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Re-imagine transition and adult  
success: a critical reflection program for  
parents of transition-aged youth with  
autism spectrum disorder involving  
disability studies

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BOSTON UNIVERSITY  
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**RE-IMAGINE TRANSITION & ADULT SUCCESS:  
A CRITICAL REFLECTION PROGRAM FOR PARENTS OF  
TRANSITION-AGED YOUTH WITH AUTISM SPECTRUM  
DISORDER INVOLVING DISABILITY STUDIES**

by

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Submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Occupational Therapy

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## **DEDICATION**

This work is dedicated to adolescents with Autism Spectrum Disorder and their support systems. May the content from this work find you and guide you during your transition journey. May it help to showcase the amazing variety of “abilities” that exists in today’s world with the utmost of pride.

## ACKNOWLEDGMENTS

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**ABSTRACT**

Current research highlights that adolescents with Autism Spectrum Disorders (ASD) are less likely to pursue and complete post-secondary education, less likely to obtain and maintain employment, have fewer social supports or friends, and are less likely to maintain independent living arrangements compared to their peers without disabilities or with other disabilities (Newman et al., 2011). These traditional markers of post-transition success embody medicalized conceptualizations of disability by implying that adolescents with ASD lack inherent skills to engage in post-secondary education, competitive employment, maintain friendships, live independently, etc. (Smith & Routel, 2010). This perpetuates disabling roles in adolescents with ASD and restricts the ways in which they can successfully participate as adult members in their communities by failing to consider the impact of social and attitudinal barriers on adulthood outcomes. Current intervention approaches to address transition primarily target the adolescent by building skills in the aforementioned areas, while few consider the role that their parents play in



facilitating adolescents' transitions (Hendricks & Wehman, 2009; Taylor et al., 2012; Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). Those interventions that do target parents of transition-aged youth with ASD focus primarily on understanding the complexities of the adult service system for individuals with disabilities, and/or the clinical presentation of autism (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Similarly, a lack of evidence-based programs exists for parents of children with disabilities to explore their biases, attitudes and assumptions for more positive disability acceptance.

*Re-Imagine Transition and Adult Success* is a theory-driven and evidence-based critical reflection program for parents of transition-aged youth with ASD that seeks to integrate disability studies content into transition planning. The course is an innovative approach to addressing transition issues in adolescents with ASD as it considers the impact of social and attitudinal barriers on this population's success in adulthood. Employing reflective learning tenants, the program aims to increase parents' knowledge about disability studies concepts, apply these concepts to the transition process, and support parents to become critically aware of their own assumptions regarding disability and adulthood success.

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## LIST OF ABBREVIATIONS

AOTA .....	American Occupational Therapy Association
ASD .....	Autism Spectrum Disorder
DSM-V .....	Diagnostic Statistical Manual - 5
FES .....	Family Empowerment Scale
NJOTA .....	New Jersey Occupational Therapy Association
OT .....	Occupational Therapy
P2P .....	Parent to Parent
VAP-T .....	Volunteer Advocacy Program – Transition
VARK .....	Visual, Aural, Read/Write, Kinesthetic

## **CHAPTER ONE - Introduction**

### **Definition and Importance of the Problem**

Individuals with autism spectrum disorder (ASD) like their peers' with other disabilities are living longer, necessitating that our society helps these individuals successfully lead adult lives within their communities. The planning for adulthood typically occurs as "transition planning" services that have historically been offered in schools as part of the Individuals with Disabilities Education Act (IDEA) (Prince, Katsiyannis, & Farmer, 2013). Within educational, psychological, and healthcare fields, "transition" and "transition planning" refer to an individual with disability exiting secondary schooling, and pursuing post-secondary options. These options have traditionally included securing employment, attending post-secondary schooling, living independently, managing or contributing to a household, maintaining personal and social adult relationships, being part of a community, etc. (Henninger & Taylor, 2013; Repetto & Correa, 1996). The current research for adolescents with ASD underscores not only the complexities of managing the adult service system as an individual with a disability, but more importantly also continues to emphasize these individuals' limited attainment of a label, widely known as "positive transition outcomes" (Newman et al., 2011). Positive transition outcomes have become synonymous with the abovementioned (i.e. an individual with disability has successfully "transitioned" into adulthood if he/she has attained one or more post-transition markers, such as attending post-secondary schooling, gaining competitive employment, etc.). As such, transition services are garnering attention amongst educational and healthcare professions as current research has

documented a shortcoming in outcomes for adults with disabilities, including those with ASD (Newman et al., 2011).

Concurrently, the field of disability studies has also gained increased attention within the general public, and especially amongst healthcare communities. Disability studies is an interdisciplinary field involving anthropology, sociology, economics, law, gender studies, and art (Oliver, 2009; Longmore, 2003). Its basic tenant states that disability is not a result of an individual's impairment (i.e. decreased mobility, decreased social awareness, decreased intellectual capacity, etc.) but rather a byproduct of how society's structures, culture, and attitudes perpetuate these individuals into "lesser" or "disabled" roles (Oliver, 2009; Longmore, 2003). The field cautions against employing individualized, medical definitions of disability in which the disability is a result of a bodily difference that must be "fixed" to a social understanding in which disability results when our world is not accommodating to the individual with an impairment. Thus, applying the basic tenant of disability studies to transition and transition planning, disability studies would suggest that the label of "poor transition outcomes" is rooted in unattested assumptions of "normal", rendering the label as socially oppressive and negligent to the different ways adults with disabilities can lead successful lives (Smith & Routel, 2010). Together, the former and the latter problems create an even greater issue in regards to how to best assist transition-aged youth with disabilities as they move onto adulthood.

Current programs for transition-aged youth with ASD focus primarily on fostering and teaching skills that equip the youth to attain these unattested social markers for



success (i.e. independent living, competitive employment, etc.) (Cheak-Zamora, Teti & First, 2015; Smith & Anderson, 2014; Weiss, Tint, Paquette-Smith & Lunsky, 2016). Fewer programs are catered towards parents of transition-aged youth with ASD, regardless of research highlighting the parents' critical role in supporting their youth with a disability into adulthood (Smith & Anderson, 2014). In addition, those programs that do exist for parents of transition-aged youth with ASD primarily educate parents about the adult service system or the adult clinical presentation of autism. Moreover, these available programs for both the transition-aged youth with ASD and their parents operate utilizing theoretical models which assume traditional, medicalized conceptualizations of disability (i.e. the need to equip individuals with disabilities with skills in order to emulate unidimensional ideas of adult success or to educate the parents on services that their soon-to-be adults with disabilities require to live within society). Thus, the problem lies twofold in that both current education/medical research and disability studies find that adults with ASD are not transitioning "successfully" (albeit based on different set of criteria set forth by each perspective), but the need for them to do so still remains.

### **Contributors to the Problem**

While a growing research body is accumulating to better understand the supports and barriers with implementing transition services that meet its intent for individuals with ASD to achieve current post-transition outcomes (some of which are noted above), a gap in the literature still exists in regards to understanding how these barriers and supports may exist within a social model of disability framework. This doctoral project works to synthesize the current literature and apply it within a social model of disability

framework to better understand exactly how and why current transition services are lacking in supporting adolescents with ASD and their families as the adolescents move onto adulthood.

Some research suggests that the problem of “poor transition outcomes” results as a lack of skills inherently present in adolescents with ASD (i.e. social skills, vocational skills, etc.) indicating that interventions be in place that bolster these skills to thereby positively influence transition outcomes (Hendricks & Wehman, 2009). However, the results of these skill-based interventions have not always significantly correlated with improvements in transition outcomes. Instead, research is now highlighting the importance of supporting the family unit, especially the parents, during the transition planning process (Hagner et al, 2012). Parents have and will continue to play a critical role in their adolescent with ASD as he/she moves onto adulthood, especially in regards to providing assistance and/or decision-making (Smith & Anderson, 2014). Thus, factors which influence parents will ultimately affect how these parents’ provide care and make decisions with and/or for their adolescent with ASD that relate to their adolescents’ transitions. Some of these internal impacting factors include parents’ personal feelings regarding raising a child with autism and coping strategies with adversity, while immediate contextual factors include parent-child relationship and their child’s clinical presentation of autism. Finally, external factors include the attitudes, biases and stereotypes that parents have been and continue to be exposed to in regards to disability and constitutions of adult success. The interplay of these factors and their impact are described in further detail in Chapter 2.

Overall, parents are overwhelmed when it comes to determining the best way to assist their child with a disability into adulthood. In addition, the social model of disability framework work suggests that parents are subjected to continual exposure of attitudes, biases, and stereotypes about disability, adult success, and best practices with parenting. The combination of these forces ultimately impacts the parents' decision-making and service seeking during transition planning years, which currently leads to the adoption of intervention approaches (most of which still document shortcomings in addressing the needs of adolescents with ASD in adulthood). Thus, this doctoral project suggests that the overarching contributor to the problem of "poor transition outcomes" in adolescents with ASD is a result of how our society, especially parents who are integral in the care for their child, are viewing disability and what it means to be a successful adult.

### **Proposed Intervention to Address the Problem**

With federal mandates for assisting adolescents with disabilities including ASD within school systems during transition years, as well as, a growing demand for supporting this population to be successful in adulthood, occupational therapy as a profession has not only shown interest in asserting itself within the niche of transition planning, but is also qualified in doing so. For example, occupational therapy practitioners are skilled in understanding and analyzing the daily routines required for adult life (American Occupational Therapy Association, 2014), the functional presentation of ASD across the lifespan, roles that caregivers for an individual with a disability may need to play, and providing valuable caregiver education. As such, this

doctoral project proposes to address the identified problem from a “top-down” approach. To address the issue of “poor transition outcomes” in adolescents with ASD, an intervention is required that helps to reshape how, arguably, one of the key players involved in transition, parents, view adult success through a critical reflection program teaching and applying disability studies’ ideologies; this will ideally empower parents during transition planning decision-making.

The following chapters will explore the theory and evidence-base for the core issue of “poor transition outcomes” in adolescents with ASD and current intervention approaches to address this issue, while simultaneously reviewing these theories, evidence, and interventions through a social model of disability framework. Finally, this work proposes a critical reflection program for parents of transition-aged youth with ASD -- *Re-Imagine Transition and Adult Success* – as one of potential solutions to address the problem by building on the theoretical and research evidence noted throughout.

## **CHAPTER TWO – Theoretical and Evidence Base to Support the Project**

### **Part I: Overview of the Problem**

The purpose of this section is to provide a comprehensive overview of the problem of “poor transition outcomes” in adolescents with Autism Spectrum Disorder (ASD). The overview synthesizes findings from current research within the field of transitions and transition planning, while simultaneously analyzing the problem through a disability studies and social model of disability framework.

#### **Introduction**

Figure 2.1 describes the complex interaction of individual, and social factors that influence parents and their adolescents with Autism Spectrum Disorder (ASD) during the adolescents’ transitions into adulthood. The model overlaps the documented shortcomings in the transition process research for parents and their adolescents with ASD with the systemic pitfalls of the individualistic, medicalized notion of disability. The model, therefore, is a newly, conceptualized problem of parents’ and their adolescents’ with ASD experiences with the transition process through a social model of disability lens.

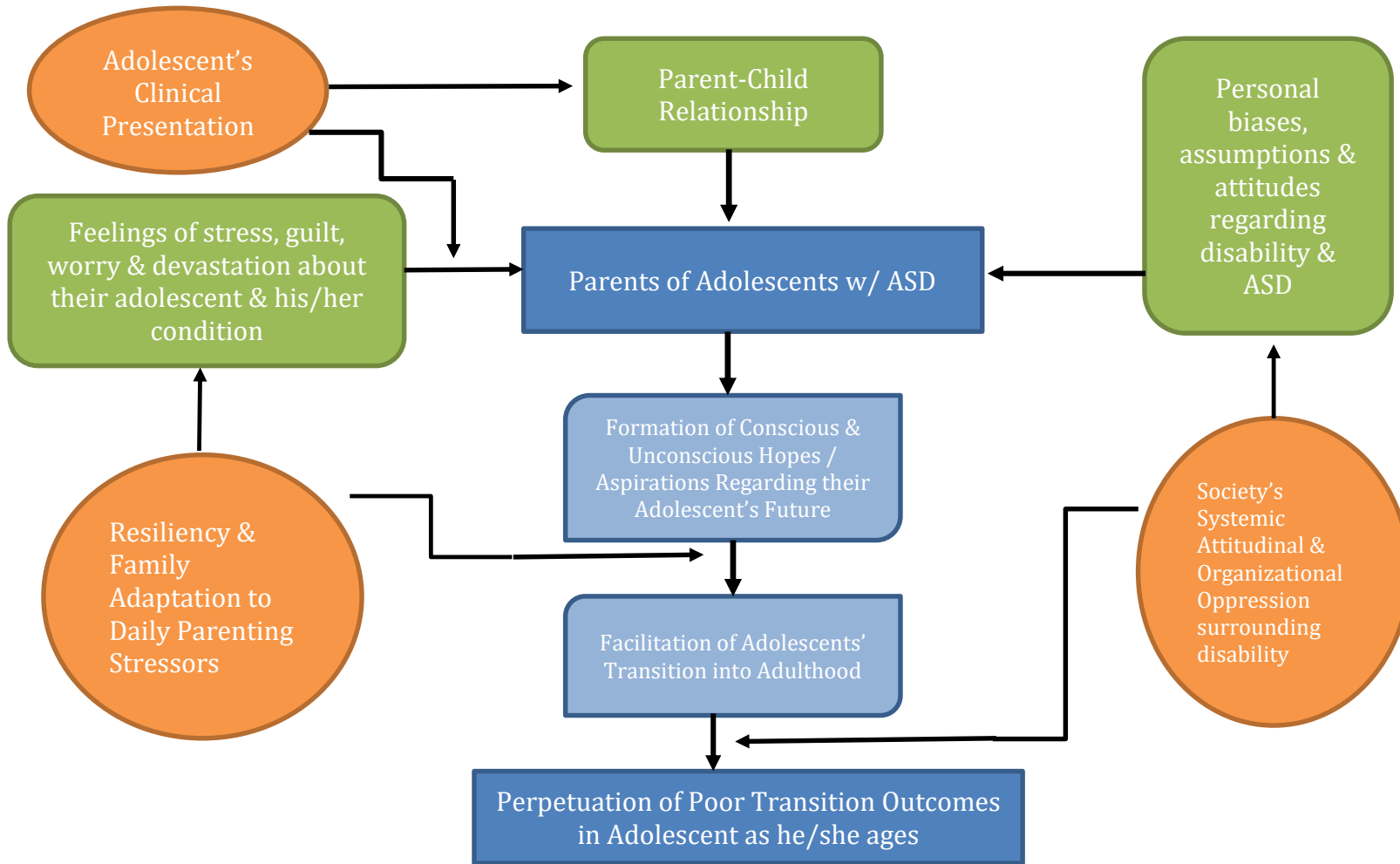
Foremost, research has consistently documented the challenges associated with the transition process for adolescents with ASD and their parents, including decreased availability or absolute lack of comprehensiveness of transition-based services (Cheak-Zamora, Teti & First, 2015; Smith & Anderson, 2014; Weiss, Tint, Paquette-Smith & Lunskey, 2016). The transition process refers to the adolescent ending secondary schooling and its services, and moving onto post-secondary options, including 2-4 year

colleges, vocational training, joining the workforce, and/or maintaining independent living (Henninger & Taylor, 2013). Participation in the transition process occurs in all adolescents regardless of disability status. However, adolescents with disabilities, especially those diagnosed with Autism Spectrum Disorder, are not achieving these traditional markers of post-transition success at the same rate as compared to adolescents without disabilities (Newman et al., 2011). Adolescents with ASD are reaching adulthood and having poor outcomes across education, vocational / employment, social, housing, and healthcare domains. Examples of these traditionally defined “poor” outcomes include less likely to pursue and complete post-secondary education, less likely to obtain and maintain competitive employment, fewer social support or friendships, and less likely to maintain independent living arrangements to name a few (Newman et al., 2011).

My proposed model of transition outcomes for parents and their adolescents with ASD also considers the influence of the social model of disability. The social model of disability stems from the field of disability studies. Disability studies as an academic field helps to re-examine society’s construct of disability through an interdisciplinary approach involving anthropology, sociology, gender studies, arts, economics, and law. Disability studies steers away from individualistic, medicalized conceptualizations of disability, and instead highlights the cultural, political, and economic structures that can influence our understanding of disability and what it means to be “disabled” (Oliver, 2009; Longmore, 2003a). Thus, the social model of disability explores how society’s structures, policies, beliefs, and history contribute to the process in which an individual becomes “disabled”. The social model contrasts with the current, more prevalent medical

model of disability in that it suggests that disability is not the product of the impairment itself, but rather the societal expectations and beliefs about normalcy which force people with the impairment into disabled roles (Oliver, 2009; Longmore, 2003a).

Overall, the model considers both the traditional factors outlined in the majority of contemporary research regarding the transition process for adolescents with ASD and the social model of disability influences that together work to perpetuate poor outcomes of adolescents with ASD post-transition.



**Figure 2.1 Explanatory Model of Poor Transition Outcomes in Adolescents with ASD through a Disability Studies Framework**



### **Parents of Adolescents with ASD and the Factors that Influence Them**

In Figure 2.1, the factors directly impacting parents are depicted in green, while factors depicted in orange indirectly impact them. As with all minors, parents have the primary responsibility to manage the provisions of care that allow their child to grow developmentally, socially, intellectually, and so forth. However, parents of adolescents with ASD face additional challenges to providing this care, as a result of the inherent impairments associated with their children's condition (ASD). The decisions parents of children with ASD make regarding care for their child will have a lasting impact on the general outcomes of their children as they age. Moreover, research shows that the parents' responsibility of care continues way past that of parents whose children do not have disabilities (Smith & Anderson, 2014). This seemingly lifelong responsibility of making decisions on behalf of their child with ASD renders a need to examine the factors (i.e. those denoted in green and orange) that impact parents of children with ASD and subsequently their decision-making for their children's transition into adulthood.

Foremost, upon their child's initial diagnosis of ASD, parents experience a multitude of emotions, including grief, loss, anger, guilt, confusion, and doubt (Altiere & von Kluge, 2009; Depape & Lindsay, 2015). These feelings exist not only at the onset of diagnosis, but also continue to persist as the child with ASD ages (Ludlow, Skelly & Rohleder, 2011; Lutz, Patterson & Klein, 2012; Pozo & Sarriá, 2015; Smith & Anderson, 2014). Across the child's lifespan, parents of children with ASD experience greater levels of psychological stress, depression, and anxiety compared to their peers, who have children without disabilities (Depape & Lindsay, 2015; Hayes & Watson, 2012; Ludlow,

Skelly & Rohleder, 2011). This is also true when compared to parents of children with other disabilities, such as Down's syndrome, cerebral palsy, and intellectual disability (Hayes & Watson, 2012). These feelings of stress and compromised well-being continue to persist in parents of children with ASD as their child ages due to the evolving needs and new challenges that emerge with their child's increased age (Ludlow, Skelly & Rohleder, 2011; Lutz, Patterson & Klein, 2012; Pozo & Sarriá, 2015; Smith & Anderson, 2014). This model highlights one particularly stressful time for many parents of children with ASD, which is during their child's adolescence and their transition (Smith & Anderson, 2014).

These feelings of grief, loss, anger, guilt, confusion, and doubt are mediated and moderated by the adolescent's unique clinical presentation. The adolescent's clinical presentation or the unique attributes of the condition which he/she exhibits not only in part manifest the negative feelings mentioned above, but also can magnify the intensity at which parents experience these feelings. Autism Spectrum Disorder (ASD) is a developmental disorder, characterized by impaired social functioning, difficulties in communication, and restricted/repetitive interests (American Psychiatric Association, 2013). As denoted by its name, ASD has a wide clinical presentation with each individual showcasing different symptoms and severity (American Psychiatric Association, 2013). ASD is a pervasive, and life-long condition impacting the child and his/her daily functioning, and the family unit and its well-being. The adolescents' clinical presentation for the purposes of this model comprises of the child's age, gender, behavioral deficits, other symptom severity, and the presence of co-occurring, morbid conditions. These

factors have documented correlations to the degree to which parents experience psychological stress, anxiety, and depression, since these clinical factors directly impact their child's functioning, and thus the parents' daily lives (Lounds, Seltzer, Greenberg & Shattuck, 2007). Parents, whose adolescent presents with clinical factors that result in more "severe" behavioral attributes impacting daily functioning require more time and additional supports for caregiving, which in turn will increase levels of caregiver burden, and impact the parents' perception towards meeting their child's needs (O'Brien, 2016; Weiss, Tint, Paquette-Smith & Lunsky, 2016). Thus, the adolescents' clinical presentation is an indirect mediator on the overall perpetuation of poor transition outcomes, as it can affect the level of distress parents feel and the subsequent decision-making the parents do for their child's transition.

Moreover, the parents' negative feelings of grief, loss, anger, guilt, confusion, and doubt are also moderated by the parents' ability to develop resilience and family adaptation against the daily stressors and challenges of parenting a child with autism. Initially, as parents learn about ASD and receive services for their child, they begin an ongoing adaptation process in which they come to terms with their child's diagnosis, create family routines which support their child's unique needs, immerse themselves in a positive social support system, and derive new meaning to their lives with the advent of having a child with special or different needs (Depape & Lindsay, 2015; Lutz, Patterson & Klein, 2012; O'Brien, 2016; Pozo & Sarriá, 2015). The abovementioned research presents these resiliency factors as an adaptation process. These factors for resiliency allow the family unit to cope, develop self-efficacy surrounding parenting, and respond to

the unexpected change in the family dynamic (i.e. the birth and parenting of a child diagnosed with autism). The process for adaptation and resiliency is ongoing as the parents take on each new stressor or challenge, including the facilitation of the transition process. Drawing upon the tenants of resiliency theory and its associated research in this field, I propose that the extent to which parents successfully adapt and develop resiliency will in turn influence the degree to which they are plagued by the abovementioned feelings; finally, I hypothesize that this direct mediated relationship is in itself an indirect mediator to the adolescents' transition outcomes. For example, if parents successfully adapt to various daily stressors for parenting a child with autism, the more resilient and self-efficacious they will feel with providing care for their child, which ultimately will allow them to feel confident in the decision-making required to facilitate their adolescent's transition.

Next, parents of adolescents with ASD are influenced by their personal relationship with their adolescent. All parents have and develop strong feelings of affection, protective instincts, and unique bonds to help keep them attuned to their children's needs. Parents of adolescents with ASD also develop through their own processes this relationship with their child. However, the parent-child relationship in adolescents with ASD is also moderated by the adolescent's unique clinical presentation, such as behavioral symptoms (Orsmond, Seltzer, Greenberg & Krauss, 2006; Lounds, Seltzer, Greenberg & Shattuck, 2007; Pozo & Sarriá, 2015). The adolescent's clinical presentation can impact the degree to which the parents feel capable of meeting their child's needs (i.e. self-efficacy), which in turn can impact their relationship quality with

their child. Thus, similar to the indirect mediated relationship of resiliency and family adaption on transition outcomes, the adolescent's clinical presentation can indirectly mediate transition outcomes by influencing the quality of the parent-child relationship, the parents' feelings of self-efficacy for caring for their child, and thus their confidence in meeting the transition needs of their adolescent.

Finally, parents of adolescents with ASD are impacted by their personal biases, assumptions, and attitudes regarding disability and Autism Spectrum Disorder. Parents of adolescents' with ASD, like the rest of society, are plagued with biases and assumptions about disability, which historically have included individualistic, medicalized conceptualizations (Longmore, 2003b). An individualistic, medicalized conceptualization of disability involves the need to "fix" the impairments or to help their child "overcome" the impairments inherent in their condition, so that the adolescent appears or acts like the majority of others; this adaptation is considered the desirable "normal" (Oliver, 2009; Priestley, 1998). Parents, like most other non-disabled individuals, are susceptible to viewing children with disabilities, including those with ASD, as having substantial dependency needs, while also overemphasizing the child's impairments over the child's other identities or abilities (Priestley, 1998). These views of disability are individualistic and medicalized in that they fail to consider the societal structures and policies that brought about and continue to perpetuate those views.

These overarching views about disability can also influence the parents' specific beliefs surrounding their adolescents' transition into adulthood in that they will likely advocate or search for services which preserve their ideas surrounding "normal"

adulthood. What each parents constitutes as “normal” varies based on their personal beliefs, which are mediated by the systemic, organizational structures and attitudes about disability from both the parents’ upbringing and current environment. Furthermore, Kirby (2016) found that parental expectations for their adolescent with ASD were mediated by family background (i.e. parent education, race, income, etc.), as well as, the functional performance of their adolescent. This current transition literature indirectly corroborates disability studies’ historical and political examination of the beliefs people hold of individuals with disabilities. These beliefs include that the construction of the notion of disability is a result of societal factors, upbringing, subjective experiences with individuals with disabilities, and the comparison of what one believes someone with a particular impairment or functional status is able to achieve (Longmore, 2003a; Longmore, 2003b & Oliver, 2009). Thus, parents’ personal biases and assumptions regarding disability, ASD, and normalcy are directly influenced by historical and societal attitudes, structures, and policies surrounding disability; together both society’s attitudinal and organizational structures and the parents’ personal biases indirectly mediate the parents decision-making regarding their adolescent’s transition.

### **Critique of the Current Evidence**

While research in the area of adolescents and young adults with autism spectrum disorder is a growing field, there are notable shortcomings in the current breath of transition literature. Generally, more research is dedicated towards younger individuals with autism between the ages of infancy to 12 years of age, and their parents. Moreover, in the literature that does exist regarding transition-age youth with autism, either

qualitative or quantitative, the population demographics include mainly White, middle to upper socioeconomic status families in primarily English-speaking, Western countries. In this model, the use of Depape & Lindsay (2015) meta-analysis provides a glimpse into the discrepancy regarding demographics, as 21 of the 31 included research articles were conducted in English-speaking, Western countries. Similarly, only 10 of the included 31 research articles reported race /ethnic background in which 84.4% identified as non-Hispanic White (Depape & Lindsay, 2015). This means that the majority of literature fails to examine the transition experiences of parents of other races and socioeconomic statuses; these minority groups have historically been subjected to additional systemic racism, barriers, and oppression across different life domains, which appear not to be captured within the current body of literature surrounding ASD youth transitions. However, some notable exceptions include Pozo and Sarria (2015), which included participants from across urban, suburban, and rural Spain, and Weiss, Tint, Paquette-Smith & Lunskey (2016), in which 14.5% of the 324 study participants' parents identified as an immigrant to Canada.

Moreover, the qualitative research utilized to inform this model have small sample sizes due to the nature of the thematic analysis, which limits generalizability to the broader population of all transition age youth with ASD and their families. Also, the majority of qualitative research informing this model utilized convenience and snowball sampling with local autism service agencies. Thus, the parents whose opinions are captured by this literature likely have greater access or less barriers to service utilization, may have more post-secondary education, thus an increased propensity towards research

participation, greater socioeconomic status, and/or have a greater social support system compared to those parents of adolescents with ASD who do not utilize autism service agencies. This may also mean that not only is there a subset of families with children with autism who are not receiving or are not connected to community resources whose opinions are not captured by the current literature, but that there may be additional confounding factors, such as service use, post-secondary education, socioeconomic status, social support, and so forth of which impact towards the transition process is not being evaluated in the current research body.

In terms of parents included in the research, mothers are consistently overrepresented compared to fathers and other caregivers, as mothers tend to be the primary caregivers in this population. For example, amongst the articles cited in this model, only two had an equal number of father and mother participants (Altiere & von Kluge, 2009; Pozo and Sarria, 2015). However, neither Alterie & von Kluge (2009) nor Pozo and Sarria (2015) conducted specific analyses to compare how or if the experiences of fathers differed or were similar to those of the mothers. This indicates that further research is warranted to determine if or how fathers' and/or other caregivers' experiences with the transition process differ from mothers' experiences.

The qualitative literature aimed to capture the experiences and opinions about raising a child/adolescent with autism involved the use of semi-structured to structured interviewing. In general, semi-structured and structured interviewing leads way to potential researcher bias in regards to the questions asked (i.e. leading questions). From a disability studies lens, these researchers are likely also influenced by the same systemic



organizational and attitudinal barriers which impact parents of adolescents with ASD, and therefore the researchers' conceptualizations of autism are likely medicalized by nature due to society's prevalent stereotypes. This leads to directed research questions which inadvertently continue to perpetuate the medicalized notion of disability. Examples amongst the current cited body of literature include "What do you believe to be the cause of your child's autism?" (Alterie & von Kluge, 2009), or "As a parent of a child with autism, what makes things difficult or challenging for you?" (Ludlow, Skelly & Rohleder, 2011). These two questions highlight how the researchers indirectly imply that having a child with autism, and/or raising a child with autism are inherently problematic or difficult because of the autism, rather than the other societal factors.

In regards to the utilized disability studies literature, the majority involves editorial pieces creating overarching assumptions regarding disability based on general historical, social, and political events. Therefore, the disability studies literature is not empirically tested for confirmation of these assumptions. Lastly, disability studies by nature focuses on the lived experiences of people with disabilities, and therefore presents with limitations in regards to the experiences of parents or the caretakers.

Overall, the literature utilized to inform this model is primarily qualitative, involving thematic analysis of the experiences parents of adolescents with autism have in regards to providing care for their adolescents and participating in the transition process. This literature is limited in generalizability due to small sample size, overrepresentation of mothers, Caucasian race, and higher socioeconomic status. There is potential for bias in the interview questioning. Similarly, disability studies literature utilized in this

literature is editorial in nature with claims made without empirical testing.

### **How Parents Facilitate Transitions in their Adolescents with ASD**

The previous sections highlight the various direct, indirect, individual and social factors that influence parents of adolescents with ASD and their ability to facilitate their adolescent's transition into adulthood. In this section, I will integrate that information to explain how these influences impact the direct pathway of parents facilitating their child's transition (i.e. depicted in blue). Parents of adolescents with ASD face feelings of guilt, worry, devastation, and doubt about their adolescent and his/her future (Altiere & von Kluge, 2009; Depape & Lindsay, 2015). The parents are also influenced by their personal biases and assumptions regarding disability and ASD (Oliver, 2009). Lastly, parents are influenced by their unique relationship with their adolescent. Together these three factors, each mediated by their own set of additional factors, including family adaptation/resiliency (Lutz, Patterson & Klein, 2012), the adolescent's clinical presentation (Lounds, Seltzer, Greenberg & Shattuck, 2007), and societal attitudes / organizational barriers surrounding individuals with disabilities (Longmore, 2003b), work together to dictate the unconscious and conscious hopes or aspirations that the parents have for their adolescent as he/she ages into adulthood.

These unconscious and conscious hopes or aspirations are primarily rooted in the traditional, individualistic model of disability (Oliver, 1999). Parents have hopes or expectations for their adolescent to lead functional, protected, and happy lives, but often these hopes are based within the confines of what they believe their adolescent can realistically achieve as compared to others (Lutz, Patterson & Klein, 2012). However,

disability studies ideologies would state that comparing adolescents with ASD to what others without ASD are achieving post-transition marginalizes them, and reinforces the concept of ableism or “fixing” the impairment. For example, aspirations rooted in the medical models’ focus on symptomology could include parents wanting their adolescents with ASD to have decreased adverse reaction to sensory stimuli, the ability to cope with changes to one’s routine, social skills/awareness, expanding their restricted interests, and so forth. I hypothesize that these potential hopes and aspirations of parents for their adolescents with ASD impact the parents’ decision-making during the transition process, and inadvertently align with society’s concepts of “normal” adulthood, such as post-secondary schooling, competitive employment, independent living, etc.

After the parents make these decisions on behalf of their adolescent with ASD to facilitate their adolescents’ transitions, I hypothesize that the perpetuation of poor transition outcomes persists not only from the inherent biases within the parents, but also because the parents must make these decisions within a system that continues to be plagued by attitudinal and organization barriers. For example, these attitudinal and organizational barriers include lack of accommodations for individuals for ASD to succeed in traditional post-secondary settings, limited number of services, long wait time to access services, poor qualification criteria, lack of funding or policy supporting services, etc. (Cheak-Zamora, Teti & First, 2015; Smith & Anderson, 2014). Ultimately, in this model, I propose the direct pathway as parents of adolescents with ASD engage in decision-making, which helps to facilitate their adolescents’ transitions into adulthood with the influences of biases and assumptions regarding disability, ASD, and normalcy.

These influences likely continue to perpetuate poor adulthood outcomes for their child.

### **Concluding Synthesis**

Parents of adolescents with ASD are influenced by a variety of factors both internal and external that impact their ability to facilitate their adolescents' transitions into adulthood. Moreover, the systemic influences of the individualistic, medicalized model of disability continue to permeate across all decision-making and services for individuals with disabilities, including those with ASD. As such, adolescents with ASD, as they transition into adulthood are plagued with the label of having "poor transition outcomes" (Newman et al., 2011). However, these "poor transition outcomes" are the product of ableism and its conceptualizations of adult "success". Therefore, the overarching problem depicted in this model arises from society evaluating the success of adolescents with ASD as they age based on criteria that is often rooted in assumptions of "normal" that are primarily ableist, and therefore oppressive. Lastly, the model depicts how parents of adolescents with ASD inadvertently are subjected to these same societal stereotypes, thereby playing a role into the continual perpetuation of these stereotypes regarding adult "success"; thus necessitating their education to elicit greater awareness and decision-making for facilitation of different, more attainable, and more meaningful outcomes for adolescents with ASD.

### **Part II: Previous Attempts to Address the Problem**

While the majority of the literature cites the shortcomings in the outcomes achieved by adolescents with ASD as compared to other peers, as well as, the limited availability of programs for adolescents to prepare for the transition, less literature is

available regarding programs or services tailored towards the adolescents' parents. In addition, much of the literature also fails to acknowledge the impact of ableism on the measurable outcomes for transition-aged youth with ASD, or the impact of societal attitudes on the transition process. There is also limited research regarding interventions to help programs assess their biases and develop positive disability acceptance.

Therefore, to better conceptualize the dual-folded nature of the problem, this section examines two bodies of literature: 1) transition programs for parents of adolescents with ASD, and 2) programs for parents of children with disabilities focusing on parental empowerment through a disability studies lens.

### **Evaluative Summary: Transition Programs for Parents of Adolescents with ASD**

A sizable portion of transition literature for youth with ASD involves the adolescent, and preparing him/her for post-transition through fostering life, social, vocational, and post-secondary educational skills. Nonetheless, a small subset amongst this transition literature outlines programs catered for the parents of the adolescents with ASD. Typically, in this literature, adolescence is defined as being between ages 15 and 23. This section of the evaluative summary examines this body of literature in order to critically appraise the programs' content, implementation procedures, and measurable outcomes on parents' preparedness for their adolescents' transition

#### *Content in Parental Programs on Transition*

The content within the currently available transition programs for parents of adolescents' with ASD have notable similarities and differences. For example, three of the four transition programs specific for parents of transition-aged youth with ASD have

sections that outline either federal and/or state specific legal and financial information related to an adolescent transitioning into the adult service system, including information about Medicaid, Medicare, Supplemental Security Income, and Social Security Disability Insurance (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Moreover, three of the four programs have modules discussing post-secondary schooling, employment options, and strategies for attainment of these options (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Similarly, three of the four programs explore the impact of the adolescent transitioning into adulthood on the family system, including topics such as autism presentation in adulthood, family well-being, and creating family habits / routines for supporting an adolescent's transition into adulthood (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015). Next, two of the four programs provide content regarding person-centered planning, and thinking (Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Finally, in all four of the programs, parents discuss community resources and opportunities, alongside specific advocacy strategies to maneuver and manage the complexity of the adult service system (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

#### *Implementation and Procedures in Parental Programs on Transition*

Each program varied in parent instruction with the shortest including 12 hours of multi-family instruction (DaWalt, Greenberg, & Mailick, 2018, p. 255), and the longest

involving 30 hours (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017, p. 850). Each parent-training program varied in overall duration with the shortest occurring across 8 weeks (DaWalt, Greenberg, & Mailick, 2018, p.255) and the longest occurring across 15 weeks (Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015, p. 460). The average length of parent-training program appears to be 12 consecutive weeks (DaWalt, Greenberg, & Mailick, 2018, Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

Two programs held groups concurrently for the adolescents (DaWalt, Greenberg, & Mailick, 2018; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015), while the other two programs did not include a concurrent component (Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). However, one of the programs which did not include a concurrent program did have separate sessions with both the adolescent and his/her family to practice person-centered planning (Hagner et al., 2012). Moreover, three out of four programs were implemented by masters-level mental health professionals, such as social workers and psychologists (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). The other program was implemented by an occupational therapist (Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015). All program implementers had well-documented years of experience working with individuals with autism and their families (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017), as well as, two programs also included professionals who had experiences with person-centered planning (Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

*Mechanisms of Action in Parental Programs on Transition*

Upon review of the four abovementioned programs, several themes and specific approaches for structuring parent training interventions for parents of children with ASD were identified and outlined below:

*Goal setting & individualization:* Goal setting was used in two of the four interventions (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012). Goal setting allows the adolescent and their families to have a vision for their future, and provides specific, yet measurable means to attain this vision (Hagner et al., 2012, p. 45). In addition, goal setting permits the adolescent to be active participants in the discussion regarding their transition outcomes, which increases post-transition expectations for the adolescent (p. 47). Whereas, individualization provides opportunities for families to generalize and apply any taught concepts to their specific situation, as well as, generate practical solutions for problems that may arise when attempting to meet their child's transition goals to their own context and daily life (DaWalt, Greenberg, & Mailick, 2018). Lastly, while two of the programs did not explicitly include sessions for individualized goal setting, these programs also provided opportunities for parents to provide examples of personal situations and challenges relevant to different content areas for group problem-solving and strategy development (Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

When discussed across a gradient, Specific Planning Encourages Creative Solutions (Hagner et al., 2012) had the highest level of individualization for family. For



example, after a multi-family group instruction involving full day meetings across 3 weeks, each family (i.e. parents, any relevant caregivers, and the adolescent) also received 3 to 5 separate sessions with a program facilitator (p. 45). In these sessions, the adolescent was provided accommodations and adaptations to voice their vision for the future, as well as, opportunities for parents and caregivers to share their own expectations for the adolescent (p. 45). Then, the program facilitator worked alongside the family to devise a specific plan for attainment of the family's transition vision. Finally, the program facilitators provided an additional 4 to 6 months of ongoing assistance after the conclusion of the program on an as needed basis to monitor plan attainment and provide career exploration opportunities for the adolescent (p. 46).

Lastly, while the Specific Planning Encourages Creative Solutions program provided highly individualized programming to meet each adolescent and his/her family's needs, the other parent transition programs had opportunities for individualization but not to the same degree. For example, the Volunteer Advocacy Program – Transition offered 30 hours of group, didactic instruction on relevant content areas with opportunities for some but likely not all families to share personal antidotes relevant to each content area (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017, p. 850). The only other method of individualization during this program included each parent writing a “letter of intent” regarding each content area to self-assess services they thought their adolescent required, and potential strategies for obtaining them (p. 850). Overall, all programs provided opportunities for parents / caregivers to share their experiences, but they each varied on the level of specificity, and one-on-one assistance.

*Social learning:* A group format was used in all 4 interventions. Delivering interventions in groups provides parents with the opportunity to build social networks (Hagner et al., 2012, p. 847). In addition, the group format is consistent with a multi-family psychoeducational model, which helps in reducing family distress, and improving well-being outcomes for all family members (DaWalt, Greenberg, & Mailick, 2018, 2018). Finally, a group format provides opportunities to carry out guided practice in problem-solving with other families who may be experiencing or working through similar situations (Dawalt et al., 2018; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015). For example, all four interventions utilized group discussion for problem-solving parents' common barriers associated with content-specific information (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). All programs involved in-person instruction and discussion, with one program providing distant learning options through technological means (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

*Didactic Instruction:* All programs have some component involving specific, didactic instruction regarding various content areas, as noted above (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). However, specific strategies for implementing such didactic instruction were not outlined explicitly in the available literature. The only available information regarding didactic instruction includes the use of PowerPoint and guest lecturers as a means to present content (Taylor,

Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Thus, while all cited programs involve didactic teaching for adults, these program do not appear to present content systematically or in accordance to well-established theories involving knowledge gain or change in adult learners. Lastly, the literature does not elucidate as to whether program content was presented in accordance to different learning styles, which may impact program effectiveness in producing the desired knowledge change or gain.

#### *Outcomes and Results in Parental Programs on Transition*

The different transition programs for parents of adolescents with ASD measured success of their programs through different outcome measures, including, qualitative interviews, validated questionnaires or assessments, or tests created specifically for the intervention. Outcomes across programs address three broad constructs: knowledge, positive affect/characteristics, and negative affect/characteristics

*Knowledge:* Three of the four interventions measured increase in parental knowledge specific to the transition process for their adolescent (Table 2.1). Of these three interventions, only one intervention utilized a measure which allowed quantitative comparison of knowledge gained through a multiple-choice questionnaire (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). In this program, parents' increase from pre- to post-intervention in adult service system knowledge was found to be significant (p.853). Whereas the other two interventions utilized interview and thematic analysis to assess for any changes in knowledge acquisition regarding the transition process (Table 2.1). Qualitative themes reflecting knowledge change included “swapping family stories”, and having “a safe place to ask questions” Loukas, Raymond, Perron,

Mcharg, & Lacroix Doe, 2015, p. 461). These themes suggest that by creating a “safe place to ask questions”, families had opportunities to “swap stories” regarding each family’s transition process, and any concerns they may have faced in this process. In turn, they likely experienced an increase in knowledge about the logistics of the process and potential solutions. Similarly, when asked specifically “did you learn anything new”, parents identified guardianship/powers of attorney, department of vocational rehabilitation, planning and advocacy, resources on services and community involvement / validation, specific strategies for addressing concerns with teen, and college planning as major themes of knowledge gain through participation in the program (DaWalt, Greenberg, & Mailick, 2018, p. 258). Overall, all three programs found some change in knowledge acquisition whether it was quantitatively measured through assessments or qualitatively through thematic analysis.

*Positive affect:* All four parent training interventions measured aspects of what I am labelling as “positive affect” or “positive characteristics” (Table 2.1). “Positive affect” or “positive characteristics” refer to attributes which are useful or preferable for the parent in relation to their child’s transition process. Of note, both Transitioning Together and Volunteer Advocacy Training – Program (VAP-T) utilized the Family Empowerment Scale (FES) to capture different domains of parental empowerment (Table 2.1). Transitioning Together utilized only the Problem-Solving Subscale of the FES, while VAP-T utilized the full FES (Table 2.1). Nonetheless, both Transitioning Together and Volunteer Advocacy Training – Program reported that parents in the intervention group had statistically significant higher scores on the respective measurements for

parental empowerment utilized post-intervention compared to their control groups (DaWalt, Greenberg, & Mailick, 2018; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Similarly, Loukas, Raymond, Perron, Mcharg, & Lacroix Doe (2015) reported themes related to parental empowerment. For example, parents noted “experiencing an epiphany”, in regards to feeling as if they could better support and help their adolescent into adulthood (p. 461). Moreover, parents reported that they both saw and were beginning to support their adolescents’ “transformations”, as their adolescents completed a concurrent adolescent program (p. 461). Finally, parents felt that through their parental support group they gained tools and strategies that were “enlightening” in terms of supporting their adolescent (p. 461). Thus, three of the four transition programs outlined in this module found notable results in regards to empowering parents to either “tackling” the intricacies of their adolescents’ transition process and/or gaining new insight into the adolescent / their transition process.

Next, for Transitioning Together, only one of the three remaining positive affect outcomes (i.e. expressed feelings of happiness / proudness of their adolescent) was statistically significant in the intervention group post-intervention compared to the control group (DaWalt, Greenberg, & Mailick, 2018, p. 258). Therefore, the two other positive affect outcomes (i.e. expressed feelings of warmth / positive remarks towards adolescent and the parent-child relationship quality) did not significantly increase post-intervention in the intervention group compared to the control group (p. 258). Moreover, in the Volunteer Advocacy Training Program – Transition, both positive affect outcomes (i.e. parental empowerment and parental self-perceived comfort / skill in their ability to

advocate for their adolescent) were found to increase significantly post-intervention in the intervention group compared to the control group (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017, p. 853). Finally, in *Specific Planning Encourages Creative Solutions*, the one reported positive affect outcome (i.e. parental expectations for their adolescent) changed significantly in the intervention group compared to the control group post-intervention (Hagner et al., 2012, p. 47). Thematically, Loukas, Raymond, Perron, Mcharg, & Lacroix Doe (2015) noted that parents reported learning the importance of “holding their adolescent to higher standards” after undergoing their support group, which correlates to increasing parental expectations of their adolescent (p. 461). Thus, collectively, it appears that transition programs catered towards parents of adolescents with ASD help to increase parental advocacy for their adolescent, help them hold higher expectations for their adolescent, and/or increase feelings of happiness and proudness towards their adolescent. Conversely, these transition programs appear no to change or target positive affect outcomes related to how parents act and/or interact with their adolescent.

Lastly, while only one parent transition program (Transition Together) considered positive affect outcomes related to parent-child relationship, parental expressions of warmth towards their adolescent, and their use of positive remarks about their children, all four programs had notable similarities in regards to program content and format (see above). Thus, a loose generalization can be drawn to suggest that the available transition programs for parents of adolescents with ASD may not be structuring content so as to make noticeable changes in this positive affect outcome area as intended. One possibility

for this phenomenon may include the programs' emphasis on departing knowledge regarding the transition process, which on its own does not address the parent-child relationship or parental interactions with their adolescents. Thus, modifications to program content or format may be warranted in order for these parent programs to make significant gains in this area.

Overall, all four transition programs for parents of adolescents with ASD measured some form of positive affect or characteristics involving either parental empowerment, problem-solving, parental advocacy ability, increasing parents' expectations regarding their adolescents' post-transition outlook, parent-child relationship, and parental interactions (Table 2.1). However, only outcomes of parental empowerment, problem-solving, advocacy ability, and increasing expectations for their adolescent were found to significantly improve post-intervention, suggesting areas of growth for future transition programs.

*Negative Affect:* Only one of the four transition programs measured aspects of what I am labelling as "negative affect" or "negative characteristics" (Table 2.1). "Negative affect" or "negative characteristics" represent attributes that are undesirable and/or attributes that present as a challenge to the parents within the process of helping their adolescent through the transition process. In three of the four negative affect outcomes measured in Transitioning Together, the intervention group did not reach significance compared to the control group for reducing perceived parental general life stress, decreasing perceived burden in regards to parental interactions with their adolescent, and decreasing frequency of expressed emotion related to criticism (DaWalt,

Greenberg, & Mailick, 2018, p. 257). However, after intervention, parents in the intervention group did have a statistically significant decrease in self-reported depressive symptoms compared to the control group (p. 257). No other studies' interventions targeted similar negative affect characteristics / attributes (Table 2.1). This could suggest that these currently available transition programs do not present content or exist in a format that specifically target negative outcome areas. On the contrary, these programs may be equipping parents with knowledge and/or positive experiences, rather than "reducing" or "overcoming" negative attributes.



<b>Intervention</b>	<b>Measures of Knowledge</b>	<b>Measures of Positive Affect</b>	<b>Measures of Negative Affect</b>
<p>Transitioning Together</p> <p>(DaWalt, Greenberg, &amp; Mailick, 2018)</p>	<p>Open-ended question survey to assess for salient content learned through the program</p>	<ul style="list-style-type: none"> <li>• Parental problem solving (Problem-Solving Subscale from the Family Empowerment Scale)</li> <li>• Parent-Child Relationship Quality (Positive Affect Index)</li> <li>• Feelings of Happy / Proud towards Adolescent (5-point Likert scale to assess for frequency)</li> <li>• Five Minute Speech Sample (FMSS coded for expressed emotion towards adolescent – Warmth and Positive Remarks)</li> </ul>	<ul style="list-style-type: none"> <li>• Parental Depressive Symptom (CES- Depression Scale)</li> <li>• General Life Stress (Perceived Stress Scale)</li> <li>• Parental Subjective Burden in Interactions with the Adolescent (Zarit Burden Interview)</li> <li>• Five Minute Speech Sample (FMSS coded for expressed emotion towards adolescent – Criticism)</li> </ul>
<p>Volunteer Advocacy Training – Autism</p> <p>(Taylor, Hodapp, Burke, Waitz-Kudla, &amp; Rabideau, 2017)</p>	<p>Knowledge regarding Adult Service System (Researcher-developed involving 25 multiple choice question)</p>	<ul style="list-style-type: none"> <li>• Parental self-perceived comfort and/or skilled ability in advocating for their adolescent (Researcher-developed measure with 10-items involving 5-point Likert Scale ratings)</li> <li>• Parental Empowerment (34-item Family Empower Scale measuring three domains: family, service system, and larger community/political environment)</li> </ul>	<p>None reported</p>
<p>Specific Planning Encourages Creative Solutions</p> <p>(Hagner et al., 2012)</p>	<p>None Reported</p>	<ul style="list-style-type: none"> <li>• Adolescent &amp; Parent Expectations for the Future (Expectation Sub-Section of the National Longitudinal Transition Study – 2)</li> </ul>	<p>None Reported</p>

<b>Intervention</b>	<b>Measures of Knowledge</b>	<b>Measures of Positive Affect</b>	<b>Measures of Negative Affect</b>
Parent Support Group guided through Model of Human Occupation (MOHO)  (Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015)	Qualitative thematic analysis regarding feasibility and acceptability of parent support program (Themes for knowledge acquisition include “swapping family stories”, and “creating safe space to ask questions”)	Qualitative thematic analysis regarding feasibility and acceptability of parent support program (Themes related to positive outcomes / attributes and “experiencing an epiphany”, “holding adolescent to higher standards”, “transformation”, and creating “meaningful moments”)	None Reported

**Table 2.1 Parent Outcomes Measured in Transition Intervention Programs**

<b>Parent Training Program</b>	<b>Strengths to Promote Validity</b>	<b>Threats to Validity</b>
Transitioning Together (DaWalt, Greenberg, & Mailick, 2018)	<ul style="list-style-type: none"> <li>• Manualized Intervention allowing for future replication</li> <li>• Specific steps taken to maintain treatment fidelity               <ul style="list-style-type: none"> <li>○ Intervention staff participated in training to learn about study goals and procedures, review curriculum</li> <li>○ Checklists</li> <li>○ Role-playing sessions</li> <li>○ Debriefing after each session</li> <li>○ Group facilitators had 2x/month supervision meetings</li> </ul> </li> <li>• Selected assessments with strong Cronbach’s alpha for the population, suggesting that measures are sensitive and appropriate for measuring the desired outcomes</li> <li>• Utilized a mixed method of both quantitative and qualitative results to help support / bolster one finding to another.</li> <li>• No statistical group difference for parent variables of parental education, ethnicity, income, or employment status</li> <li>• Randomized Control Trial</li> </ul>	<ul style="list-style-type: none"> <li>• Although controlled for during statistical analyses, there was a statistical significance in the groups regarding the IQ of the child (i.e. intervention group adolescents had higher IQ), with researching noting that higher IQ related to lower scores related to warmth, parent–child relationship quality, and feeling happy/proud</li> <li>• Outcomes were primarily related to parental well-being or parent-child interactions rather than those specific to the transition process</li> <li>• Predominantly white, higher income families with all participants from Midwest region</li> <li>• Convenience Sampling potentially resulting in recruitment bias</li> <li>• Only one parent in the family was asked to participate in assessments for reports’ findings, with the majority of those participating being mothers</li> <li>• Parents had children with “high-functioning” autism which may make results less generalization for parents who have children with other presentations of ASD</li> <li>• No follow-up to see if findings were sustained any time after post-intervention &amp; 8.8% attrition rate</li> </ul>
Volunteer Advocacy Program – Transition	<ul style="list-style-type: none"> <li>• Statistical exploratory analyses to see within and outside group differences in results,</li> <li>• Statistically controlled for baseline characteristics in all reports’ findings as relevant</li> </ul>	<ul style="list-style-type: none"> <li>• Attrition of participants but no mention of accounting for attrition during analyses</li> <li>• Convenience Sampling which may lead to recruitment bias</li> </ul>

Parent Training Program	Strengths to Promote Validity	Threats to Validity
(Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017)	<ul style="list-style-type: none"> <li>• Offered both in-person and off-site (distant learning) options to parents, which separate statistical analyses for all.</li> <li>• Randomized Control Trial</li> <li>• Follow-up of outcomes at 6 months and 12 months to determine if changes to results occurred or if effects remained the same</li> <li>• Manualized intervention with some level of individualization as appropriate for area</li> </ul>	<ul style="list-style-type: none"> <li>• Weak fidelity measures, involving creating six learning objectives specific to each session with group facilitators reviewing at the end to see if objectives were met on a 3-point scale.</li> <li>• Demographics include primarily white, mainly educated / middle class, in Southern U.S. reducing generalizability of results to other demographics</li> </ul>
Specific Planning Encourages Creative Solutions (SPECS)  (Hagner et al., 2012)	<ul style="list-style-type: none"> <li>• Specific steps taken to maintain treatment fidelity through use of a manual with opportunities for high individualization <ul style="list-style-type: none"> <li>◦ Checklists and Observations with two raters establishing .91 inter-rater reliability</li> </ul> </li> <li>• Delivered any parent training sessions individually if parents were unable to attend the group</li> <li>• Randomized Control Trial</li> <li>• Statistical Analyses indicated no pre-intervention differences for between groups for age, race, gender, and adaptive behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Attrition of two participants but no statistical analyses to determine if attrition rate affected results</li> <li>• Lack of statistical analyses to determine power for reaching significant, especially with a small sample size.</li> <li>• Use of convenience sampling which may result in recruitment bias</li> <li>• Predominantly White, no reported SES, only participants in the Northeast, and predominantly male sons for parents.</li> <li>• Only one parent per family participated in data collection even though other family members received the intervention</li> </ul>
Parent Support Group guided through Model of Human Occupation (MOHO)	<ul style="list-style-type: none"> <li>• Created an intervention utilizing principles from a well-established theory (i.e. Model of Human Occupation)</li> </ul>	<ul style="list-style-type: none"> <li>• No manualized intervention reducing ability to replicate the intervention</li> <li>• Lack of fidelity measures for ensuring intervention ran as intended</li> <li>• Small Sample size with substantial attrition rate</li> </ul>

<b>Parent Training Program</b>	<b>Strengths to Promote Validity</b>	<b>Threats to Validity</b>
(Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015)		<ul style="list-style-type: none"> <li>• Convenience sampling which may lead to recruitment bias</li> <li>• No reporting of demographic information of included participants reducing ability to generalize findings to other groups</li> </ul>

**Table 2.2 Critical Appraisal of Parent Training Programs Regarding Transition**

*Critically Appraising Parental Programs on Transition*

Table 2.2 highlights key strengths and threats to validity for each of the four programs in order to critically appraise the research rigor of the evidence available for parent training programs for parents of transition-aged youth with ASD. Table 2.2 elucidates trends in regards to the different strengths and threats to validity that were determined for each study outlining a specific parent training program for parents of transition-aged youth with ASD. Of note, three out of four studies utilized a randomized control trial study design, which randomly assigns all participants to either the intervention or control group, as well as, attempts to minimize group differences so that measurable outcomes are related to the intervention thereby increasing credibility of findings (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). In addition, at least three out of four interventions were manualized, suggesting that some level of training, and fidelity were maintained, as well as, the potential to replicate the intervention. (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Finally, in the same three out of the four interventions, researchers found no statistical significance in differences within key demographic factors at baseline for all parents in each group per study, which increased confidence that the observed outcomes were a result of each study's respective intervention as opposed to differences between groups at baseline. (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

Similarly, in regards to threats to validity, in three out of the four intervention

studies all parental participants were predominantly white, from middle to high socioeconomic status, and/or had college-level or greater education (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Also the majority of results that were reported were from mothers (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). This reduces the ability to generalize results to populations with different racial, socioeconomic, and educational backgrounds, as well as, to fathers / other caregiver. The last study did not report any demographic information (Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015). In all four studies, the parents had adolescents with “high functioning” autism, which may impact the ability to replicate results to parents whose children have a presentation of autism resulting in more behavioral and/or social challenges, especially in regards to changing expectations.

All four studies utilized a small sample size, with the smallest being 6 parents and the largest being roughly 50 parents, which as a whole prevents generalizability to the larger population (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Lastly, all four studies utilized convenience sampling, which may potentially have resulted in recruitment bias and/or a subset of the population not being represented due to that population’s lack of availability to agencies / resources from which the participants were recruited (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Finally, all four studies experienced some level

of attrition, but none of the researchers conducted statistical analyses to determine if those participants who left were different in any key demographic manner compared to those participants who stayed (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Overall, training programs for parents of transition-aged youth with ASD are preliminary as reported in each of the studies, and therefore each study faced notable, and yet similar threats to validity that should be considered for future trials and/or development of training programs.

*Critically Appraising Parental Programs on Transition through a Disability Studies  
Framework*

As noted in both Chapter 1 and earlier in Chapter 2, much of the research literature regarding individuals with disabilities fails to acknowledge how societal attitudes, and other socio-temporal factors impact our construction of the notion of disability. As such, the research studies detailing training programs for parents of transition-aged youth with ASD face similar challenges in regards to considering the disability studies perspective on their research outcomes. For example, researchers measure the parents' expectations for their adolescent through preconceived, tradition and/or bias benchmarks regarding success, such as the adolescent attaining competitive employment, attending 2 or 4 year colleges, living independently, etc. These benchmarks do not consider other markers of post-transition success that are meaningful to the adolescent, such as ability to advocate for self in a variety of contexts, maintaining a level of independence that is desirable for the adolescent, etc. In addition, only two of the four



training programs for parents include components for their adolescent to explore his or her own aspirations for the future, so that parents could better understand and support their adolescents' visions (Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015). The lack of adolescents' exploration of post-transition outcomes suggests that other programs failed to consider the inherent biases that parents place on their adolescent due to these parents' own preconceived notions of success. Finally, none of the abovementioned programs addressed the problem outlined in the previous section, which includes understanding how the parents' biases and assumptions regarding adult success and normalcy may be contributing to their adolescents' attaining positive post-transition outcomes. Only one program measured a change in parental expectations for their adolescent post-transition; however, this concept was measured through the expectation section given during the National Longitudinal Transition Study- 2, which considered important changes in expectations in markers such as "obtaining a driver's license" or "being financial self-sufficient", which continue to both arbitrary and related to a bias construction of "normalcy" (Hagner et al., 2012). Thus, the research outlining training programs for parents of transition-aged youth with ASD noted in the abovementioned sections do not appear to consider social factors which present as biases in regards to our construction of the notion of disability.

### **Evaluative Summary: Parent Support Programs for Positive Disability Acceptance**

The previous section within Chapter 2 highlighted research literature regarding transition programs catered towards parents of transition-aged youth with ASD, while this section considers literature outlining programs for parents of children with

disabilities, which promote positivity in accepting disability and parental empowerment. The peer-reviewed literature for these programs are limited; however, the two programs (*Parent to Parent and Disability is Natural*) are outlined due to their emphasis on parental empowerment and/or the use of a disability studies lens' to influence parents' preconceived notions regarding disability and their adolescent.

#### *Parent to Parent Programs – Purpose and Background History*

Parent to Parent (P2P) Training Program is a mentorship program designed to match parents of children with special needs, who have had experience embracing accepting, and understanding their child's disability to parents of special needs who are currently experiencing challenges with doing the former (Santelli, Turnbull, Marquis & Lerner, 1995). The programs' premise involves a "having been there" mentality in which parents who have had similar challenges, issues, and/or experiences can serve as a means to be the most beneficial support to other parents of special needs. Parent to Parent Programs involve "one-on-one" matching of mentor and mentee families so as to individualize and cater a mentee family's needs, which usually involve both emotional and factual support (Santelli, Turnbull, Marquis & Lerner, 1995). P2P programs exist on a local, state, and nationwide scale.

Parent to Parent Programs stemmed from grass-root efforts by parents and service professionals, working in early intervention services (S. Singer et al., 1999). These parents voiced a need for professionals to practice sensitivity when working with the parents as these parents began to accept and maneuver the complexities of their children's disability (Santelli, Turnbull, Marquis & Lerner, 1995). The first formal P2P

program was founded in 1970 in Omaha, Nebraska to service parents of children with what was then deemed as mental retardation (Nelson, 2015). Since, the program has expanded to include parents of children with all different types of disabilities and special healthcare needs, across most states in the country (Parent 2 Parent, n.d.).

*Disability is Natural – Purpose and Background History*

Disability is Natural is a shorthand for a parent resource book (full title: Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities) authored by Kathie Snow. While not explicitly a program, the book outlines content related to raising a child with a disability through “spreading [the] word” regarding the ways people “see and think” about disability (p. 7). By elucidating and questioning common perceptions regarding individuals with disabilities, parents can critically appraise their current decision-making for their child, steer away from more traditional parenting methods, and attempt to re-direct their decision-making to promote greater success for their child with a disability (Snow, 2013).

Disability is Natural is product of Kathie Snow’s own parenting experience with raising a son who has cerebral palsy (Snow, 2013, p.9). When her child was less than three years of age, Kathie attended a Partners in Policymaking program which sparked her interest in the field of disability studies, and understanding the needs of adults with disabilities (p. 12). As part of her project with Partners in Policymaking Program, Kathie wrote about “people first language”, and presented the topic to another class (p. 19). From this initial presentation, Kathie began “public speaking” at more conference (p. 19). Finally, her public speaking led to publishing this book, because the book served as a

resource for parents to reference and answer questions they may have that were not answered during conferences due to lack of time (p. 20).

*Comparing Content and Implementation in Parent Support Programs for Positive  
Disability Acceptance*

Table 2.3 outlines key program content, suggested implementation, and program references to individuals with disability within adulthood (i.e. transitions) in both the Parent to Parent Training Program and *Disability is Natural* Training Materials. Both Parent to Parent Training Programs and *Disability is Natural* have limited guidelines in regards to program content, and implementation. For Parent to Parent Training Programs, the implementation varies by state, and per the preferences of both families involved (S. Singer et al., 1999; Santelli, Turnbull, Marquis & Lerner, 1995; Nelson, 2013). Currently, *Disability is Natural* is not implemented as a program, but rather content is presented either by the author (Kathie Snow) or individual sites / programs, which adapt the content to their needs (*Disability is Natural*, n.d.). Thus, due to the lack of rigorous program procedures for both programs, there is limited research evidence to critically appraise the programs for their intent. However, both programs suggest the need for parents to feel a sense of “hope” for their child’s future, and learn from the experiences of other parents and young adults with disability.

Program	General Content of Programs	Suggested Implementation (i.e. procedures, delivery, duration, intensity, etc.)	References to individuals with disability in adulthood / transition
Parent to Parent Training Program	<ul style="list-style-type: none"> <li>• Program is unique and individualized to each of the referred parents’ needs, and support is given by the mentor parents to the mentee parents in whatever way is deemed natural and effective to both parents (Parent 2 Parent, n.d.).</li> <li>• Identified types of support include (Santelli, Turnbull, Marquis &amp; Lerner, 1995): <ul style="list-style-type: none"> <li>• Emotional <ul style="list-style-type: none"> <li>○ Someone to listen and understand</li> <li>○ Helping in feeling less alone</li> <li>○ Knowledge of others who are doing OK</li> <li>○ Hope for the future</li> <li>○ Way to deal with stress</li> <li>○ Problem-solving support</li> </ul> </li> <li>• Informational <ul style="list-style-type: none"> <li>○ Disability information</li> <li>○ Care for child</li> <li>○ Ways to find and get services</li> <li>○ Community resources</li> <li>○ Financial information</li> <li>○ Respite care information</li> </ul> </li> <li>• Other Program Supports <ul style="list-style-type: none"> <li>○ Group meetings for emotional support</li> <li>○ Group meetings for education</li> <li>○ 24-hour warm line</li> <li>○ Social events</li> <li>○ Activities for other family members</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Each state varies in regards to the programs’ implementation.</li> <li>• Training is provided to “support parents”, who provide the support to the “referred parents”. Training is left to the responsibility of the state (Nelson, 2015)</li> <li>• Frequency and duration of meetings is typically dependent on each family (Nelson, 2015)</li> <li>• No consistent information was available for format of program delivery, as the program is dependent on state and parent preferences.</li> </ul>	<ul style="list-style-type: none"> <li>• No specific mentions about children’s disability in adulthood or the transition process. However, implicitly can be deduced that support parents can provide assistance in this area as referred parents find the need to discuss transition and adulthood.</li> </ul>

Program	General Content of Programs	Suggested Implementation (i.e. procedures, delivery, duration, intensity, etc.)	References to individuals with disability in adulthood / transition
	<ul style="list-style-type: none"> <li>○ Chance to tell others about program</li> </ul>		
Disability is Natural  (Snow, 2013)	<p>Contains several chapters of content based on both personal experiences and disability studies references:</p> <ul style="list-style-type: none"> <li>● <b>History:</b> Provides a brief overview of the Euro-American disability history. The author hopes to educate parents of the past in order for parents to understand current systems, and also make more informed decisions (p. 21-42).</li> <li>● <b>Yesterday’s Influence on Your Child:</b> This chapter provides self-rating assessments to help each parent understand the way “disability” impacts their family; it is meant to be a tool to critically reflect on each parents’ current attitudes, actions, etc. (P. 43-56)</li> <li>● <b>Disability World:</b> This chapter critically examines today’s disability services, laws, and infrastructure by drawing connections to how current practices continue to reflect historical ways of conceptualizing disability (p 57 – 110).</li> <li>● <b>New Attitudes and Actions:</b> This chapter provides the “new attitude” or the different mentality that can be utilized to counter the issues that were highlighted in the previous chapter(s). In this chapter, language is consistently with disability studies ideologies, and the authors provide strategies / suggestions</li> </ul>	<ul style="list-style-type: none"> <li>● Disability is Natural is a book without any associated suggestions for presenting content</li> <li>● Kathie Snow (author) presents as a public speaker and can be booked to present on any of the content areas outlined within the book (Disability is Natural, n.d.).</li> <li>● The website notes how other programs and/or professionals have taken content and adapted it to present to others. However, there is no mention of how these individuals / programs did so, what was the intended outcome, and/or if outcomes were measured to determine effectiveness of the content (Disability is Natural, n.d.).</li> </ul>	<p>Several explicit and implicit references to disability and adulthood are noted throughout the book, some examples include:</p> <ul style="list-style-type: none"> <li>● Discussion of the unemployment rate for adults with disabilities, including potential stereotypical attitudes which may contribute to high rate (p. 59).</li> <li>● Provides personal antidotes regarding conversations with adults with disabilities, including how these adults felt about receiving therapy services as a child (i.e. feeling as if they were never “good” enough or that their functional abilities were not “acceptable”) (p. 13).</li> <li>● Discussing strategies that parents can employ to</li> </ul>

Program	General Content of Programs	Suggested Implementation (i.e. procedures, delivery, duration, intensity, etc.)	References to individuals with disability in adulthood / transition
	<p>on how act in accordance with these ideologies when faced with challenges highlighted in the previous section(s) (p.111-163).</p> <ul style="list-style-type: none"> <li>• <b>A new Therapeutic Landscape and Tools for Success:</b> This section provides suggestions or recommendations apart from “Traditional Therapy”. It considers what ways a child with a disability can receive support / services, which do not perpetuate the need to “fix” the child. The chapter also discusses adaptive technology (p. 164-212).</li> <li>• <b>Real Lives at Home and in the Community:</b> This chapter discusses ways that parents can modify and approach their home life in order to better support their children with disabilities. The chapter discusses the importance for parents to provide their children with disabilities an environment and tools that promote their full participation in our world (p. 213 – 244).</li> <li>• <b>Babies, Toddlers, and Preschoolers:</b> This chapter discusses the early childhood service system, and ways that parents can acknowledge and address the stereotypes within the service system during this time of their child’s life (p. 245 – 276).</li> </ul>		<p>help teach their children with disability to advocate for themselves, so that as adults they can get the correct assistance they may need (p. 169).</p> <ul style="list-style-type: none"> <li>• During select chapters, mentions the importance of “dreaming” in order to maintain aspirations or expectations for a child with a disability (p. 154).</li> <li>• Discusses throughout the book about “Real Life”, which includes adults with disabilities being “fully-participating, responsible members of their homes and communities” (p. 64).</li> </ul>

Program	General Content of Programs	Suggested Implementation (i.e. procedures, delivery, duration, intensity, etc.)	References to individuals with disability in adulthood / transition
	<ul style="list-style-type: none"> <li>• <b>Inclusive Education:</b> This chapter discusses special education, including current service models, laws, etc. It also outlines ways to make education more inclusive / support individuals with disabilities that aligns with the disability studies' ideologies presenting thus far (p.277-346).</li> </ul>		

**Table 2.3 Key Content, Implementation Procedures, and Adulthood References in Disability Acceptance Programs**



### **Implications for Proposed Program Development**

The preceding review of evidence regarding both transition programs for parents of adolescents with ASD, and programs for parents of children with disabilities centered on disability acceptance provides notable insights for informing development and implementation of a program that combines these two focuses (as outlined in the overview of the problem). Foremost, the current evidence of transition programs for parents of adolescents with ASD supports the use of a group format to promote social learning; These groups provide a place for parents to share their thoughts / concerns about their adolescent's transition into adulthood, and creates an environment conducive to shared problem-solving opportunities. In addition, these programs emphasize the use of goal-setting as a means for parents to individualize group content to their specific needs, while also providing a means to hold themselves accountable for applying learned content. The complexities of the transition process necessitate that knowledge regarding service systems and procedures be imparted to parents in these groups to improve their readiness to both understand and handle the transition process. Similarly, current programs and/or resources for parents of children with disabilities centered on disability acceptance underscore the importance of establishing emotional support for parents to move parents' into positively accepting their child's disability. Finally, both parental programs for transition preparation and disability acceptance appear to utilize some didactic components involving learning about disability, albeit one group doing so conventionally (i.e. learning about the adult clinical presentation of symptoms of the condition, etc.), while the other considering socio-temporal factors contributing to

disability issues.

Overall, while the literature regarding both programs for parents of transition-aged youth with ASD regarding the transition process and programs for parents of children with disabilities regarding positive disability acceptance provide some clear, effective guidelines for how to structure these programs, considering their limitations may also shed light as to how to design / implement a future program for parents of transition-aged youth with ASD which looks to extend disability acceptance (through a social model) in regards to transition process. For example, many current parent programs for transition-aged youth fail to present content following known, reputable knowledge change theories. In addition, only half involve the adolescent in these conversations. It appears that an effective program addressing the problem outlined in Chapter 2 involves opportunities for parents to critically reflect about their own biases and assumptions regarding disability in relation to how it impacts their expectations for their child. Involving the adolescent may help to address parents' biases, and allow for opportunities for joint decision making, and the creation of new expectations that better reflect the adolescents' aspirations.

## **CHAPTER THREE – Description of the Proposed Program**

### **Program Description and Overview**

*Re-Imagine Transition and Adult Success* is a proposed critical reflection program for parents of transition-aged youth with Autism Spectrum Disorder (ASD) that recognizes that these parents are key decision-makers who will continue to influence the lives of their children as they age. The program also recognizes that these parents are impacted by their own biases and assumptions regarding disability and traditional markers of adult success. These assumptions and biases likely are permeating throughout parents' decision-making, thereby contributing to the perpetuation of "poor transition outcomes" in their adolescents as adults. *Re-Imagine Transition and Adult Success* serves as a means to disrupt this cycle by helping parents critically evaluate and identify their expectations for their adolescent. Utilizing a group format, parents will first learn about the field of disability studies and the social model of disability. Once gaining a basic knowledge base, parents will work alongside a trained professional (i.e. occupational therapist) to use this knowledge as a means to critically reflect on their own assumptions about disability, including how these views shape their visions about their children's future. Finally, the program will provide guided opportunities for parents to employ their new reflections as a catalyst for reshaping their post-transition expectations for their children, which will ultimately target the greater issue previously outlined.

### **Program Features**

As outlined in Chapter 2, both the research literature involving parent education and training programs for parents of transition-aged youth with Autism Spectrum

Disorder (ASD), as well as, parent programs fostering position disability acceptance for parents of children with disabilities were reviewed in order to select key content and features for this proposed program. The following subsections include an outline of these key program features, including methods, delivery, content, etc.

#### *Program Methods & Process of Delivery*

*Re-Imagine Transition and Adult Success* will be a six-week group program occurring once per week for two-hour sessions. Led by a trained healthcare professional (i.e. occupational therapist), the group will consist of between six to twelve parents who have a transition-aged youth with an ASD diagnosis. The group method allows for social learning, one of the critical components involved in eliciting the desired change in the outcomes for the parent-training transition programs highlighted in Chapter 2. The program will involve mixed didactic training regarding disability studies content pertinent to the development of post-transition outcomes, as well as, group critical reflection, regarding learned content, personal assumptions, and personal feelings with exposure to content.

The program facilitator will utilize multi-modal teaching strategies during the didactic training portion, including PowerPoint presentations, use of concrete, real life examples, hands-on learning opportunities, written prompts, etc. in order to cater to different learning styles, as outlined in the VARK, guide to learning preferences (Othman & Amiruddin, 2010). The VARK guide to learning preferences states that each learner has preferences to visual, aural, reading/writing, and kinesthetic learning means, and presenting material to these preferences can help to increase attention and interest to

content (p. 652). Use of this model to inform presentation of materials throughout the course acknowledges the importance presenting didactic components in a way that can be reached by most if not all participations. As noted in Chapter 2, other parent-training programs for transition likely did not consider the impact of personal learning styles on content delivery which may have impacted the effectiveness of knowledge gain in participants. Finally, both individual and group critical reflection regarding adolescents' post-transition outcomes will be targeted through discussions and rating scales.

Foremost, parents will partake in activities which promote individualization of content to their specific life situation and/or adolescent, as well as, provide a means for goal setting in order to hold themselves accountable for generalizing learned content (i.e. letter of intent, implicit association bias test); Goal setting and individualization were other key mechanisms of actions found in current parent training programs related to transition (Chapter 2). Lastly, group critical reflection, which was a component not necessary targeted in the current parent training programs outlined in Chapter 2 but deemed necessary in *Re-Imagine Transition and Adult Success* for eliciting one of the desired program outcomes of critically evaluating parents' current post-transition expectations for their adolescent with ASD, will be incorporated through tenants of reflective practice (Thompson & Campling, 1996). For example, group sessions are structured so as to promote the reiterative process of reflective practice, such as exposing parents to relevant content (i.e. disability studies), answering / asking guided questions to the program facilitator, other parents, and adults with ASD, watching videos and other adults with disabilities living as adults, unpacking their assumptions (i.e. feelings),

sharing personal antidotes, and identifying the impact of their realizations. This employs reflective learning tenants which include reading about topics that interest you, asking others why they do the things they do, watching what goes on around you, being attuned with your feelings regarding the presented information, discussing viewpoints, and thinking about the value of content learned (Thompson, 2015). Overall, *Re-Imagine Transition and Adult Success* utilizes a multi-faceted approach, involving social learning, multi-modal didactic training, and reflective practice to elicit change in its desired outcomes.

#### *Program Content*

The program will be grouped to promote the reiterative reflection process:

**Individual Exploration, Content Exploration, and Group Reflection.** The **Individual Exploration** sessions occur during Week 1 and Week 6. During Week 1, the group establishes safe-discussion practices, group norms, reviews the transition process and its importance for their adolescents, as well as, establishes baseline regarding content knowledge. Similarly, during Week 6, the group applies content knowledge learned from previous weeks in activities to demonstrate knowledge gain on the relevant content areas, and summarizes ways to apply content to their lives as the group concludes. These activities during both Week 1 and Week 6 allow for parents to individualize the group's content and purpose to their specific needs.

The **Content Exploration** sessions include Week 2 and Week 4, and embody the first three components noted in reflective practice (i.e. reading about relevant topics, asking others around you about said topics, and watching one's environment)

(Thompson, 2015, Reflective Practice Section, para.1, para. 3). For example, during Week 2, the group learns about the field of disability studies, including the disability rights movement, social model of disability, ableism, and constructions of normalcy. During Week 4, the group learns about current post-transition markers of success, and receives exposure to the first-hand experiences of alternative post-transition outcomes for adults with ASD. During both these weeks, multi-modal learning strategies are utilized to deliver content to parents that best caters to each of their learning styles as outlined through VARK's learning style guide (Othman & Amiruddin, 2010).

Finally, the **Group Reflection** sessions include Week 3 and Week 5, and incorporate activities, which bolster the final three components of reflective practice (i.e. being attune to your emotions or assumptions, talking or sharing your view points, and thinking about how these realizations matter) (Thompson, 2015, Reflective Practice Section, para. 4-5). During Week 3, parents are provided guided discussion questions as to unpack assumptions, share viewpoints, and think of the impact of the content learned during Week 2 (Disability Studies). Similarly, during Week 5, parents partake in similar activities, including guided discussion as during Week 3, but in order to help process content learned during Week 4 (Post-Transition Outcomes). Sessions under the **Group Reflection** theme take into consideration that disability studies as a field provides an “alternative” way to conceptualize everyday disability ideas, which likely requires reflective practice as a means to dissect assumptions and eschew new ways of thinking. Special consideration is placed on understanding parents' personal assumptions as they relate to making important decisions for their adolescents during the transition process (as

noted in Chapter 2 during the model of the problem).

Table 3.1 provides a break-down of each week's suggested learning objectives presented with the key content and suggested activities per week. Appendices A, B, C, and D present detailed examples of some key program activities, including select activities in Weeks 1 and 2.



Week	Meeting Topic	Learning Objectives	Key Concepts	Suggested Activities
1	Introduction & Establishing Group Dynamics	<ul style="list-style-type: none"> <li>- Complete Pre-Intervention Assessments</li> <li>- Brief overview of “transition”, “transition outcomes”, and “transition process”</li> <li>- Familiarize one another with each parents’ backgrounds, including adolescent</li> <li>- Establish group norms and expectations, including guidelines for safe, effective group participation</li> <li>- Discuss “Letter of Intent”, including what it is, purpose, and provide examples</li> <li>- Draft Initial “Letter of Intent”</li> </ul>	<ul style="list-style-type: none"> <li>- Transition in Children with ASD: refers to the adolescents’ movement from primary / secondary school / school-based services, to post-secondary options / adult-based services</li> <li>- Letter of Intent: a tool for parents to document their preferences, wishes, and expectations on providing care for / supporting their child with ASD as they transition into adulthood.</li> </ul>	<ul style="list-style-type: none"> <li>- Complete Implicit Association Test –Disability</li> <li>- Draft “Letter of Intent”</li> <li>- Complete Rating Scale of Social and Medical Model Factors</li> </ul>
2	Disability Studies Overview	<ul style="list-style-type: none"> <li>- Discuss Brief History of Disability Rights / Disability Studies Field</li> <li>- Distinguish Medical versus Social Model of Disability</li> <li>- Review Common Stereotypes / Misconceptions about Disability</li> </ul>	<ul style="list-style-type: none"> <li>- Disability Rights Movement</li> <li>- Social Model of Disability</li> <li>- Discussion about Normalcy and Ableism</li> </ul>	<ul style="list-style-type: none"> <li>-PowerPoint Presentation / Lecture</li> <li>-Readings from <i>Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities</i></li> <li>- Case Scenarios Evaluated through Social Model Lens</li> <li>-YouTube Videos</li> </ul>
3	Group Reflection I – Disability Studies	<ul style="list-style-type: none"> <li>- Critically reflect on pre-existing biases/assumptions about disability, the social model of disability, disability studies, and the implications for decision-making for parenting</li> </ul>	<ul style="list-style-type: none"> <li>- Provide awareness regarding pre-existing assumptions about disability and its impact on parenting a child with a disability, including how it</li> </ul>	<ul style="list-style-type: none"> <li>-Facilitated group discussion through verbal, written, and digital means</li> </ul>

Week	Meeting Topic	Learning Objectives	Key Concepts	Suggested Activities
			<ul style="list-style-type: none"> <li>contributes to the formation of the child's expectations</li> <li>- Utilize modified Neil Thompson's reflective practice reiterative tenants</li> </ul>	
4	Awareness of Different Post-Transition Outcomes	<ul style="list-style-type: none"> <li>- Familiarize with "Expected" Post-Transition Outcomes (as outlined in research)</li> <li>- Showcase Different Post-Transition Outcomes from Empowered Adults with Autism</li> </ul>	<ul style="list-style-type: none"> <li>- Traditional Markers of Post-Transition Success</li> <li>- Provide real-life contact / stories from adults with ASD as a means to foster "reflexive" awareness</li> </ul>	<ul style="list-style-type: none"> <li>- Interview Adults with Autism</li> <li>- PowerPoint Presentations</li> <li>- Examples for Current Peer-Reviewed Research Highlighting Research Outcomes</li> <li>- Examples of Self-Advocate Materials / Promotional Materials Highlighting Transition Outcomes</li> </ul>
5	Group Reflection II – Post-Transition Outcomes	<ul style="list-style-type: none"> <li>- Critically reflect on traditional, expected post-transition outcomes compared to alternatively, conceptualized post-transition outcomes</li> </ul>	<ul style="list-style-type: none"> <li>- Provide comparison between what is "expected" as successful post-transition outcomes versus alternative, yet also successful post-transition outcomes (as conceptualized through a disability studies lens)</li> </ul>	<ul style="list-style-type: none"> <li>- Facilitated group discussion through verbal, written, and digital means</li> </ul>
6	Conclusion & Future Implications	<ul style="list-style-type: none"> <li>- Revise Letter of Intent</li> <li>- Complete Post-Intervention Assessments</li> <li>- Provide Local Community Resources</li> <li>- Discuss Future Implications of Course Content</li> </ul>	<ul style="list-style-type: none"> <li>-Summarize the reflective practice tenants to program content, and for future use</li> </ul>	<ul style="list-style-type: none"> <li>-Re-complete the IAT-Disability</li> <li>-Re-complete the Rating Scale of Social and Medical Model Factors</li> <li>-Revise Letter of Intent</li> <li>-Complete Additional Case Scenario to Code for Disability Studies Knowledge</li> </ul>

**Table 3.1 Weekly Program Content Outline for *Re-Imagine Transition and Adult Success***

### *Roles of Program Personnel*

*Re-Imagine Transition and Adult Success* is still in the development phase. As such, the following represents potential roles and responsibilities required to initiate a pilot program:

- *Partner Organization* The partner organization will include two personnel – the funder and the overseer of operations.
  - o *Funder* – The funder is responsible for providing all overhead costs of the program, including materials to run each group session, such as copies of worksheets, a laptop computer, access to the internet, writing implements, overhead projector, and refreshments. Other overhead costs will include small compensation for each program participant (i.e. \$25 Visa™ Gift Cards), and recruitment advertising. Lastly, the funder will secure a room at the facility for each 2-hour session, occurring 1x/week for 6 weeks.
  - o *Overseer of Operations* – The overseer of operations is a representative from the partner organization whose primary role is to serve as a liaison between the program facilitator / implementer, and the partner organization’s personnel, including the program funder. Prior to the program implementation, the overseer of operations will recruit program participants through the partner organization’s clientele and advertising channels, providing a list of potential participants to the program implementer. During the program, the overseer will provide weekly updates to the funder about the use of all allocated funds, be available on-

site to ensure the availability / continual access of all requested materials during each group session, and contact all participants prior to each group session to decrease the likelihood of attrition. Lastly, the overseer of operations will be involved in collecting weekly feedback from participants and program implementer, brainstorming and implementing solutions to on-site problems that may arise during the course of the program with the program implementer, and presenting feedback for the funder and other important partner organization personnel at the conclusion of the program.

- *Program Staff* - The program staff will include the program implementer, program facilitator, program volunteers, and two to three adults with ASD from local community.
  - o *Program Implementer* - The program implementer will be the creator (this author) or another doctorate-level healthcare professional who has received training about the program manual, and program implementation by said author. The doctorate-level healthcare professional should ideally have experience in facilitating said group at least 4 to 5 times prior to becoming a program implementer. Before the start of the program, the program implementer is responsible for securing a partner organization by presenting research literature, program objectives, and breakdown of costs to both the funder and overseer of operations. In addition, prior to the start of the program, the program implementer must meet with and train the

program facilitator and program volunteers regarding program content, and outcome measures; the program implementer will also assist in the recruitment and screening of potential program participants. Finally, prior to the start of the program, the program implementer will schedule all weekly follow-up meetings with all relevant personnel for the duration of the program. During the program implementation phase, the program implementer will have weekly meetings with program facilitator for fidelity checks, as well as, be present during all group sessions to serve as support as necessary. During the program implementation phase, the program implementer will work with the program volunteers to administer any relevant outcome measures. Finally, at the conclusion of the program, the program implementer will provide final checks regarding all analyzed outcome measures with the program volunteers, provide an updated summary of program results to partner organization members, and conduct meetings to gather feedback on program from participants and program staff for future revisions.

- *Program Facilitator* – The program facilitator will be a master-level or higher healthcare professional, including but not limited to occupational therapist, psychologist, social worker, etc. with at least 2 to 5 years' experience working with individuals with ASD, and their families. During pilot program initiation, I will serve as the program facilitator. Special consideration will be given to those professionals with additional

experience working with transition-aged youth with ASD. Prior to program start, the program facilitator is responsible to attend 4 to 5 -hour training with program implementer to learn content, and implementation as outlined in the program manual. During program implementation phase, the facilitator will conduct each group session (1x/week for 2 hour sessions, for 6 consecutive week), which will comprise of presenting content, facilitating group discussion, managing group dynamics, and fielding parent questions. Also, after each week, the program facilitator will meet with program implementer for fidelity checks to ensure implementation as outlined in the program manual, and communicate about group dynamics, including any potential issues related to participation, and content presentation. Finally, at the conclusion of the program, the facilitator will participate in all post-program meetings with other program staff to offer feedback and opportunities for continual improvement of the program.

- *Program Volunteers* – Two to three program volunteers will be recruited from a local university. A volunteer must be a student currently enrolled in a masters-level or doctorate-level degree program for either occupational therapy, psychology, or social work. The volunteers' primary responsibilities will be to assist the program implementer with assigned administrative tasks, including but not limited to creating information pamphlets about the program, administering assessments and other

program outcome measures to participants, analyzing program outcome measures under the supervision of the program implementer, answering program inquiries, etc. Program volunteers must routinely communicate with program implementer to ensure fidelity with administering and analyzing any outcome measures. At least one program volunteer (on a rotating basis) can assist the program facilitator on the day of each group session with technical and other logistical tasks. Finally, all program volunteers will participate in post-group meetings with other program staff and partner organization members to provide feedback about future program implementation.

- *Adults Volunteers with ASD from Local Community* – Either two or three adults with ASD from the local community will be recruited by the program implementer at least one month in advance from the start of the program utilizing local agency and partner organization channels. The adults with ASD volunteers must each meet individually with the program implementer and program facilitator to discuss program learning objectives, and to develop necessary accommodations for each individual. During week 3, all adults with ASD volunteers will meet again at the partner organization in a group to help in didactic / experiential components involved during Week 3, including sharing their personal antidotes to program participants. At the conclusion of program, the adults with ASD will be invited to provide feedback to the program implementer.

### *Intended Recipients and Recruitment Procedures*

The intended recipients for *Re-Imagine Transition and Adult Success* include parents and/or other legal caregivers of transition-aged youth with ASD. Parents and/or legal caregivers should be 18+ years of age, and identified as either the mother, father, and/or legal guardian of the transition-aged youth. Both parents are encouraged to participate, but each family should not exceed three parents and/or legal caregivers in attendance during the course of any given program. The transition-aged youth should be between 13 and 18 years of age, and diagnosed with ASD as determined through the DSM-V. The main exclusion criteria for parent participants may include lack of informed consent, inability to complete written questionnaires despite being provided appropriate accommodations, and less than 70% of class attendance (for recording of outcomes).

Recruitment will occur by the program implementer and partner organization by advertising through the partner organization channels, as well as, through other local autism agencies, including but not limited to hospitals, outpatient facilities, schools, group homes, etc. Advertising can include ads in each organizations' monthly newsletters, and/or websites. Screening will involve parents filling out demographic questionnaires, and providing legal documentation (i.e. driver's license or state ID) as a means to check questionnaire data. The autism diagnosis can be confirmed through either the administration of the Autism Diagnostic Observation Schedule (ADOS) by an independent, blind assessor (ideally provided by the partner organization) to each parents' transition-aged youth prior to the start of the program or through most recent medical documentation. More information about recruitment can be found in **Chapter 6-**



**Dissemination Plan.****Program Outcomes**

There are two primary goals for *Re-Imagine Transition and Adult Success* 1) to increase knowledge or awareness regarding disability studies, disability rights, the social model of disability, and the implications all the former have regarding adolescents' post-transition outcomes and 2) to support parent participants in identifying and critically reflecting upon disability, and what constitutes as adulthood success. The secondary goal will be to determine the program's acceptability and feasibility for parents.

The first primary goal (i.e. increasing knowledge and awareness about disability studies, disability rights, and the social model of disability through application of content to understanding the implications of all the former on adolescents' post-transition outcomes) will be measured through a researcher-created, 9-point Likert scale. This scale is called The Rating Scale of Social and Medical Model Factors Impacting Adulthood Outcomes, and fully outlined in Appendix E. The rating scale involves rating the extent to which the parents believe their child's ability to engage across employment, educational, housing, adult daily life skills, and leisure participation relies on skill deficiencies or social, physical, and attitudinal barriers. This scale will measure awareness and/or knowledge of disability studies in that if parents are more knowledgeable or aware of disability studies content then they will be more likely to rate factors related to this content as influential to their child's future success as an adult.

The second primary goal (i.e. identifying and critically reflecting upon participants' current assumptions regarding disability and what constitutes as adulthood

success) will be measured through pre/post-completion of the Implicit Association Test – Disability. The Implicit Association Test – Disability rates the strength of automatic preference an individual has for either abled or disabled preference across a 5-point scale (i.e. Strong Automatic Preference for Abled Persons, Slight Automatic Preference for Abled Persons, Neutral, Slight Automatic Preference for Disabled Persons, and Strong Automatic Preference for Disabled Persons) (Pruett & Chan, 2006). This measure will assess parents' ability to identify and critically reflect upon their assumptions and/or expectations regarding disability and what constitutes as adulthood success in that if parents are exposed to an intervention that provides a means to identify and critically reflect on topics of disability and adulthood success, then they will likely experience a reduction in their bias towards abled individuals and/or ableist notions. Finally, the secondary goal of evaluating program acceptability and feasibility will be measured through an open-ended questionnaire that allows parents to list likes, dislikes, feedback, and other suggestions. Interviews will be conducted with participants after group participation as needed.

### **Potential Barriers and Challenges to Program Implementation**

As with any other program development, *Re-Imagine Transition and Adult Success* has its own set of likely barriers and challenges in order to actualize and implement the program content. Table 3.2 outlines these potential barriers and challenges, while also proposing several solutions.

Potential Problem	Proposed Solution
Securing Funding for Program Implementation	<ul style="list-style-type: none"> <li>- Apply for local, state, and/or federal grants related to transition services for children with disabilities</li> <li>- Partner with local organization with allocated budget for transition services and/or parent training (i.e. school districts, Partner 2 Partner, hospitals, outpatient facilities, private practices, etc.)</li> </ul>
Limited Attendance	<ul style="list-style-type: none"> <li>- Provide on-site childcare (if possible) if parents cite difficulty of attendance due to difficulties securing childcare during group sessions</li> <li>- Provide distant learning / education opportunities (i.e. stream classes through a digital platform) to accommodate for last minute changes in schedule</li> </ul>
Attrition	<ul style="list-style-type: none"> <li>- Provide small incentive for completion of program (i.e. gift card or certificate)</li> <li>- Provide refreshments during each group session</li> <li>- Contact the parents who may miss a session, and provide personalized solution to prevent attrition of group</li> </ul>
Limited Participation with Group Discussion	<ul style="list-style-type: none"> <li>- Establish group norms, and discuss with each group their specific needs to promote safety in participating in group discussion</li> <li>- Provide multiple modes to participate, including written, verbal, and digital means to cater to different learning styles and personality types</li> </ul>
Negative Feedback about Program Feasibility / Acceptability	<ul style="list-style-type: none"> <li>- During the course of the program provide parents with both anonymous and in-person opportunities to give feedback about course content and program implementation to make accommodations as problems arise</li> <li>- At the conclusion of a program, provide opportunity to leave feedback in multiple methods to ensure continual development of program to meet future participants' needs.</li> </ul>
Filling Program Personnel Positions	<ul style="list-style-type: none"> <li>- Apply for local, state, and/or federal grants that can provide monetary compensation for program implementer and partner organization personnel dedicated</li> <li>- Recruit volunteers from local universities providing programs in relevant fields</li> </ul>

**Table 3.2 Potential Barriers and Proposed Solutions to Implementation**

### Program Conclusive Remarks

*Re-Imagine Transition and Adult Success* is a critical reflection program for parents of transition-aged youth with ASD. The program seeks to address transition

issues in adolescents with ASD by acknowledging that social and attitudinal barriers may be preventing these individuals from being successful in adulthood. As such, content is structured to help dismantle social and attitudinal barriers regarding the transition process by targeting parents, who may be inadvertently perpetuating and/or harboring stereotypes which act as these barriers. The program also draws upon the current literature of parent programming pertaining to transition by employing a group format, imparting knowledge regarding transition, and providing opportunities for goal-setting to individualize content to meet each family's needs. However, the program builds upon the current literature by combining reflective learning tenants and VARK learning styles to help present material in a way that appeals to a variety of adult learners and promotes application of content in a way that is meaningful for each participant.

## CHAPTER FOUR – Evaluation Plan

### Overview and Vision

*Re-Imagine Transition & Adult Success* seeks to address the two primary outcomes of 1) increasing parents' awareness and knowledge regarding disability studies content, including its relevance for transition / transitioning planning for adolescents with Autism Spectrum Disorder (ASD) and 2) identifying, as well as, critically reflecting on these parents' current assumptions regarding disability and what constitutes as success within adulthood. The secondary goal is to determine the intervention's acceptability and feasibility to parent participants.

A program evaluation is required for this course in order to determine which aspects, such as particular program content, service delivery by program implementers, program duration, and environmental factors, need to be altered, intensified, or maintained. Moreover, in the literature there are few if any similar programs; therefore, a program evaluation for this program will be beneficial in expanding upon the limitations of the current body of literature and providing justification for the widespread implementation of this program across other settings. Lastly, program evaluation findings will be shared with the program creator, other program implementers, current and future program participants, and current and future program funders to increase effectiveness of the program delivery, improve upon desired outcomes, and garner support to fund for the continuation of services. In the following sections, the evaluation plan to appropriately measure the programs' outcomes will be outlined.

### **Logical Model**

Figure 4.1 represents a logic model regarding the interactive components of the reflection program

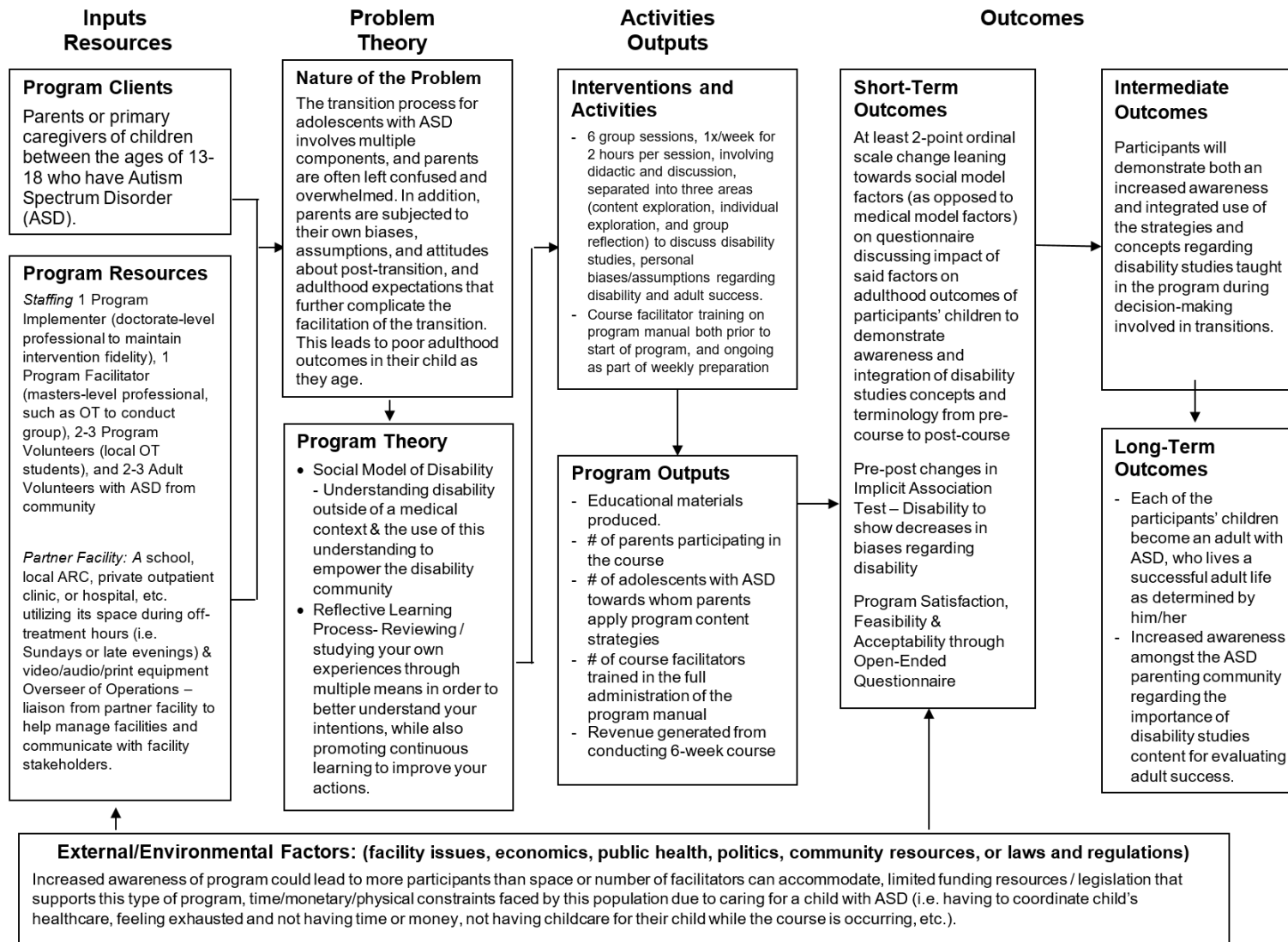


Figure 4.1 Logic Model for Re-Imagine Transition & Adult Success

### **Evaluability Assessment**

To help prepare for a full program evaluation, an evaluability assessment will begin through a small gathering of key stakeholders, such as program implementers including one to two occupational therapists, one future program participant, one young adult with ASD, current or prospective program funders, and all other members involved in program evaluation data collection and management. This meeting will help to solidify program goals and their feasibility of attainment, the means of collecting data, and the future use of evaluation findings. To help refine program goals and reach consensus, supporting documentation, such as relevant research articles regarding the supports and barriers to transition planning with adolescents with ASD, current scope of parental involvement in transition planning, and the value of disability studies content will be used. Other important supporting documentation that will be presented include the preliminary logic model, relevant legislation, the executive summary, and a prospective budget. Finally, the evaluability assessment will involve a negotiation process during large and smaller group meetings with targeted groups of stakeholders to help elicit input from all parties, and to synthesize this input in order to facilitate the readiness of the program for evaluation.

### **Core Purpose**

The core purpose of the program evaluation for this parent critical reflection program is descriptive. As a descriptive program evaluation, the aim will be to determine program participants' level of satisfaction with selected program activities and with the general program intervention delivery. This will be achieved through an open-ended



questionnaire given to parents at the conclusion of the program. In addition, the program evaluation will involve thematic analysis of qualitative information obtained via focus groups and individual interviews from both program implementers and program participants regarding likes, dislikes, benefits, challenges and opinions regarding the various aspects of the program. Ideally, the program evaluation will also be causative to determine if the intervention leads to changes in the desired outcomes noted earlier. Limitations for a causative evaluation exist due to the nature of the program, as the content is meant to be applied in an individualized manner in order to meet each parent's unique family situation. Thus, the main purpose of the evaluation will be descriptive in order to help gather as much information as possible about the various aspects of the program and their effects on the parents' ability to critically reflect.

### **Scope of Evaluation**

The current time period for the evaluation will be for the duration of the initial course, which is six weeks, with each class occurring once a week for two hours. Ideally, the initial course would take place in a pediatric practice, including not limited to an outpatient facility, local hospital, school district, or a local Arc for individuals with intellectual or developmental disabilities. This pediatric practice would also ideally be located in a major New Jersey metropolis. In addition, a partnership with a local university would be secured. Likely, there will be between 6 to 12 program participants for the initial course. Each program participant will complete pre-program and post-program Implicit Association Test – Disability to determine changes in biases / assumptions regarding persons with disability. In addition, a researcher-created, 9-point,

Likert-scale questionnaire will be given for each program participant to rate the degree to which he/she perceives medical model and/or social model factors to impact their adolescent's anticipated outcomes across educational, employment, housing, daily life skills, and leisure both pre- and post-program. This scale will be administered to assess for the intended program outcome of knowledge gain of disability studies concepts, and its ability to integrate this knowledge to informing transition-related decision-making. This Likert-scale is found in Appendix E, and named the Rating Scale of Social and Medical Model Factors in Adulthood Outcomes. The open-ended questionnaire given at the end of each course to participants to determine program acceptability and feasibility will include the following:

- Which components of this course did you enjoy? Why?
- Which components of this course did not meet your expectations? Why?
- Would you recommend this course to another parent? Why or why not?
- What recommendations would you give to the program staff about delivery or content? Why?

### **Evaluation Questions**

At the conclusion of the intervention, program participants will also complete both qualitative, open-ended survey about program content (as seen above) and an interview for general program feedback. Program implementers will engage in interviews to gather their feedback and opinions. In Table 4.1, some additional program evaluation questions to be asked to each relevant stakeholder in order to gather information regarding the programs' effectiveness, acceptability, and feasibility have been included:

Targeted Stakeholder	Relevant Evaluation Question
Primary Population (Parents of Adolescents with Autism Spectrum Disorder)	<ul style="list-style-type: none"> <li>• Does this course help parent participants to identify and critically reflect upon their own biases and assumptions regarding disability and adulthood success by changes in scores of the Implicit Association Test – Disability from pre-course to immediately post-course?</li> <li>• Did program participants demonstrate an increase in knowledge and application of disability studies ideologies as determined through the Rating Scale of Social and Medical Model Factors Impacting Adulthood Outcomes</li> <li>• What were program participants’ thoughts and opinions regarding program content, content’s relevancy, and content presentation?</li> </ul>
Secondary Population (Adolescents with Autism Spectrum Disorder )	<ul style="list-style-type: none"> <li>• What transition-related decision did program participants make with or for their adolescents with ASD that suggests application of disability studies’ ideologies at 3 month follow-up? at 6 month follow-up?</li> </ul>
Program Facilitators	<ul style="list-style-type: none"> <li>• Is a 6-week duration sufficient and/or required to produce the desired results?</li> <li>• Which of the curriculum activities demonstrated a positive correlation with the desired outcomes? To what extent?</li> </ul>
Funders	<ul style="list-style-type: none"> <li>• Is this program cost-effective and is this program well received by the community?</li> </ul>

**Table 4.1 – List of Potential Program Evaluation Questions**

### **Research Design and Methods**

A mixed-methods approach will be utilized. The quantitative research methods will involve a prospective, quasi-experimental repeat measures (pre-test and post-test) design in which program participants serve as their own controls. Both the Implicit Association Test- Disability and the researcher-created, Rating Scale of Social and Medical Model Factors in Adulthood Outcomes will be analyzed utilizing this approach. Finally, qualitative thematic data analysis using NVivo Software will be utilized to

examine parents' open-ended responses and interviews regarding program acceptability, feasibility, and satisfaction to determine key themes in these areas. Emergent themes will ideally help to cross-validate quantitative results from both the Implicit Association Test-Disability and the Rating Scale of Social and Medical Model Factors.

### **Planned Approach to Data Gathering**

The main pathway for all data collection will occur at the start of the class at Week 1 and at the conclusion of class at Week 6 (i.e. 30 to 45 minutes will be allocated for data collection of each participant during these times). Participants will be presented with a paper copy of the Rating Scale of Social and Medical Model Factors in Adulthood Outcomes (i.e. researcher-created Likert-scale) both pre-test and post-test for completion. Accommodations will be provided as needed (i.e. digital means to complete written responses, questions being read to the participant, etc.). Participants will be given the Implicit Association Test – Disability via a program computer during the same data collection points. At Week 6, parents will also be given a written, open-ended questionnaire regarding program acceptability, feasibility, and satisfaction.

After each data collection point, program volunteers will input participants' responses onto program computers designated for data analysis. Ideally, all data will be stored immediately after being collected, requiring careful transcribing by program staff. The Implicit Association Test- Disability will be given online to each program facilitator with responses being recorded after the test. Finally, data collection will be reviewed periodically, about every 2 weeks, to assess for effectiveness and ease of collection

### **Data Management Plan and Data Analysis**

Ordinal data will be obtained from both the Implicit Association Test – Disability and the Rating Scale of Social and Medical Model Factors in Adulthood Outcomes at pre-intervention and post-intervention. In regards to the Implicit Association Test-Disability, appropriate ordinal coding will be conducted (i.e. ranging from -2 for strong preference for abled persons to +2 for strong preference for disabled person. Utilizing Microsoft Excel, statistical analyses will be conducted to determine the percentage of participants who experienced any change in the degree to which participants' automatic preferences align with abled persons or disabled persons (i.e. changing from having a strong automatic preference towards abled persons at pre-test to slight preference to abled persons, and/or to neutral post-test). In addition, the appropriate statistical analyses will occur to determine correlation of changes in Implicit Association Test- Disability with participants' program session attendance, and self-reported satisfaction with program content.

Next, for the researcher-created, Rating Scale of Social and Medical Model Factors in Adulthood Outcomes, ordinal coding will involve a range from -4 (associated with a definitely likely association of medical model factors impacting the participant's child's adulthood outcome attainment) to +4 (associated with a definitely likely association of social model factors impacting the participants' child's adulthood outcome attainment). Similarly, Microsoft Excel will be utilized to perform statistical analyses to determine the percentage of participants who experienced any change in how strongly he/she believed medical model factors versus social model factors impact their child's

ability to attain certain adulthood outcomes (i.e. from definitely likely association with medical model factors to equally both medical and social factors, etc.). Statistical analyses will also be conducted to determine correlations with changes in the Rating Scale of Social and Medical Model Factors in Adulthood Outcomes with participants' program session attendance, and self-reported satisfaction with program content. Each adulthood outcome (i.e. education, employment, housing, daily life skills, and leisure) will be analyzed with the appropriate statistical methods individually, with correlation analysis between outcomes as well. In addition, responses from both ordinal scales will be analyzed for any correlation between changes in one instrument (i.e. Implicit Association Test – Disability) and changes in the other (i.e. Rating Scale of Social and Medical Model Factors in Adulthood Outcomes).

Lastly, the program implementer (myself) will conduct qualitative data analysis by coding themes that emerge through the open-ended questionnaire provided to parents regarding program acceptability, feasibility, and satisfaction through the use of NVivo Software. The frequency of these themes (i.e. 1 point for theme of “enjoyed this program” or 1 point for theme of “learned a lot) will be tallied for each participant and appropriate statistical analyses will be conducted to determine the correlation between frequency of certain themes and changes in the two ordinal measures noted above.

Overall, the data analyses will be done by the program staff, and overseen by the program implementer (myself). Data will be presented utilizing visual graphs and charts, and presented to key stakeholders through a PowerPoint presentation.

### **Conclusion**

A critical reflection program for parents of transition-aged youth with ASD involving disability studies concepts requires intensive program evaluation due to the novelty of such a program. The program is meant to address a critical need identified both throughout the literature and through the lived experiences of these parents. The proposed program evaluation will help to inform and improve upon original program content, and gather support and awareness regarding important societal issues.

## CHAPTER FIVE – Funding Plan

### Program Description

*Re-Imagine Transition and Adult Success* is a proposed parent training program designed towards parents of transition-aged youth with Autism Spectrum Disorder (ASD). This program is designed to help parents' critically examine their expectations for their youth as they enter adulthood through a social model and disability studies' lens. The program will be a six-week course, occurring once per week for two hour sessions (totaling 12 hours of instruction) with groups consisting between 6 to 12 parents. The program combines social learning tenants, multi-modal learning for didactic training, and reflective practice to elicit change in the desired outcomes of increasing disability studies awareness, as well as, critically examining biases/assumptions regarding the transition process, and future adult life for the participants' adolescents. The program is divided into three sections (i.e. individual exploration, content exploration, and group reflection), with activities structured during each section that involves didactic learning, experiential learning, and individual/group reflection through experience sharing. The intent of this structure and the accompanied activities will promote the reiterative reflective process required for parents to become aware of their own biases and assumptions regarding transition and adulthood in order to empower parents to make informed decisions about transition that best supports their adolescents.

In order to potentially actualize *Re-Imagine Transition and Adult Success* within a local community institution in New Jersey which services the intended recipients (i.e. parents of transition-aged youth with ASD), several costs and expenses are to be



expected. This chapter highlights these expenses as well as, potential funding sources that may be procured in order to bring *Re-Imagine Transition and Adult Success* from its current developmental stage into primary implementation phase (i.e. a two year out-look).

### **Available Local Resources**

Currently, no local resources are confirmed for the implementation phase of *Re-Imagine Transition and Adult Success* other than this author's time as the first, trained group facilitator. However, this program's successful creation and implementation will and should rely heavily on the local community resources surrounding the intended recipients of this program. The long term vision for *Re-Imagine Transition and Adult Success* is to create communities in which adults with ASD can lead successful lives, based on the criteria that they choose for themselves and through the support of their community. Thus, in order to actualize this long-term vision, the continuous availability of local resources is necessary to initiate, and maintain the program as a means to empower parents as the primarily catalyst involved in guiding their adolescents through the transition process.

Table 5.1 lists the key local resources that ideally would be procured during the first two years of program implementation:

Local Resource Type	Year 1 (Pilot Phase)	Year 2
Two or three volunteer graduate students (i.e. master or doctorate in occupational therapy levels degree programs for occupational therapy, psychology or social work) from local universities If there are challenges to find long-term volunteers; Level II Fieldwork Students may also be recruited	5 – 10 hrs./week per volunteer for each cycle (6 –weeks) for a total of three cycles to assist in administrative tasks, administering assessments, analyzing data, answering program inquiries, etc. Each volunteer would be recruited to serve one-year terms for continuity	Same as during Pilot Phase
Two or three adults volunteers with ASD from the local community (i.e. contact through disability organizations, group homes, supported employment facilities, etc.)	4 – 6 hours/course per volunteer. Long-term participation is encouraged whenever possible. Each volunteer will meet with program implementer and program facilitator prior to week three to familiarize with program goals / objectives, participate in implementing group activities during Week three of course, and provide feedback at the conclusion for program implementer / facilitator.	Same as during Pilot Phase
Gift cards from local merchants to compensate adults with ASD volunteers and participants for completing programs	Through marketing and advocacy (as done through the roles of the program implementer and/or program volunteers), local merchants may donate gift cards for the first year program participants for compensation in participation (i.e. three courses)	Not applicable as this local resource should be phased out during Year 2 since participant recruitment should ideally be more stable as program gains acceptability and popularity.
Facilities for program (i.e. room, wireless service, phone, and computer) through partner organization	Ideally, during pilot phase the program organization should donate the use of a room to conduct group sessions, store program materials/ assessments, and utilize internet/wireless services to log data onto computers, make phone calls as appropriate, and stream media content during groups as appropriate	During Year 2 and subsequent years, these costs should be added into the budget of the partner organization (see section below for an estimate)

**Table 5.1 – List of Potential Local Resources for Re-Imagine Transition and Adult Success**

As Table 5.1 highlights, several key local resources will be required, especially during the pilot phase, in order to ensure the successful start-up and monitoring for *Re-Imagine Transition and Adult Success*. After completion of the pilot phase, dissemination of outcomes, acceptability of program content, and continual exposure will all be paramount for securing additional funds for subsequent program implementation and promoting sustainability of the program as a long-term community resource for parents of transition-aged youth with ASD.

#### **Needed Resources – Budget**

This section contains a comprehensive budget which estimates all potential expenses required within the first year (i.e. pilot phase), and second year of the program. This includes aspects such as salary, materials, supplies, facilities, etc. In addition, dissemination costs have been estimated, despite a partner organization for this program has not yet being secured. Additional costs for dissemination may occur should the initial pitch towards the selected partner organization (see dissemination plan for more information) is not successful and additional bids to different organizations must be made. As much as possible, expenses have been estimated as they pertain to the State of New Jersey, as it is my current state of residence and the state in which I hold a license to practice occupational therapy. Moreover, if a partner organization chooses to invest in *Re-Imagine Transition and Adult Success* some of the costs related to space, equipment, materials and supplies would ideally be assumed by the partner organization as part of its current budget. For example, if the partner organization is a local high school, the high school's desks, chairs, office supplies, projectors, and screens may be used for the

implementation of the program or programmed into the school's own budget.

Nonetheless, the following budget represents all potential expenses that may be required if the program were to be implemented as a stand-alone entity within the community.

In Table 5.2, estimated costs associated with implementing the program both in Year 1 (Pilot Phase) and Year 2 have been outlined with appropriate justification:

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
<i>Salaries of Personnel</i>			
<p><b>• Program Implementer</b></p> <p>Estimated time of work in role: 10-15 hours/week</p>	<p>During Year 1, it is likely that I will serve as both the program implementer and group facilitator as I would be the only one knowledgeable about the program and trained to administer the content.</p> <p><math>\\$35.00/\text{hr.} \times 15 \text{ hrs.} = \\$525/\text{wk.} \times 6 \text{ wks.} = \\$3150 \text{ per session} \times 3 \text{ sessions (per year)} = \mathbf{\\$9,450}</math></p>	<p><math>\\$35.00/\text{hr.} \times 15 \text{ hrs.} = \\$525/\text{wk.} \times 6 \text{ wks.} = \\$3150 \text{ per session} \times 3 \text{ sessions (per year)} = \mathbf{\\$9,450}</math></p>	<p>Currently, I envision implementing this program on a part-time basis, as I would likely need to support myself with additional income working elsewhere. Due to family support, I will not need to seek additional benefits for this position.</p> <p>The rate \$35/hr. is calculated from the national median hourly wage (Bureau of Labor Statistics, 2018a)</p>
<p><b>• Group Facilitator</b></p> <p>Estimated time of work in role: 3-5 hrs./week</p>	<p>Add cost of an additional 3 hrs./wk. at abovementioned rate to accommodate the work I would do for the role of group facilitator</p> <p><math>\\$35.00/\text{hr.} \times 3 \text{ hrs.} = \\$105/\text{wk.} \times 6 \text{ wks.} = \\$630 \text{ per session} \times 3 \text{ sessions (per year)} = \mathbf{\\$1,890}</math></p>	<p>Hiring an additional healthcare professional (occupational therapist, social worker, and/or masters-level psychologist). The extra 2 hours per week as compared to year 1 includes meeting times with program implementer</p> <p><math>\\$30.00/\text{hr.} \times 5 \text{ hrs.} = \\$150/\text{wk.} \times 6 = \\$900 \text{ per session} \times 3 \text{ sessions (per year)} = \mathbf{\\$2,700}</math></p>	<p>The rate of \$30/hr. was selected as it is likely that the hired group facilitator may be a newer clinician without as many years of experience, as well as, to make role delineation apparent in Year 2 between the program implementer and group facilitator.</p>

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
<p>• <b>Overseer of Operations</b></p> <p>Estimated time of work in role: 3-5 hrs./week</p>	<p>Ideally, during Year 1, Overseer of Operations would assume the responsibilities of this role as part of his/her current position within the partner organization (i.e. administrative assistant).</p> <p>If needed, an additional service pay/stipend can be given to overseer of operations should he/she assume this role in addition to his/her current position within the organization:</p> <p><math>\\$27.00/\text{hr.} \times 5 \text{ hrs.} = \\$135/\text{wk.} \times 6 \text{ wks.} = \\$810 \text{ per session} \times 3 \text{ sessions (per calendar year)} = \mathbf{\\$2,430}</math></p>	<p>Again, in Year 2, this role should ideally be performed by an administrative assistant or representative from the partner organization as part of his/her job description.</p> <p>Additional service pay or stipend can be given as needed:</p> <p><math>\\$27.00/\text{hr.} \times 5 \text{ hrs.} = \\$135/\text{wk.} \times 6 \text{ wks.} = \\$810 \text{ per session} \times 3 \text{ sessions (per calendar year)} = \mathbf{\\$2,430}</math></p>	<p>The rate of \$27/hr. was determined as the national median hourly rate for an administrative assistant is \$18.71/hr., and overtime was calculated as the standard time and half (Bureau of Labor Statistics, 2018b).</p>
<i>Equipment</i>			
<p>• 3 Laptop Computers</p>	<p>Acer Predator Helios 300 Laptop Computer 15.6"</p> <p>Current Price on Amazon.com: \$1,197.00 (02/12/2019)</p> <p><math>\\$1,197.00 \times 3 = \mathbf{\\$3,591}</math></p>	<p>No cost during second year as this equipment should be maintained and likely will not be out-of-date within one year's time.</p>	<p>Currently, listed within several lists as a reliable computer to handle data analysis required for this program (cite here), as well as, built in with Windows 11, the preferred interface for NVivo (see below).</p>
<p>• 1 Cellphone for Program Inquiries</p>	<p>Samsung Galaxy Note 9: 128 GB</p>	<p>No cost during second year as this equipment should be</p>	<p>A smartphone will be necessary to take program inquiries, contact program</p>

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
	Current Price for Unlocked Phone on Samsung.com: \$999.99 (02/12/2019)  <b>\$999.99</b>	maintained and likely will not be out-of-date within 1 year time.	participants, and maintain communication between program staff by the program implementer. A smartphone will allow for text message, data use, and syncing of files as needed.
<ul style="list-style-type: none"> <li>• 1 Computer Projector + Screen</li> </ul>	Vankyo Leisure 3 Mini Projector, Full HD 1080P & 170" Display Supported \$79.99 (Amazon.com, 02/12/2019)  VIVO 100" Portable Indoor/Outdoor Projector Screen \$69.99 (Amazon.com, 02/12/2019)  Total: \$79.99 + \$69.99 = <b>\$149.98</b>	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1 year time.	A portable computer projector with an associated screen will be helpful during both dissemination (i.e. presenting about program to potential funders and stakeholders), as well as, during implementation phase for making media accessible as needed during group sessions.
<ul style="list-style-type: none"> <li>• 1 Computer Adapter for Projector</li> </ul>	Acer HDMI to VGA Converter – White Current Price: \$39.99 (CDW.com, 02/12/2019)  <b>\$39.99</b>	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1 year time.	A computer adapter will be necessary in order to project course content from program laptops onto screen during group sessions for optimal learning experiences.
<ul style="list-style-type: none"> <li>• 1 Portable Speaker</li> </ul>	Logitech Multimedia Speakers Z200 with Stereo Sound for Multiple Devices – Black Current Price: \$29.99 (Amazon.com, 02/12/2019)	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1 year time.	Portable speakers will project media within course content that has sound, and associated audio.

<b>Budgeted Item</b>	<b>Year 1 (Pilot Phase)</b>	<b>Year 2</b>	<b>Justification</b>
	<b>\$29.99</b>		
<ul style="list-style-type: none"> <li>• At least 15 Desks with Chairs for Group Sessions</li> </ul>	Classroom Set – 20 Flavors 19” Chairs & 20 Wing Desks by Smith System #81D58 Current Price: \$4279.95 (Worthington Direct, 02/12/2019)  <b>\$4279.95</b>	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1-year time. Can replace if damage occurs.	These desks with accompanied chairs have a modern style and may appeal to the potential adult learners participating in this group. In addition, the desks can be arranged into small groups seamlessly which will be key during small group and large group discussions.
<ul style="list-style-type: none"> <li>• 1 Office Grade Copy/Fax/Printer</li> </ul>	Brother MFC-L5850DW Monochrome Laser All-In-One Printer, Copier, Scanner, Fax Current Price: \$329.99 (Office Depot, 02/12/2019)  <b>\$329.99</b>	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1-year time. Can get service if needed due to any equipment failure or errors.	An office grade copy/fax/printer will allow for long-term use and sustainability for printing needs. Copy/Fax/Printer will be utilized by program staff to print and manage program content documents, prepare group session content to distribute to participants, and print/send/receive documents to stakeholders, etc.
<ul style="list-style-type: none"> <li>• 2 Work Station Desks + Office Chairs</li> </ul>	At Work Two Person Complete Compact Office Current Price: \$1,880 (OfficeFurniture.com, 02/12/2019)  Essentials Swivel Mid Back Mesh Task Chair with Arms – Ergonomic Computer / Office Chair (ESS – 3001)	No cost during second year as this equipment should be maintained and likely will not be out-of-date within 1-year time. Can replace if damage occurs.	The two work station desks will be necessary for the program staff to complete data analysis of program evaluation, and administrative tasks required to run the program.



Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
	1 chair = \$48.30 (Amazon.com, 02/12/2019) x2 = \$96.60  \$1880 + \$96.60 = <b>\$1976.60</b>		
<i>Supplies</i>			All office supplies will be utilized to complete the administrative and other day-to-day functions involved in running program, including but not limited to making notes, storing paper documents, etc. Certain supplies are needed in order to provide program participants assessments and activities to be completed during the course of a program.
• Printer Paper	Quill Brand Copy Paper (8 ½" x 11") Case of 10 reams Current Price: \$53.99 (Quill.com, 02/12/2019)  \$53.99 x 3 cases (1 per 6-week session) = <b>\$161.97</b>	Quill Brand Copy Paper (8 ½" x 11") Case of 10 reams Current Price: \$53.99 (Quill.com, 02/12/2019)  \$53.99 x 3 cases (1 per 6-week session) = <b>\$161.97</b>	
• Toner & Ink	Brother TN Black Toner Cartridge, Standard (TN-820) Current Price: \$65.49 each for 3+ (Quill.com, 02/12/2019)  \$65.49 x 3 (1 per 6-week session) = <b>\$196.47</b>	Brother TN Black Toner Cartridge, Standard (TN-820) Current Price: \$65.49 each for 3+ (Quill.com, 02/12/2019)  \$65.49 x 3 (1 per 6-week session) = <b>\$196.47</b>	
• Pens & Pencils	Quill Brand Ballpoint Stick Pens, Medium Point (1.0 mm), Black, Dozen Pack \$1.39 each for 6+ quantity (Quill.com, 02/12/2019)  Ticonderoga The World's Best Pencil Wooden Pencils, No. 2 Soft Lead, Dozen Pack	Quill Brand Ballpoint Stick Pens, Medium Point (1.0 mm), Black, Dozen Pack \$1.39 each for 6+ quantity (Quill.com, 02/12/2019)  Ticonderoga The World's Best Pencil Wooden Pencils, No. 2 Soft Lead, Dozen Pack	

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
	\$3.29 each for 12+ quantity (Quill.com, 02/12/2019)  \$1.39 x 12 Boxes = \$8.34 \$3.29 x 12 Boxes = \$39.48 <b>Total: \$47.82</b>	\$3.29 each for 12+ quantity (Quill.com, 02/12/2019)  \$1.39 x 12 Boxes = \$8.34 \$3.29 x 12 Boxes = \$39.48 <b>Total: \$47.82</b>	
• Folders	Quill Brand® Premium 3Tab File Folders, Letter, Assorted Tabs, Manila, 100/bx (741137) Current Price: \$17.54/box (Quill.com, 02/12/2019)  \$17.54 x 2 boxes = <b>\$35.08</b>	Quill Brand® Premium 3Tab File Folders, Letter, Assorted Tabs, Manila, 100/bx (741137) Current Price: \$17.54/box (Quill.com, 02/12/2019)  \$17.54 x 2 boxes = <b>\$35.08</b>	
• Refreshments + paper goods for weekly meetings	\$30.00/week x 6 weeks = \$180.00 per group session x 3 =  <b>Total: \$540.00</b>	\$30.00/week x 6 weeks = \$180.00 per group session x 3 =  <b>Total: \$540.00</b>	
Materials Preparation			All prepared materials' costs are necessary to ensure successful dissemination of the program for funding support, recruitment for participants, and maintaining course materials during implementation phases of group .
• 1 Copyright for Manualized Intervention	Hire an Intellectual Property Attorney to Help File  Average Attorney Rate in Piscataway, NJ: <b>\$400/hr.</b> (Thumbtack, n.d.)  Total: Unable to determine at this time as total cost will be determined based on the lawyer's appraisal of case.	Not applicable, unless changes to original manual are made from results of Pilot Program evaluations / assessments.	

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
	<b>Estimate: \$4,000 (Requiring seven hours of attorney work + additional fees)</b>		
<ul style="list-style-type: none"> <li>• 1 Bound Copy of Manual</li> </ul>	<p>This price is unavailable at this time as the full manual is not yet complete. Prices for bound copy of manual are dependent on the file</p> <p><b>Estimated: \$50.00</b></p>	<p>Not applicable, unless changes to original manual are made from results of Pilot Program evaluations / assessments</p>	
<ul style="list-style-type: none"> <li>• 100 Brochures for Dissemination and Recruitment</li> </ul>	<p>FedEx Office Print Full-color, double-sided 100 count for \$135.99 (FedEx, 02/12/2019)</p> <p><b>\$135.99</b></p>	<p>FedEx Office Print Full-color, double-sided 100 count for \$135.99 (FedEx, 02/12/2019)</p> <p><b>\$135.99</b></p>	
<ul style="list-style-type: none"> <li>• 100 Personal Business Cards for Dissemination and Recruitment</li> </ul>	<p>FedEx Office Print 2" x 3.5" 100 Count for \$19.99</p> <p><b>\$19.99</b></p>	<p>FedEx Office Print 2" x 3.5" 100 Count for \$19.99</p> <p><b>\$19.99</b></p>	
<ul style="list-style-type: none"> <li>• PowerPoint Presentation for Dissemination and Course Materials</li> </ul>	<p>No cost as original content for both dissemination and pilot phase will be created utilizing my own computer which is equipped with Microsoft Office Suite already (no cost incurred).</p> <p>Please see below for the cost of Microsoft 365 Office</p>	<p>Not applicable, any changes to PowerPoint Presentations from feedback provided during Pilot Phase can be edited utilizing the program, and would not cost anything. Changes will be made by program staff with appropriate monetary compensation for putting together materials as part of hourly salary (see above).</p>	

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
<i>Facility Fees / Rental</i>	At this time, this cost is difficult to estimate as a partner organization has yet to be determined (see dissemination information for more information). Ideally, a partner organization would be a school district within the State of New Jersey. As such, the fee of utilizing rooms within a school in the district would depend on each district and/or availability. Depending, the district may subsume the cost due to benefits of the program to its parents.	<i>See previous column.</i>	At least one room within the partner organization would be dedicated as a work area in which the program staff can store paperwork, prepare materials for weekly classes, analyze assessment data, and answer program inquiries / calls. The second room would be for holding 2 hour weekly sessions spanning 18 weeks (in 6 week blocks), with breaks in between for analyzing data, and recruitment. This space needs to be consistent in order to promote attendance and monitor outcomes for the program.
<ul style="list-style-type: none"> <li>• 1 Room at Partner Organization to Hold Weekly Sessions (36 total hours across 18 weeks within 1 calendar year)</li> </ul>	On average, the rent for office space in Northern New Jersey is \$25.11 per sq ft / month (Sitar Reality Company, 2017).		
1 Room at Partner Organization to maintain equipment, materials, supplies, and serve as work stations for program personnel.			
<i>Communication</i>			
<ul style="list-style-type: none"> <li>• Wireless cellphone service</li> </ul>	Verizon Wireless Unlimited Plan for 1 Line Current Price: \$75.00/month for 1 year (Verizonwireless.com, 02/12/2019)  Total: <b>\$900.00</b> per year	Verizon Wireless Unlimited Plan for 1 Line Current Price: \$75.00/month for 1 year (Verizonwireless.com, 02/12/2019)  Total: <b>\$900.00</b> per year	Wireless cellphone service for the Program Cellphone is required to maintain program inquiries, contact participants, recruitment, and communicate to program personnel / stakeholders.

<b>Budgeted Item</b>	<b>Year 1 (Pilot Phase)</b>	<b>Year 2</b>	<b>Justification</b>
<ul style="list-style-type: none"> <li>Wireless internet service</li> </ul>	Fios ® Verizon Internet for Businesses Current Price: \$39.99/month for 1 year (fios.verizon.com, 02/12/2019)  Total: <b>\$479.88</b> per year	Fios ® Verizon Internet for Businesses Current Price: \$39.99/month for 1 year (fios.verizon.com, 02/12/2019)  Total: <b>\$479.88</b> per year	Wireless Internet Service is required on all 3 Laptop Computers utilized in order to advertise about program, manage recruitment, and perform administrative tasks.
<ul style="list-style-type: none"> <li>Microsoft Office 365 Service</li> </ul>	Premium Microsoft Office 365 for Businesses Current Price: \$12.50/month for 1 year (Microsoft.com, 02/12/2019)  Total: <b>\$150.00</b> per year	Premium Microsoft Office 365 for Businesses Current Price: \$12.50/month for 1 year (Microsoft.com, 02/12/2019)  Total: <b>\$150.00</b> per year	Microsoft Office 365 for Business provides access to Microsoft Word, PowerPoint, and Publisher which is essential for preparing program materials for dissemination and implementation. In addition, it can assist in scheduling weekly sessions, maintaining email, and website.
<i>Evaluation / Assessment</i>			NVivo 12 Pro Software will be utilized to qualitatively code Letter of Intents (one of the assessment measures to capture intended outcomes). Microsoft OneDrive Storage is necessary to securely store participant data for reference and future use.
<ul style="list-style-type: none"> <li>NVivo 12 Pro Software</li> </ul>	NVivo 12 Pro Software Perpetual License \$1599.00 (NVivo.com, 02/12/2019).  <b>\$1599.00</b>	Not Applicable (License is for lifetime use)	
<ul style="list-style-type: none"> <li>Microsoft OneDrive Storage</li> </ul>	1 TB of storage included with a Business License for Microsoft Office 365	1 TB of storage included with a Business License for Microsoft Office 365  Additional storage can be bought: 50 GB at \$1.99/month	

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
		<b>Total: \$23.88</b>	
<p><i>Miscellaneous Expenses</i></p> <ul style="list-style-type: none"> <li>• Website domain for program</li> <li>• Program e-mail</li> <li>• Social media accounts to promote the program</li> </ul>	<p>Website Domain: Free Website Set-Up by Google My Business (Google My Business, 02/12/2019)</p> <p>Program Email: Free Gmail Account (Gmail.com, 02/12/2019)</p> <p>Social Media (Facebook, Instagram &amp; Twitter): Free (Facebook.com, Instagram.com, LinkedIn.com, Twitter.com)</p>	<p>Purchase website domain: \$17.99/year (GoDaddy.com, 02/12/2019)</p> <p><b>Total: \$17.99</b></p>	<p>Website domain, program email, and social media accounts will be helpful in raising awareness about program and assisting in program recruitment.</p>
<p><i>Dissemination Costs</i></p>	<p>Prior Implementation Phase of Year 1, I will likely drive to potential partner organizations and provide a presentation regarding the benefits of the program (i.e. NJ Board of Education, NJ Arc Association, etc.). The cost will include gas and compensation from time off from work. A car will be donated by my family, and lodging will be for free with my family. All other materials required for the presentation (i.e. printed brochures, business cards, bounded manual, etc. are noted in the materials section).</p> <p>Total Estimate Cost:</p>	<p>During Year 2, dissemination costs may include presentation regarding results of pilot phase to stakeholders, poster presentation at AOTA, poster presentation at NJOTA, and/or publishing articles in OT Practice/NJOTA Newsletters</p> <p>For brevity, one potential dissemination route of results is considered for the purposes of this budget (i.e. poster presentation at AOTA):</p>	<p>Please see the Dissemination Plan Chapter (Chapter 6) for more information regarding justification of these costs.</p>

Budgeted Item	Year 1 (Pilot Phase)	Year 2	Justification
	\$2.10/gallon of gas x 18.5 gallons (of family Hyundai 2016 Model) = <b>\$38.85</b> (Gasbuddy.com, 02/17/2019) Time-off from Work (single day off): \$28.85 / hr. x 8 hrs. = <b>\$230.80</b> <b>Total: \$269.65</b>	Conference Registration: \$451 (American Occupational Therapy Association, 02/17/19) Room: \$350 estimated for 2-3 nights Flight: \$400 estimated in/out of current state and host state Printing Poster: \$87.00 (Fedex.com, 02/17/2019)  <b>Total: \$1,288</b>	
Total Costs	Year 1: <b>\$33,753.25</b>	Year 2: <b>\$18,577.07</b>	

**Table 5.2 – Budgeted Expenses for Year 1 and Year 2 for *Re-Imagine Transition and Adult Success***

### Potential Funding Resources

As outlined in the previous section, the expenses for disseminating and implementing the program for two years is quite substantial. As such, different potential funding sources will be explored to ensure successful program development, dissemination, and implementation. In addition, securing funding sources should promote long-term sustainability of the program, as well as, keep the cost of the program to a minimum for participants. I envision the program to be a free resource for the community, and thus will heavily rely on these potential funding sources to actualize this vision.

Table 5.3 outlines potential funding sources at a federal, state, and local levels, as well as, non-grant related sources of funding:

<b>Grant Type / Name</b>	<b>Applicable Grant Criteria</b>
Federal Grants	<ul style="list-style-type: none"> <li>• RFA-MH-19-101, <a href="#">K18</a>: NIMH Career Enhancement Award to Advance Autism Services for Adults and Transition-Age Youth (K18 Clinical Trials Required)               <ul style="list-style-type: none"> <li>○ “Support(s) research training and career development experiences and small-scale research project(s) that will provide experienced investigators with the scientific competencies required to conduct research relevant to services for adults or transition-age youth with Autism Spectrum Disorders” (National Institutes of Health, 2018)</li> <li>○ Includes funding for pilot studies that:                   <ul style="list-style-type: none"> <li>▪ “Provider and systems-level strategies to ensure coordinated, continuous care during transition to adult services (e.g., interventions to increase provider attention to transition planning, strategies to develop cross-system collaboration, novel financing strategies to bridge from child and adult service systems)” (National Institute of Health, 2018).</li> <li>▪ “Approaches for enabling providers to tailor transition strategies to an individual's intellectual abilities, health and housing needs and key functional skills to eliminate disparities in the receipt of</li> </ul> </li> </ul> </li> </ul>



	<p>services and improve outcomes”. (National Institute of Health, 2018)</p> <ul style="list-style-type: none"> <li>○ Eligible organization include higher education institutions, nonprofits, for-profit businesses, government, independent school districts, etc.</li> <li>○ \$2 Million awarded to 7 recipients</li> </ul>
State Grants	<ul style="list-style-type: none"> <li>● New Jersey State: Autism Postdoctoral Fellowship Research Grant Program CAUT19AFP (NJ Department of Health, 2018) <ul style="list-style-type: none"> <li>○ “Seeks to support all areas of basic science and clinical research that examines the origins, pathophysiology, and treatment of Autism Spectrum Disorder (ASD)</li> <li>○ Up to \$130,00 per grantee for a total of two years</li> <li>○ Groups or Entities Eligible: Institution of Higher Education and OTHER</li> <li>○ Must hold a Ph.D. and/or M.D. or equivalent graduate degree <ul style="list-style-type: none"> <li>○ Link: <a href="https://healthapps.state.nj.us/noticeofgrant/noticegrants.aspx#">https://healthapps.state.nj.us/noticeofgrant/noticegrants.aspx#</a></li> </ul> </li> </ul> </li> </ul>
Foundation Grants	<ul style="list-style-type: none"> <li>● Dudley Allen Sargent Research Fund (Boston University, n.d.) <ul style="list-style-type: none"> <li>○ Gives financial assistance to students involved in various areas of research when there is a lack of assistance that might result in the project not being completed or delayed in competition</li> <li>○ Open to students enrolled in a Sargent College post-professional doctoral degree program</li> </ul> </li> <li>● The Doug Flutie, Jr. Foundation Signature Grant <ul style="list-style-type: none"> <li>○ To 501(c) (3) organization and qualified schools in MA, Northeast, NJ, and NY to support an organization or project that promotes 1) access to services 2) active lifestyles and 3) adult independence to individuals across the autism spectrum (cite here)</li> <li>○ Up to \$9,999 per grant (Doug Flutie Jr. Foundation, n.d.)</li> </ul> </li> <li>● Organization for Autism Research (OAR) – Applied Research Grant <ul style="list-style-type: none"> <li>○ Competitive line of funding for 1-2 year grants around since 2002, supporting over 200 autism pilot studies</li> <li>○ Maximum Rewarded Amount: \$40,000</li> <li>○ Criteria includes: one member of the research team holding a Ph.D., M.D., or equivalent degree and maintain a faculty position at a college, university, medical school, or research facility</li> <li>○ Research “serves the immediate need of the research community” (OAR, n.d.).</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Similar Past Research Awarded: <i>Measuring What Matters: Understanding the Meaning of Outcomes for Adults on the Autism Spectrum</i> Authors: Collette Sosnowy, Ph.D., Paul Shattuck, Ph.D., Chloe Silverman, Ph.D.</li> </ul>
Corporate Grants	<ul style="list-style-type: none"> <li>● Walmart Foundation: Community Grants <ul style="list-style-type: none"> <li>○ Provided to organizations holding a current tax-exempt status but cannot include a nationally sponsored organization, government gentility, K-12 public/private schools, church, etc. (Walmart Foundation, n.d.)</li> <li>○ Areas of funding include Health and Human Service, Quality of Life, Education, Diversity and Inclusion (which are all relevant areas of this doctoral project)</li> <li>○ Awarded \$250-5000 for community grants and 250,000 for national grants</li> <li>○ Link: <a href="http://giving.walmart.com/apply-for-grants/local-giving-guidelines">http://giving.walmart.com/apply-for-grants/local-giving-guidelines</a></li> </ul> </li> <li>● State Street Foundation: Nonprofit Grants <ul style="list-style-type: none"> <li>○ Grants are provided to nonprofits and nongovernmental organizations with a primary strategic focus in education and workforce development.</li> <li>○ Investment in helping “disadvantaged individuals earn and make a living”, by providing measurable results in “education, job-readiness, college success, credentials, work experience, and employment” (State Street, n.d.)</li> <li>○ Link: <a href="http://www.statestreet.com/values/social-consciousness/non-profit-grants.html">http://www.statestreet.com/values/social-consciousness/non-profit-grants.html</a></li> </ul> </li> </ul>
Crowdsourcing & Angel Capital	<ul style="list-style-type: none"> <li>● Utilize GoFundMe to establish a platform to receive donations from family, friends, and colleagues, as well as, promote the page through personal social media accounts to gather additional support through individuals who are interested in the cause.</li> </ul>

**Table 5.3 – Grants and Potential Funding Sources for Re-Imagine Transition and Adult Success**

### Conclusion

As noted through the previous sections, the cost to run *Re-Imagine Transition and Adult Success* may be quite substantial. However, the necessity and benefits of running such a program as outlined in Chapters 2 and 3 may motivate a future organization to make a budget for these costs in order to affect change in the intended participants. As

the program development solidifies (i.e. completion of a program manual), additional costs may result. Moreover, continual networking with professionals who may be interested in this program may also help to reduce some of the start-up costs noted above. Overall, the importance of applying for grants and funding sources will be paramount in order to maintain the program as a valuable community resource for years to come.

## CHAPTER SIX – Dissemination Plan

### Brief Description of the Program

*Re-Imagine Transition and Adult Success* is a proposed critical reflection program for parents who have transition-aged youth (i.e. adolescents) diagnosed with Autism Spectrum Disorder (ASD). Compared to other parent programs for this population, *Re-Imagine Transition and Adult Success* embodies disability studies' ideologies, including the social model of disability, as means to critically examine and reflect upon biases/assumptions regarding the transition process, such as conceptualizations of successful adulthood outcomes. The program is designed as a six-week course with once/week, two-hour sessions totaling 12 hours of instruction. The program is divided into three sections (i.e. individual exploration, content exploration, and group reflection) through a reiterative, reflective process which involves didactic learning presented through multi-modal means, experience learning, individual reflection, and group reflection. The program's aims include increasing awareness about the field of disability studies, and the social model of disability, and critically examining biases and assumptions regarding adulthood. By providing a structured, systematic approach to reflection, this program allows parents a safe place to gain awareness of their own biases and assumptions for their adolescent as they enter adulthood. Once gaining this awareness, ideally, parents will feel empowered to make better, more informed decisions throughout their adolescents' transition process to best meet the needs of their adolescent into adulthood.

As with any proposed program, the key for successful program implementation

and continual sustainability requires the program's intent be communicated to a variety of different stakeholders, including funders, potential recipients, the community, etc. In the following sections of this chapter, the dissemination plan to convey the key messages *Re-Imagine Transition and Adult Success* are outlined.

### **Dissemination Goals**

For the purpose of this dissemination plan, it is assumed that both the program, and the associated evaluation plan (Chapter 4) has been completed, with the evaluation plan yielding generally positive results on the program's intended outcomes (Chapter 3). The following sections includes both long-term and short-term goals related to successful dissemination of the program and its key messages:

- **Long-Term Goals (2–5+ years after initial program implementation)**
  - The dissemination of program results will help the program gain credibility as an evidenced-based, theory-driven intervention for integrating disability studies' ideologies into parent training for the primary audience.
  - The program results will bolster support and funding for adoption of the program on a nationwide basis, across either school-based or community institutions that service parents of transition-aged youth with ASD.
  - The program will instigate a positive change in how practice within the transition planning field reports outcomes for adults with ASD, which will reflect more positive, post-transition outcomes for adults with ASD as conceptualized through a social model of disability lens.

- **Short Term Goals (6 months to 1 year after initial program implementation)**
  - Program implementation and dissemination of results to parents of transition-aged youth with ASD, administrators in local organizations, funders and occupational therapy practitioners will yield a greater awareness regarding the importance of integrating disability studies' ideologies, such as the social model of disability, into transition services for adolescents with ASD.
  - Dissemination of initial program implementation results to both primary and secondary audiences will yield community support and funding for the program in at least one local institution within Middlesex County, NJ.

### **Target Audience**

The primary audience for the program includes parents of transition-aged youth with ASD. However, in actuality, this program is yet to be implemented so the specific subgroup for this primary audience has not been finalized (i.e. parents of transition-aged youth with ASD in Middlesex County, NJ or Hudson County, NJ etc.). Another primary audience includes occupational therapy practitioners interested in parent training, and transition-services, who work in the previously mentioned organizations.

The secondary audience for the program includes administrative staff within organizations which service adolescents with ASD and their parents. Examples of organizations may include the local and state Boards of Education, the Arc for People of Intellectual and Developmental Disabilities, local hospitals/outpatient facilities focusing on transition services or other relevant organizations

## Key Messages

### **For the primary audience of parents of transition-aged youth with ASD:**

- As parents of a child with ASD, you will play a critical role in the life of your adolescent well into adulthood as compared to their non-disabled peers (Smith & Anderson, 2014). This role manifests in the form of decision-making on several personal, financial, and organizational levels (Cheak-Zamora, Teti & First, 2015). As such, this program will provide you with the opportunity to learn content that will help you make informed choices for your adolescent as they transition into adulthood.
- This program employs reflective practice with social support of other parents with transition-aged youth diagnosed with ASD as a means to spark conversation regarding how your own biases, assumptions, and worries may be impacting your decision-making when it comes to your adolescents' transition needs. The tools in this program will help you unpack these assumptions and provide you with a unique lens to view your child's disability, which in turn will better empower you during moments of transition-based decision-making.

### **For the primary audience of occupational therapy practitioners within the organizations that service transition-aged youth with ASD and their parents:**

- *Re-Imagine Transition and Adult Success* is an opportunity for occupational therapy practitioners to become more involved in transition-related services, a growing niche practice area as outlined by the American Occupational Therapy Association (AOTA, n.d.)

- The occupational therapy profession's values and training make occupational therapy practitioners qualified for implementing this program. For example, occupational therapy practitioners have a foundational understanding of performance patterns, including the different roles that parent of adolescents with ASD may have to assume (i.e. decision-making) (American Occupational Therapy Association, 2014, p. S8). Occupational therapy practitioners have specific training in group dynamic theories which promote the ability to lead this type of group intervention. Finally, occupational therapy practitioners acknowledge the cultural, temporal, and social contexts that their clients may have to perform their daily occupations, which positions them to better understand and teach the influence of disability studies' ideologies (p. S9).

**For the secondary audience of administrative staff within organizations that service transition-aged youth with ASD and their parents:**

- Adults with ASD are consistently labeled as having “poor transition outcomes” compared to both their peers without a disability or peers with other disabilities (Newman et al., 2011). Some factors reported in the current evidence literature that may contribute to this label include decreased or lack of social and vocational skills in the adolescents (Newman et al., 2011). Other factors reported include decreased availability and comprehensiveness of transition planning services, including managing the complexities of the adult service system, understanding different types of outcomes, etc. (Cheak-Zamora, Teti & First, 2015; Smith & Anderson, 2014; Weiss, Tint, Paquette-Smith & Lunskey, 2016). Finally, this label



may result from rigid, age-old conceptualizations of what it means to lead a successful adult life (Oliver, 2009). A need to employ an intervention which addresses these concerns is paramount.

- Adopting *Re-Imagine Transition and Adult Success* will help bolster the comprehensiveness of transition services your facility provides by approaching transition through a lens which helps to “tackle” the issue of “poor transition outcomes” at its root. This program considers how disability studies, a growing academic field which helps to re-examine society’s construct of disability through an interdisciplinary approach involving anthropology, sociology, gender studies, arts, economics, and law, may be the unique lens for viewing transition for adolescents with ASD. Ultimately, *Re-Imagine Transition and Adult Success* considers that the label of “poor transition services” may be a result of how society both conceptualizes what it means to be disabled and what it means to be a successful adult. This program provides the tools to change this conceptualization in order to re-imagine successful, adult participation for individuals with ASD.
- *Re-Imagine Transition and Adult Success* is an evidenced-based, theory-driven intervention catered for parents of transition-aged youth in your community. The program employs reflective practice in a group format to educate parents on disability studies ideologies, and provides them a safe platform to discuss their hopes and aspirations for their child as they transition into adulthood. It will ideally empower the parents in your community to make informed choices for

transition that places the adolescents' well-beings and livelihoods into the forefront of decision-making in order to shape these adolescents' future roles as adult citizens in your community.

### **Sources and Messengers**

#### **For the primary audience of parents of transition-aged youth with ASD:**

- Kathie Snow, parent of child (now an adult) with cerebral palsy, who was empowered by her time working with Partners in Policymaking, including advocacy on People First Language. She is the author of [\*Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities\*](#), a book designed to guide parents of children with disabilities into new ways of thinking about disability (Snow, 2013). Many supplemental readings for this program are taken from this text. Kathie Snow is a public speaker, and presents on a variety of different topics related to the content in her book. She will provide potential participants of the group a model of a parent who has critically reflected on her own biases / assumptions about disability and adult success, and what implications it had for her own son.

#### **For the primary audience of occupational therapy practitioners within the organizations that service adolescents with ASD and their parents:**

- Occupational Therapy and Disability Studies Network: An online community comprised of occupational therapists across several different practice areas who are passionate about disability studies as a field. It may be beneficial to recruit occupational therapy practitioners from this platform as potential spokespeople

discuss how and why they incorporate and value disability studies' ideologies into their practice, while also providing antidotes of client stories when providing treatment through this mindset.

- American Occupational Therapy Association CommunOT: An online community messaging board for AOTA members dedicated to different practice areas, including transition services, to ask questions, raise awareness about practice areas, etc.

**For the secondary audience of administrative staff within organizations that service adolescents with ASD and their parents:**

- After initial program implementation, program participants and program staff may provide their firsthand testimonies to advocate for both the importance and impact the program made in reaching its intended outcomes. This in turn may be beneficial in persuading administrative staff to continue to allocate funding for additional program implementation.

**Dissemination Activities**

In Table 6.1, different dissemination activities, spanning written, electronic, and in-person outlets have been outlined alongside their priority and timing so as to best convey the key messages to both the primary and secondary audiences mentioned above

Dissemination Activity	Target Audience	Description	Priority & Timing
Written: Brochures Explaining Program Purpose/ Content / Benefits	Primary: Parents of Transition-Aged Youth with ASD  Secondary: Administrative Staff within Organizations that Service Target Population	These brochures will be self-created by this author to succinctly describe the program’s purpose, the intended content, and the benefits in language that is friendly to both the primary and secondary audiences its intended for These brochures will be printed to serve as hard copies to be given during recruitment of program participants and during meetings with stakeholders. In addition, the brochure can be submitted electronically to reach a larger group within both primary and secondary audiences.	Priority: High Timing: Immediately  This dissemination activity is of high priority and likely will occur both prior to and immediately upon initial adoption of the program by a partner organization. The brochures will be helpful visual aids during in-person presentations to both administrative staff to secure adoption of the program initially and for subsequent growth of the program to different organizations. Moreover, the brochures can be given to parents during recruitment events and/or emailed to listservs during recruitment.
Written: <i>OT Practice</i> Article	Primary: Occupational Therapists working with Transition- Aged Youth	<i>OT Practice</i> is a magazine subscription available to members of the American Occupational Therapy Association that discusses current practice trends, continuing education opportunities, professional news, etc. It reaches more than 60,000 occupational therapy practitioners and is published to this audience once a month (AOTA, n.d.-b).	Priority: Medium Timing: 1-2 Years After Continual Program Implementation  This dissemination activity is of medium priority as it will likely occur only after the program is successfully running at a partner organization between 1 to 2 years. The purpose of this dissemination activity is to achieve a long-term goal of implementing this program at a nationwide-level; ideally publishing in <i>OT Practice</i> will allow a greater number of occupational therapy practitioners to become aware and/or inspired to adopt / implement this program at potential new partner organizations. Moreover, it

Dissemination Activity	Target Audience	Description	Priority & Timing
			educates occupational therapy practitioners on new, potential best practices within the field of transition planning.
Written: Journal Article in Peer-Reviewed Research Journal	Primary: Occupational Therapists working with Transition-Aged Youth	At least one published article within a reputable, well-indexed, and peer-reviewed research journal, such as the <i>American Journal of Occupational Therapy</i> , <i>Disability Studies Quarterly</i> , <i>Research in Developmental Studies</i> , etc. that outlines the program's development and preliminary outcomes.	Priority: Low Timing: After 2+ Year of Program Implementation  This dissemination activity is of low priority as it will likely not occur until after the first 2 years of program implementation. This author would need to compile outcome data from preliminary groups to have substantial / relevant data to analyze, as well as, gain experience in writing in such research rigor. This dissemination activity would assist in the long-term goal of changing how research reports outcomes for transition-aged youth.
Electronic: Program Website and Social Media Accounts	Primary: Parents of Transition-Aged Youth with ASD  Primary: Occupational Therapists Working with Transition-Aged Youth with ASD  Secondary: Administrative Staff within Organizations that	Purchasing, creating, and maintaining a program website will provide an electronic platform to detail program content, news, and/or updates in a timely fashion to a large pool of primary and secondary audiences, especially of that audience who searches for relevant key terms (i.e. adolescents, transition, autism, program, parent training, etc.). In addition, social media accounts, such as Facebook, Instagram LinkedIn, and Twitter will allow for succinct, easily digestible	Priority: High Timing: Immediately  This dissemination activity is of high priority as it will occur immediately (i.e. just after initial program implementation if not before). The purpose of this dissemination activity is to alert both the primary and secondary audiences of the programs' existence, purpose, and content. It will also serve as an opportunity to share testimonials and convey program outcomes to help influence stakeholders and recruitment future participants in the program.

<b>Dissemination Activity</b>	<b>Target Audience</b>	<b>Description</b>	<b>Priority &amp; Timing</b>
	Service Target Population	mode to relay program initiatives, intent, etc.	
In-Person: Briefings / Meetings with Stakeholders from Partner Organization	Secondary: Administrative Staff within Organizations that Service Target Populations	In-person briefings at regular intervals during program implementation will be important to build transparency with stakeholders about the use of allocated funds, convey preliminary program findings make alterations as needed to program administration, and discuss acceptability of program to its intended recipients. In-person briefings may include PowerPoint presentation, participant testimonies, budget information, etc.	Priority: High Timing: Immediately  This dissemination activity is of high priority as it will occur likely prior to program implementation and during regular intervals during the first and second year of implementation to keep stakeholders apprised of program progress in order to promote the longevity and continual funding of the program.
In-Person: Poster Presentation at American Occupational Therapy Association and at New Jersey Occupational Therapy Association	Primary: Occupational Therapists Working with Transition-Aged Youth with ASD	This in-person dissemination activity includes presenting a poster on the program's development and preliminary implementation to contribute to the evidence-based interventions for this population within the field of occupational therapy	Priority: Medium Timing: After 1 <sup>st</sup> Year of Program Implementation  This dissemination activity is of medium priority as it will help gain awareness about the program to the secondary audience. However, it will take some time to present a poster with all the relevant information (including program outcome data) to help bolster the credibility of its theory and evidence-base.

**Table 6.1 – Dissemination Activities for *Re-Imagine Transition and Adult Success***

### Budget for Dissemination Plan

In order to implement the dissemination activities previously outlined, funding and resources should be considered. Table 6.2 outlines resources related to both funding and time for the dissemination plan:

<b>Dissemination Activity</b>	<b>Potential Time Requirements</b>	<b>Estimated Expense</b>	<b>Justification of Expense</b>
Brochures	Estimated 5 hours to draft brochure, contact colleagues for review, and implement feedback	Printing 100 Brochures at <b>\$135.99</b> (FedEx.com, n.d.) Digital File created through Microsoft Publisher (Actual Cost – \$0.00) as program is already owned by author on her personal computer Time: <b>\$150</b>	Brochures will be printed to disseminate to stakeholders and potential participants during recruitment events and presentations. Digital copies of the brochure can be emailed to listservs as needed. Labor is calculated at \$30/hr for this authors' time
<i>OT Practice</i> Article	Estimated 15 hours to draft article, submit to publication, receive feedback, and make proposed corrections	Compensation of Time: <b>\$450</b>	The only expense for this dissemination activity would be compensation for the time the author puts into writing the work. This cost may be included as part of the authors' job responsibilities as the program facilitator (see Funding Plan). Labor is calculated at \$30/hr.

<b>Dissemination Activity</b>	<b>Potential Time Requirements</b>	<b>Estimated Expense</b>	<b>Justification of Expense</b>
Journal Article in Peer-Reviewed Journal	Estimated 50 hours to draft Institute Review Board approval, analyze data, draft article, submit to publication, receive feed, and make proposed corrections.	Compensation of Time: <b>\$1,500</b>	The only expense for this dissemination activity would be compensation for the time the author puts into writing the work. This cost may be included as part of the authors' job responsibility as the program facilitator (see Funding Plan). Depending on the peer-reviewed journal selected, may have to consider any application fees for submission. Time is calculated at \$30/hr.
Program Website + Social Media Accounts	Estimated 5 hours per week to maintain website, and associated social media accounts	Website domain <b>\$17.99</b> / year (GoDaddy.com, n.d.)  Social Media Accounts (Free to Create – may pay for ads or promotions as needed)	The time to maintain the website and associated social media accounts will be split amongst different program staff, including the program facilitator, program implementer, and program volunteers as part of each members' job responsibilities. Appropriate compensation is outlined (see Funding Plan).
In-Person Briefings with Stakeholders	Estimated 30 hours spanning across each year program is implemented at facility, including time to prepare all necessary materials for presentation (i.e. PowerPoint presentation, testimony compilation, etc.)	Compensation for Time: <b>\$900.00</b>	The only expense for this activity includes time to write presentation materials and presenting to stakeholders. This will be included in the salary of this author's role as the program facilitator



<b>Dissemination Activity</b>	<b>Potential Time Requirements</b>	<b>Estimated Expense</b>	<b>Justification of Expense</b>
Poster Presentation at AOTA Conference	Estimated 2 days of personal time off required (~ 2, 8 hour workdays) to attend the conference. Estimated 10 hours to draft poster presentation, edit poster pending feedback, and present findings in-person	Conference Registration: <b>\$451</b> (American Occupational Therapy Association, 02/17/19) Room: <b>\$350</b> estimated for 2-3 nights Flight: <b>\$400</b> estimated in/out of current state and host state Printing Poster: <b>\$87.00</b> (Fedex.com, 02/17/2019) Total: <b>\$1,288</b>	Time required to write, edit, and print poster presentation will be compensated as part of program implementer salary (see Funding Plan). The cost of attending the conference will help to reach a large audience of occupational therapy practitioners.
Poster Presentation at NJOTA Conference	Estimated 1 day of personal time off	Will use author's own car for transportation and lodging at her current residence (actual cost limited) Cost of Membership: <b>\$50</b>	Time required to write, edit and print poster presentation will be compensated as part of program implementer salary.
Total		<b>\$3,755.99</b>	

**Table 6.2 Dissemination Plan Budget for Re-Imagine Transition and Adult Success**

### **Evaluation of Dissemination Plan**

Each dissemination activity should be monitored and assessed to determine the effectiveness in reaching its intended audience. Evaluation markers will be dependent on the dissemination activity, but all markers are concrete and measurable to help track the effectiveness in a systematic approach. The following contains each dissemination activity with the proposed evaluation markers:

- Brochure

- When disseminated in person: Keep running total on Excel of the number of brochures handed to each individual, while also noting the total number of brochures given out per activity (i.e. five brochures given to five individuals during tabling event for participant recruitment or two brochures given to two individuals during potential, new stakeholder briefing, etc.).
- When disseminated electronically: Track the number of emails with brochure attached that are sent compared to the number of “read” receipts that are received. Also categorize all recipients into primary and secondary audiences.
- At least 100 brochures being disseminated per year either in person or electronically would be considered successful.
- *OT Practice Article*
  - Request information from the American Occupational Therapy Association in regards to the number of times the article is downloaded / accessed online, as well as, how many copies of the issue are sent out to homes. If the article is accessed at least 100 times the dissemination activity will be considered successful.
  - Include contact information (i.e. program email) at the end of the article and monitor the number of inquiries or questions sent regarding the article. At least 5 personal inquiries regarding the article would be considered successful dissemination.

- Journal Article in Peer-Reviewed Journal
  - Monitor the number of times the article has been accessed electronically. Accessed at least 50 times within the first year would be considered successful dissemination.
  - Monitor the number of times the article has been cited in other works, and categorize authors who cite the article into the type of audience (i.e. primary and secondary), and sub-categories (i.e. type of profession, institution, etc.). Cited at least five times by authors would be considered successful dissemination.
- Program Website & Social Media
  - Monitor website and social media traffic on monthly basis to determine the reach of the program. Receiving at least 100 visits per month would be considered successful dissemination.
  - Provide opportunity for feedback / comments on website and all social media accounts to gain additional information about effectiveness of online display and content. Receiving at least 10 comments per three months would be considered successful dissemination / outside of content via website.
- In-Person Briefings with Stakeholders / Potential Stakeholders
  - Administer brief survey to all participants of briefings to determine comprehension and acceptability of content, willingness to adopt program, etc.

- Track the number of surveys given to determine reach of the overall audience
- At least 10 – 20 surveys per year would be considered successful dissemination.
- Poster Presentation at AOTA / NJOTA
  - Track number of visitors to the poster presentation, number questions asked about the presentation, categorize each question (i.e. content question, logistic question, theory question, etc.) and track frequency of question in each category.
  - Provide opportunity to take brief survey about presentation to assess for comprehension and acceptability of content and willingness to adopt program.
  - Successful dissemination would include at least 50 visitors to the presentation per conference.

Overall, these individual markers for each dissemination activity will provide a means to track the breadth of individuals within each of the respective audiences (i.e. primary or secondary) that were targeted, as well as, provide some qualitative means to capture attainment towards long-term and short-term goals as noted above.

### **Conclusion**

*Re-Imagine Transition and Adult Success* is a parent training program for parents of transition-aged youth with ASD employing ideologies from the field of disability studies as means to critically examine and reflect upon disability and assumptions

regarding adult success. The program's intended outcomes include: 1) increasing parents' awareness about the field of disability studies, including the social model of disability, disability rights, etc. and 2) engage in critical reflection about participants' personal biases and assumptions regarding disability and adult success. Assuming the program is implemented and evaluation yields successful attainment of the abovementioned outcomes, this dissemination plan outlines several different activities to convey these findings to both the primary audiences of parents of transition-aged youth with ASD and occupational therapy practitioners interested in transition planning, as well as, the secondary audiences of administrators in organizations that service transition-aged youth with ASD and their families. Future target audiences may be considered as the program seeks popularity. For example, targeting social workers and other personnel about this program and its benefits may help create a channel in which more parents of transition-aged youth with ASD can become aware of this program. Dissemination activities will include maintaining a website, conducting poster presentations, scheduling in-person briefings, publications, and contributing to online message forums. Ideally, this dissemination plan hopes to establish *Re-Imagine Transition and Adult Success* as an evidenced-based, theory-driven intervention for parents of transition-aged with ASD on a national level, while simultaneously increasing occupational therapy practitioners' role in transition-planning.

## CHAPTER SEVEN - Conclusion

Adolescents with Autism Spectrum Disorders (ASD) are reported to have “poor transition outcomes”, such as less likely to pursue and complete post-secondary education, less likely to obtain and maintain competitive employment, have fewer social supports or friends, and are less likely to maintain independent living arrangements as compared to their peers with other disabilities and without disabilities (Newman, et al., 2011). However, these traditional markers of post-transition success if critiqued through a social model of disability framework would be considered arbitrary and oppressive, as they are not encompassing of the different ways that adults with disabilities may lead successful lives.

Furthermore, parents are integral players in the facilitation of transition into adulthood for their adolescents with ASD (Smith & Anderson, 2014). However, parents are impacted by multiple personal and social factors that may complicate their ability to undertake decision-making roles that permit service acquisition that best meets their adolescents’ needs during the transition process (DePape & Lindsay, 2014). This doctoral project also examined factors through a social model of disability framework and suggested that parents are subjected to their own biases, assumptions, and attitudes regarding disability and adulthood success. These biases, assumptions, and attitudes may inadvertently be shaping parental post-transition expectations for their children as they age. Ultimately, the analysis of the current literature through this social model of disability framework underscores an alternative approach to addressing transition issues. This alternative approach involves assisting parents to become more aware of their

biases, assumptions, and attitudes about disability and the transition process while also elucidating how these biases, assumptions, and attitudes may affect both them and their adolescents. If parents are more critically aware of these biases, assumptions, and attitudes when facilitating and making decisions with their adolescent, this awareness may lead to seeking supports that more appropriately meet the needs and desires of their adolescents in adulthood. *Re-Imagine Transition and Adult Success* is an intervention that hopes to address transition in this manner.

Current interventions related to transitions and transition planning for parents who have adolescents with ASD are limited, as only four parent training programs were found. All four programs varied in duration, intensity, and structure. However, three main themes for mechanisms of actions emerged: 1) goal-setting for individualization of content to parents' specific needs 2) didactic instruction and 3) social learning (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). The programs also varied in which outcomes they reported, but all outcomes fell across three different main themes 1) knowledge 2) positive attributes (desirable characteristics related to transition) and 3) negative attributes (non-desirable characteristics impacting transition) (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). In addition to the variation in implementation procedures and reported outcomes between programs, other shortcomings in this literature included 1) vague or unclear mentions if didactic training materials were presented in accordance to known

knowledge-change theories, and 2) the use of outcome measures which promote traditional, medicalized conceptualizations of adulthood success. None of the programs considered parental biases, attitudes, and assumptions related to disability and transition.

Similarly, programs for parents of children with disabilities centered on positive disability acceptance are also limited. Those that exist fail to be evaluated through rigorous, peer-reviewed research means and have no clear guidelines for implementation. However, the two that were found (i.e. Parent 2 Parent and *Disability is Natural*) do underscore the importance of parents feeling a sense of “hope” for their child’s future, and learning from the experiences of other parents and young adults with disability (Santelli, Turnbull, Marquis & Lerner, 1995; Snow, 2013).

Synthesizing both common themes and shortcomings between both sets of programs aforementioned, *Re-Imagine Transition and Adult Success* is an innovative intervention approach to address transition challenges through the use of disability studies concepts. The program considers the impact that biases, assumptions, and attitudes have on how parents approach transition and transitioning planning for their adolescents with ASD. The program employs the same mechanisms of actions noted in other transition programs, including creating opportunities to individualize group content, group sessions to promote social learning, and didactic training. However, *Re-Imagine Transition and Adult Success* also extends the work of current literature by incorporating multi-modal presentation of content to reach a wide variety of adult learners, and reflective learning tenants to promote critical awareness about biases, assumptions, and attitudes regarding disability and transition.



*Re-Imagine Transition and Adult Success* is an opportunity for occupational therapy (OT) practitioners to continue to assert their role in transition planning. OT practitioners have experience conducting psychosocial groups (similar to the one presented here) in accordance with group dynamic theories. Moreover, the OT profession has a commitment to understanding performance patterns, and different roles that caregivers must play throughout the course of the lives of their children with disabilities. Finally, OT practitioners have budding awareness of the importance of infusing disability studies content in their practice, while also being more involved in caregiver education.

Overall, *Re-Imagine Transition and Adult Success* is a novel approach to address transition in adolescents with ASD. The program considers that “poor transition outcomes” in this population is not solely caused by each individuals’ limitations in skills or ability to engage in and perform within traditional adulthood activities (i.e. competitive employment, living independently, etc.). Instead, “poor transition outcomes” for adolescents with ASD may be more a result of the social and attitudinal barriers which restricts our society’s conceptualizations adulthood success. *Re-Imagine Transition and Adult Success* hopes to elucidate these social and attitudinal barriers within parents to bring greater disability acceptance, and improvement in how they assist their youth. The program both builds upon current parent training programs related to transition, and attempts to elevate the research rigor for programs of positive disability acceptance in parents. Ultimately, *Re-Imagine Transition and Adult Success* seeks to integrate disability studies concepts in transition and transition planning interventions in order to make a meaningful impact on the lives of adolescents with ASD.

## APPENDIX A: Letter of Intent

Below is the sample template for the letter of intent that will be provided to parents during the first and last week of the training program to fill out and complete in order to informally track changes in their post-transition expectations. The content that parents fill out in this letter of intent will be utilized as points of discussion during group discussion times. Typically, a letter of intent includes additional sections. However, these particular sections were chosen for the purpose of this program as they correspond the greatest with the adulthood outcomes that parents will be asked to reflect upon in regards to their biases in these areas.

Template adapted from: <https://www.bridges4kids.org/letter-of-intent-form.pdf>

### LETTER OF INTENT

Prepared By \_\_\_\_\_

Date: \_\_\_\_\_

Relationship to individual with special needs:

---

To Whom It May concern,

This letter, although not legally binding, is intended to give guidance to anyone involved in my / our child's future care. It expresses my / our wishes for this very special child. It is my / our hope that this letter be a guidepost for providing the best life possible for my / our child.

### INFORMATION ABOUT

---

(Your Child's Name)

### GENERAL INFORMATION

---

Name:

Important Numbers:

Gender

Languages

Religion (if applicable)

Citizenship

Birth & Birth History

Siblings

Marital Status

Other Important Relationships

Guardians  
Trustee  
Power of Attorney

INFORMATION ABOUT

---

(FATHER'S NAME)

General Information  
Marital Status  
Family

INFORMATION ABOUT

---

(MOTHER'S NAME)

General Information  
Marital Status  
Family

WHAT WORKS WELL FOR

---

(CHILD'S NAME)

HOUSING

---

Present Living Conditions

Future Living Condition Expectation

Relatives home, supported independent living, group home, private group home,  
foster care for a child, adult foster care, parent-housing with or without  
supervision, housing owned by your child

Size

Adaptation

Favorites

Community

DAILY LIVING SKILLS

---

Current Activities

Monitoring

Self-care skills:

Domestic activities

Reinforcement of social and interpersonal activities

Other areas

Caregiver's attitudes

Self esteem

---

---

**EDUCATION**


---

Schools  
 Current programs  
 Academics  
 Emphasis  
 Integration

---

**DAY PROGRAM AND/OR WORK**


---

Present  
 Future  
 Assistance

---

**LEISURE AND RECREATION**


---

Structured recreation  
 Unstructured activities  
 Vacations  
 Fitness

---

**RIGHTS AND VALUES**


---

Please list the rights and values that should be accorded your child.

---

**OTHER**


---

Give an overview of your child's life and your feeling and vision about the future.  
 Describe anything else future caregivers and friends should know about your child.

---

Please provide any other wishes you have for your child or information you feel is important to his/her care. Any message you would like to convey to your child upon your death. You may choose to attach a note, an audio or a video to this letter. Any message to siblings or close friends may be included here. As we continue this special journey with our child, we hope that this letter is an expression of our love and dedication to her/him and that by memorializing our hopes we will continue to help our child develop his/her uniqueness in the world. Sincerely,

---

Father's Signature / Date

---

Mother's Signature / Date

## **APPENDIX B: Select Readings Materials for Program**

The following is a list of readings selected from *Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities* (Kathie Snow). These readings will help as conversation starters and topics of discussion during group discussion times of the program.

### **For Use in Reflective Practice**

Pg. 47: Your Child's Responsibility and Opportunities

Pg. 48: Your Family and Community Activities

Pg. 49: Your Child's Future and Potential

### **For Use Regarding Current Assumptions about Disability**

Pg. 62 to 67: The Medical Model & Quality of Life, The Prevision / Cure Mentality, and The Hierarchy of Disability

### **For Use Regarding Disability Studies Ideologies**

Pg. 113-122-: What *is* Disability

A Medical Diagnosis and a Passport to Services

Disability: A Natural Part of the Human Experience

One of the Many Human Characteristics

A Body Part that works differently

A Consequence of the Environment

Personal Tragedy or Social Oppression

### **For Use Regarding Post-Transition Expectations**

Pg. 216 –220: Our Families Our Homes

Age-Appropriate Starts at Home

Interdependence, Not Independence

Natural Assistance

Reciprocity is Critical

Pg. 220- 228: Self-Direction

Eliminate Learned Helplessness

Privileges and Responsibilities

Children's Decision-Making

Problem-Solving

Making Changes

### APPENDIX C: Select Media Example for Program

The following is a list of different types of media examples that can be utilized to facilitate group discussion during different sections of the program. In addition, these media examples provide parents with the opportunity to see different types of biases regarding adulthood outcomes for their adolescents across different mediums and available resources.

#### *YouTube Videos Regarding Disability Studies, Social Model of Disability and/or Disability Rights*

##### General Overview / Definition

- <https://www.youtube.com/watch?v=YmuUaJJ4tVY>

##### Explanation Regarding Social Model of Disability (Mike Oliver)

- <https://www.youtube.com/watch?v=gDO6U0-uaom>

##### To Imagine Disability Studies (Linda Ware)

- [https://www.youtube.com/watch?v=i7tS3e\\_F9vM](https://www.youtube.com/watch?v=i7tS3e_F9vM)

#### *Examples of Peer Reviewed Literature Discussing Adolescents' Post-Transition Expectations*

\*\*\* Henninger, N., & Taylor, J. (2012). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism*. Advance online publication. doi:10.1177/1362361312441266

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*, 1042–1049.

Taylor, J. L., & Seltzer, M. M. (2011). Employment and postsecondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, *41*, 566–574.

#### *Examples of Current Self-Advocacy and/or Information Available to Parents Regarding Adolescents' Post-Transition Expectations*

Autism Speaks – Transition Toolkit For Families on a Journey from Adolescent to Adulthood

- <https://www.autismspeaks.org/sites/default/files/2018-08/Transition%20Tool%20Kit.pdf>

## APPENDIX D: Critical Reflection Questions

The following is a list of potential critical reflection questions that will be utilized throughout the program during the specific weeks. These questions are meant to facilitate the process of reflective learning as outlined by Neill Thompson. Questions can be presented verbally or visually. Parent participants can have opportunities to engage in the questions individually and in the larger group settings. (Content versus Group Exploration).

### *Content Exploration Questions for Disability Studies (Week 2)*

- Before presenting (**Insert Media Name**), how do you define disability? After presenting (**Insert Media Name**), would you change your definition of disability? Why or why not?
- In (**Insert Media Name**), what were 2–3 main ideas that emerged? How did these main points make you feel? Do you agree or disagree with these main ideas? Why or why not?
- After reading / watching (**Insert Media Name**), would you address an impairment in your child (i.e. decreased social functioning, restricted/repetitive interests, sensory imbalances, behavioral outburst, etc.) differently? Why or why not?
- After reading / watching (**Insert Media Name**), do any of the ideas presented feel unclear? What follow-up questions would you ask the author / creator if you could? Why? What do you hope to learn from potential responses to your questions? What are some anticipated responses you envision the author / creator would give you?

### *Group Exploration Questions for Disability Studies-Related Content (Week 3)*

- What relevance do you see of the social model of disability or disability studies content to your everyday life with your adolescent? What aspects of the model do not feel applicable to your everyday life with your adolescent? Why?
- Let's consider one daily life activity that your son / daughter currently engages in and you perceive he/she has difficulty completing successfully. Why do you think he/she has difficulty completing this activity? Would a disability studies perspective / a social model perspective view the cause of the problem in this activity differently? If yes, then how? If no, then explain more.
- If other professionals (i.e. educator, therapist, doctor, etc.) in your son / daughter's life embodied a disability studies perspective, how would they act towards your son / daughter? Why do you feel this way?
- Can you identify an instance when you felt as if your child was experiencing a barrier that prevented him/her from engaging in an activity he/she wanted? How would you classify this barrier utilizing a disability studies' perspective (i.e.

physical/environment, social/attitudinal, and/or legal/policy barrier)? What are potential ways to remove the barrier? Do you think these solutions are feasible? Why or why not?

*Content Exploration Questions for Post-Transition Outcomes' Content (Week 4)*

- In **(Insert Media Name)**, what expectations did the authors/creators have for adolescents with ASD when they reach adulthood? Why do you think they hold these expectations? How do holding these expectations affect the adolescent / adult with ASD?
- In **(Insert Media Name)**, what were 2-3 main ideas (attitudes, assumptions, etc.) that emerged about transition outcomes, transition planning, adulthood success, etc.? How did these main points/attitudes/assumptions make you feel? Do you agree or disagree with any of these? Why or why not?
- Before interviewing the adult with ASD, what do you expect to see or what do you expect will happen? After interviewing the adult with ASD, were any of your expectations validated? What did you see or hear that was the same as what you expected? What was different? Why do you think this is the case?
- What does Kathie Snow suggest parents do in **(Insert Media Name)** to help their child with ASD prepare for transition? Which of these strategies resonate with you? Which of them do not? Why is this the case?

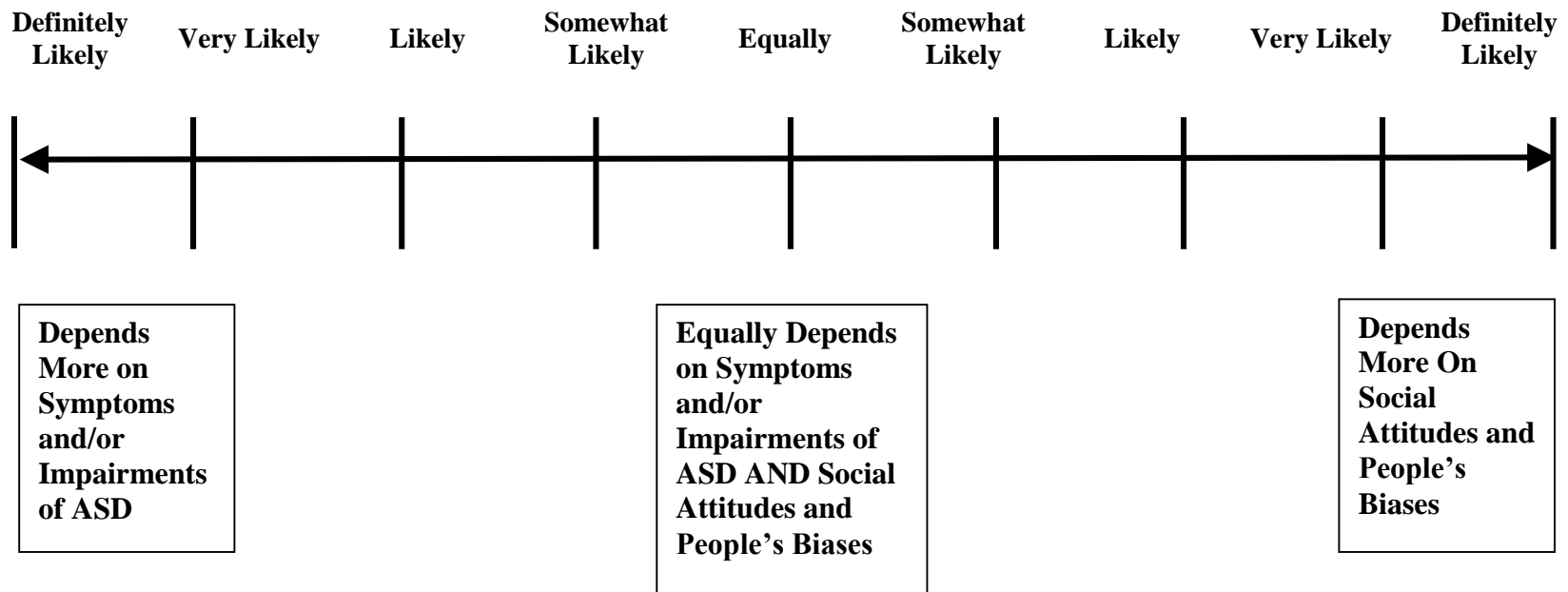
*Group Exploration Questions for Post-Transition Outcomes-Related Content (Week 5)*

- How do you measure your own success as an adult living in your community? Would you hold these same expectations for your child? Why or why not?
- What do you believe is realistic for your adolescent with ASD to achieve in adulthood? Why do you feel so? Do you believe these are the same expectations or aspirations your adolescent has for their future? Why or why not?
- What do you believe are your child's specific obstacles for meeting your expectations in (employment, housing, education, daily life activities, leisure activities)? Why? Which of these barriers consider disability through a medical model? Which of these consider disability through a social model? Why did you choose to classify that particular barrier under that category (i.e. social or medical)? What are some ways you might address these barriers?
- What are your greatest fears about your child's future as an adult with ASD in your community? Why do you think these fears exist? What can you do to feel less uncomfortable about these less desirable outcomes?

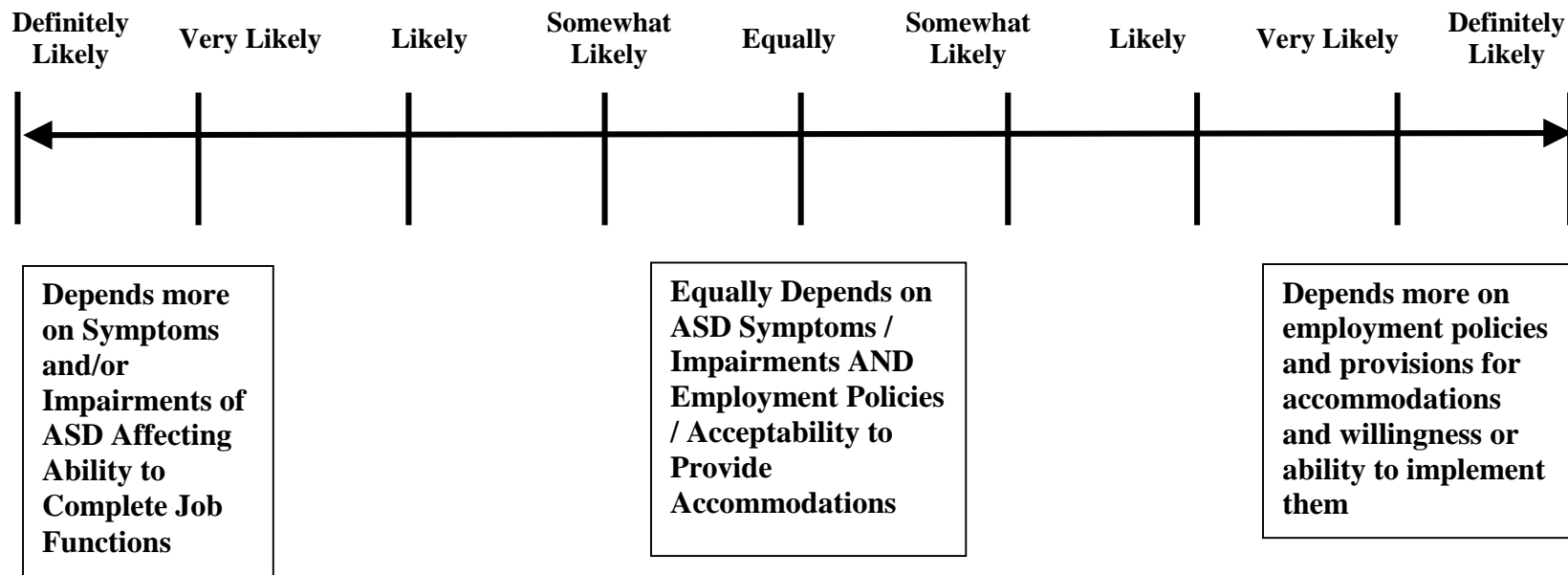


**APPENDIX E: The Rating Scale of Social and Medical Factors Impacting Adulthood Outcomes**

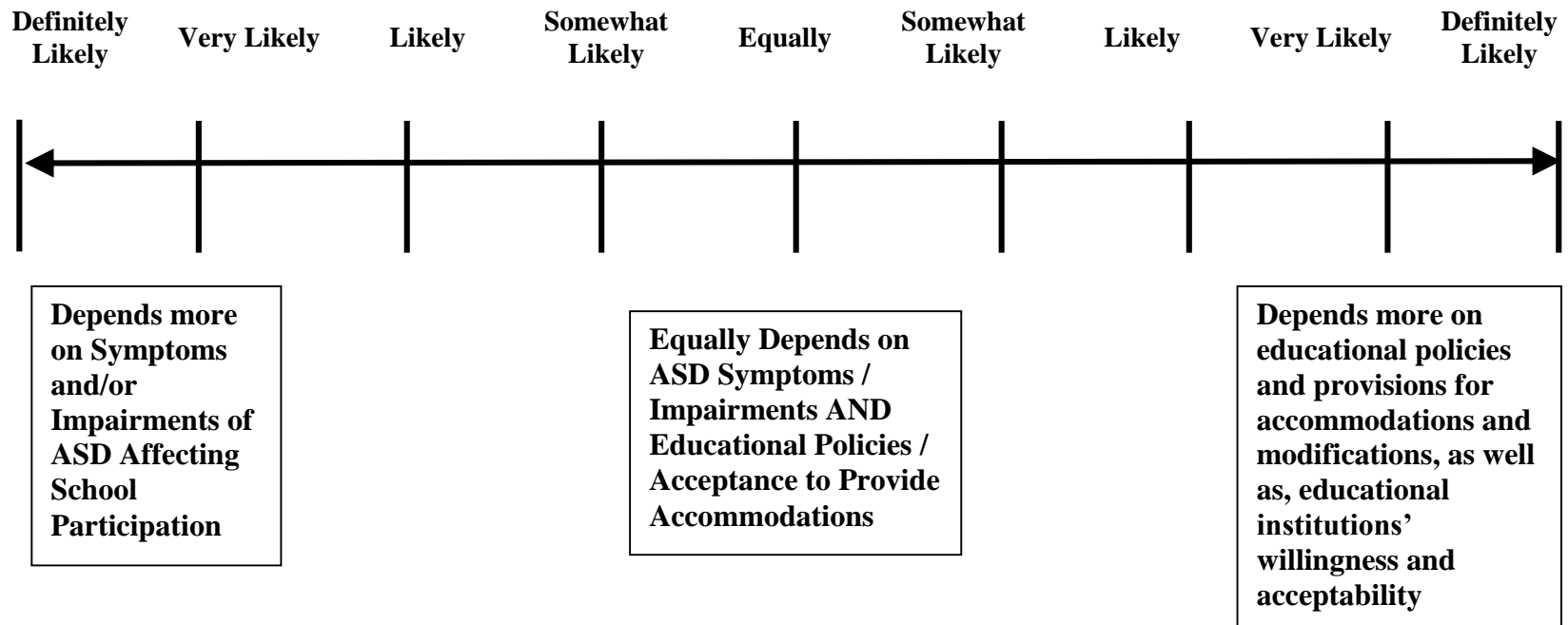
- 1) Does your child’s future success in his/her adulthood depend more on his/her ASD symptoms and impairments (i.e. decreased social functioning, restricted /repetitive interests, sensory imbalances, cognitive capacity, etc.) OR more on societal attitudes, people’s biases, and other social policies currently in place?



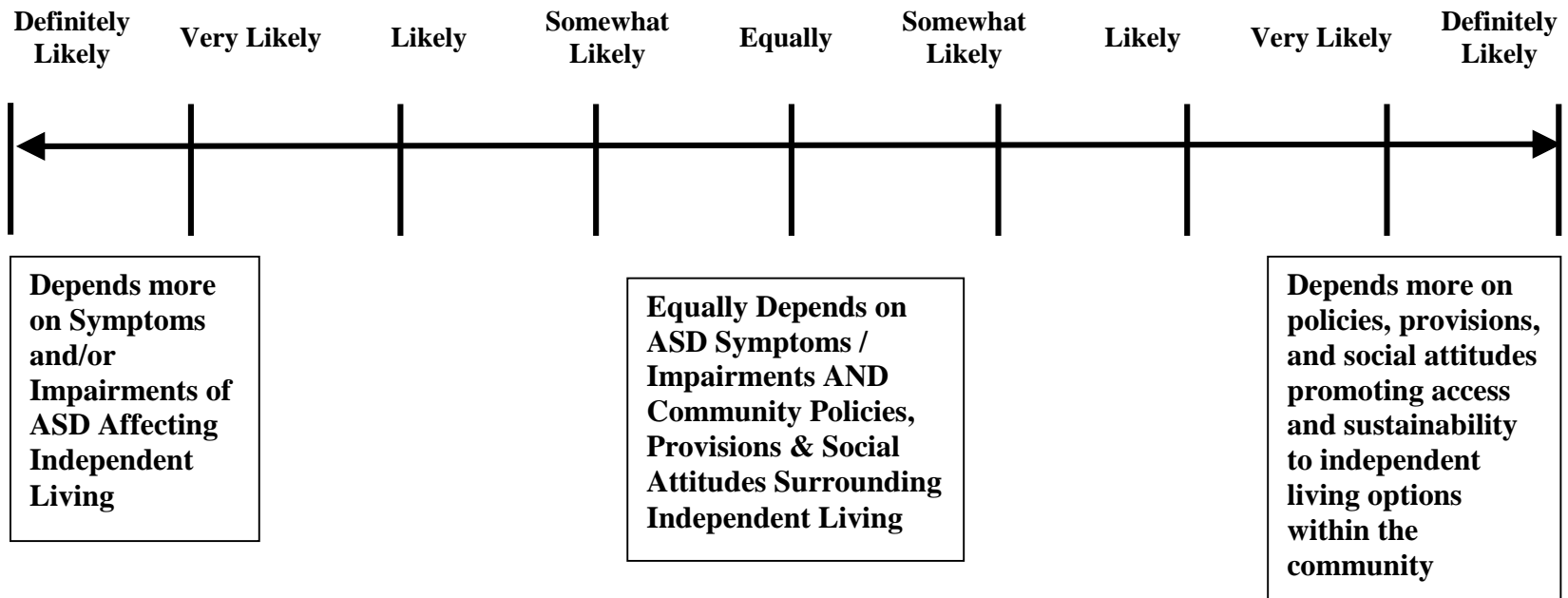
2) Does your child’s ability to hold and maintain an employment, volunteer or job opportunity depend more on the impact of his/her ASD symptoms and impairments (i.e. decreased social functioning, restricted / repetitive interests, sensory imbalances, cognitive capacity, etc.) on completing essential job functions OR does it depend more on the employment policies related to people with disabilities that permit appropriate accommodations for my child to work and the employer’s willingness to implement them?



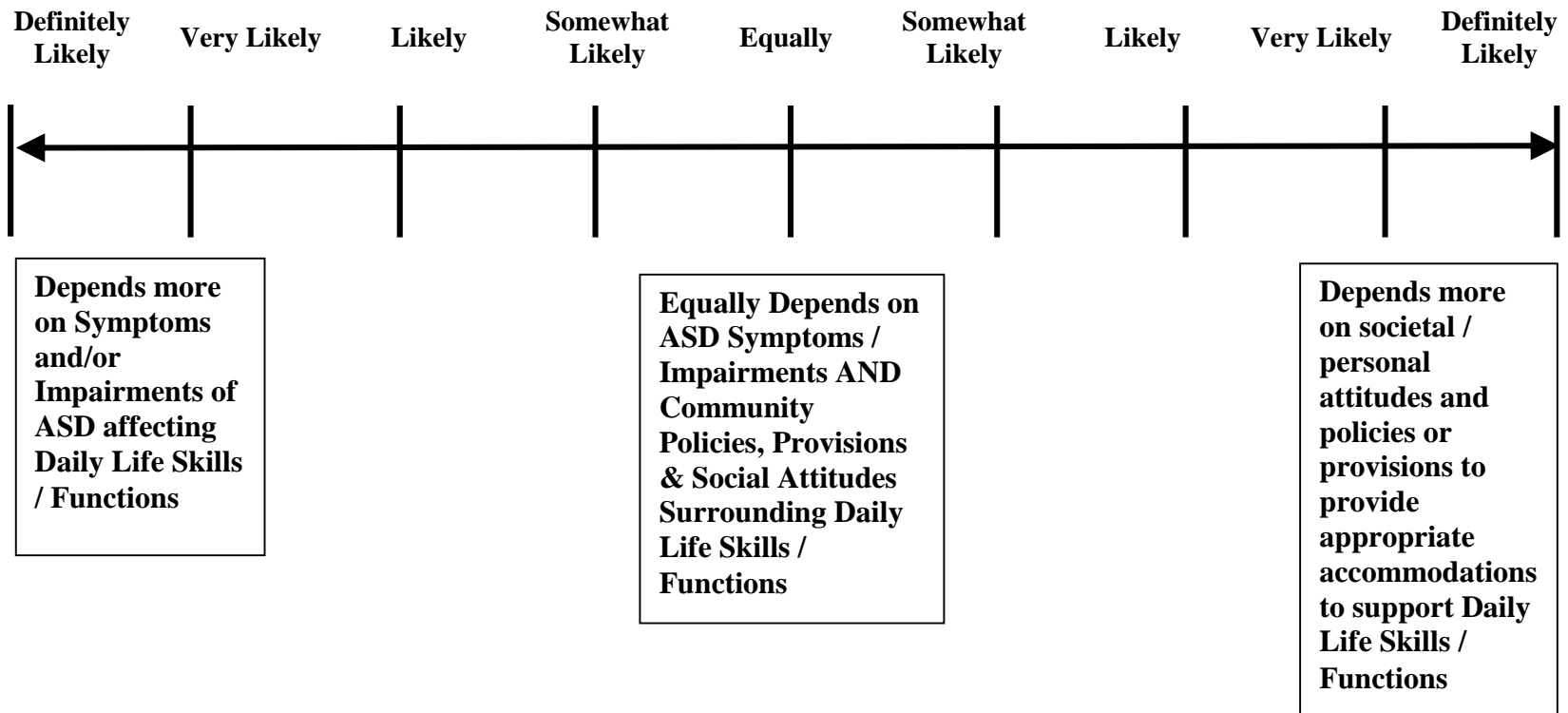
3) Does your child’s ability to participate in post-secondary schooling options (i.e. 2 or 4 year colleges, vocational programs, online college courses, certificate programs, etc.) depend more on his/her ASD symptoms or impairments (i.e. decreased social functioning, restricted / repetitive interests, sensory imbalances, cognitive capacity, etc.) OR depend more on post-secondary schooling policies, laws, and/or provisions which provide appropriate accommodations, modifications, and acceptance to access the classroom / curriculum.



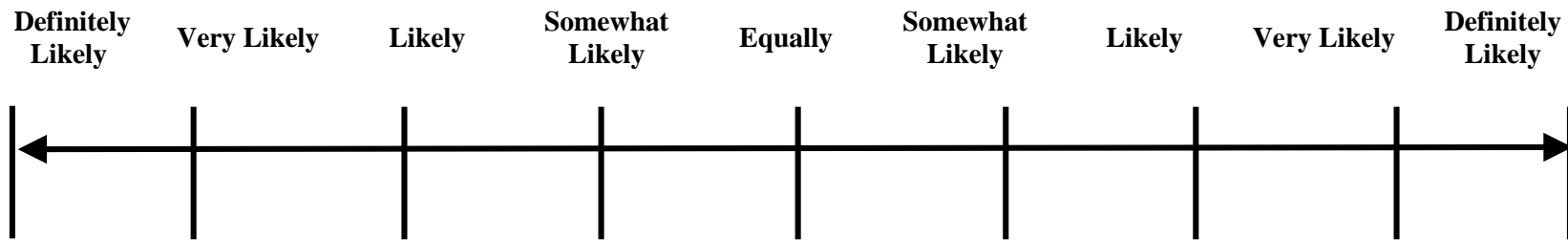
4) Does your child’s ability to live outside of his/her current, “childhood” home (either independently, in a group home, with personal care attendant, etc.) depend more on his/her ASD symptoms and impairments (i.e. decreased social functioning, restricted / repetitive interests, sensory imbalances, cognitive capacity, etc.) OR depend more on the federal, state, and community laws, services and/or policies which ensure financial ability, access, and/or acceptance for your child to live outside of his/her “childhood” home?



5) Does your child's ability to carry out his every day functions as an adult depend more on his/her ASD symptoms and impairments (i.e. decreased social functioning, restricted / repetitive interests, sensory imbalances, cognitive capacity, etc.) OR on societal and personal beliefs about what someone with your child's condition can or cannot do and/or the availability of appropriate policies, provisions, and accommodation to support every day functions?



6) Does your child’s ability to engage in purposeful, leisure activities as an adult depend more on his/her ASD symptoms and impairments (i.e. decreased social functioning, restricted / repetitive interests, sensory imbalances, cognitive capacities, etc.) OR on the inclusion of people with disabilities in leisure opportunities and/or availability of community programs, provisions, supports, or accommodations to allow engagement in leisure activities as an adult?



**Depends more on Symptoms and/or Impairments of ASD affecting leisure participation**

**Equally Depends on ASD Symptoms / Impairments AND Community Programs, Supports & Social Attitudes Surrounding Leisure Participation**

**Depends more on societal inclusion and/or the availability of community supports / accommodations to promote leisure participation**

## **EXECUTIVE SUMMARY**

### **Introduction**

Transition refers to the process in which adolescents leave secondary schooling and its associated pediatric services and move onto post-secondary options, including adult service utilization. Traditionally, post-secondary options have included attending a two- or four-year college, securing employment that offers an affordable living wage, living independently, contributing to one's community, and maintaining adult personal social relationships (Henninger & Taylor, 2013). While all adolescents undergo a transition into adulthood, special services are provided for adolescents with disabilities to aid with the transition process. These transition services for adolescents with disabilities, including those with autism spectrum disorder (ASD), are given due to the growing evidence-based literature outlining that individuals with ASD appear to have poorer post-transition outcomes compared to their peers' with or without other disabilities post-transition (Newman et al., 2011). Examples of these poor transition outcomes include less likely to pursue and complete post-secondary education, less likely to obtain and maintain employment fewer social supports or friends, and less likely to maintain independent living arrangements (Newman et al., 2011). This disparity in post-transition outcomes for individuals with ASD has propelled educational and healthcare professionals to delve further into their provision of services in hopes to minimize this gap in outcomes.

In contrast, disability studies, as an academic discipline, has also garnered increased attention amongst educational and healthcare professions. Disability studies is

an interdisciplinary approach involving anthropology, sociology, law, gender studies, art, and economics which examines how our society constructs the notion of what it means to be disabled (Oliver, 2009; Longmore, 2003a). The discipline suggests that disability is not a result of a skill deficit in an individual, but rather a byproduct of how our society fails to accommodate to these different skills levels (Oliver, 2009; Longmore, 2003a). Applying this basic tenant of disability studies to adulthood transitions, disability studies would denote the problem of “poor transition outcomes” as society’s failure to eschew different ideas of adult success. If our society were more accommodating to how it views an individual living successfully, while simultaneously offering appropriate supports to each individual, then individuals with ASD could attain “post-transition” success. Moreover, parents, as primary caregivers, play a role in perpetuating the label of “poor transition outcomes” by internalizing society’s pre-disposed notions of successful transition expectations, and utilizing these internalized notions as guiding pillars during critical decision-making opportunities for their adolescent.

Overall, when considering both current healthcare disciplines’ literature and disability studies literature, our society and its currently offered services are not adequately addressing transition in individuals with ASD. By not adequately addressing transition (by either disciplines’ approach), individuals with ASD are at a considerable disadvantage in regards to how they can lead productive lives in our society. The call for healthcare and educational professionals, such as occupational therapists, to address this gap is paramount.



### **Project Overview**

This project proposes a potential solution to the problem of “poor transition outcomes” in adolescents with ASD through the creation of a critical reflection program for the parents of these youth by utilizing disability studies ideologies. Parents play an invaluable role in the lives of their children with ASD throughout the lifespan, including participation in decision-making affecting their child’s adult lives (Smith & Anderson, 2014). Despite this research, few parent programs exist that educate and empower parents about transition so that they can support their adolescents with ASD into adulthood. *Re-Imagine Transition and Adult Success* is a six-week course conducted by an occupational therapist, once a week for two-hour sessions totaling 12 hours of instruction. The program’s aim is to promote parents’ critical reflection about biases, assumptions, and stereotypes regarding disability and adulthood success through the use of critical disability studies concepts. Using a reiterative process, the program involves three sections: 1. individual exploration, 2. content exploration, and 3. group exploration. The program utilizes multi-modal learning strategies to present concepts, while also offering experiential learning and structured individual/group reflection. The proposed if/then statement is: If parents become more critically aware about their own biases regarding disability and success in adulthood, then they will be empowered to make decisions with/for their adolescent with ASD that best supports him/her through the transition process. These decisions will hopefully have a positive influence on transition outcomes for the adolescents.

### **Key Findings**

Foremost, utilizing both the social model of disability and family resiliency theory frameworks, an explanatory model was created to explain the problem of “poor transition outcomes” in adolescents with ASD. After conducting a comprehensive review of current evidence-based literature from multi-disciplinary fields, the model revealed the multi-faceted interplay of individual, family, social, and societal factors that influence parents as they provide care for their adolescents (Depape & Lindsay, 2015; Orsmond, Seltzer, Greenberg & Krauss, 2006; Lounds, Seltzer, Greenberg & Shattuck, 2007). Next, these factors were analyzed through a social model of disability lens to hypothesize how parental decision-making for adolescents’ transitions may be contributing the greater problem of “poor transition outcomes” in these youth. The resulting analysis in the model suggests that adolescents with ASD have “poor transition outcomes” due in part to how society, especially their parents, maintain stereotypes regarding success in adulthood (Longmore, 2003b). These views inadvertently subject individuals with ASD to only a few possible options for their adult life. The model, therefore, explicates that a potential solution to “poor transition outcomes” in adolescents with ASD is to critically inform these youths’ parents about their own biases and assumptions about disability.

Next, the current literature regarding training and/or educational programs for parents of transition-aged youth with ASD was reviewed. Only four parent-targeted interventions related to transition planning for adolescents with ASD were found and reviewed, suggesting a limitation in the research. While many differences between these programs exist in regards to duration, length, structure, and content, some themes did

emerge. For example, all programs employed a group format for social learning, goal-setting to individualize program content to meet the needs of the family, and provided knowledge regarding transitions, transition planning, and adult service systems (DaWalt, Greenberg, & Mailick, 2018; Hagner et al., 2012; Loukas, Raymond, Perron, Mcharg, & Lacroix Doe, 2015; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). In addition to reviewing transition programs for parents of adolescents with ASD, parental programs on disability acceptance were also examined. There are few parental programs on disability acceptance, and those that exist fail to be critically evaluated in peer-reviewed, evidence-based literature (Santelli, Turnbull, Marquis & Lerner, 1995; Snow, 2013). However, these programs and training materials suggest the importance of providing parents emotional support as they work to positively accept their child's disability (Santelli, Turnbull, Marquis & Lerner, 1995; Snow, 2013).

Finally, occupational therapy practitioners may be acutely positioned to address transition in adolescents with ASD by means of conducting parent psychosocial groups. For example, occupational therapy practitioners are taught to both understand and assist in facilitating potential roles and routines individuals must maintain, including those for parents / caregivers (American Occupational Therapy Association, 2014). In addition, occupational therapy practitioners are knowledgeable about group processes, and its implications for conducting therapeutic group interventions. They are also skilled in client education, especially for caregivers. Lastly, occupational therapy practitioners have made headway in addressing transition in adolescents with ASD, while also showing budding acceptance of the contributions the field of disability studies can present to its

practice (Kielhofner, 2005).

### **Recommendations for Program Implementation**

To address “poor transition outcomes” in adolescents with ASD, a potential “top-down” approach can be employed which targets these youth’s parents. By targeting parents of adolescents with ASD, healthcare professionals, like occupational therapists, may find a meaningful mechanism to positively influence adolescents’ adult lives through empowering parents during transition-based decision-making opportunities. A critical reflection program involving disability studies concepts may help elicit positive disability views and changes in the criteria by which adolescents with ASD are evaluated for adulthood success. Drawing from the current literature, social learning through a group format, goal-setting, didactic experiences, and emotional support will be systematically offered to promote adequate reflection in the program, *Re-Imagine Transition & Adult Success*.

*Re-Imagine Transition & Adult Success* will be presented for potential adoption to several New Jersey community institutions, including but not limited to local and state Boards of Education, school systems, the Arc for People of Intellectual and Developmental Disabilities, local hospitals / outpatient facilities focusing on transition services or other relevant organizations. Once adopted, the program will be evaluated on its ability to meet the intended outcomes of: 1) increasing awareness and knowledge of disability studies’ content, especially related to transition and 2) identifying and critically reflecting upon parents’ current biases, assumptions, and/or stereotypes about disability and adulthood success. The acceptability and practicality of the program and its

associated content for the participants will be assessed. Finally, a dissemination plan will be created to spread results of the evaluation plan to future participants, current/future organizational administrative staff, and occupational therapists.

### **Conclusion**

*Re-Imagine Transition and Adult Success* is a critical reflection program for parents of transition-aged youth with ASD that employs disability studies concepts. By utilizing disability studies concepts parents will be more critically aware of their own biases, assumptions, and stereotypes regarding disability and what it means to be a successful adult in our society. By increasing this awareness, parents may feel more empowered during transition-related decision-making with/for their adolescents with ASD. By influencing how parents are making or assisting in decision-making, adolescents with ASD may achieve positive, and more meaningful outcomes in adulthood. Thus, *Re-Imagine Transition and Adult Success* is an innovative, “top-down” approach to address transition in adolescents with ASD. This reiterative, reflective program structure should ideally elicit positive change in transition-related outcomes for adolescents with AS through the use of theory, evidence, and a disability studies framework.

### *References for Executive Summary*

- American Occupational Therapy Association (2014). OCCUPATIONAL THERAPY PRACTICE FRAMEWORK: Domain & Process 3rd Edition. *The American Journal of Occupational Therapy*, 68, S1–S48. doi:10.5014/ajot.2014.682006
- DaWalt, L., Greenberg, J., & Mailick, M. (2018). Transitioning Together: A multi-family Group Psychoeducation Program for Adolescents with ASD and Their Parents. *Journal of Autism and Developmental Disorders*, 48(1), 251–263.  
<https://doi.org/10.1007/s10803-017-3307-x>
- DePape, A.-M., & Lindsay, S. (2015). Parents' Experiences of Caring for a Child With Autism Spectrum Disorder. *Qualitative Health Research*, 25(4), 569–583.  
<https://doi.org/10.1177/1049732314552455>
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a Family-Centered Transition Process for Students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 42–50.
- Henninger, N. A., & Taylor, J. L. (2013). Outcomes in Adults with Autism Spectrum Disorders: A Historical Perspective. *Autism: The International Journal of Research and Practice*, 17(1), 103–116.  
<https://doi.org/10.1177/1362361312441266>
- Kielhofner, G. (2005). Rethinking disability and what to do about it: disability studies and its implications for occupational therapy. *The American Journal of Occupational Therapy*, 59(5), 487. <https://doi.org/10.5014/ajot.59.5.487>

- Longmore, P. K. (2003a). The second phase: From disability rights to disability culture. *Why I burned my book and other essays on disability* (pp. 204 – 212). Philadelphia, PA: Temple University Press.
- Longmore, P. K. (2003b). Screening stereotypes – Images of disabled people in television and motion pictures. *Why I burned my book and other essays on disability* (pp. 131 – 146). Philadelphia, PA: Temple University Press.
- Loukas, K. M., Raymond, L., Perron, A. R., Mcharg, L. A., & Lacroix Doe, T. C. (2015). Occupational transformation: Parental influence and social cognition of young adults with autism. *Work*, 50(3), 457. <https://doi.org/10.3233/WOR-141956>
- Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. T. (2007). Transition and Change in Adolescents and Young Adults with Autism: Longitudinal Effects on Maternal Well-Being. *American Journal on Mental Retardation*, 112(6), 401–417. [https://doi.org/10.1352/0895-8017\(2007\)112\[401:TACIAA\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[401:TACIAA]2.0.CO;2)
- Newman L, Wagner M, Knokey A, Marder C, Nagle K, Shaver D, et al. (2011) *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International.
- Oliver, M. (2009). Social model in context. In T. Titchkosky & R. Michalko (Eds.), *Rethinking normalcy: A disability studies reader* (pp. 19-30). Toronto, Ontario: Canadian Scholars' Press Inc.
- Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (2006). Mother-Child Relationship Quality among Adolescents and Adults with Autism. *American*

*Journal on Mental Retardation*, 111(2), 121–137. [https://doi.org/10.1352/0895-8017\(2006\)111\[121:MRQAAA\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111[121:MRQAAA]2.0.CO;2)

Santelli, B., Turnbull, A.P., Marquis, J.G., & Lerner, E.P. (1995). Parent to parent programs: A unique form of mutual support. *Infants and Young Children*, 8, 48-57

Smith, L. E., & Anderson, K. A. (2014). The Roles and Needs of Families of Adolescents with ASD. *Remedial and Special Education*, 35(2), 114–122. <https://doi.org/10.1177/0741932513514616>

Snow, K. (2013) *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. San Antonio, TX: BraveHeart Press.

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial. *Journal of Autism and Developmental Disorders*, 47(3), 846–857. <https://doi.org/10.1007/s10803-016-2994-z>



## FACT SHEET



*Re-Imagine Transition & Adult Success* – A Critical Reflection Program for  
Parents of Transition-Aged Youth with Autism Spectrum Disorder (ASD)  
involving Disability Studies  
Janvi Patel MS, OTR/L

### The Problem: Adolescents with ASD have “Poor” Outcomes in Adulthood

- Current research indicates that adolescents with Autism Spectrum Disorder (ASD) are less likely to pursue and complete post-secondary education, less likely to obtain and maintain employment, have fewer social supports or friends, and are less likely to maintain independent living arrangements compared to their peers without disabilities or with other disabilities (Newman et al., 2011).
- Disability studies is an interdisciplinary approach which examines how our society constructs the notion of what it means to be disabled (Oliver, 2009; Longmore, 2003). This field postulates that the abovementioned “poor transition outcomes” results from society’s failure to eschew different ideas of how adults can lead successful lives.
- Parents partake in decision-making throughout the life of their child with ASD; these decisions have lasting implications to their child’s adult lives (Smith & Anderson, 2014).
- Interventions which aid parents with decision-making roles related to their child’s adulthood outcomes or explore how parental biases and assumptions impact perceived adulthood outcomes for their child and the subsequent decision-making required for transition are both limited.

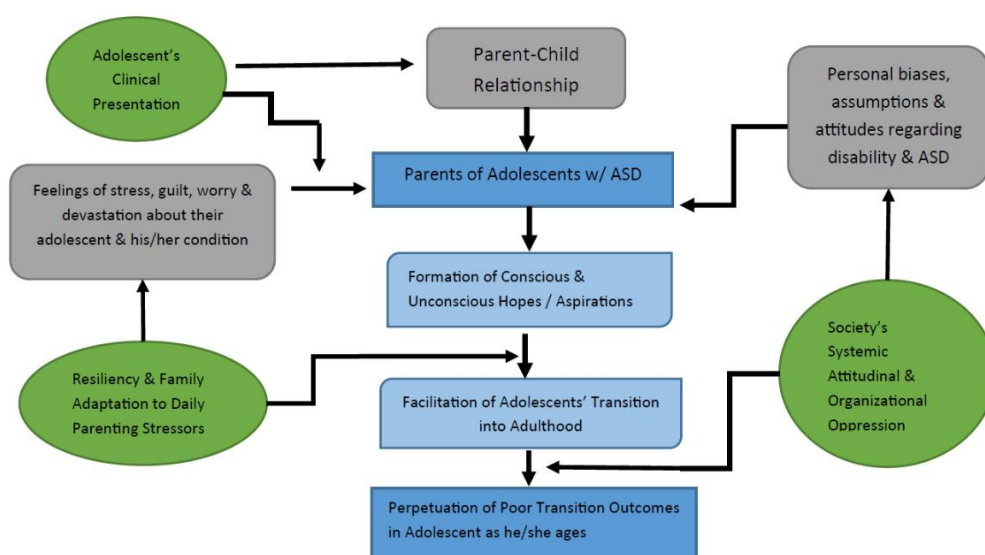


Figure 1: Explanatory Model for “Poor Transition Outcomes” in Adolescents with ASD

### Figure 1

- Conceptualizes how parents may be inadvertently perpetuating the label of “poor transition outcomes” through various personal, familial, social, and societal factors.
- Considers the influential factors through a disability studies framework

### Current Evidence-Based Interventions

- Few transition-related programs that are designed for parents of youth with ASD actually exist, and research assessing these programs’ effectiveness have methodological shortcomings.

***Re-Imagine Transition & Adult Success*** is the first program targeted for parents of transition-aged youth with ASD that incorporates disability studies when planning for adulthood.

### About the Program

*Re-Imagine Transition and Adult Success* is a six-week course designed for 6 to 12 parents and to be conducted by an occupational therapist. It would occur once a week for two-hour sessions totaling 12 hours of instruction in a community organization servicing parents of transition-aged youth with ASD.

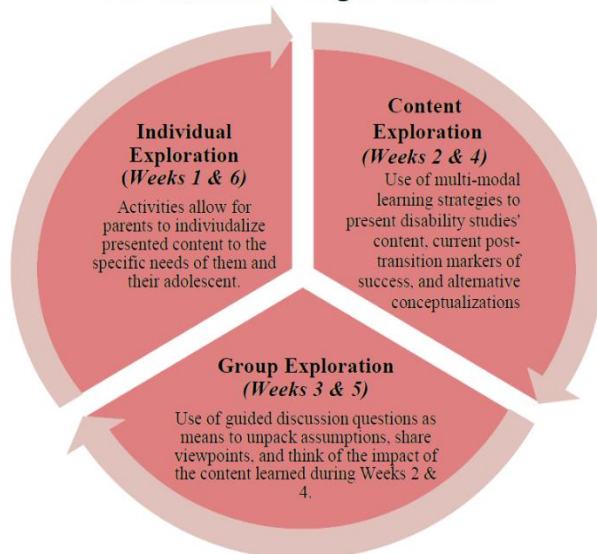
### Intended Outcomes

- 1) Increase parents' knowledge of disability studies concepts, and the relevance of those concepts for transition planning in adolescents with ASD
- 2) Support parents to identify and critically reflect on their assumptions regarding disability and what constitutes as adult success

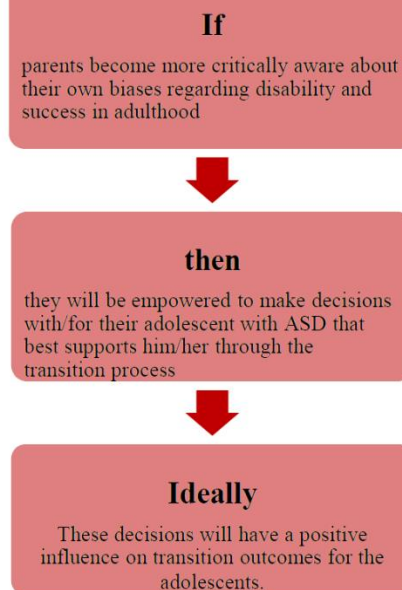
### Theory and Evidence-Base

- *Social Model of Disability*— viewing disability as a byproduct of barriers within our society (i.e. including physical, social, and attitudinal barriers) that fail to accommodate to an individual's impairment or difference for effective participation (Oliver, 2009)
- *Reflective Learning Process*—By reviewing and studying one's own experiences, that person gains a better understanding of his/her intentions, which promotes continuous learning for improvements in his/her actions (Thompson & Pascal, 2012).

### Three Reiterative Program Sections



### Proposed Pathway to Affect Change in Clinical Problem



### Occupational Therapy Implications

- OTs have experience conducting psychosocial groups
- OTs have an emerging role in assisting with transitioning planning
- OTs have expertise in providing caregiver education

### References

- Longmore, P. K. (2003a). The second phase: From disability rights to disability culture. *Why I burned my book and other essays on disability* (pp. 204 – 212). Philadelphia, PA: Temple University Press.
- Newman L, Wagner M, Knokey A, Marder C, Nagle K, Shaver D, et al. (2011) *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSEER 2011-3005). Menlo Park, CA: SRI International.
- Oliver, M. (2009). Social model in context. In T. Titchkosky & R. Michalko (Eds.), *Rethinking normalcy: A disability studies reader* (pp. 19-30). Toronto, Ontario: Canadian Scholars' Press Inc.
- Smith, L. E., & Anderson, K. A. (2014). The Roles and Needs of Families of Adolescents with ASD. *Remedial and Special Education*, 35(2), 114–122. <https://doi.org/10.1177/0741932513514616>
- Thompson, N., & Pascal, J. (2012). Developing critically reflective practice. *Reflective Practice*, 13(2), 311–325. <https://doi.org/10.1080/14623943.2012.657795>

## REFERENCES

- Altiere, M. J., & Von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability*, 34(2), 142–152.  
<https://doi.org/10.1080/13668250902845202>
- Amazon.com, Inc. (n.d.). *Acer Predator Helios 300 Gaming Laptop, 15.6" full HD IPS, Intel i7-7700HQ CPU, 16GB DDR4 RAM, 256GB SSD, GeForce GTX 1060-6GB, VR Ready, Red Backlit KB, Metal Chassis, Windows 10 64-bit, G3-571-77QK*. Retrieved from [https://www.amazon.com/Acer-Predator-i7-7700HQ-1060-6GB-G3-571-77QK/dp/B06Y4GZS9C/ref=as\\_li\\_ss\\_tl?ie=UTF8&linkCode=sl1&tag=homsmag-20&linkId=0c7f1f4ad07feb41df0162b687969200&language=en\\_US](https://www.amazon.com/Acer-Predator-i7-7700HQ-1060-6GB-G3-571-77QK/dp/B06Y4GZS9C/ref=as_li_ss_tl?ie=UTF8&linkCode=sl1&tag=homsmag-20&linkId=0c7f1f4ad07feb41df0162b687969200&language=en_US)
- Amazon.com, Inc. (n.d.). *Essentials swivel mid back mesh task chair with arms - ergonomic computer/office chair (ESS-3001)*. Retrieved from [https://www.amazon.com/OFM-Essentials-Back-Task-Chair/dp/B01L2Q1YS2?ref=Oct\\_MWishedForC\\_3733721\\_3&pf\\_rd\\_r=B6510E8TEHAXXZNB1M41&pf\\_rd\\_p=7c6ecd75-17ac-504f-ae08-f9542d464b35&pf\\_rd\\_s=merchandise-search-10&pf\\_rd\\_t=101&pf\\_rd\\_i=3733721&pf\\_rd\\_m=ATVPDKIKX0DER](https://www.amazon.com/OFM-Essentials-Back-Task-Chair/dp/B01L2Q1YS2?ref=Oct_MWishedForC_3733721_3&pf_rd_r=B6510E8TEHAXXZNB1M41&pf_rd_p=7c6ecd75-17ac-504f-ae08-f9542d464b35&pf_rd_s=merchandise-search-10&pf_rd_t=101&pf_rd_i=3733721&pf_rd_m=ATVPDKIKX0DER)
- Amazon.com, Inc. (n.d.). *Logitech Multimedia Speakers Z200 with Stereo Sound for Multiple Devices – Black*. Retrieved from <https://www.amazon.com/Logitech-Multimedia-Speakers-Multiple->

[Devices/dp/B00EZ9XKCM?ref=Oct\\_BSellerC\\_172471\\_1&pf\\_rd\\_p=fb0b8233-2ff6-5399-bd66-04689c26c901&pf\\_rd\\_s=merchandise-search-6&pf\\_rd\\_t=101&pf\\_rd\\_i=172471&pf\\_rd\\_m=ATVPDKIKX0DER&pf\\_rd\\_r=RZWD813FD8XESAF7HCV1&pf\\_rd\\_r=RZWD813FD8XESAF7HCV1&pf\\_rd\\_p=fb0b8233-2ff6-5399-bd66-04689c26c901](https://www.amazon.com/Devices/dp/B00EZ9XKCM?ref=Oct_BSellerC_172471_1&pf_rd_p=fb0b8233-2ff6-5399-bd66-04689c26c901&pf_rd_s=merchandise-search-6&pf_rd_t=101&pf_rd_i=172471&pf_rd_m=ATVPDKIKX0DER&pf_rd_r=RZWD813FD8XESAF7HCV1&pf_rd_r=RZWD813FD8XESAF7HCV1&pf_rd_p=fb0b8233-2ff6-5399-bd66-04689c26c901)

Amazon.com, Inc. (n.d.). *VANKYO LEISURE 3 Mini Projector, Full HD 1080P and 170"*

*Display Supported, 2400 Lux Portable Movie Projector with 40,000 Hrs LED*

*Lamp Life, Compatible with TV Stick, PS4, HDMI, VGA, TF, AV and USB.*

Retrieved from [https://www.amazon.com/Leisure-Upgraded-Portable-Projector-Compatible/dp/B078KF8CSX/ref=sr\\_1\\_3?keywords=computer+projector&qid=1549995399&s=gateway&sr=8-3](https://www.amazon.com/Leisure-Upgraded-Portable-Projector-Compatible/dp/B078KF8CSX/ref=sr_1_3?keywords=computer+projector&qid=1549995399&s=gateway&sr=8-3)

Amazon.com, Inc. (n.d.). *VIVO 100" Portable indoor outdoor projector screen, 100 Inch*

*Diagonal Projection HD 4:3 Projection Pull Up Foldable Stand Tripod (PS-T-*

*100)*. Retrieved From [https://www.amazon.com/VIVO-Portable-Projector-Diagonal-](https://www.amazon.com/VIVO-Portable-Projector-Diagonal-Projection/dp/B00MR607RQ/ref=zg_bs_392442011_5?encoding=UTF8&psc=1&refRID=RQ1RFKQ3EYESZM5CHVTK)

[Diagonal-](https://www.amazon.com/VIVO-Portable-Projector-Diagonal-Projection/dp/B00MR607RQ/ref=zg_bs_392442011_5?encoding=UTF8&psc=1&refRID=RQ1RFKQ3EYESZM5CHVTK)

[Projection/dp/B00MR607RQ/ref=zg\\_bs\\_392442011\\_5?encoding=UTF8&psc=1&refRID=RQ1RFKQ3EYESZM5CHVTK](https://www.amazon.com/VIVO-Portable-Projector-Diagonal-Projection/dp/B00MR607RQ/ref=zg_bs_392442011_5?encoding=UTF8&psc=1&refRID=RQ1RFKQ3EYESZM5CHVTK)

American Occupational Therapy Association (2014). OCCUPATIONAL THERAPY

PRACTICE FRAMEWORK: Domain & Process 3rd Edition. *The American*

*Journal of Occupational Therapy*, 68, S1–S48. doi:10.5014/ajot.2014.682006

American Occupational Therapy Association (n.d.-b). *About OT Practice magazine.*

Retrieved from <https://www.aota.org/Publications-News/otp/about.aspx>

American Occupational Therapy Association (n.d.-b). *Occupational therapy's role in transitions*. Retrieved from [https://www.aota.org/Practice/Children-](https://www.aota.org/Practice/Children-Youth/Transitions.aspx)

[Youth/Transitions.aspx](https://www.aota.org/Practice/Children-Youth/Transitions.aspx)

American Occupational Therapy Association (n.d.-c). *Registration rates*. Retrieved from <https://www.aota.org/Conference-Events/annual-conference/cost.aspx>

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Association 978-0-89042-557-2.

Boston University College of Health & Rehabilitation Sciences (n.d.). *Dudley Allen Sargent Research Fund*. Retrieved from

<https://www.bu.edu/sargent/research/research-funding-administration/dudley-allen-sargent-research-fund/>

Bureau of Labor Statistics. (2018 March 30). *29-112 Occupational therapist*. Retrieved from <https://www.bls.gov/oes/2017/may/oes291122.htm>

Bureau of Labor Statistics. (2018 August 8). *Secretaries and administrative assistants*.

Retrieved from <https://www.bls.gov/ooh/office-and-administrative-support/secretaries-and-administrative-assistants.htm#tab-1>

CDW Corporation (n.d.). *Acer HDMI to VGA Converter video converter – white*.

Retrieved from [https://www.cdw.com/product/Acer-HDMI-to-VGA-Converter-video-converter-white/3826319?cm\\_cat=GoogleBase&cm\\_ite=3826319&cm\\_pla=NA-NA-ACE\\_CC&cm\\_ven=acquirgy&ef\\_id=Wka79wAAAFehKR-](https://www.cdw.com/product/Acer-HDMI-to-VGA-Converter-video-converter-white/3826319?cm_cat=GoogleBase&cm_ite=3826319&cm_pla=NA-NA-ACE_CC&cm_ven=acquirgy&ef_id=Wka79wAAAFehKR-)

[l:20190212183545:s&gclid=EAJaIQobChMI3fbC\\_em24AIVULbACh33NgXvE  
AQYASABEgLOiPD\\_BwE&s\\_kwcid=AL!4223!3!242808590562!!!g!31919447  
3991](https://doi.org/10.1111/jar.12150)

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). “Transitions Are Scary for Our Kids, and They’re Scary for Us”: Family Member and Youth Perspectives on the Challenges of Transitioning to Adulthood with Autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548–560.

<https://doi.org/10.1111/jar.12150>

DaWalt, L., Greenberg, J., & Mailick, M. (2018). Transitioning Together: A multi-family Group Psychoeducation Program for Adolescents with ASD and Their Parents. *Journal of Autism and Developmental Disorders*, 48(1), 251–263.

<https://doi.org/10.1007/s10803-017-3307-x>

Disability is Natural (n.d.). *Presentations by Kathie Snow*. Retrieved from

<https://www.disabilityisnatural.com/presentations.html>

DePape, A.-M., & Lindsay, S. (2015). Parents’ Experiences of Caring for a Child With Autism Spectrum Disorder. *Qualitative Health Research*, 25(4), 569–583.

<https://doi.org/10.1177/1049732314552455>

Doug Flutie Jr. Foundation for Autism, Inc. (n.d.). *The Doug Flutie, Jr. Foundation 2018 Signature Grant Cycle Guidelines*. Retrieved from

<http://www.flutiefoundation.org/apply-grant>

FedEx (n.d.). *Brochures*. Retrieved from [https://www.fedex.com/en-](https://www.fedex.com/en-us/printing/marketing-materials/brochures.html#details)

[us/printing/marketing-materials/brochures.html#details](https://www.fedex.com/en-us/printing/marketing-materials/brochures.html#details)

- FedEx (n.d.). *Business Cards*. Retrieved from <https://www.fedex.com/en-us/printing/business-cards.html#details>
- FedEx (n.d.). *Poster printing*. Retrieved from <https://www.fedex.com/en-us/printing/posters/prints.html#details>
- GasBuddy (n.d.). *Top 10 lowest gas prices and best gas stations in New Jersey*. Retrieved from <https://www.gasbuddy.com/GasPrices/NewJersey>
- GoDaddy Operating Company, LLC. (n.d.). *Parentingexpectations.com availability*. Retrieved from [https://www.godaddy.com/domains/searchresults.aspx?isc=cjc99com&checkAvailability=1&tmskey=&key=dpp\\_leaf\\_com&domainToCheck=Parentingexpectations&tld=.com](https://www.godaddy.com/domains/searchresults.aspx?isc=cjc99com&checkAvailability=1&tmskey=&key=dpp_leaf_com&domainToCheck=Parentingexpectations&tld=.com)
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a Family-Centered Transition Process for Students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 42–50. <https://doi.org/10.1177/1088357611430841>
- Hayes, S. A., & Watson, S. L. (2013). The Impact of Parenting Stress: A Meta-Analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629–642. <https://doi.org/10.1007/s10803-012-1604-y>
- Hendricks, D. R., & Wehman, P. (2009). Transition from School to Adulthood for Youth with Autism Spectrum Disorders: Review and Recommendations. *Focus on*

*Autism and Other Developmental Disabilities*, 24(2), 77–88.

<https://doi.org/10.1177/1088357608329827>

Henninger, N. A., & Taylor, J. L. (2013). Outcomes in Adults with Autism Spectrum Disorders: A Historical Perspective. *Autism: The International Journal of Research and Practice*, 17(1), 103–116.

<https://doi.org/10.1177/1362361312441266>

Kirby, A. V. (2016). Parent Expectations Mediate Outcomes for Young Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 46(5), 1643–1655. <https://doi.org/10.1007/s10803-015-2691-3>

Longmore, P. K. (2003a). The second phase: From disability rights to disability culture. *Why I burned my book and other essays on disability* (pp. 204 – 212). Philadelphia, PA: Temple University Press.

Longmore, P. K. (2003b). Screening stereotypes – Images of disabled people in television and motion pictures. *Why I burned my book and other essays on disability* (pp. 131 – 146). Philadelphia, PA: Temple University Press.

Loukas, K. M., Raymond, L., Perron, A. R., Mcharg, L. A., & Lacroix Doe, T. C. (2015). Occupational transformation: Parental influence and social cognition of young adults with autism. *Work*, 50(3), 457. <https://doi.org/10.3233/WOR-141956>

Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. T. (2007). Transition and Change in Adolescents and Young Adults with Autism: Longitudinal Effects on Maternal Well-Being. *American Journal on Mental Retardation*, 112(6), 401–417. [https://doi.org/10.1352/0895-8017\(2007\)112\[401:TACIAA\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[401:TACIAA]2.0.CO;2)



- Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), 702–711. <https://doi.org/10.1177/1359105311422955>
- Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping With Autism: A Journey Toward Adaptation. *Journal of Pediatric Nursing, 27*(3), 206–213. <https://doi.org/10.1016/j.pedn.2011.03.013>
- Microsoft (n.d.). *Get the most from Office with Office 365*. Retrieved from <https://products.office.com/en-us/compare-all-microsoft-office-products-test?tab=2&tab=2>
- Microsoft (n.d.). *OneDrive plans*. Retrieved from <https://onedrive.live.com/about/en-US/plans/>
- National Institute of Health (2018 November 26). *NIMH Career Enhancement Award to Advance Autism Services Research for Adults and Transition-Age Youth (K18 Clinical Trial Required)*. Retrieved from [https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-19-101.html#\\_Section\\_III\\_Eligibility](https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-19-101.html#_Section_III_Eligibility)
- Nelson, Nina. "Parent to Parent Support for Parents of Children with Autism Spectrum Disorders: Perspectives of Parents and Program Staff." Order No. 10126925 University of South Carolina, 2015. Ann Arbor: *ProQuest*. Web. 28 Nov. 2018.
- New Jersey Department of Health (2018 August 23). *Autism postdoctoral fellowship research grant program*. Retrieved from <https://healthapps.state.nj.us/noticeofgrant/noticegrants.aspx#>

- Newman L, Wagner M, Knokey A, Marder C, Nagle K, Shaver D, et al. (2011) *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International.
- NVivo (n.d.). *Buy NVivo*. Retrieved from <https://www.qsrinternational.com/nvivo/products>
- O'Brien, S. (2016). Families of Adolescents with Autism: Facing the Future. *Journal of Pediatric Nursing*, 31(2), 204–213. <https://doi.org/10.1016/j.pedn.2015.10.019>
- Office Depot, Inc. (n.d.). *Brother MFC-L5850DW Monochrome Laser All-In-One Printer, Copier, Scanner, Fax*. Retrieved from [https://www.officedepot.com/a/products/456699/Brother-MFC-L5850DW-Monochrome-Laser-All/?jsessionid=0000A\\_iOAlaLRMeIjZuAT54Kz-4:17h4h7cou](https://www.officedepot.com/a/products/456699/Brother-MFC-L5850DW-Monochrome-Laser-All/?jsessionid=0000A_iOAlaLRMeIjZuAT54Kz-4:17h4h7cou)
- Office Furniture.com, Inc. (n.d.). *At Work Two Person Complete Compact Office*. Retrieved from <https://www.officefurniture.com/8807979.aspx>
- Oliver, M. (2009). Social model in context. In T. Titchkosky & R. Michalko (Eds.), *Rethinking normalcy: A disability studies reader* (pp. 19-30). Toronto, Ontario: Canadian Scholars' Press Inc.
- Organization for Autism Research (OAR) (n.d.). *Applied research competition*. Retrieved from <https://researchautism.org/research-grants/apply-for-a-grant/applied-research/>

- Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (2006). Mother-Child Relationship Quality among Adolescents and Adults with Autism. *American Journal on Mental Retardation*, *111*(2), 121–137. [https://doi.org/10.1352/0895-8017\(2006\)111\[121:MRQAAA\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111[121:MRQAAA]2.0.CO;2)
- Othman, N., & Amiruddin, M. H. (2010). Different Perspectives of Learning Styles from VARK Model. *Procedia - Social and Behavioral Sciences*, *7*, 652–660. <https://doi.org/10.1016/j.sbspro.2010.10.088>
- Quill Lincolnshire, Inc. (n.d.). *Brother TN Black Toner Cartridge, Standard (TN-820)*. Retrieved from <https://www.quill.com/brother-tn-black-toner-cartridge-standard-tn-820/cbs/51627332.html>
- Quill Lincolnshire, Inc. (n.d.). *Quill Brand® Ballpoint Stick Pens, Medium Point (1.0mm), Black, Dozen (50730-QCC)*. Retrieved from [https://www.quill.com/quill-brand-ballpoint-stick-pens-medium-point-10mm-black-dozen-50730-qcc/cbs/52395764.html?promoCode=&Effort\\_Code=901&Find\\_Number=50730QL&m=0&isSubscription=False](https://www.quill.com/quill-brand-ballpoint-stick-pens-medium-point-10mm-black-dozen-50730-qcc/cbs/52395764.html?promoCode=&Effort_Code=901&Find_Number=50730QL&m=0&isSubscription=False)
- Quill Lincolnshire, Inc. (n.d.). *Quill Brand Copy Paper, 8 1/2" x 11", 92 Bright, 20 LB, Case of 10 reams*. Retrieved from [https://www.quill.com/8-5-11-a4-letter-20lb-copy-paper-printer-carton/cbs/200885.html?promoCode=&Effort\\_Code=901&Find\\_Number=720222CT&m=0&isSubscription=False](https://www.quill.com/8-5-11-a4-letter-20lb-copy-paper-printer-carton/cbs/200885.html?promoCode=&Effort_Code=901&Find_Number=720222CT&m=0&isSubscription=False)

Quill Lincolnshire, Inc. (n.d.). *Quill Brand® Premium 3-Tab File Folders, Letter,*

*Assorted Tabs, Manila, 100/Bx (741137).* Retrieved from

<https://www.quill.com/quill-brand-premium-3-tab-file-folders-letter-assorted-tabs-manila-100-bx->

[741137/cbs/019557.html?promoCode=&Effort\\_Code=901&Find\\_Number=741137&m=0&isSubscription=False](https://www.quill.com/quill-brand-premium-3-tab-file-folders-letter-assorted-tabs-manila-100-bx-741137/cbs/019557.html?promoCode=&Effort_Code=901&Find_Number=741137&m=0&isSubscription=False)

Quill Lincolnshire, Inc. (n.d.). *Ticonderoga The World's Best Pencil Wooden Pencils, No.*

*2 Soft Lead, Dozen (13882).* Retrieved from [https://www.quill.com/ticonderoga-](https://www.quill.com/ticonderoga-worlds-best-pencil-wooden-pencils-no-2-soft-lead-dozen-13882/cbs/002575.html)

[worlds-best-pencil-wooden-pencils-no-2-soft-lead-dozen-13882/cbs/002575.html](https://www.quill.com/ticonderoga-worlds-best-pencil-wooden-pencils-no-2-soft-lead-dozen-13882/cbs/002575.html)

Parent 2 Parent USA. (n.d.). *What is parent to parent?* Retrieved from

<http://www.p2pusa.org/parents/>

Pozo, P., & Sarriá, E. (2015). Still Stressed but Feeling Better: Well-Being in Autism

Spectrum Disorder Families as Children Become Adults. *Autism: The*

*International Journal of Research and Practice*, 19(7), 805–813.

<https://doi.org/10.1177/1362361315583191>

Priestley, M. (1998). Childhood disability and disabled childhoods: Agendas for

research. *Childhood*, 5(2), 207-223.

Prince, A. M. T., Katsiyannis, A., & Farmer, J. (2013). Postsecondary Transition under

IDEA 2004: A Legal Update. *Intervention in School and Clinic*, 48(5), 286–293.

<https://doi.org/10.1177/1053451212472233>

- Pruett, S. R., & Chan, F. (2006). The development and psychometric validation of the Disability Attitude Implicit Association Test. *Rehabilitation Psychology, 51*(3), 202–213. <https://doi.org/10.1037/0090-5550.51.3.202>
- Repetto, J. B., & Correa, V. I. (1996). Expanding Views on Transition. *Exceptional Children, 62*(6), 551–563. <https://doi.org/10.1177/001440299606200606>
- S. Singer, G. H., Marquis, J., Powers, L. K., Blanchard, L., Divenere, N., Santelli, B., ... Sharp, M. (1999). A Multi-Site Evaluation of Parent to Parent Programs for Parents of Children With Disabilities. *Journal of Early Intervention, 22*(3), 217–229. <https://doi.org/10.1177/105381519902200305>
- Samsung (n.d.). *GalaxyNote 9*. Retrieved from <https://www.samsung.com/us/mobile/galaxy-note9/buy/s/Device/>
- Santelli, B., Turnbull, A.P., Marquis, J.G., & Lerner, E.P. (1995). Parent to parent programs: A unique form of mutual support. *Infants and Young Children, 8*, 48-57.
- Sitar Realty Company (2017). *Market watch: First quarter 2017*. Retrieved from <https://sitarcompany.com/wp-content/uploads/2017/03/Sitar-Market-Watch-Q1-2017-2.pdf>
- Smith, L. E., & Anderson, K. A. (2014). The Roles and Needs of Families of Adolescents with ASD. *Remedial and Special Education, 35*(2), 114–122. <https://doi.org/10.1177/0741932513514616>
- Smith, P., & Routel, C. (2009). Transition Failure: The Cultural Bias of Self-Determination and the Journey to Adulthood for People with Disabilities.

*Disability Studies Quarterly*, 30(1). <https://doi.org/10.18061/dsq.v30i1.1012>

Snow, K. (2013) *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. San Antonio, TX: BraveHeart Press.

State Street Corporation (n.d.). *Nonprofit grants*. Retrieved from

<http://www.statestreet.com/values/social-consciousness/non-profit-grants.html>

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017).

Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial. *Journal of Autism and Developmental Disorders*, 47(3), 846–857.

<https://doi.org/10.1007/s10803-016-2994-z>

Taylor, J. L., Dove, D., Veenstra-Vander Weele, J., et al. (2012). *Interventions for adolescents and young adults with autism spectrum disorders (Comparative Effectiveness Reviews, No. 65)*. Rockville, MD: Agency for Healthcare Research and Quality (US), August.

Thompson, N. (2015). Reflective Practice. In N. Thompson (Ed.), *People Skills* (Ch. 30) Retrieved from Amazon Digital Services, LLC.

Thompson, N., & Campling, J. (1996). Reflective practice. In N. Thompson & J.

Campling (Eds.), *People Skills* (pp. 221–232). [https://doi.org/10.1007/978-1-349-13737-4\\_21](https://doi.org/10.1007/978-1-349-13737-4_21)

Thumbtack, Inc. (2017 August 28). *How much does a patent lawyer cost?* Retrieved from

<https://www.thumbtack.com/p/patent-lawyer-cost>

Verizon (n.d.). *Choose from three unlimited plans*. Retrieved from

<https://www.verizonwireless.com/plans/unlimited/>

Verizon Fios (n.d.). *Fios internet and phone bundles*. Retrieved from

<https://fios.verizon.com/fios-business.html>

Walmart Foundation (n.d.). *Community grant guidelines*. Retrieved from

<http://giving.walmart.com/apply-for-grants/local-giving-guidelines>

Weiss, J. A., Tint, A., Paquette-Smith, M., & Lunsky, Y. (2016). Perceived Self-Efficacy in Parents of Adolescents and Adults with Autism Spectrum Disorder. *Autism: The International Journal of Research and Practice*, 20(4), 425–434.

<https://doi.org/10.1177/1362361315586292>

Whitney-Thomas, J., McIntyre, J., Butterworth, J., & Allen, D. (2004). Managing Service Delivery Systems and the Role of Parents During their Children's Transitions. *Journal of Rehabilitation*, 70(2), 19–26.

Worthington Direct (n.d.). *Classroom Set- 20 Flavors 18" Chairs & 20 Wing Desks by Smith System, 03095/11849/20 - Stock #81D58* Retrieved from

<https://www.worthingtondirect.com/desks/030951184920-classroom-set-20-wing-desks-20-flavors-chairs-18-h.htm>

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