the support of his coworkers in the ICU, but was perceptive about which coworkers had approved of him:

Lindsay: [Coworkers are] like, “oh, I had no idea he was autistic, or that he was part of a program that works with people like that...” Some people are nice, and sensitive to certain situations, and other people are not. So I really think it depends on the person.

PI: Has he been able to sort of figure out who that is, do you think?

Lindsay: I feel like that yeah, so, there’s just a couple people up there that I see him talk to more, and me... he talks to me. (Interview, Lindsay, October 31, 2018)

Interns expressed valuing honesty, concrete, clear language, and consistency in interactions. Though neurotypical culture may also express a value in clear communication and honesty, the language and social structures utilized in neurotypical culture were often perceived by interns as a literal contradiction to those values, as the contradiction appeared to be a “hidden rule”. For example, Alex felt he would be lying to his coworker if he did not say the absolute truth, even though the truth statement was hurtful to the coworker. “And that's what I'm trying to avoid. I'm trying to say things that are true and trying really not to say things that aren't basically” (Interview, Alex, August 31, 2018). Alex also believed his supervisors at the grocery store were deceitful, because of an off-handed remark made by one of his coworkers.

Our breaks were 15 minutes or I think. And I would take a break at, you know, 20 minutes ‘til [the hour] and my managers told me, you know, that we couldn't do that, and I had somebody who was there said, “I think they made that rule up because they hadn't told me not to do that.” (Interview, Alex, August 31, 2018)

Stakeholders who attempted to “interpret” or bridge the miscommunication, often expressed feeling protective of the intern. John remarked, “I guess we're protective of him more so than most employees, but now I catch myself doing it, I mean, I think the world of Alex” (Interview, June 18, 2018).

I fear that [social rejection for interns with HFASD]. I fear that because people, the social norm is that we shake hands, we smile, that we look each other in the eye, that we nod our head when we listen. I think it's so the norm to people, that they still wouldn't understand or give as much grace to those [interns] even if they were more aware of it [someone having an HFASD]. (Interview, Jane, July 13, 2018)

**Work culture.** Different departments also had unique cultural characteristics that seemed to dictate their work patterns, interaction styles, and communication, depending on the type of work and the professionals involved on each team. The culture values or norms of a department came up frequently in the context of goodness of fit, and acceptance, in particular. For example, the culture in central supply was described as a fast-paced environment, but one that uses humor to build team comradery and to relieve job related stress. The style of humor was to tease or chide coworkers.

Pace, accuracy, accountability, and professionalism are valued by John and in the department. In the confines of the department, employees show affection towards each other by joking, poking fun, or playing tricks on each other. (Investigator reflection, June 18, 2018)

You know that we would kind of cut up down there, [Alex] goes along with it...[Alex is] doing great interacting with the staff and, like I said, we do cut up, and it is a high-stress environment... 'course I don't think anybody has gotten very aggressive with him.

(Interview, John, June 18, 2018).

The coworkers in Alex's department decided to enculturate him by engaging them in their style of humor. "[Alex's coworkers] tell me about how much they like working with Alex, and how they are determined to teach him to tell jokes" (Investigator reflection, June 13, 2018).

Coworker: You've got a little shadow today! (smiling, strokes his own chin, indicating a beard)

Alex: Yeah (looking embarrassed). That's just somethin'.

Coworker: (smiles). Just somethin', eh?

Alex admits he doesn't always know how to interpret their comments to him or others, but tends to stay quiet if he is not sure:

Like, I know when they're teasing me. But if they're having a bad day and they're just blurting out some random stuff I'm thinking, "Okay." You know, "just kind of walk. They won't do it if I go to walk." (Interview, Alex, August 31, 2018)

The culture in the nursing departments within the hospital was described as, "sink or swim," a very fast-paced, intense environment, in which most of the employees keep to themselves and function autonomously. Jane expressed her frustration because her intention was to be able to leave Justin on the nursing unit alone during his first week, but she felt uncomfortable leaving him there because the staff were unconcerned if he had anything to do or was productive at all. She stated, "They think a casual walkthrough of EVERYTHING you need to know is enough – sink or swim" (Field notes, September 12, 2018). During the planning phase, Jane advocated strongly for additional departmental training, stating, "we are having a hard time cracking the culture of the ICU, in particular... The staff do not seem to be aware of

who Justin is, or why he is there, and don't make an effort to talk to him or include him" (Field notes, September 19, 2018).

In, "sink or swim," environments, approval seemed to lie in the intern's ability to "pick up on" what needed to be done with very little instruction or support.

An LPN who floats between the units will be his mentor during this rotation. She had given a tour to him earlier in the day, explaining his duties, showing him the supplies, closets, and how to get in and out of the Pyxis machine. According to Jane, she talked for about 45 minutes while she toured them around, never stopping to make sure that Justin was understanding...Lindsay left them, "I need to get back to work, come find me if you need me." At that point, everything on the list was done, what else should he do? Lindsay replied, "well, whatever is on the list, I guess." (Field notes, September 12, 2018)

But sometimes I get super busy and I don't even see [Justin] until he's leaving, and he's like, "alright, see you tomorrow"... I'm like, "Oh! Thank you so much!" I should [provide feedback] more, but I just get so sidetracked and I'm so busy sometimes. (Interview, Lindsay, October 31, 2018)

Justin is able to articulate how he feels the "sink or swim" culture in the ICU has impacted his social interaction:

I think [my lack of progress] is because of how intimidating it is to talk to people. They are so focused on their work. People are really busy in that department...I know in another department I can do better at talking to coworkers. I have run out of things in my head to talk about, and I don't want to make them talk to me. (Field notes, November 7, 2018)

Both the home decorating store and the nutrition department where Mary worked seemed to have a “crisis management” culture. The employees were primarily autonomous, and were left to do their work and handle conflict with very little oversight or management. The work environment seems to be in a constant state of change, and course correction by management tended to be in a moment of crisis, and was more reactive and dramatic.

But, because there at that particular store they really don't care, as long as you get it out on the shelf. I mean, that's their goal because they have another [truck] coming in, and another one coming, so no one there has really emphasized to her the way it's supposed to be done... Until corporate shows up, and then it hits them all at once....[Store traffic] can you get slammed in waves, like you're standing there doing nothing and all of a sudden, you look up and you've got 15 people tapping their fingers, like, “let's go!” (Interview, Kay, May 30, 2018)

Cory: Yeah, so I mean some of the issues she deals with are normal issues that I deal with most of my (pause) well not most of my employees, but I have a few stragglers who still don't get the whole, “Change your gloves after you touch something off the floor, change your gloves after you touch your face.”

PI: Do you constantly just keep reminding or do you have sort of system for...

Cory: I keep reminding people.

Cory depends on her team leads to share information with her about performance issues, but she has not invested time into training them or communicating what she wants to know about. They seem to only bring issues to her once they become unbearable and a solution must be found. Though Mary wasn't able to articulate it in conversation, her behavior indicates that she was able to perceive the “crisis management” culture, and she adapted by texting her

supervisor frequently to voice her preferences. This method of advocacy was directly contradictory to how Mary was taught to communicate with her supervisor in the Project SEARCH program.

Cory uses “squeaky wheel” management. She responds to the desires of her subordinates when they complain or repeatedly request something. Mary seems to have picked up on this, and now doesn’t hesitate to text to tell Cory where she would like to work. Cory seems fine with this, and adds, “They’re adults, if they won’t ask, I won’t move them.” (Investigator reflection, September 25, 2018)

**Building a bridge.** Throughout the data, stakeholders and mentors provided many descriptions of ways they provided instruction, or advocated for the interns during times of social conflict. Many of these descriptions articulate a process of interpreting for the intern, and on behalf of the intern, in order to bridge a language and cultural breakdown between the two. “So, I think a big part of my job is really to observe, um, these individuals and to help them process specific tasks, specific things in their own terms, in their own language, in their own visual way” (Interview, Chris, May 30, 2018).

The coworker asked Dory later, “why did he do that?” and Dory served as the bridge (interpreter) between Alex and the coworker. She told the coworker, “he’s highly focused, he’s just not focused on the social part of it [the conversation].” I thought this was a unique and interesting way to talk to the coworker about the cultural difference – as simply a shift in focus away from empathizing with the coworker to the task at hand. She reframes things for her coworkers, just the same way she reframes things for Alex, so that they can better understand and accept each other. (Investigator reflection, September 12, 2018)

At times, even the Project SEARCH staff struggled with whether or not they should interact in certain ways with interns, even though their strategy was culturally sensitive for the intern:

Kay feels “harshly blunt” when she gives straightforward directions to Mary. This seems to be a cultural expectation that being straightforward about an error might be offensive to someone. However, Kay acknowledges that Mary needs this type of communication, and does not become offended by it. (Investigator reflection, June 15, 2018)

When interns with HFASD were left to receive instruction from another intern with HFASD, however, the communication style was markedly different than the neurotypical norms, yet seemed effective for the intern with HFASD who was learning. During a consultation with Jane and Justin, the principal investigator notes the cultural difference in the interaction between Justin and the intern showing him the sterile supply department, who also has HFASD.

The intern looks at Justin, grabs a discarded head cover from the top of the waste can and offers it to Justin: “Here, you can just use this,” he says, snickering. “No way, man!” Justin states, and the two share a laugh, not once looking at each other...The two men walk away from Jane and me, through the department, [the intern] demonstrating his tasks [to Justin] without any verbal narrative about what he is doing or why. Though this is disconcerting for Jane, I coach her to allow them to continue, commenting that he doesn’t seem to think in words, and is using visual strategies to show Justin the job. Since Justin is very attentive and engaged, this might be more effective for him in terms of being able to get a feel for the job without a complicated list of procedures. (Investigator reflection, November 7, 2018)

Presenting HFASD as a cultural difference rather than a disorder was helpful for the interns with HFASD. This knowledge seemed to have an empowering effect that made it easier for them to have self-awareness and make decisions about how to change their own behavior. It also led to self-advocacy.

...I wouldn't say [teaching Alex to be] appropriate because it wasn't that he was inappropriate, but, you know, he changed his feelings. He learned how to hold his tongue. He learned how to not criticize certain people. So we did a lot of that just through honestly discussing the disability, how it impacted his brain and his thoughts and his emotions and his feelings and then how other people have different thoughts, emotions and feelings, and how he's going to have to like, adjust himself. And he did. I mean, it was amazing. (Interview, Jane, July 13, 2018)

I think it's good. I never really knew that stuff. I mean, I never really had an explanation but I think this could really help me explain it. Could I have a copy? I really want to show this to my girlfriend. I just, I really need her to know this stuff about me. (upset)...she doesn't understand the way I think or what I say. She gets frustrated with me.... And I think this would really help. (Interview, Justin, November 7, 2018)

**Bias.** Subconscious bias that influenced expectations of interns with HFASD also seemed to be reflected in comments and observations in the work setting.

The department's expectations of Mary seem lower than the expectations of others, as there are some aspects of her role that she doesn't complete without reminders, and they seem fine about having to call in her mother for support. Even though Cory states it doesn't matter, they seem to act on the assumption that they are pleasantly surprised

when she can do the job like others. This is a limiting bias for Mary, and an obstacle to helping her achieve competence in her role...Cory seemed to change her mind about what Mary was able to do the longer we talked. Maybe she realized how she was thinking about it and caught her own bias as she articulated her concerns? (Investigator reflection, September 25, 2018).

[Some Project SEARCH staff] seem to believe that empowering the intern to voice such choices or preferences might set them up for failure if a change cannot be made. Or, it may validate their complaint to an extent that sends the wrong message about authority. (Investigator reflection, October 31, 2018)

Chris was able to acknowledge his previous assumptions about task complexity, and how his views didn't previously take into account the unique challenges associated with HFASD:

Chris mentions how others make assumptions about what is "easy" for an individual based off of what they already know; these expectations may set someone up for failure, in a sense. Chris talks about strategies he uses to communicate how to do these tasks without making any assumption about their previous exposure to doing them, or how easy or difficult the task might be. (Investigator reflection, May 30, 2018)

However, Chris continued to have an assumption that his primary role was to address the "deficits" interns with HFASD have, rather than considering occupational and environmental adjustments, as well:

Chris believes that Justin needs to master flexibility and communication better before he can be given more complex work. I think he still views the skill deficit as the primary

issue. Though he feels it can be learned, he couldn't really talk about how it would occur other than taking time. (Investigator reflection, October 17, 2018)

The vocational counselor was almost grandfatherly with him, and told a couple of stories about his own work-life in order to normalize some of the experiences Justin related with feeling like the gaps in his schedule were "wasting his time." The counselor commented this was an indicator of Justin's strong work ethic, downplaying the specific need Justin has for structure in his work setting. Justin understands that he is in this program to gain work skills. If he isn't doing anything and no one is able to generate work for him, there simply isn't enough work for him to do. Chris has told him that this means he is doing his work better than anyone anticipated he would, but I feel this is also demeaning to Justin, as it implies that they didn't expect much from him because of his diagnosis.

(Investigator reflection, October 17, 2018)

Towards the end of the project, Jane, the program coordinator, started to recognize how bias may impact the program's intervention and placement strategies for interns with HFASD.

You can look at them [interns with HFASD] and try to place them in a very low social interaction job: "Oh well, they don't need the interaction because they don't seem to desire it...." I think people try to work in a more rigid bubble. You have to follow these procedures, you have to follow these protocols. Everybody [other Project SEARCH staff members] came in seeking a procedure or protocol to help fix, say, a behavior in students [with HFASD]. That's a lot of what [Project SEARCH skills trainers] were talking about that day [of the training]. Prior to you [principal investigator] talking, it was (pause) everybody went site to site and they talked about behaviors that are bothering them.

(Interview, Jane, October 29, 2018)

When Jane suggested they find out the intern's perspective on the behavior as a solution, she got "shut down." "And my supervisor said, "No, you don't need to do that. You don't need to get that personal, because you are trying to get them work ready and, that opens the door for something bad" (Interview, Jane, October 29, 2018). As Jane became more aware of bias, one of the strategies for communication used in the training room for interns with HFASD that Jane had previously approved, started to bother her:

Kay created a system for these individuals to talk to us. If they need to talk to us, they need to basically get permission. So she made these signs. It's a red sign for "I'm busy, don't come to my desk." If I have the sign on green, "I'm ready to talk, I'm ready to listen, I'm available." ...Yeah, it's a good idea because they- they do, they want to tend to lag and talk and whatnot. But then the other morning we had an issue between Kay and myself... she started talking to me with just a bunch of work stuff really early [in the morning]. I thought, "We have expectations of these individuals and they're told to do these things and to set these boundaries and limits in life but it's like, do we? No, we don't. (Interview, Jane, October 29, 2018)

### **Psychological Needs for Self-Determination**

Another over-arching theme noted in the data was the high frequency of comments around the ideas of autonomy, self-awareness of competency (or perceived competency) and relatedness. These three themes articulate what Ryan and Deci (2000) called the "innate psychological needs for well-being" (p. 68) and are related to internal motivation and self-determined behavior, such as self-advocacy (Ryan & Deci).

**Autonomy.** Comments related to the role of autonomy in developing independence and increased confidence were frequently found in the data. Interns voiced preference, had more

motivation to work in settings where they could make some decisions about work tasks, and demonstrated higher work performance when they felt they had choices.

[Cassie] doesn't want to work with that amount of people. But in the- in the food court in the mall...there are plants, she likes plants. There's plants, there is sunlight. She likes the outside sunlight, natural light. She only has to go directly to one supervisor and she likes that person...so those were the things that we discovered. (Interview, Jane, July 13, 2018)

[Alex] has chosen to not receive benefits and he wanted to work full time and gain his financial needs from working and his insurance. He wanted health insurance and everything through work, not through the state. (Interview, Jane, July 13, 2018)

PI: What do you like the best about your job?

Alex: Well, probably, I probably get more, um, I guess a little bit more freedom compared to what I used to. (Interview, Alex, August 31, 2018)

I had several work friends but some of them kind of were, you know, they kind of led me down a dirt road I didn't want, I didn't want to go on. Or didn't feel like I needed to get into. (Interview, Alex, August 31, 2018)

Interns with HFASD had difficulty making decisions or initiating a choice when they were in new roles or unfamiliar environments.

As we come off the elevator and approach the doors to the ICU, Justin states, "I hate having to use my badge, it doesn't work right." Indeed, he tries to swipe into the ICU and it doesn't work. I wait. He stands there a moment, tries it again.

PI: Should you do something about that?

Justin: Probably, yes

PI: Ok, who could you ask?

Justin: Maybe the job coaches.

PI: Ok, who else?

Justin: (shrugs, looks down)

PI: Maybe Emma could help?

Justin: Maybe I'll have to go back to HR. They gave me the badge. (Field notes, September 19, 2018)

I need to improve on knowing what to do on my list and when I'm supposed to do it. I also need to have more self confidence in myself and learn not to be told by my mentor what I need to do next because sometimes they have to deal with the patients and do not have time to explain everything on what is required of me. (Personal reflection, Justin, September 12, 2018)

As Justin became more comfortable in his role, his problem solving improved:

Justin put gloves on but couldn't find the wipes so went to get some from the other unit. The wipes in this unit were mounted on the wall. "Well, personally, I think they should keep some wipes on the counter in both stations, but I can just go to the other one and get them if I can't find them. Some things I get from CI, some things from SI." (Field notes, September 19, 2018)

Mary had difficulty communicating with her supervisor after a major change in her department's process, but she was able to voice preference with her support staff:

PI: So, is there a job now, the way they do things now, that you think is the best job? If you were to stay-like if you could change your role within what they were doing?

Mary: Now I would like to be like on the tray line. And make like sweet teas and making the soup, like the broth and stuff. Because the people on the tray line, the middle person has to make like the soup and the teas and all that stuff. (Interview, Mary, September 19, 2018)

Project SEARCH Staff began to see autonomy support as an avenue to improve motivation and work performance after the Implementation phase. The program coordinator was particularly interested in seeing more autonomy support implemented for interns with HFASD:

In order to find their [interns with HFASD] motivation, you've got to look at what drives them, what pleases them, what makes them happy, what, um, what do they need out of the job? Not just what does the job need out of them....I think sometimes our setup in Project Search is that their thoughts aren't as valued as the instructor and the skills trainer. And so, I've been trying to reflect on that a lot more this year after, you know, your [principal investigator] trainings and your help is that, we've really got to value their opinions. (Interview, Jane, October 29, 2018)

We honored that- that feeling of his [Justin's] and we fostered [deciding to take break] "You can take a break when and if... like first do your list, but then take this break." It's been so much better. And then he communicated just last week, "Hey, it's my break time. I left my wallet in the car and I wanted something to drink. Can I go grab it?"...One, he problem solved. Two, he went to his chain of command. Three, he felt comfortable enough to ask me. Whereas previously he probably wouldn't have. He would have just tried to find something else to do and work. (Conversation, Jane, October 31, 2018)

**Perceived competence.** Stakeholders noticed that interns with HFASD demonstrated more social engagement and motivation for work tasks when the intern perceived they were competent in their role. Jerry, the shift lead in central supply, reflects on a shift in Alex’s dedication to his work tasks as he felt more competent:

Jerry: I noticed that he pretty much takes ownership of whatever area he's given and that's a big plus for anybody.

PI: Did he do that from the beginning, or was that more like after he got comfortable?

Jerry: No, that's not just him, that's with anybody. It takes a while. This job, you don't learn it in a month or two months, it takes a period of time.

Justin’s perceived competence improved when his skills trainer coached him on seeing his increase in “down time” in his internship as a sign of his increased speed with getting tasks done, and was then able to assist his skills trainer in problem solving to find more work on the unit.

And I have seen a change in- I've seen a change in the way that he talks....The way that he describes himself for sure. He may have previously... blamed him[self] for not having anything to do and I would have to tell him...“that's actually a positive thing because you're doing your job so well that they're running out of things for you to do.”

(Interview, Chris, October 17, 2018)

Visual supports were also extremely effective in improving Justin’s perceived competence, which in turn, increased his work performance. This was very important for Justin in the ICU, because of the “sink or swim” culture that resulted in a less supportive internship structure for him. His mentor commented,

So when he first started, I would show him how to do something, and then if I had to leave, he would just stop working. And wait for me to come back to continue doing it. And now, he just comes in with his little book and his checklist, and he just goes through his day. And at the end of the day, he'll say, "bye, see you later!" And, I'm like, "okay!" (Interview, Lindsay, October 31, 2018)

**Relatedness.** A sense of belonging and the impact it had on the intern's attitude and behavior at work was a common idea in many of the comments. Relatedness was an important concept that bridged over many themes, including acceptance, extrinsic factors, and advocacy. Feeling a part of the work culture was so important to the interns with HFASD that they often prioritized acceptance over other motivation when they felt uncertain about whether or not their needs would be understood or respected by others, such as getting to do a preferred job, asking for assistance or clarification, or expressing dissatisfaction. Dory, Alex's mentor, noticed Alex's initiative to interact with coworkers and take risks by cracking jokes improved when he felt more accepted. "But anyway, yes, he's taking the initiative now. And it's, I think, all about being accepted and comfortable" (Interview, Jerry, September 12, 2018). Mary preferred not to have support on the job because she felt it made her stand out from her peers. Mary chose not to disclose her disability to her coworkers, in any of the settings where she worked. Mary's skills trainer felt very conflicted about this:

Do you educate people about her disability? Or do you continue to let them think of her as an equal peer, you know what I mean? Because typically we can look most people look at the individual and can quickly identify um, not necessarily by their physical traits, but by some type of behavior, but hers is really hard. There really wasn't a lot until you

got into the nitty gritty, she just wasn't doing what you asked. It was really difficult, so we struggled. (Interview, Kay, May 30, 2018)

Alex experienced significant anxiety and stress with the conflict he experienced involving a misunderstood joke, feeling that it may have jeopardized his acceptance in the department. Even though Jerry, a trusted coworker was present when the incident happened, Alex hesitated to ask him for clarification on why Jerry's comment was taken as a joke, but Alex's was offensive.

Alex: [Jerry] he probably knew what happened better than I did, basically.

PI: Did he tell you anything about it?

Alex: No. He didn't say a word.

PI: Okay. Do you think it would help you to get Jerry's perspective on what happened? Would it help you understand it better? Or is it better just to leave it alone?

Alex: Probably leave it alone.

PI: Well, even if you didn't say anything else to her about it, would it help you in future interactions with people to hear how Jerry understood the conversation?

Alex: Probably. [I should] ask him, you know? Or why this kid blurted out, "No." Or why [Jerry] said, "Hey, I'll put you to work right now." (Interview, Alex, August 31, 2018)

Justin interpreted a lack of relatedness with coworkers in his internship in the ICU to be the result of his own lack of competence, preventing him from going to his department mentor for guidance. "I mostly go all over the place and will sometimes stress myself on figuring out what I need to do" (Personal reflection, September 23, 2018). During consultation with his mentor, Lindsay, ways of filling Justin's time were discussed as a way to improve his

motivation. Bridging the communication gap between Lindsay and Justin appeared to be very helpful for Justin:

We discussed the communication goal as the one that Justin really wanted to [continue to] work on. Talking to coworkers is anxiety provoking because Justin doesn't feel confident in his ability to determine when a conversation partner is available. So I told him that Lindsay had suggested it would help the department if he could sit with lonely patients. He seemed hesitant about this. "So, like going into their rooms? What would I talk to them about?" We talked about how he wouldn't have to worry the [patients] were too busy to talk, and they could request to have him sit with them, so he would know that he was wanted. He was excited about this. (Field notes, November 7, 2018)

## **Discussion**

### **Overview of Findings**

The intention of this action research project was to analyze the specific needs of interns with high functioning ASD (HFASD, without intellectual impairment) in the Project SEARCH program and to explore the potential role for occupational therapy within the Project SEARCH model. The perspectives of three interns with HFASD as they transitioned into full time competitive employment were examined. Specific program recommendations that may improve effectiveness of the Project SEARCH program for interns with HFASD were developed. Over the course of the six-month long project, over 60 separate data sources were analyzed, including program records, interviews with stakeholders and interns, and field notes and reflections from numerous observations, collaborative meetings, and intervention activities. Several important findings emerged through thematic analysis of the data.

- The needs of interns with HFASD in the Project SEARCH program were described as distinctly different from the needs of other interns in the program.
- Data from both the interns and the stakeholders indicated that the unique needs of interns with HFASD are not adequately addressed within the current structure of the Project SEARCH program.
- Occupational therapy interventions specifically aimed at addressing goodness of fit between the intern and their occupational context and improving self-determined behaviors of interns with HFASD were judged effective by participants in improving the outcomes of interns with HFASD.
- Data suggest that there may be a unique and valuable role for occupational therapy practitioners to play in providing direct intervention, consultation, and education on multiple levels within the Project SEARCH program in order to improve outcomes for interns with HFASD.

### **Distinctly Different: The Culture of HFASD**

Several significant strengths and challenges unique to interns with HFASD were identified early in the data collection process. As the study evolved and more specific examples of these strengths and challenges emerged, it was apparent that these strengths and weaknesses did not fit into a pure deficit-minded framework. Rather, the patterns of behavior noted in interns with HFASD seemed more accurately described as a cultural difference within this subgroup. Culture can be expressed by an individual through language or behaviors that are, “elicited and influenced by knowledge that is shared... between groups (Gupta, p. 4). Culture can be thought of as a “process that is learned, patterned, value-based and adaptive” (Bonder &

Martin, 2013, as cited in Gupta, 2016). Simply put, autism can be considered a culture based on a distinctive quality in language and behavior that is shared within the group.

The primary reason for this conclusion was the realization that the “core deficits” of interns with HFASD did not always result in functional impairment within the work setting. In fact, in some cases, these differences equipped the interns with exceptional capacity for the work they were performing. Stakeholders identified that interns with HFASD rarely had difficulty mastering the tasks associated with their internships or work positions. Stakeholders often reported that interns with HFASD mastered job-related tasks faster than neurotypical employees and performed their job tasks with equal or greater proficiency than their coworkers. Stakeholders observed that interns with HFASD were often talented in certain job roles, specifically due to aspects of their HFASD that allowed the interns to have exceptional skills. Stakeholders commented on the interns’ remarkable attention to detail, task completion, accuracy with technical work, and ability to follow policies and procedures without deviation. Some soft skills were also noted to be particular strengths, such as time management, dependability and objectivity.

Interns with autism also presented unique challenges in the workplace, due to their differences in social communication and thought patterns. Challenges in areas such as communication, self-awareness, and poor problem solving with tasks were often related to the same specific differences that led to the exceptional strengths in other aspects of work. Further, when interns with HFASD had expectations or values that were dramatically different from their mentors or coworkers, the interns experienced heightened anxiety, self-perceived inadequacy, and protective strategies that did not lead to a resolution of a challenge, such as masking feelings or rejecting help from skills trainers. Project SEARCH staff reported that interns with HFASD

required more support and instruction related to their behavior at work than support related to specific task mastery.

Neurodiversity, the idea that HFASD represents one end of a neurological spectrum of differences between humans, is a relatively new concept, and is somewhat controversial. The broadest interpretation of neurodiversity purports ASD is a natural human variation, discussion of which is beyond the scope of this project. However, the current, evolving literature seems to support the idea in a narrower scope that HFASD could be seen as a difference, rather than a disability (Jaarsma & Welin, 2012). Increasingly, the strengths of individuals with HFASD are being recognized as an asset in the workplace. The demand-side search for employees that can innovate and solve a host of 21<sup>st</sup> century problems has led to a revolution in how to recruit and retain the virtually untapped market of neurodiverse workers (Austin & Piasano, 2017; Booth, 2016; Nelson, 2018; Wallis, 2012). Whether or not HFASD is seen as a natural evolution of neurological development, neurodiversity has come to the forefront as a way to promote equality for individuals with HFASD. In that respect, neurodiversity remains valid as an irrefutable issue of disability rights (Jaarsma & Welin, 2012). As many stakeholders echoed within the data, neurodiversity can be utilized to address prejudices in society, and change our societal impression of what is “normal” and what should be “corrected.”

One of the challenges clearly expressed in the data was the increased anxiety experienced by interns with HFASD. All three of the interns in the study exhibited internalizing symptoms and increased anxiety as they transitioned into employment. Two of the interns required outside intervention to treat their symptoms of anxiety during their time in Project SEARCH. Studies have documented the increased incidence of depression and anxiety in individuals with HFASD (Baldwin, Costley, & Warren, 2014; Duncan & Bishop, 2015; Ghaziuddin et al., 2002; Sterling

et al., 2008). Jaarsma and Welin (2012) go on to propose that much of the comorbid anxiety and depression within the HFASD population may be the result of extremely negative experiences, rather than a part of the HFASD condition, itself; similar to the experiences that have been reported by other marginalized populations, such as person who are homosexual.

Jaarsma & Welin conclude that, although autistic people do not share a common origin or history, they do share specific behavioral traits that distinguish them as a group. An earlier article provides some evidence to this effect, by explaining the unique behaviors and thought processes shared by individuals with HFASD as a product of the proposed theoretical foundations for their “core deficits” (Ochs, Kremer-Sadlik, Sirota, & Solomon, 2004). In a series of experiments, Ochs and colleagues take an anthropological stance to autism, and describe how communication patterns may be related to concepts of theory of mind, low central coherence, executive function differences, and cultural indexicality. For example, the authors propose that low central coherence or, the ability to get the “big picture” from a set of details, may give an individual with autism exceptional attention to detail and affinity towards accuracy. In social interactions, however, low central coherence can make it difficult for the individual to attend to and integrate contextual details that imply specific meaning or expectations of culturally normed behavior. The authors claim that this may account for an individual’s tendency to get “stuck” in idiosyncratic associations. Ochs and colleagues go on to state that, since all humans learn how to interpret contextual cues over time in the context of spontaneous interactions in daily life, drilled imitation techniques may actually serve as a barrier to the individual with HFASD interpreting the context of a given interaction as both shaped and renewed by the interchange itself. While each of these specific issues can create problematic social interactions, re-framing them as a cultural barrier can contribute more effectively to solving communication breakdown through

increased societal understanding and acceptance. For this reason, viewing HFASD as a cultural difference seems a more feasible strategy than is attempting to train interns with HFASD to utilize the social communication strategies that have become the majority's cultural norms.

### **Bridging the Cultural Divide**

Personal accounts from interns and stakeholders highlight the differences in the thought patterns, values, and expectations of interns with HFASD compared to their neurotypical counterparts in the workplace. Interns expressed confusion when presented with contradicting body language and verbal communication from peers. They often described values and expectations based in rule-bound logic systems that were valid in some circumstances but could not be generalized to every situation. For example, one intern reported dissatisfaction with his previous job because the owner of the restaurant had conducted his interview but was never in the restaurant, leaving the operational responsibilities to his managers. All of the interns with HFASD in the study had difficulty with subjective standards for their work performance and repeatedly commented that certain supervisors treated them unfairly, even though the supervisor may have simply had a slightly different definition of "clean," or may have assigned an extra task if the intern had completed all of their work for the day. In her book, *Autism Equality in the Workplace*, Janine Booth reports a multitude of personal accounts from adults with HFASD facing similar struggles at work (2016). She articulates the communication breakdown this way:

Autistic workers may struggle to ask for help or information, fearing they will be misunderstood or ridiculed. Mistakes may follow. Alternatively, the autistic worker, keen to get everything absolutely right, may ask no end of questions and be judged. (p. 38).

Both of the behavioral patterns Booth refers to were observed repeatedly in the three cases involved in this study. However, interns with HFASD were far more likely to self-advocate or ask questions of their support staff in Project SEARCH than to seek clarification from their direct supervisors. This made transition to full-time employment difficult, as managers often noticed the tendencies for the intern to internalize their questions or insecurities, but lacked the rapport or the skill to do much about it. Other managers seemed oblivious to the struggles the intern might be having, perceiving the improvement in “nodding and smiling” or other masking behaviors as a sign the intern was acclimating well to their work environment. Additionally, interns with HFASD were much more likely to attempt to resolve confusing situations or express discomfort or dissatisfaction when they viewed themselves as “interns” and not as “employees.” This also made supporting their transition after graduation difficult for the Project SEARCH staff.

Conversely, coworkers and supervisors, and even skills trainers, expressed positive regard or acceptance for interns that demonstrated social niceties commonly valued within cultural norms, such as greetings, small talk, and polite words and gestures. When interns failed to use these superfluous forms of communication, coworkers began to wonder what was “wrong” with the intern, creating a form of social disconnectedness between coworkers and interns. These forms of communication seemed largely artificial or “dishonest” to interns, but they largely adapted to the expectation by creating rules around when and how to produce these social expectations with coworkers in order to be accepted by their peers. Mentors, supervisors and coworkers were noted to advocate for interns with HFASD and supported their ability to learn explicit rules about social expectations in the work environment by acting as interpreters, bridging a gap between the intern and other workers in the department. Stakeholders sometimes

referred to the “language” of interns with HFASD, indicating their perception of sociocultural difference rather than a set of skill deficits. Interpreting behaviors included finding solutions to overwhelming environments, intuitively assisting the intern with solving a problem they had not yet articulated, and explicitly stating someone’s thought process or perspective to eliminate confusion resulting from the intern’s difficulty in reading the individual’s body language. Interpreters also voiced explicitly stating “hidden” social rules for the intern. Some coworkers could even demonstrate and debrief on these social rules in the context of daily work, such as pointing out their own mistakes, or calling attention to a specific expectation for greetings.

In addition to articulating implicit social rules to interns with HFASD, stakeholders commented on their efforts to interpret the actions of interns for coworkers who did not clearly understand the intern’s intention. Both skills trainers and mentors were noted to advocate for interns with HFASD by articulating the meaning behind the intern’s actions within the intern’s own logic and understanding of social structure in order to improve the intern’s social capital within the workplace. This finding supports the outcomes reported in Giarelli and colleagues’ (2013) work, who also noted the benefits of the specific mentorship interns with ASD received in the workplace. Further, the findings in this study highlight a well-articulated relationship between perceived acceptance and increased satisfaction and work performance, which is echoed in the study by Giarelli and colleagues, who also found acceptance to be a primary factor in workplace success (2013). In the early stages of the project, it seemed that interns with HFASD who had the benefit of coworkers and mentors who understood how to advocate for them did so by virtue of serendipity. Three of the mentors who supervised Project SEARCH interns had spent time with close relatives who were also on the spectrum, which enhanced their abilities to interact with the intern and bridge cultural differences between the intern and coworkers.

## **Goodness of Fit**

Comments related to goodness of fit were a primary theme in the data, including comments regarding factors that contribute to goodness of fit. Two main themes were identified that described these contributing factors: intrinsic factors (characteristics specific to the intern with HFASD) and extrinsic factors (characteristics of the built, social, cultural, and temporal environment). Combined, these three themes represented more than half of all coded data, with extrinsic factors as the most prevalent theme.

Within the theme of extrinsic factors, issues related to social and cultural context were most frequently mentioned, particularly in data sourced from interns and department supervisors. Conversely, comments related to goodness of fit from Project SEARCH staff were primarily in reference to the match between the intern's skill set and the task demands of the internship. As Project SEARCH staff participated in occupational therapy interventions, their comments started to reflect more conscious awareness of environmental impact on interns' performance.

**Job satisfaction.** Within the theme of goodness of fit, two subthemes emerged that reflected potential outcomes of goodness of fit. Job satisfaction was identified as an indicator of the intern's perception of goodness of fit, while valued added to the workplace was identified as an indicator of the supervisor or hiring manager's impression of goodness of fit. Interns commented on work satisfaction in relation to how they felt in the context of the work environment (person-environment fit) much more frequently than how well they felt they could perform the tasks (person-task fit). In fact, the interns as a group seemed to have low self-awareness of their strengths in the work setting and made many more negative than positive statements about their ability to do the work. One of the interns expressed low job satisfaction related in part to the physical and sensory elements of her position in the dish room of a hospital.

However, her low job satisfaction was also related to her lack of social interaction and difficulty interpreting the expectations of her supervisors. The other two interns in the study associated low job satisfaction primarily with poor fit within the sociocultural context of the work setting. For example, one intern reported feeling miserable at work because he perceived that the managers could “make up their own rules,” and they gave him demeaning tasks. Another intern expressed intense anxiety from interpersonal conflict with a manager he felt picked on him. Though supervisors rarely complained to Project SEARCH staff regarding work performance issues for any of the interns with HFASD during the study, interns with HFASD expressed a lower perceived level of competence at work when they were dissatisfied with the job and seemed to attribute this to their own deficits. Alternatively, stakeholder comments described interns as exhibiting more confidence and initiative in social interactions and work responsibilities when they felt socially comfortable in their work environment.

These findings affirm the results of recent studies that examine environmental factors in creating goodness of fit for adults with HFASD in the workplace. Both physical and social elements of person-environment fit have been found to influence job satisfaction for adults with ASD in the literature. A study by Pfeiffer, Braun, Kinnealey, Matczaka, & Polatajko (2017) used phenomenology to examine perceptions of individuals with ASD regarding facilitators and barriers to work performance and work satisfaction. The authors uncovered two key themes, each with related facilitating and impeding factors: environmental factors and person-fit characteristics. Sensory aspects of the environment were identified as a major consideration of environmental fit, while person-fit was defined as factors related to how well the individual’s specific skills, interests, and abilities matched the demands of the job. The authors conclude that both elements are central to finding goodness of fit.

A subsequent study by Pfeiffer, Brusilovskiy, Davidson, and Persch (2018) further examined person-environment fit issues in job satisfaction for individuals with ASD. This article emphasized the specific ways in which person-environment fit characteristics might impact the employee with ASD, depending on the individual presentation of ASD symptoms. Specific analysis around sensory differences yielded significant correlations between sensory avoidance characteristics and physical discomfort at work, while individuals with low sensory registration characteristics were more likely to have lower levels of physical discomfort at work. Sensory avoiding individuals reported less overall job satisfaction than respondents without sensory sensitivity. In addition, the authors reported positive associations between person-environment fit and social context aspects of work, such as peer cohesion and perceived supervisor support.

**Value added.** Supervisors, mentors, and skills trainers often expressed goodness of fit in terms of the value the intern added to the workplace. In general, perceiving that the intern added value to the workplace was primarily related to the goodness of fit between the intern's skill set and the demands of the job. Although the program coordinator and skills trainers were receptive to feedback from departments about whether or not the intern was well-suited to the work they had been assigned, they had difficulty coming up with solutions to behavioral or communication issues. Initially, comments from supervisors indicated they were more likely to perceive behavioral differences as a result of lack of motivation for the work, as opposed to a challenging issue in the work environment.

Goodness of fit concepts are considered a critical component in the Project SEARCH model, but were primarily considered related to person-task fit by stakeholders in this study. The Vocational Fit Assessment (VFA) is an assessment tool developed by occupational therapists utilizing a Person, Environment, Occupation framework that assists Project SEARCH staff in

identifying internships or work positions for which the intern might be well-matched (Persch, Gugiu, Onate, & Cleary, 2015). A 2015 mixed-methods study using the VFA examined the job matching preferences of professionals in the Project SEARCH program (Persch, Cleary, Rutkowski, Malone, Darragh, & Case-Smith, 2015). Though participants saw job matching as having positive effects on work performance, few sites were accessing a standardized tool to assist with systematic job matching procedures. Further, defining a “good match” seemed subjective and inconsistent across participants. Only a few key stakeholders acknowledged the greater societal benefits of effective job matching. This study highlighted the need for additional job matching instruction, training, and concept formation among Project SEARCH programs. A tool such as the VFA could be extremely useful for engaging interns with HFASD and skills trainers in examining the intern’s needs for goodness of fit between the intern’s strengths and the specific work tasks involved for positions the interns are interested in. However, the VFA does not concentrate heavily on environmental characteristics of the work context, which may necessitate further ecological evaluation of potential work opportunities. At the time of this study, the VFA was not used consistently across any Project SEARCH sites in the state. When skills trainers attempted to address goodness of fit issues, they reported addressing behavioral concerns that did not fit with cultural norms by addressing them as a skill deficit to correct with the intern, rather than modifying the environment or training staff to reduce communication and social barriers.

After the Implementation phase of this study, which included specific training content on contextual factors and goodness of fit, skills trainers and supervisors articulated more awareness of environmental factors that influenced the intern’s productivity and behavior. Even though supervisors reported goodness of fit in terms of person-task fit, when behavioral issues arose,

supervisors perceived the intern was “not a good fit,” even when the behavioral issue was not related to the task demands of the position. Occupational therapy consultation within internship sites facilitated supervisor understanding of person-environment fit factors that may influence motivation, task performance, and soft skills, such as task completion or attention to task.

### **Self-Determination**

A critical component to the successful transition into employment for Project SEARCH centers around independence on the job site. Independence in competitive, community-based work is the cornerstone of the Project SEARCH program. Yet, this transition can be a giant leap for interns accustomed to close support and supervision who suddenly begin receiving only periodic check-ins. The national agenda for the organization announced its move towards facilitating “aspirational development” for its interns; a raised bar in terms of not only getting interns placed into competitive jobs, but high quality jobs that the intern desires to sustain (E. Rheile, personal communication, July 31, 2018). Thus, transitioning successfully into a follow-along level of support after graduation was a main objective for the inclusion of occupational therapy services for interns with HFASD. In order for the intern to make the transition to independent work with occasional supervision and support, interns with HFASD needed to feel competent with their tasks, accepted in their work environment, and capable of self-advocacy. Throughout the data, comments related to the innate psychological needs of autonomy (a sense of freedom), perceived competence (feeling effective), and relatedness (feeling belonging or acceptance) emerged as an over-arching way to describe the intern’s experiences and how they impacted the intern’s ability to thrive in the workplace (Ryan & Deci, 2000).

Thriving in the workplace was recognized to be of particular importance for interns with HFASD after the first phase of data analysis. A primary barrier identified in the data by

stakeholders was the lack of motivation interns with HFASD associate with money. Repeatedly, Project SEARCH and vocational counselors reported interns' lack of interest in hours of work or pay, making it difficult for interns with HFASD to tolerate undesirable aspects of the position in order to receive a paycheck. Interns also expressed prioritizing enjoyment or interest in the work tasks, comfort in the work environment, and feeling socially accepted at work as the primary motivations for working. Interns rarely made decisions about taking or keeping a position based on the rate of pay or number or work hours available. Rather, their choices were based on whether or not they felt goodness of fit within the context of the work. As a result, traditional external behavioral reward systems and supports were perceived by interns with autism as demeaning, and ultimately weren't independently used or carried over by the department or the intern if the skills trainer was not present. In some cases, the interns refused to use supports suggested by the coordinator or skills trainer, fearing they would stand out from their peers. This prompted a need for understanding goodness of fit from the intern's perspective in order to effectively build intrinsic motivation for the work itself.

Much has been written about Self-Determination Theory (SDT) and its importance for success in all facets of life, including work. A Dutch study in 2010 sought to validate the *Work-related Basic Need Satisfaction Scale*, an assessment tool aimed at measuring how psychological needs are met in the workplace (Van den Broeck, Vansteenkiste, De Witte, Sorens, & Lens). The authors found job satisfaction to be positively correlated with each of the three psychological needs for self-determined behavior: autonomy, perceived competence, and relatedness. Further, exhaustion was negatively correlated with all three needs. Finally, the authors found that relatedness at work was positively correlated with life satisfaction. Though this study focused on the general population, the finding that increased relatedness led to higher

life satisfaction is particularly interesting when considering workers with autism. Relatedness at work is especially important for individuals with autism, as they are more likely to have decreased connectedness in their community and may view work as their primary social outlet (Renty & Royers, 2006; Sterling et al., 2008).

Several researchers have focused specifically on building self-determination in individuals with autism. A study by Chou and colleagues (2013) compared components of self-determined behavior between individuals with ASD, individuals with intellectual disability (ID), and individuals with learning disability (LD; Chou, Palmer, Wehmeyer, & Lee). The authors found that individuals with ASD demonstrated the least amount of autonomy compared to the other two groups and that individuals with ASD scored lower in self-regulation, psychological empowerment, and self-realization than individuals with LD (Chou et al.). In 2010, the Division on Autism and Developmental Disabilities published an article as a precursor to a text on research-based educational principles related to SDT for students with autism, articulating that adolescents with autism lack goal directed behavior, interpersonal skills, and problem solving skills, primarily from lack of contextualized experience (Wehmeyer, Shogren, Zager, Smith & Simpson). Wehmeyer and colleagues suggest that individuals with autism have the capacity to learn self-determined behavior when they are supported to do so, but that it requires a shift towards internal motivation. The authors propose a social-ecological model for self-determination development that focuses supports and interventions on facilitating self-direction through environmental changes, rather than teaching specific skills (2010).

In 2015, the Functional Theory of Self-Determination was updated as the Causal Agency Theory, which expands on the work of Wehmeyer and colleagues and envelops ideas from the field of positive psychology (Shogren et al., 2015). Causal Agency Theory is embedded in

*doing*; that is, the focus is on the action of making choices and causing change in one's own situation. This has particular relevance for this project, as the aim of our interventions were to promote job satisfaction and motivation for work through the work itself. Shogren and colleagues propose that, as individuals act as causal agents in their own lives, they learn from those experiences. This then influences their beliefs, ultimately contributing to increased autonomy, perceived competence, and relatedness.

### **Occupational Therapy and SDT in Project SEARCH**

Causal Agency Theory suggests that individuals with autism could experience greater personal causation by acting in self-determined ways, thereby increasing their perception of goodness of fit in their work environment. This cycle would self-perpetuate and lead to thriving at work. Indeed, information collected from interns and stakeholders seems to support this theory. For example, when Justin voiced concern that he was stressed because he wasn't given a scheduled break, the occupational therapist coached the skills trainer to allow Justin to schedule his own breaks as they fit into his day and to use his own discretion about break length and choice of break activity. Justin kept a log of how he felt before and after his break, how long the break was, and the kinds of break activities he engaged in, so that he could make adjustments to his break schedule and activities that helped him feel more comfortable at work. This was a complete departure from a traditional behavioral skills training strategy, which may have involved pre-scheduled breaks with parameters about what would be "appropriate" for him to do. The freedom to choose allowed Justin to practice autonomy, learn from natural consequences, and adopt the patterns of activity that his peers were engaging in. This led to improved perceived competence and relatedness. After the intervention, the coordinator and skills trainer remarked on the increased initiation and problem solving skills Justin exhibited.

Thus, autonomy support in the context of work activities was a primary focus for direct, consultative, and educational services implemented during the intervention. Project SEARCH skills trainers and department supervisors both commented on increased job performance when interns felt they had increased autonomy and perceived competence. In turn, this seemed to help the intern feel as equally valued as were their work peers, increasing perceived competence and relatedness. In response to feedback and collaboration with stakeholders about their specific needs, training sessions were held for multiple stakeholder groups, including parents, Project SEARCH skills trainers for the state, vocational counselors, and departmental supervisors. All of the training sessions were designed to highlight cultural awareness of autism, goodness of fit in the environment, and how to support self-determined actions, such as goal setting, making a plan, evaluating one's performance, or making a decision based on preferences.

For the Project SEARCH staff, the treatment strategies used by the occupational therapist represented a significant paradigm shift and a departure from the traditional developmental model of scaffolding skills commonly used with other interns. Since the occupational therapist was frequently engaged with the three interns and their support staff in this study through direct intervention, consultation, and formal trainings, the local staff exhibited greater understanding and support for the strategies than Project SEARCH staff who only received the training. Data from post-intervention analysis seemed to indicate that the training alone was insufficient for implementing a change in instruction strategies for interns with ASD.

Historically, Project SEARCH has adopted a more behaviorally-based model of intervention for interns with ASD that focuses on skill acquisition and reduction of “inappropriate behavior.” Several sites have piloted a structured teaching curriculum, while others have incorporated applied behavioral analysis consulting and intervention into the Project

SEARCH model to promote success with interns with ASD (Wehman et al., 2013; Wehman et al., 2014). However, these strategies may not be successful in assisting interns with HFASD to maintain gainful employment that fits their interests and capacities over time, particularly if they are capable of attaining work above an entry-level position. Interns who participated in this study commented frequently on the need to feel valued and equal in the workplace, and were able to express an improvement in their basic psychological needs when they were given opportunities to act on their own internal motivations. Utilizing supports that facilitate personal causation are not only effective, but they are also culturally sensitive. This approach honors the desires of individuals with HFASD as human beings, recognizing that many of their goals are no different than those of their neurotypical peers.

### **Role of Occupational Therapy**

Throughout the course of this action research project, a role for occupational therapy was demonstrated at a variety of levels, including program support and education, advocacy, consultation, and direct client intervention. In actuality, the occupational therapist's role during this project was two-fold; to address the needs of the interns with HFASD effectively, but also to consider the Project SEARCH program site as a client. Affecting change within a large system of care that requires a fundamental change in perspective is a long-term undertaking that is best built on understanding the unique perspectives of all stakeholders. The action research format of this project allowed the investigator to systematically evaluate the system of care and address goodness of fit with the program's format and the intern's specific needs.

During the action research process, the initiatives and goals of the Project SEARCH program were also important, since they are the viable vehicle through which interns will access services. The investigator employed the Person Environment Occupational Performance (PEOP)

Model (Baum, Christiansen, & Bass-Haugen, 2015) to evaluate the match between the consumer and the program, and to engage the program in implementing an intervention strategy that required a shift in their instructional strategy. At the individual level, the primary focus was on consultation with the work supervisor and skills trainer, although specific intervention was provided at times to the intern, if needed. The support provided to Project SEARCH in this capacity was aimed at providing skilled integration of information for the purposes of occupational analysis, and recommending strategies for addressing problems, identifying skill deficits, and instructing on evidence-based practices to meet the needs of the intern. For the purposes of this project, both roles were equally important and valuable, particularly since there is not a formal role for occupational therapy within the Project SEARCH model at this time.

### **Recommendations for Future Directions**

Based on the findings from this project, the following are recommendations for Project SEARCH to consider as they serve individuals with HFASD.

- Continue to develop autism awareness training for Project SEARCH and host site staff that specifically focuses on autism as a cultural difference.
- Embed autism awareness training into onboarding orientation information for all Project SEARCH staff and host sites.
- Consider offering autism cultural awareness training to community business through Business Advisory Councils.
- Adopt the VFA as a standard assessment tool to implement during the initial orientation and training phase of the program in order to have a standard process for assessing goodness of fit that can be utilized for collaborative goal development with the intern and goal-directed internship placement.

- Incorporate additional questionnaires and checklists that specifically target sensory preferences, interests, and special skills or attributes for interns with HFASD into assessment protocols in order to promote autonomy in internship and job selection.
- Advocate for adaptations and accommodations to the hiring and onboarding processes at host sites that specifically support the needs of individuals with HFASD.
- Facilitate autonomy support through the transition to work by creating specific training activities centered on decision making, goal setting, job hunting and application, and interviewing. Involve interns with HFASD in every step of this process.
- Consider adopting a modification of the Project SEARCH model for interns with HFASD that utilizes Causal Agency Theory or principles of self-determination, particularly in occupation-based ways, such as in goal setting or self-evaluation of progress.
- Explore additional funding streams to secure consistent, regular support from an occupational therapist in order to address issues related to environmental accommodation, consultation and advocacy with stakeholders, and direct intervention as needed.

### **Conclusion and Future Implications for Research**

The findings from this action research project indicate that interns with HFASD can be successful in attaining meaningful employment by participating in the Project SEARCH program, with the addition of specific interventions and supports that foster occupation-based autonomy and sociocultural support. Mentorship from coworkers was found to be extremely beneficial, however, ongoing on-site support from skills trainers was less well-received by graduates of the program with HFASD. Stakeholders from a variety of system structures benefitted from enhanced training targeting the cultural differences in HFASD, as well as

consultative support from an occupational therapist in addressing issues related to person-environment fit and autonomy support.

Presenting autism as a cultural difference was an extremely useful tool in educating stakeholders on common traits in HFASD, and productive strategies for environmental modifications to mitigate potential communication breakdown or differences in behavioral expectations. Stakeholders reported a paradigm shift in their understanding of autism, and after specific training and consultation in a culturally sensitive framework, the Project SEARCH staff were better able to recognize cultural bias in themselves and others, and establish communication with departments that more effectively allowed them to influence cultural expectations in the department.

### **Limitations**

While this study provides a wealth of data specific to the participating Project SEARCH site, the results may not be generalizable to Project SEARCH as a whole or to other employment training programs because of its specificity and few number of intern participants. Additionally, the study was limited by time constraints that made it unfeasible to adequately assess outcomes related to the trainings implemented in the intervention phase. If the project were to continue, effort towards streamlining and embedding autism specific training into the host site orientation process and systematically implementing the VFA assessment along with an ecological measure would be strongly recommended.

### **Future Research**

Project SEARCH is a viable employment training solution that has the capacity for program enhancements aimed specifically to meet the needs of individuals with HFASD, in promoting their self-determined behavior while creating a more accepting workplace culture.

Further research is needed in examining the VFA as an effective goodness of fit placement tool for evaluating person-environment fit. Further research is also needed in describing self-determination in individuals with autism, and how they might benefit from autonomy support or specific instruction in goal setting or self-monitoring in the work environment.

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## Appendix A

### *Study Activities Timeline*

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Reflection	4/23/18	All	Reflection	Discovery	Meeting with National Leadership
Cassie	5/7/18	Cassie	Field Note	Discovery	Laundry observation
Reflection	5/7/18	Cassie/ All	Reflection	Expanded Understanding	Jane and Kay conversation
Reflection	5/15/18	All interns	Reflection	Discovery	Consult Jane and Kay
Reflection	5/29/18	*Cassie	Reflection	Discovery	Consult with Jane
Jane/Mary	5/30/18	Mary	Field Note	Discovery	Observation Jane with Mary
Chris	5/30/18	Mary	Interview	Discovery	Interview Chris
Alex	6/13/18	Alex	Field Note/ Interview	Discovery	Observe Alex in central supply/ Interview
Alex	6/13/18	Alex	Records	Discovery	Chart Review Alex
Mary	6/13/18	Mary	Records	Discovery	Chart review Mary
Reflection	6/13/18	Alex	Reflection	Discovery	Reflection on observation Alex
Kay	6/15/18	Mary	Interview	Expanded Understanding	Interview Kay

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Reflection	6/15/18	Mary	Reflection	Expanded Understanding	Reflection interview Kay
Reflection	6/16/18	Alex	Reflection	Expanded Understanding	Reflection interview with John
John	6/18/18	Alex	Interview	Expanded Understanding	Interview John
Reflection	6/25/18	All	Reflection	Expanded Understanding	Reflection conversation with Jane
Mary	6/27/18	Mary	Field Note	Discovery	Observation Mary
Reflection	6/27/18	All	Reflection	Expanded Understanding	Phone meeting Erica
Reflection	6/27/18	All	Reflection	Expanded Understanding	VFA training with Jane
Mary	7/13/18	Mary	Field Note	Discovery	Observation Mary in Nutrition
Jane	7/13/18	All	Interview	Expanded Understanding	Interview Jane
Reflection	8/4/18	All	Reflection	Expanded Understanding	PS Training Modules
Reflection	8/15/18	All	Reflection	Expanded Understanding	Reflection Laude Presentation
Jane	8/22/18	All	Field Note/Reflection	Discovery	Reflection on conversation with Jane
Mary	8/22/18	Mary	Interview	Discovery	Interview Mary

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Reflection	8/22/18	Mary	Reflection	Expanded Understanding	Reflection interview with Mary
Stakeholders	8/29/18	All	Field note	Expanded Understanding	Steering committee field notes
John	8/29/18	Alex	Interview	Expanded Understanding	Conversation with John
Alex	8/31/18	Alex	Interview	Discovery	Interview Alex
Reflection	8/31/18	Alex	Reflection	Discovery	Reflection interview with Alex
Justin	9/12/18	Justin	Field Note	Discovery	Observation Justin ICU
Dory/Jerry	9/12/18	Alex	Interview	Expanded Understanding	Interview Dory and Jerry
Reflection	9/12/18	Justin	Reflection	Discovery	Reflection conversation with Jane
Reflection	9/12/18	Alex	Reflection	Expanded Understanding	Reflection interview Dory and Jerry
Justin	9/18/18	Justin	Field Note	Discovery	Observation 2 Justin ICU
Analysis	9/12/18 to 9/19/18	All	Analysis of early data	Planning	Thematic coding and strategic planning meeting prep

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Stakeholders	9/19/18	All	Field Note/Reflection	Planning	Steering committee strategic plan mtg
Mary	9/19/18	Mary	Interview	Expanded Understanding	Interview Mary
Cory	9/25/18	Mary	Interview	Expanded Understanding	Interview Cory
Reflection	9/25/18	Mary	Reflection	Expanded Understanding	Reflection interview with Cory
Justin	10/3/18	Justin	Interview	Discovery	Interview with Justin
Reflection	10/3/18	Justin	Reflection	Discovery	Reflection Justin Interview
Chris	10/17/18	Justin	Interview	Expanded Understanding	Interview Chris
Reflection	10/17/18	Justin	Reflection	Expanded Understanding	Reflection interview with Chris
Reflection	10/15/18	All	Reflection	Implement	Presentation to parents
Justin	10/17/18	Justin	Field Note/Reflection	Implement	Reflection Justin Employment Planning Meeting (EPM)
Reflection	10/17/18	All	Reflection	Implement	Reflection EPM
Intervention	10/19/18	All	Intervention	Implement	Training for ACCESS Staff

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Jane	10/29/18	All	Interview	Discovery 2	Interview with Jane
Reflection	10/29/18	All	Reflection	Discovery 2	Reflection interview with Jane
Intervention	10/30/18	All	Intervention	Implement	Training for Arkansas Rehab Services Office
Jane/Chris	10/31/18	Justin	Field Note/Reflection	Discovery 2	Conversation with Jane on Justin
Mary	10/31/18	Mary	Field Note/Reflection	Discovery 2	Reflection on Mary in Nutrition
Lindsay	10/31/18	Justin	Interview	Expanded Understanding	Interview with Lindsay re Justin
PS Staff	10/31/18	All	interview/reflection	Discovery 2	Training debrief with PS staff
Reflection	11/1/18		Reflection	Discovery	Personal bias reflection
Kay	11/1/18	All	Reflection	Implement	Consultation with Kay
Stakeholders	11/7/18	All	Field Note/Reflection	Discovery 2	Reflection post-supervisor training
Justin	11/7/18	Justin	Field Notes	Discovery 2	Intervention observation Justin

<b>Participant</b>	<b>Date</b>	<b>Case</b>	<b>Data Type</b>	<b>Phase</b>	<b>Description</b>
Justin	11/7/18	Justin	Field Notes	Discovery 2	Observation Justin sterile supply
Justin	11/7/18	Justin	Field Notes	Discovery 2	Conversation with Justin
Justin	11/7/18	Justin	Interview	Discovery 2	Interview with Justin post - intervention
Justin	9/4/18 to 10/31/18	Justin	Records	Discovery -- Discovery 2	Records of journal prompts: Justin
Analysis	11/7/18 to 11/19/18	All	Analysis	Analysis	Analyze all sources of data

*Note.* The first case in the timeline was a consented participant who was not able to participate in the interview process due to expressive language difficulty. Reflections and observations of her experiences were included in the data analysis, but she did not participate as a case study.

## Appendix B

### *Researcher's Statement on Personal Bias*

As I begin to make sense of the data I have collected throughout this project, I feel it's important to pause and reflect on my own life experiences and knowledge, and how those influence my perspectives on the analysis I will perform. I have been thinking about this for some time, and reflecting on my bias in the area of transitions and autism is multifaceted, and very personal for me. In some ways, I think many of my personal and professional experiences have led me to this project; a culmination of my own emotions and thought processes as I have journeyed through autism personally and professionally.

My career in occupational therapy began as the result of an internship course I took as an undergraduate student in psychology. I was assigned as a classroom aide in the Challenges program, a self-contained classroom for children with ASD that was part of the Babyfold, a private school and child welfare agency that served foster children and children with emotional, behavioral, or intellectual disabilities. The Challenges program developed out of a need to serve children who could not be served in their home school districts. Some of them would travel as far as 90 minutes one way on a school bus every day to participate in the program. One of the students in my classroom was a girl named "Ellie". Ellie was one of these children that had to travel a distance. She came in every day looking like the Tasmanian devil, crying and disheveled, with this wild hair she wouldn't allow anyone to touch.

There was an occupational therapist who consulted with the school that would come into the Challenges room once a week. I watched her closely as she worked with Ellie. I knew there was something distinctly different she did with her that helped Ellie feel calm and secure. I was intrigued. Barb, the occupational therapist started leaving me little projects and programs to do

with Ellie, many of them geared towards sensory processing and communication. By the end of the semester, Ellie was not only calm and happy when she came in, we were French braiding her hair every morning! I was sold. I would be an occupational therapist.

This experience was my first taste of what effective occupational therapy could look like. Barb was not a direct therapist in the school, but she was an excellent consultant; she could evaluate her students' needs quickly and accurately, and she knew how to get the teachers and aides to buy in to what she wanted them to try. She respected them as professionals in their own right, acting as a problem-solver or collaborator.

While in graduate school, I worked as an applied behavioral analysis (ABA) line therapist part time for St. Louis Special School District. My "client" was a five-year-old with ASD. When I first started working with him, he was not toilet trained, and nonverbal. Our consultant from the Center for Autism and Related Disorders trained our team in how to implement discrete trials, observed our sessions to make sure we were consistent, and coached our techniques. I was amazed at how rapidly my client would gain skills, but I always wondered how he would use them in the "real world." I talked our team leader into using ABA strategies outside of his bedroom, such as taking walks through the park to work on color recognition, or breaking down toilet training into steps we could reward. We worked with his school-based occupational therapist for the toileting program, and I began to see the benefit of occupation based behavioral training.

After graduation, my first job was in a residential school for children with ASD and comorbid ID or mental health diagnoses. All of the children at the school were there because no one else could help them. I distinctly remember one mother breaking down in sobs at the transition meeting when she placed her 10 year old son. I went up to her to reassure her, and she

told me I didn't understand... that she wasn't upset, she was crying tears of joy. She was going home to unbolt all of her furniture from the floor. She had to secure it to the floorboards to prevent her son from throwing it at them. It was then I understood that I didn't know anything. I had no idea what that life must be like.

But it wasn't too long after that, I did know.

My first born son, Sean, was born in 2005. I was working full time in private practice as an early intervention therapist, and I had more clients than I could possibly see. I worked long hours, while my husband was also running his own business. Sean was a difficult baby from the day we brought him home. No one could console him, he would only calm when I held him. He had "colic" for several months, and never took a bottle. He dealt with chronic constipation and was never content. After trying two daycares and leaving work daily to nurse him every day, I finally gave up and hired my sister to stay at home with him. I gave him the Infant Toddler Sensory Profile before he was six months old, thinking there must be something I could do to help him. He came apart every time someone flipped on a light or ran the vacuum cleaner.

Once he was a little older, I remember he used to sit and watch cars out our front window for long periods of time. When most babies would cry for mommy when she was out of sight, Sean was content to sit on his blanket and stare out the window. He rarely played with toys, and sometimes gagged just touching them. Once, we stayed home from church because he was cutting teeth and had a fever, and to quiet him I found *Thomas the Tank Engine* on TV and sat with him on the couch. He was mesmerized. When he started talking, Sean could recite entire episodes of Thomas, but couldn't ask me for a drink. I took him to the doctor three times, concerned. The doctor blew me off, telling me I was "over therapizing" him. We ended up

moving to another town, and at the first well-child check, the doctor gave us an MCHAT, which he failed.

We were referred to Easter Seals for evaluation immediately. Sean was diagnosed with severe autism, a sleep disorder, and a feeding disorder at 32 months. I remember the day we met with the developmental pediatrician. He started by spouting 10 or so names of famous people he purported had and ASD and were successful... Albert Einstein... Tiger Woods... "it's not a death sentence," he said. All I could think about was how we would manage the therapy and the expenses, as I held my second son in my arms, who was only six months old. Would they ever be "real" brothers? Would they both have ASD? That night, my husband and I held each other on the couch, and cried, saying nothing. And then we made a pact: that would be the last time we would ever cry about autism.

Having Sean might have been the best thing that ever happened to my career. I learned more from raising him than I could ever learn from a textbook or a seminar. I began to understand his special talents, and learn who he is. We decided against ABA, after a developmental therapist we were working with became trained in Floortime. Eventually, I became trained, as well. Sean went from being nearly catatonic to an amazing, funny, highly intelligent and creative little boy. It wasn't overnight, but gradually, he felt better. We figured out how to communicate with him. He knows how much we love him. He was lucky enough to have some incredible teachers and therapists. He also had a very good doctor who paid attention to all of the GI issues he was having. But, none of that would have ever happened if we hadn't advocated for him, surrounded ourselves with professionals who understood him, took him halfway across the country to a doctor who would listen. I have always been his advocate, and I will be, until he is able to advocate for himself.

When Sean was around seven years old, we had friends who lived around the corner from us who had a 19-year-old son with ASD. He was very “high functioning” and liked many of the same things Sean did. He really took to my husband, and they would spend a great deal of time talking. They even played guitar together. “Jay” considered my husband a mentor, and when he had a girlfriend in high school, it was my husband that Jay wanted to talk to about it. Jeff got Jay his first full time summer job at the local Easter Seals camp, which he loved. The summer after his senior year of high school, Jay stayed behind to live at home and go to the community college. His girlfriend left for nursing school in Chicago. Six weeks after she left, Jay got a call from his girlfriend, she was breaking up with him.

None of us were surprised, but Jay was devastated. He quit coming by. He sank into depression. His parents took him to a psychiatrist, and he started medication. One day, Jeff received three calls from Jay while he was at work. He called back but didn’t get him... then a call from Jay’s mother. Jay was on life support in the ICU. He had strangled himself. My husband went to the hospital to say goodbye, and then they pulled him off of life support. That experienced changed my husband and I forever. Neither one of us can help but look back and wonder what else we could have done. We look at Sean, and we’re scared about the lack of support for young adults. Even though I have been a pediatric therapist most of my career, I have watched Sean grow into an adolescent with alarm. He will be a high school graduate in five years... I have this gnawing feeling that we too, will fall off of the proverbial “IEP cliff.”

Now that he is older, I have watched him fight the bias. When we moved here, the first school district we enrolled in gave him the mandatory IQ test as part of special education eligibility requirements. He didn’t care for the school psychologist so he didn’t pay any attention to her and didn’t take the testing seriously... but she still scored it, and told us he had an IQ of

72. I laughed. The previous summer, Sean had written an 18 chapter book, just for fun, and they wanted to put him in a self-contained classroom. We pulled him out and home-schooled for a semester until we could get into another district...Sean hated it. He felt isolated, like he was being punished. He loved school, and couldn't wait to get back. His first semester in the new school district was turbulent. His resource teacher was too authoritarian, and didn't know what to do when Sean got frustrated. She told him he was, "being ugly" which he took to mean he *was* ugly.

Valentine's Day his sixth grade year, everything blew up. Sean was having trouble with a girl he liked. He was being openly rejected at school by her and her circle of friends, as well as a group of boys he was trying to fit in with. Every day he tried a new strategy for "being nice" and it only made it worse. They called him "stalker." At the time, he was really into comic books. In counseling one day, he drew a picture of the girl with an armed tank pointed at her, which he titled, *Nemesis*. I got a call from the school, concerned he may have violent tendencies. Before we could have a meeting with school personnel, rejection on Valentine's Day did him in. He walked out of class, humiliated. They couldn't find him for a full 20 minutes. He finally went to his counselor's office, but then another student complained to the principal that he asked the student if he could bring a gun to school. The school expelled Sean, and told us we couldn't bring him back until we agreed to an inpatient psychiatric evaluation. We refused the evaluation and home schooled him for the remainder of the semester. They allowed him a fresh start at the Junior High for the next school year. Sean was so anxious to see all of the people he had trouble with. It took a few months to convince him no one was going to take him back to the sixth grade. But, to our amazement, he made a complete turn-around, because he wanted to stay. He wanted to prove that he belonged. Unbeknownst to me or anyone, Sean started doing his math

and English resource work, AND asking for the work the general education class was doing, too. We found it all completed in his back pack. It was all correct. At his IEP, his teachers were dumbfounded. It begged the question why he was in special education classes at all. So, we fully mainstreamed Sean, starting with English and moving to Math by the end of seventh grade. He started in the band, in percussion (also a fight, because “everyone with autism starts on the clarinet”). He ran for student council representative, and won, and then was named eighth grade basketball manager.

He is doing great, and feeling accepted, but is he, really? Would anyone at that school talk to him if they didn't feel like they “should?” How artificial is that belonging, and is there anything I can do about it? The more time I spend as his mother, I realize there is only so much I can protect him from, and eventually, he will have to go out into a world of people who don't understand him. And he will have to work twice as hard for everything. What will he have to live for? Will he feel like he can live for himself? He feels so much, can he learn to experience love and loss without feeling crushed by it? I have spent a good deal of time the past several years thinking about autism and quality of life, and mental well-being. I believe my son is a whole, complete, unbroken, amazing individual. I haven't always had that mindset... there was a time when all I could focus on were his deficits. He has so much to offer, just like Jay did. Just like so many misunderstood young adults on the autism spectrum do.

I think there must be a way to foster a sense of well-being in individuals with ASD, a way to teach Sean what Jay couldn't grasp... that he can be what he wants to be. So, this project is a labor of love for me. Because Sean and all of the young adults with ASD I have had the privilege of knowing, deserve to have their voice be heard, and for others to seek to understand them.

## Appendix C

### *Strategic Planning Meeting 9-19-18 SWOT Analysis*

<b>Strengths</b>	<b>Weaknesses</b>
<p>Multiple systems are represented here today!</p> <ul style="list-style-type: none"> <li>• Vocational Rehab</li> <li>• Business Liaison – Hospital</li> <li>• Human Resources VP</li> <li>• ACCESS Leadership and Staff</li> <li>• Transition Coordinator</li> <li>• Parent</li> <li>• OT</li> </ul> <p>Business Council, Parent Council forming</p> <p>Good outcomes for most in last graduating class</p> <p>Secondary Transition Planning changes have been very positive</p> <ul style="list-style-type: none"> <li>• OWLS program – high school work experience</li> <li>• CIRCLES – promoting self-advocacy with interview fairs</li> </ul>	<p>One intern with ASD still not employed after graduation</p> <p>One intern with ASD struggling to keep job due to lack of communication strategies</p> <p>Lack of generalized training specific to autism on many levels!</p> <p>Limited time to create public awareness, marketing</p> <p>Difficulty “cracking the culture” -- ICU</p> <p>VR – “interns fall through the cracks” on AT referrals</p> <p>Training needs to be followed by a summary of “take-aways” to be re-iterated, or held accountable for – temporary effect?</p>
<b>Opportunities</b>	<b>Threats</b>
<p>Bigger businesses are getting interested in more training – recent training in Little Rock for Dillard’s</p> <p>CIRCLES meetings opportunity to spread the word about PS to target students with autism</p> <p>Two hospital depts. Reported to business liaison they were “blown away” with how much the interns are able to do.</p> <p>Parent Advisory Board has great leadership, will be starting to meet soon... start with autism awareness and building skills for self-advocacy? Commitment to full time employment?</p>	<p>Interns with ASD hesitant to self-disclose, lack of self-awareness, but have “hidden disability”</p> <p>Lack of coworker/supervisor training could create a culture mismatch</p> <p>Lack of training for ACCESS staff specific to autism – need to be aware of strengths, challenges, differences. Need other tools and strategies?</p> <p>Parents not invested in helping the intern seek competitive employment after graduation – low expectations for independence?</p> <p>parents withholding money to “keep it safe”</p>

*Strategic Planning Meeting 9-19-18 Action Plan*

<b>Goal</b>	<b>Action Item</b>	<b>Person Responsible</b>	<b>Follow-Up Date</b>
Parents will have information and skills for supporting independence and gainful employment.	Provide training to parents of adolescents/young adults with ASD to improve support for gaining competitive employment.	Jessie Janna Jane	Already Scheduled for 10-15-18. Check on dates for Parent Advisory Meetings
	Additional avenues for providing SSDI Benefits counseling will be explored, implemented for next orientation.	Jane Shayne	
ACCESS Staff will gain knowledge specific to interns with autism and learn additional ways to look at the environment for support (outside of behavioral strategies for skills training)	Offer training during all-staff institute days in October	Jessie Janna	TBD- week of Oct 13
VR Counselors will gain knowledge about the specific needs of consumers with ASD, and when to refer for AT evaluation.	Provide training for VR Counselors at upcoming monthly meeting.	Jessie Shayne	TBD
Department supervisors and staff will gain knowledge about autism culture and effective communication strategies.	Provide training to department supervisors and mentors for existing internships.	Jessie Jane Anne	TBD – Anne to help with scheduling

<b>Goal</b>	<b>Action Item</b>	<b>Person Responsible</b>	<b>Follow-Up Date</b>
Interns with ASD will become more self-aware of their individual strengths and needs to promote self-advocacy and self-disclosure	Provide information during training times to interns	Jessie Jane	TBD
	Look into resources for money management training to improve independence.	Jamie Janna	