

Thriving with Down Syndrome: A Multiple Case Study

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ABSTRACT

The purpose of this study is to better understand the phenomenon of thriving in the population of people with Down syndrome (DS). DS is a chromosomal abnormality associated with intellectual disability (ID) as well as serious medical complications. However, despite these significant deficits related to the disability, there are people with DS who are thriving in our community. Thriving can be defined as a state of high subjective well-being (SWB) coupled with an upward developmental trajectory. Thriving with ID occurs within a series of supportive systems, with self-determined and meaningful social inclusion. While there exists a great deal of information on the needs and pathology of individuals with DS, there is markedly less information on those who thrive or the factors that contribute to SWB and developmental growth within this community. This study will describe the meaning of thriving for those with ID, propose a new framework for contextualizing thriving in the ID population, and specifically examine individual and environmental factors that may facilitate or impede thriving for the DS population. Results will inform service providers on possible assessment and intervention methods that may enhance quality of life for those with DS so that they might thrive in school, at home, and in life.

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ABBREVIATIONS

ASD	Autism spectrum disorder
DD	Developmental disability
DS	Down syndrome
EE	Expressed emotion
FMSS	Five-minute speech sample
FXS	Fragile X syndrome
ID	Intellectual disability
NASP	National Association of School Psychologists
PYD	Positive youth development
QOL	Quality of life
SBA	Strengths based assessment
SWB	Subjective well-being
SWPBIS	School-wide positive behavior intervention supports
VIA	Values in Action

INTRODUCTION

The vision of the National Association of School Psychologists (NASP) is to help students thrive. School psychologists promote student learning and well-being to ensure positive student outcomes in healthy and supportive school settings. School psychologists use assessments, direct intervention, consultation, and advocacy efforts to build student capacity and encourage growth. However, research indicates that students with intellectual disability (ID) have significant challenges upon exiting the public-school systems, with a lack of critical schooling experiences required for thriving in life (Lipscomb, 2017). The field of school psychology can and should do more to support this student population through effective service-delivery programs and school policies.

In order to help facilitate thriving for students with ID, the field of school psychology must dig further into the construct of thriving, including what it looks and feels like to thrive with ID and what facilitators and barriers influence thriving for this student population. This requires a solid theoretical framework to inform research in this area of scholarship. Furthermore, field research with individuals who are currently thriving and an analysis of what individual and environmental factors may facilitate their quality of life will enhance our understanding of what it means to thrive with ID.

This body of work includes two distinct, yet related, manuscripts regarding this topic of study. The first manuscript contextualizes thriving with ID and provides a newly proposed model for the field of school psychology. It includes an historic perspective on the marginalization of students with ID in our society and the currently accepted theoretical models used to conceptualize and understand a “good life” in the field of disability studies, including the quality of life (QOL) concept and the social ecological

model for human functioning. Further, the first manuscript outlines the ways in which positive psychology informs disability studies and school psychology. When all three areas of scholarship are combined, the definition of what it means to thrive with ID becomes clearer.

Integrating established models in positive psychology, school psychology, and disability studies, the first manuscript delivers a framework for identifying thriving in students with ID. Per this new framework, Transactional Ecological Thriving Model (TET-M), thriving with ID is defined a combination of high levels of subjective well-being (SWB) and state of continued developmental growth. Thriving occurs within a series of supportive systems, and requires meaningful and self-determined social inclusion. School psychologists can assess students using a bioecological lens with a data-based decision-making process to inform service-delivery within a multi-tiered system of supports (MTSS). An emphasis on thriving provides a holistic understanding of students with ID, aiming to improve developmental outcomes while also encouraging happiness and joy that contribute to QOL for this student body.

Building upon this framework, the second manuscript in this body of work applies this new definition of thriving with ID to a subpopulation: individuals with Down syndrome (DS). DS is the most common known genetic cause of ID, with a prevalence rate of 1 in 700-800 U.S. births (Roizen, 2013). Although there are multiple medical and developmental complications associated with DS, a vast majority of those living with DS report high levels of life satisfaction (Skotko, Levine & Goldstein, 2011). This population may provide a unique insight to what it means to thrive with ID.

The proposed study in manuscript two is a multiple case study of young adults

who are currently thriving (i.e., high levels of SWB coupled with an upward developmental trajectory) with DS. The case study will address three main research questions: How do individuals with DS and their families define thriving? What individual characteristics influence thriving for people with DS? And, what environmental factors influence thriving with DS? A case study analysis will allow for in-depth investigations into the lives of those with DS, including subjective inquiry and more objective analysis. Interviews with participants, parents, and other adults in the systems of support will provide insight and opinion from those experiencing the phenomenon firsthand. Observations in a variety of key support systems will provide rich, detailed, descriptive information about the settings, routines, and behaviors of those thriving with ID. A review of educational and medical documents can provide an historic account of each individual's life experiences and systemic influences. Finally, psychoeducational assessments will provide data on present levels of development and psychosocial profiles for each participant.

When combined, these two manuscripts fill a gap in the literature about how the field of school psychology can best support students with ID. A thorough and well-developed model on thriving with ID provides practitioners with an overarching philosophical approach to our work with this population. Further, it provides guidance to researchers in this area of scholarship, so that inquiry is relevant to both the population and the profession of school psychology. Application of the model to real-life individuals who are thriving contributes to the positive psychology field with a scientific study of what enables individuals with ID to thrive. It will provide detailed descriptions of those living good lives with DS, and will provide insight as to how school psychologists can

promote thriving within the school setting. Finally, this exploratory work will help to generate hypotheses for future research and prompt a new focus for the field of school psychology on the well-being and learning of this unique student body.

MANUSCRIPT 1

THRIVING WITH INTELLECTUAL DISABILITY: A FRAMEWORK FOR SCHOOL PSYCHOLOGY

"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor and some style." -Maya Angelou (2011)

School psychologists are responsible for promoting mental health and learning for all students, ages birth to 21 (National Association of School Psychologists [NASP], 2010). This indicates that school psychologists are concerned with both well-being *and* developmental growth over a wide portion of the lifespan. Furthermore, this responsibility is to all students, including those with the most significant disabilities in our schools. Students with intellectual disability (ID) require the highest levels of support and have historically been misunderstood, neglected, and even abused in our schools (Dykens, 2006; Wehmeyer, 2013). As school psychologists, we must ensure that our most marginalized students receive the most ethical and respectful education possible. We must strive to build healthy and supportive learning environments for these students, advocating for each individual to meet his or her own highest potential.

Thriving is a complex construct that emerges as a worthy goal for students with ID in our schools (Benson & Scales, 2009; Lerner, von Eye, Lerner, Lewen-Bizan, & Bowers, 2010; Weiss & Riosa, 2015). NASP's vision is that school psychologists will help students to thrive in school, at home, and throughout life (NASP, n.d.). Thriving is more than "getting by" or meeting an expectation for development. Thriving is exceeding the expectations: flourishing in one's life. Weiss and Riosa (2015) state that "thriving

reflects both well-being and an upward developmental trajectory, the demonstration of continued growth of knowledge and skills, and success in relationships with others” (p. 2474). The promotion of thriving for students is a proactive process aimed at building student capacity and capitalizing on strengths. However, current thriving theories have limited utility for school psychologists, and the field has yet to define and operationalize the meaning of thriving for students with ID.

Current theoretical models for thriving tend to be limited to specific age ranges (Benson & Scales, 2009; Lerner et al., 2010), focused solely on professional work settings (Boyd, 2015; Spreitzer, Sutcliffe, Dutton, Sonenshein, & Grant, 2005), or are exclusive of the developmental trajectory and growth that characterizes the birth to 21 age range (Buettner, 2010; Seligman, 2011; Vallerand & Carbonneau, 2013). Furthermore, to this date, there is no comprehensive framework for understanding what it means to thrive with ID in the schools, and the factors that can facilitate thriving for this population. In order to better understand and promote thriving for students with ID, the field of school psychology needs a robust theoretical model that merges research and theories from the fields of school psychology, positive psychology, and disability studies. A comprehensive model for thriving with ID in the schools must address the unique considerations of this specific student population and the contextual factors associated with schools.

Understanding Current Perspectives on Intellectual Disability

ID is currently defined as a disability characterized by significant limitations in both intellectual and adaptive functioning with an onset before the age of 18 (Schalock et al., 2010). In order to qualify for special education services with ID, students must

present with intelligence quotient (IQ) and adaptive scores falling well below average, and in some states students must also present with significantly diminished academic skills (Individuals with Disabilities Education Act [IDEA], 2004; McNicholas et al., 2017). Although only one percent of all U.S. students have ID, approximately seven percent of students receiving special education services have ID (U.S. Department of Education, 2015). Thus, although the ID student population is in the minority, it is not insignificant and merits the attention of the field of school psychology. School psychologists are an integral piece of assessment, education planning, and service delivery for students with ID. It is imperative that practitioners understand the unique history of this student population, the currently accepted theoretical models in the disabilities research field, and how to best support students with ID (Roach, 2003).

A History of Marginalization

As early as Roman times, there has been documentation of the elimination of individuals born with ID (Wehmeyer, 2013). The weak and feeble were deemed a burden to a society, and eradicated or banished. Then, starting in the late 18th Century in Europe, the focus shifted to training “educable” individuals with disabilities to remove the effects of their handicaps (Dyken, 2006). Children with ID were removed from their homes for treatment in residential school settings. Early special educators developed methods of specialized instruction to “cure” disabilities by addressing sensorimotor needs and teaching language (Gargiulo & Bouck, 2018). This era embraced the medical model for disability, where disability was viewed as pathology and interventions were aimed at eliminating the effects of the disabling condition (Dyken, 2006; Wehmeyer, 2013).

However, the focus of these institutions shifted when rehabilitation efforts were

not immediately successful, and the disabilities appeared to persist despite educational interventions (Dykens, 2006). Rather than evolving as spaces dedicated to promoting the welfare of vulnerable citizens, institutions shifted into warehouses responsible for the complete removal of those with disabilities from society. This period was marked by abuse, restraints, overcrowded facilities, complete segregation, and neglect (Blatt & Kaplan, 1966). Forced sterilization was part of the “negative eugenics” movement, where selective breeding and immigration policies were used to improve the human race by eliminating “lower stock” (Merydith, Bamanto, Stalker & Larkin, 2017, p. 31). Those born with disabilities had a poor quality of life and had little opportunity to contribute society. Additionally, the geographic isolation of facilities for those with disabilities led to an unawareness of the injustice in the broader society; out of sight, out of mind (Blatt & Kaplan, 1966; Dykens, 2006).

Starting in the 1950s, several factors contributed toward a shift in thinking about individuals with disabilities (Wehmeyer, 2013). Soldiers returning from the war with newly acquired physical and mental disabilities highlighted the issues of access and citizen rights. Parents began to resist the cultural norm of the institutionalization of their children. Medical advances improved the life expectancies and quality of life for many with disabilities. Qualitative researchers and photojournalists documented the conditions in institutions, sparking awareness and acting as a catalyst for change (Blatt & Kaplan, 1966).

By the 1970s, the country had a new focus on inclusion and anti-discrimination with federal education and civil rights laws (e.g., Education for All Handicapped Children Act of 1975 [PL 94-142]; Section 504 of the Rehabilitation

Act of 1973). Government sponsored programs increased community-based care services for those with disabilities. Over the next few decades, there would be a complete dismantling of the institutionalization system and a shift toward broad inclusion in the general society (Wehmeyer, 2013).

Social Ecological Model

Currently, a social ecological model prevails in the field of ID (Buntinx, 2014; Schalock et al., 2010). Rather than merely looking for pathology to cure through the lens of the medical model for disability, the social ecological model emphasizes the concept of *human functioning* and states that disability is a *function* of individual impairments that are inadequately accommodated by the environment (Buntinx, 2014; Schalock et al., 2010). Shifting away from a focus on individual limitations, the social ecological model highlights the match between individual needs and support systems in the environment. Supports that are individualized and bolster a person's strengths can enhance overall functioning (Schalock et al., 2010). The bioecological systems theory (Bronfenbrenner, 1979) informs the model, noting that disability exists within a series of embedded systems. Individuals with ID are surrounded by systems of support including family and friends, colleagues and classmates, general public services, and publically funded programs related to disability (Buntinx, 2014). These systems of support can enhance or detract from the individual's overall development and well-being.

Quality of Life. Underlying the social ecological model for disability is the concept of quality of life (QOL; Schalock & Alonso, 2014). QOL is a complex phenomenon influenced by interactions between an individual and the environment; it is mediated by systems of support and the opportunity to pursue life goals (Verdugo, Navas,

Gomez, & Schalock, 2012). In measuring QOL for individuals with ID, there are three main categories, each containing eight core domains (see Table 1; Schalock & Alonso, 2014). Some of the key domains of QOL are measured with subjective indicators (e.g., emotional well-being), while some can be measured objectively (e.g., rights). This highlights the value of input and perceptions of those with disabilities, but also contends that QOL depends on a supportive society and social justice. Altogether, the framework promotes “dignity, equality, empowerment, self-determination, nondiscrimination, and inclusion” for those living with ID (Schalock & Alonso, 2014, p. 46).

Table 1

Quality of Life (QOL) Categories, Domains, and Indicators (Schalock & Alonso, 2014; Verdugo, et al., 2012)

Category	Domain	Indicators
Independence	Personal development	Education status, personal skills
	Self-determination	Choices, autonomy, personal control
Inclusion	Personal relations	Friendships, social networks
	Social inclusion	Community participation and roles
	Rights	Legal access, dignity, respect, equality
Well-being	Emotional well-being	Positive experiences, safety, contentment
	Physical well-being	Health, recreation, leisure
	Material well-being	Financial and employment status

Positive Psychology

While the social ecological model for disability and the QOL concept aim to improve the lives of those who have historically led marginalized lives, they do not necessarily address the concept of thriving, flourishing in life, or exceeding expectations for happiness and growth. To better understand what allows people with ID to thrive, we can look toward the field of positive psychology. In positive psychology, the focus is on

building mental health and well-being: making life worth living (Seligman & Csikszentmihalyi, 2000). The field aims to compliment, rather than dispute the pervasive deficit model of psychology, whereby psychologists work to remediate pathology of those with mental illness. Positive psychologists, rather, work to build mental health, prevent pathology, and enhance well-being (Seligman & Csikszentmihalyi, 2000). The ultimate goal of positive psychology is to build individuals and communities that flourish (International Positive Psychology Association [IPPA], n.d.; Seligman, 2011).

Positive psychology is a broad field with multiple areas of focus. Hart and Sasso (2011) assessed the contemporary concepts within the field of positive psychology since its inception at the turn of the century. They conducted a content analysis of over 50 published articles that claimed to define positive psychology, analyzed the syllabi of college level positive psychology coursework in the US and Canada, examined the table-of-contents in positive psychology books, and interviewed experts in positive psychology. An analysis of their collected data revealed several themes under the umbrella of positive psychology, including flourishing/thriving (which the authors coupled as a unitary construct), the good life, a life worth living, life satisfaction, resilience, and happiness.

While positive psychology is oriented toward enhancing the lives of individuals and communities; making life worth living, it is much more than “happiology” (Jayawickreme, Forgeard, & Seligman, 2012, p. 338) or a simple focus on encouraging positive emotions. Rather, positive psychology aims to encourage the development and use of strengths and assets in order to meet life’s challenges (Peterson & Seligman, 2004). Positive psychology recognizes that mental illness and disasters are a natural

aspect of life. By understanding those who flourish despite, or even because of, these trials, positive psychology can promote the development of healthy, functioning individuals and societies (Seligman & Csikszentmihalyi, 2000; Seligman, 2011).

Character Strengths and Virtues

One of the most influential products of the field of positive psychology is the understanding that everyone possesses a handful of signature character strengths and virtues that contribute to their well-being (Peterson & Seligman, 2004). In their groundbreaking manual, Peterson and Seligman (2004) identified six universal core virtues and 24 character strengths, differentiated from talents (e.g., athleticism) and abilities (e.g., intelligence), as the “psychological ingredients” that make up the virtues (see Table 2; Peterson & Seligman, 2004, p. 13).

The authors argue that those who frequently use their strengths have higher levels of well-being. In further support of this proposition, the Values in Action (VIA) Institute on Character produced a survey to measure character strengths in individuals around the world. Multiple studies on character strengths using the classification system outlined above and the VIA survey have indicated that targeting either the development of one’s top five strengths or the development of one’s bottom five strengths, leads to higher levels of well-being and decreased levels of depression (Lavy, Littman-Ovadia, & Bareli, 2014; Proyer et al., 2014; Proyer et al., 2015). Therefore, in opposition to the widely utilized *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013) used to diagnose pathology, Peterson and Seligman’s (2004) *Handbook and Classification System* helps individuals and practitioners to identify, research, and promote strengths and subsequent well-being.

Table 2

Character Strengths and Virtues (Peterson & Seligman, 2004)

Virtue	Strength
Wisdom and Knowledge	Creativity Curiosity Open-mindedness Love of learning Perspective
Courage	Bravery Persistence Integrity Vitality
Humanity	Love Kindness Social intelligence
Justice	Citizenship Fairness Leadership
Temperance	Forgiveness and mercy Humility/modesty Prudence Self-regulation
Transcendence	Appreciation of beauty and excellence Gratitude Hope Humor Spirituality

Positive Psychology and Disability Studies

Positive psychology research does not typically investigate those who live with limited capacity or who have been historically marginalized; rather, it has primarily focused on those with majority status and few risk factors (Dykens, 2006; Prilleltensky, 2012; Wehmeyer, 2014). In a seminal article for positive psychology, Seligman and

Csikszentmihalyi (2000) asserted that positive psychology is about “making normal people stronger and more productive and making high human potential actual” (p. 8). This very definition is problematic for the population of those with ID. The term “normal” is pejorative and infers that those who fall outside the typical range may not be worthy of the benefits of positive psychology. However, as Michael Bérubé (1996), disabilities scholar and father of a young adult with ID states, “outside the ‘norm’ there’s all kind of variety...some of it quite normal” (p. 208). Thus, individuals who fall outside the average range on a bell curve can still strive to build capacity and thrive. Furthermore, the question of “high human potential” can be challenging in the disabilities community. After all, who decides an individual’s potential when a disability diagnosis is defined by functional limitations? And when does one consider an individual with significant disabilities’ potential to be “actualized”? Rather than examining those with ID through a strength-based perspective, most research has documented deficits and examined ways to reduce the impact of the disability (Shogren, 2014).

However, positive psychology has begun to gain traction in disability studies (Wehmeyer, 2014) with the development of the social ecological model (Schalock et al., 2010) and the advent of the QOL concept for ID (Schalock & Alonso, 2014). Research and interventions aimed at understanding and promoting the strengths and well-being of those with ID are now being created to target individuals as well as their systems of support. One the most researched positive psychology constructs for individuals with ID is that of self-determination (Shogren, 2014). Self-determination refers to individuals with ID acting as the causal agents in their own lives (Wehmeyer et al., 2012). Even those with significant personal limitations associated with ID (e.g., lack of verbal

communication skills; need for assistance with daily living) can actively direct their systems of support in order to enhance their own QOL (Shogren, 2014). Rather than addressing deficits, self-determination interventions involve the development of critical skills such as problem-solving, goal setting, self-management, and self-advocacy (Shogren, 2014). Higher levels of self-determination for those with ID are associated with higher QOL and more optimal outcomes for education and employment (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Palmer & Wehmeyer, 2003). However, despite the emphasis on self-determination and other aspects of student choice, research articles focused on positive psychology constructs not only have a narrow definition of the construct, but also represent a minority of all published articles in the most prominent ID journals (Shogren, Wehmeyer, Pressgrove, & Lopez, 2006).

Positive Psychology and School Psychology

NASP's mission to enhance mental health and learning for all students (NASP, 2010) aligns well with the field of positive psychology. School psychologists have the skills to optimize student outcomes using data-based decision making and to build healthy functioning communities through systems level interventions. Furthermore, schools are uniquely positioned for positive psychology. All children attend school; thus, schools can reach a wide variety of individuals regardless of economic resources. Moreover, students start attending school at an early age before most pathology has developed, thus allowing school psychologists to focus on preventative efforts such as building mental health and well-being rather than treating mental illness (Vella-Brodrick, 2016). Additionally, special education law requires that teams consider a student's strengths when developing educational programs (IDEA, 2004). Altogether, the school

setting, professional skill sets, and legal mandates make the field of school psychology a natural fit for practicing from a positive psychology framework.

However, school psychology research has been slow to embrace positive psychology (Gilman, Huebner, & Furlong, 2014). As evidence, Froh, Huebner, Youssef, and Conte (2011) analyzed four major school psychology journals for the number of articles with a positive psychology research orientation over the past 50 years. They found that, as of 2008, in contrast to other fields of psychology, school psychology scholarship had no growth in the number of studies with a positive focus, with only 25%-30% of all research focusing on positive constructs. The authors concluded that the historic school psychology emphasis on assessment and diagnosis of problems was still pervasive in the literature.

Still, there remains a strong contingent of school psychology researchers committed to furthering the work of positive psychology through school-based approaches. The *Handbook of Positive Psychology in Schools* (Furlong et al., 2014) highlights research to date using the theories of positive psychology in the school setting. Within the handbook, a conceptual model for the application of positive psychology to school psychology illuminates how the two fields can merge for assessment, research, and application in the schools (Gilman et al., 2014). By considering a student's individual differences (e.g., strengths) within a series of ecological systems (Bronfenbrenner, 1979), positive school psychologists can better understand, measure, and enhance student physical, social-emotional, and cognitive well-being.

One such application is strengths-based assessment (SBA). SBA is a burgeoning practice for school psychologists and can be used to supplement the more traditional

deficit-based assessment process used in schools for qualification purposes (Jimerson, Sharkey, Nyborg, & Furlong, 2004). Initial research shows promising results that by understanding a child's strengths, an educational team may have a more thorough, balanced, and hopeful picture of a child with more predictions for a student's future success (Donovan & Nickerson, 2007). The use of a child's uniquely identified strengths in school-based mental health interventions may be associated with positive change and enhanced student self-confidence (Bozic, 2013).

Understanding the strengths of students with ID is a critical step in the development of healthy community inclusion and QOL: "When all that is known about someone with ID is what he or she cannot do, it is not surprising when others struggle to envision a place for people with such labels in their workplaces, congregations, community groups, or personal networks" (Carter et al., 2015, p. 102). A study conducted by Carter and colleagues (2015) determined that character strength profiles are unique for each student with ID and include a wide variety of domains (e.g., interpersonal relations, personality traits, cognitive abilities, unique skills, and personal hobbies). Rather than solely focusing on deficits and needs for treatment and remediation, school psychologists should also examine assets in this population, so that students with ID may be known for their unique ability to contribute as they venture into the community.

In addition to assessment, positive psychological interventions can be used in the schools (Miller, Nickerson, & Jimerson, 2014; Suldo, 2017). Positive psychology interventions aimed at improving the happiness and SWB of individual students include interventions to enhance student gratitude (Roth, Suldo, & Ferron, 2016), build optimism (Brunwasser, Gillham, & Kim, 2009), understand personal strength profile (Proctor et al.,

2011), and develop mindfulness skills (Schonert-Reichel et al., 2015). Additionally, multiple universal supports use a positive psychology approach, including school-wide positive behavioral interventions and supports (SWPBIS; Horner & Sugai, 2015), class wide consultation methods (Doll et al., 2014), positive youth development-multitiered system of supports (PYD-MTSS; Hazel, 2016), and social emotional learning (SEL; Durlak, Weissberg, Dymnicki, Taylor, & Schellinger, 2011). In all, the school setting is well suited to positive psychology's goal of enabling individuals and communities to thrive.

Thriving

Although positive psychology aims to understand what enables some individuals and communities to thrive (IPPA, n.d), a clear definition for what it means to thrive is more elusive. Furthermore, the concept of thriving with ID is only beginning to be explored (Weiss & Riosa, 2015), and still lacks a solid theoretical framework of its own. Thriving appears to indicate an intersection of growth and happiness. According to the *Oxford Dictionary of English* (n.d.), to thrive is to grow or develop well or vigorously. Thriving is more than surviving; thriving is living well and enjoying the process (Angelou, 2011). A number of developmental, industrial/organizational, and positive psychologists have proposed theories on what it means to thrive, flourish, or function optimally (Benson & Scales, 2009; Lerner et al., 2010; Prilleltensky, 2012; Seligman, 2011; Vallerand & Carbonneau, 2013), yet a consensus on terms and meaning has yet to be determined.

Overall, research indicates that thriving is rooted in context, highly influenced by power and privilege, and may differ for different populations and cultures (Buettner,

2010; Prilleltensky, 2012). Thriving involves present levels of well-being, as well as a sense of growth and hope for a positive future (Gallup, 2009). There are subjective components to thriving, wherein individuals perceive their own conditions positively, as well as objective and measureable components such as relationships, learning, and income (Prilleltensky, 2012; Seligman, 2011; Spreitzer et al., 2005; Vallerand & Carbonneau). Furthermore, the literature indicates that a combination of individual factors (e.g., personal strengths and passions) coupled with contextual factors (e.g., environments that support positive relationships and opportunities for growth) must be present for thriving to occur (Benson & Scales, 2009; Boyd, 2015; Lerner et al., 2010; Vallerand & Carbonneau, 2013; Weiss & Riosa, 2015). The following four theories outline current thriving concepts in the literature and begin to provide insight and understanding for what it means to thrive with ID.

Thriving in Adolescence

Benson and Scales (2009) emphasize that thriving for adolescents is more than getting by or meeting standards. Rather, thriving is a “journey to idealized personhood” (Benson & Scales, 2009, p. 90). The authors define thriving as a process in which an adolescent identifies and exercises his or her special interests, or “sparks,” within a supportive context. Thriving involves both well-being and an “upward developmental trajectory” (Benson & Scales, 2009, p. 90). Growth is encouraged through interdependent and bidirectional relationships within the community. Youth who are thriving can identify their own passions, demonstrate positive affective states, have a strong sense of spirituality and purpose, and are motivated to develop their “sparks.” Thriving for adolescents is deeply rooted in the developmental stages of this specific age range. Teens

are developing their identity and growing in their independence (Cobb, 2001; Erikson, 1950).

Lerner and colleagues (2013) operationalized adolescent thriving with the six Cs of positive youth development: competence (youth has a positive view of his or her actions in the world), confidence (youth has a high sense of self-worth and self-efficacy), compassion (youth demonstrates caring attitudes, interpersonal warmth, empathy, and understanding), character (youth is reliable and has integrity), contribution (youth is helpful in a broader context with family, community, and society), and connection (youth has positive relationships). Adolescents who demonstrate these six strengths can be considered thriving. Supportive developmental assets (e.g., families, schools, and communities) can enhance these attributes and foster thriving for youth (Lerner et al., 2010; Lerner et al., 2013).

Flourishing

In 2011, Seligman reframed his original “authentic happiness” theory (Seligman, 2002) to a theory of well-being titled flourishing. The term flourishing is similar to the concept of thriving. In fact, Seligman (2011) states that flourishing is the ultimate goal of positive psychology (p. 26). Flourishing differs from Benson and Scales (2009) definition of thriving in adolescence in that it does not include a developmental perspective. However, the concept is similar in that it implies an ideal condition of living, rather than a mere absence of pathology. Indeed, flourishing and thriving have been identified as a single construct in systematic reviews of positive psychology literature (Hart & Sasso, 2011).

Flourishing involves five key elements known as PERMA, which stands for: positive emotions, engagement, relationships, meaning, and achievement. Positive emotions refer to the pleasant life: happiness, joy, and life satisfaction (Diener et al., 2016). These positive feelings and thoughts are crucial; yet, Seligman argues they are not enough to flourish. One must also have engagement, also referred to as “flow,” which occurs when individuals are completely immersed in an activity, lose track of time, and abandon self-consciousness (Csikszentmihalyi, 1990). Furthermore, relationships and positive interactions with other people are crucial for flourishing. Flourishing theory posits that another key element is meaning, or working for something greater than one’s self. Finally, success and mastery leave one with a feeling of accomplishment and achievement necessary for true well-being. An individual’s character strengths (Peterson & Seligman, 2004) underlie each element of PERMA, contributing to one’s positive emotions, engagement, quality of relationships, ability to find meaning, and levels of accomplishment.

Optimal Functioning in Society

Optimal Functioning in Society (OFIS) is a multidimensional construct related to thriving, made up of five key elements: psychological well-being, physical health, positive interpersonal relationships, high performance in one’s field, and contributing to society (Vallerand & Carbonneau, 2013). OFIS theory emphasizes that moving people into the upper levels of well-being is more important than merely eradicating mental illness. Vallerand and Carbonneau (2013) encourage positive psychologists to aim for promotion of the highest levels of psychological functioning with their OFIS theory. Using the analogy of a metric for mental health with a -10 to a +10 scale, the authors

state that rather than aspiring to move people from a -10 to the status quo of 0 or +1, the goal should be to move individuals into the +7 - +10 range of mental health (Vallerand & Carbonneau, 2013, p. 53). Thus, they argue the ultimate goal of positive psychology is to encourage growth in all five elements so that individuals will experience optimal levels of functioning.

Similar to Benson and Scales' (2009) notion of a "spark" as a part of thriving in adolescence, Vallerand and Carbonneau (2013) assert that passion is a major contributing factor for OFIS. Passion is defined as "a strong inclination toward a self-defining activity that one loves, finds important and meaningful, and in which one invests time and energy" (Vallerand & Carbonneau, 2013, p. 55). Two types of passion, obsessive and harmonious, are possible. Obsessive passion is marked by an individual's uncontrollable preoccupation with something and may detract from quality of life. In contrast, harmonious passion - that which is freely embedded into a person's identity without rigid obsession - is associated with and can encourage all five elements of OFIS. Thus, harmonious passion is a variable to be fortified and fostered to promote the OFIS, or thriving, for all individuals.

Thriving at Work

Spreitzer et al. (2005) define thriving at work as a combination of two key factors: vitality and learning. Vitality is similar to Seligman's (2011) concept of flourishing; it is an energetic sense of well-being. In the work place, employees with vitality have a positive affective state and a feeling of "aliveness" in their jobs (Spreitzer et al., 2005, p. 538). Learning at work refers to a cognitive process, in which the employee is gaining knowledge in his or her field, growing in the profession. Overall, these two elements

indicate a state of thriving at work that is highly influenced by internal resources (e.g., knowledge, a sense of meaning) and contextual features (e.g., healthy and positive work climates). Furthermore, a sense of community (SOC, feelings of belonging and connection) in the workplace can contribute to an employee's well-being (vitality), while a sense of community responsibility at work (SOC-R, the feeling of responsibility for the collective well-being of an organization) contributes toward an employee's work engagement and pursuit of leadership opportunities (learning) (Boyd, 2015). Work is a major part of any individual's life, and therefore thriving at work can ultimately lead to positive life outcomes such as personal development and positive physical and mental health (Spreitzer et al., 2005).

Thriving and Intellectual Disability

In order to promote thriving for students with ID, school psychologists must combine theories and research from disability studies with these existing thriving models (see Table 3). The concept of QOL (Schalock & Alonso, 2014) serves as a guide to maintaining relevance and validity for this specific population while encompassing many of the most prominent models of thriving outlined above.

As indicated in Table 3, several thriving models involve aspects of well-being and happiness (Seligman, 2011; Spreitzer et al., 2005; Vallerand & Carbonneau, 2013) as well as personal growth, achievement, and skill development (Lerner et al., 2013; Seligman, 2011; Vallerand & Carbonneau, 2013; Spreitzer et al., 2005). Furthermore, relationships have been identified as vital to both thriving and QOL (Lerner et al., 2013; Seligman, 2011; Vallerand & Carbonneau, 2013). However, the major thriving models lack several critical elements deemed necessary in the population of people with ID.

Table 3

Alignment of Quality of Life (QOL) concept with four major thriving theories

Quality of Life for Individuals with ID (Schalock & Alonso, 2014)	Adolescent Thriving: 6 Cs of Positive Youth Development (Lerner et al., 2013)	Flourishing: PERMA (Seligman, 2011)	Optimal Functioning In Society (Vallerand & Carbonneau, 2013)	Thriving at Work (Spreitzer et al., 2005)
Personal development	Competence Character	Achievement	High performance	Learning
Self determination	Confidence			
Interpersonal relations	Connection Compassion	Relationships	Positive relationships	
Social inclusion	Contribution	Meaning	Contributing to society	
Emotional well-being		Positive emotions Engagement	Psychological well-being	Vitality
Physical well-being			Physical health	
Material well-being				
Rights				

Specifically, a discussion of thriving for individuals with ID requires the acknowledgement that those who thrive do so within structures of power and oppression (Buettner, 2010; Prilleltensky, 2012). Prilleltensky (2012) places thriving on a well-being continuum that is directly correlated with levels of justice. Suffering is the lowest state of

well-being and is associated with continuous discrimination and inequality. Thriving is the highest level of well-being and only occurs under optimal conditions of justice. He asserts that the notion of growing and succeeding because of internal drive, hard work, and skill is only possible in an equitable situation. When contextual variables lead to inequity, an individual will struggle to achieve or experience feelings of well-being and is unlikely to thrive.

For those with ID, the notion of social justice is, indeed, a prerequisite for thriving. The QOL for individuals with ID is dependent on successful and meaningful social inclusion and participation in the community as well as broader socio-cultural beliefs, policies, and practices that enhance statutory rights and material/physical well-being (Schalock & Alonso, 2014). The social ecological model for disabilities (Schalock et al., 2010) must inform the construct development of what it means to thrive with ID.

To date, only one study has directly examined the construct of thriving for those with ID (Weiss & Riossa, 2015). This pioneering study was based on the six C's of positive youth development (PYD) framework for thriving in adolescence (Lerner et al., 2013). In their study, the authors used a survey methodology to sample the parents of 330 children ages 11 to 21 who had ID and participated in the Special Olympics. Results indicated that, in the population of individuals with ID, those with a comorbid diagnosis of autism spectrum disorder (ASD) demonstrated significantly fewer thriving indicators (i.e., fewer of the six Cs) than those with ID alone. However, a mediator analysis using both individual and contextual factors revealed that levels of social communication and community participation were better predictors of thriving than simply the presence of an

ASD diagnosis. Thus, research supports the idea that thriving is associated with a combination of individual and contextual factors in the population of those with ID.

Weiss and Riosa (2015) noted several limitations to their study, including the use of very brief survey instruments for each variable and the lack of input from the youth with ID themselves – all data were collected from parent perspectives. One notable, and unaccounted for, assumption in the study was the adoption of the PYD model for thriving in a sample of youth with ID. The PYD model for thriving and the six Cs brief survey was developed for the general population of youth (Lerner et al., 2010); construct validity for adolescents with ID has yet to be determined. Therefore, while some aspects of the six Cs appear relevant as a measure of thriving for students with ID (see Table 3), the PYD model does not entirely address some of the most pressing issues for this population such as the importance of well-being or issues of social justice and civil rights. Therefore, although the Weiss and Riosa (2015) study is an excellent start to examining the positive psychology of those with ID, it lacks a framework that is specific to the population.

Transactional Ecological Thriving Model

The Transactional Ecological Thriving Model (TET-M) is a newly proposed framework for understanding thriving for students with ID (see Figure 1). In this model, thriving involves the continuums of subjective well-being (SWB) and developmental growth within a series of support systems. Four quadrants emerge from the vertical and horizontal axes, including thriving, static, suffering, and taxed. The following sections outline in detail each element of TET-M, including the systems of support, the axes of SWB and developmental growth, and the four quadrants.

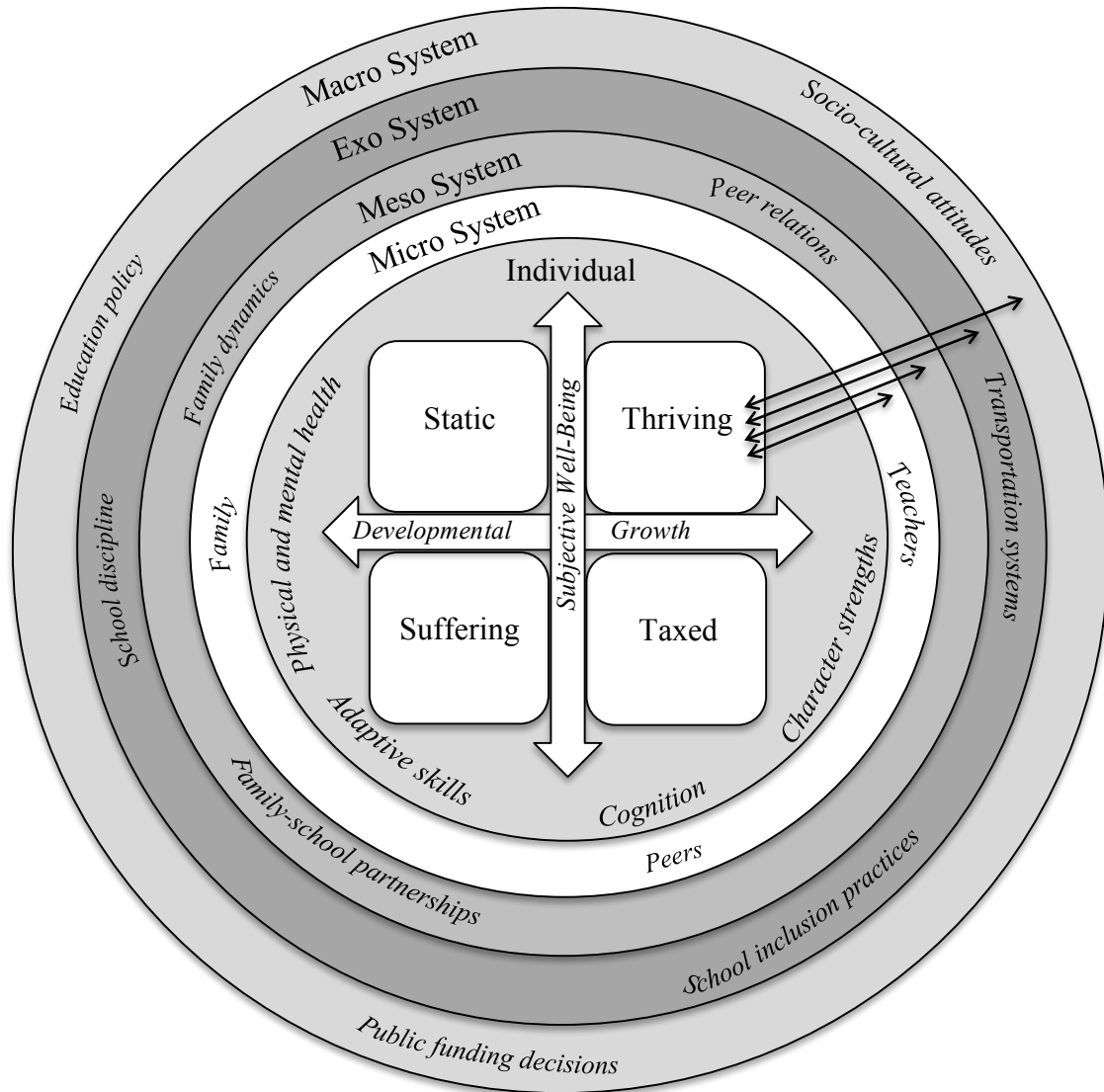


Figure 1. Transactional Ecological Thriving Model (TET-M): A theoretical framework for school psychology.

Systems of Support

Thriving requires a reciprocally supportive context to enhance and maintain both SWB and developmental growth (Bronfenbrenner, 1979; Prilleltlesnky, 2012). The TET-M embeds the individual within a series of systems of support based on the concentric circles of the bioecological systems theory (Bronfenbrenner, 1979). Bidirectional arrows in the thriving quadrant indicate a healthy and functional exchange

between the student's individual characteristics and his or her environment. These arrows reflect key domains from the QOL concept (Schalock & Alonso, 2014), including some that are missing from other critical thriving models (see Table 3). Namely, arrows between the individual and the micro and meso systems reflect the importance of reciprocal interpersonal relations. Furthermore, inward facing arrows between the individual and the exo and macro systems indicate the role of distal systems on both rights and material well-being. Outward facing arrows communicate the role of participation on social inclusion and self-determination. Altogether, these arrows indicate the transactional relationship between thriving individuals and their ecological systems.

The examples listed in each ring of the systems of support (e.g., teachers, school policies) are limited and specific to the school setting in order to enhance clinical utility for practicing school psychologists. However, this model may also be applicable to other environments and life stages (e.g., vocational, community) where other variables may be more relevant (e.g., supervisors, spouses, work-place policies, housing). After all, the NASP vision is that all students thrive in school, at home, and in life (NASP, n.d.). While our work as school-based mental health providers is typically focused on the birth-to-21 age range, we aspire to impact students throughout the lifespan, well into adulthood. Thus, the model can and should be expanded to include a variety of factors that impact long-term functioning and outcomes for any individual with ID, even those who are no longer enrolled in the schools.

Individual variables. School psychologists practicing from a positive psychology framework should begin by considering students' individual characteristics that they bring to the situation, including their character strengths (Gilman et al., 2014). Further,

the social ecological model (Buntinx, 2014; Schalock et al., 2010) states that human functioning for individuals with ID is heavily influenced by the capacity of systems to support the individual's unique needs (e.g., intellectual ability, adaptive skills, and health). In order to design effective and responsive support systems from a positive psychology and social-ecological model orientation, school psychologists must have a clear understanding of these individual traits. Individual characteristics lie at the core of the TET-M. These include character strengths, cognitive abilities, adaptive skills, and physical and mental health. All of these variables are influenced by, and subsequently influence, the systems of support in which the student develops.

Bioecological systems. Bronfenbrenner's (1979) influential theory of contextual development was originally conceptualized as a succession of instrumental systems surrounding a developing person. The theory was refined over the course of Bronfenbrenner's career to include a biological component (i.e. bioecological systems model) acknowledging the impact of child attributes on the systems (Rosa & Tudge, 2013). In the bioecological systems theory, there is an emphasis on bi-directionality and interdependency of the developing individual and others within the systems. All of this influences the nature and course of development, and is the context for the TET-M.

The innermost ring of the ecological model, closest to the developing person, is described as the microsystem. This includes the most immediate face-to-face relationships and systems surrounding an individual, such as a family unit or classroom. As with all the systems in this model, the child affects the system in which he or she interacts as much as the adult caregivers affect the child. It is not a unidirectional relationship where a parent or teacher delivers interventions and the child grows in

response; instead, both individuals' personal characteristics influence the frequency, the manner, and the quality of the interactions (Bronfenbrenner, 1979). Factors such as parental expressed emotion (EE; Magana-Amato, 2015), teacher instructional styles, and peer attitudes are all encompassed within this microsystem.

At the second level, the mesosystem is a unique "system of systems," where Bronfenbrenner (1979) noted the ways in which the relationships between microsystems can significantly impact development (p. 25). The strength and quality of interactions between key players in an individual's life can enhance or detract from a child's development. For instance, the relationships between home and school can greatly impact a child's cognitive development and academic growth (Miller, Lines, & Fleming, 2014).

Moving outward to the third ring, the exosystem refers to those systems that *indirectly* influence an individual's development. A family's extended support systems, a parent's employment situation, the policies of a school district, or neighborhood crime rates are all examples of the exosystem. While the relationship between the individual and the exosystem is less direct, it is still significant. For instance, students who attend schools with well-developed school-wide positive behavior intervention systems (SWPBIS) tend to demonstrate fewer behavior problems and more prosocial behaviors (Bradshaw, Waasdorp, Leaf, 2012).

Finally, Bronfenbrenner (1979) noted the impact of the macrosystem on an individual's development. As the outermost system, the macrosystem refers to the overarching institutional structures that surround an individual. This includes broad cultural and ideological belief systems, political influences, public program funding decisions, legal issues, education systems, and access to opportunities. This system

permeates all other systems and impacts development in an indirect, but highly influential, manner.

Systems of support and intellectual disabilities. In regard to disability studies, the bioecological systems model is highly useful. In fact, the social ecological model of human functioning (Buntinx, 2014; Schalock et al., 2010) is based on Bronfenbrenner's (1979) concept of ecological systems. People with ID rely heavily on the systems of support to facilitate development and well-being. For instance, in young adulthood, a primary developmental task may be vocational training. However, to access job skills training and, eventually, a location of employment, an individual with ID is highly dependent on his or her community's public transportation system (exosystem). If the public bus system is inaccessible, unsafe, or unpredictable, an individual with ID will be unlikely to access the training required for professional development. Human functioning is greatly affected by the systems within which an individual with ID interacts and contributes.

Axes

Two axes provide structure for the matrix embedded within TET-M. The vertical axis indicates a continuum of SWB; or a spectrum of life satisfaction and positive affective state (Diener et al., 2016). The upper half of the matrix represents relatively high levels of SWB, while the lower half represents those with lower levels of SWB. The horizontal axis signifies a *trajectory* of developmental growth (Benson & Scales, 2009). The right side of the matrix indicates continued personal development; an upward moving path. To reemphasize, this right side does not refer to normatively high developmental skills, but rather the act of continuous improvement. In contrast, the left

side represents those at a stagnant developmental state, or those who are regressing in personal growth and development.

Subjective well-being. SWB is defined as “people’s overall evaluations of their lives and their emotional experiences” (Diener et al., 2016, p.87). The concept of subjectivity in SWB is critical; it is determined by the individual him or herself through self-reflection and reporting, rather than determined externally by objective outcome measurements (Huebner & Furlong, 2016). SWB includes a cognitive component in which one assesses levels of satisfaction with life, as well as an affective component in which one experiences feelings and moods (Diener et al., 2016). Those who have positive thoughts about their lives, as well as frequent positive emotions and infrequent negative emotions, have high SWB (Nes & Roysamb, 2015). This conceptualization might cause SWB to be mistaken for a simple measure of happiness (Jayawickreme et al., 2012); however, SWB is a more complex construct. Each of the three elements of SWB (life satisfaction, positive affect, infrequent negative affect) is influenced by and influences different variables and aspects of a person’s life. For example, the quality of one’s work can influence life satisfaction, the dynamics of interpersonal relationships can influence positive affect, and internal conflicts can increase negative affect (Diener et al., 2016). Further, positive emotions may enhance sociability and negative affect may impact how an individual perceives personal problems (Diener et al., 2016). Moreover, SWB is not an inborn trait explained primarily by heritability. In fact, only 40% of SWB variance can be explained by genetics (Nes & Roysamb, 2015). Diener and colleagues (2016) caution against over-interpreting the effects of heritability based on ample evidence that demonstrates the impact of life events and support systems on an individual’s SWB.

SWB can be further categorized as hedonic or eudaimonic (Jayawickreme et al., 2012; Ryff, 2014). Hedonic well-being is primarily concerned with liking and enjoying one's life. Fredrickson's (2001) "broaden and build" theory can be considered a hedonic form of SWB. It emphasizes that those with positive emotions may have many more opportunities to engage in the world, therefore possessing higher levels of SWB. Simply experiencing a positive emotion can cause an individual to expand his or her horizons and develop new skills. For example, experiencing the positive emotion of curiosity may cause a student to explore the environment. Then, the "broadened" opportunities triggered by the positive emotion may lead to "building" new vocabulary skills, learning new concepts, and increasing social skills. Thus, development is directly related to one's SWB.

A eudaimonic approach asserts that well-being involves deeper rooted constructs than mere happiness and life satisfaction. Ryff (2014) argues for more than the traditional simplistic and reductionist views of SWB. Her model of psychological well-being includes six major elements: environmental mastery, personal growth, self-acceptance, life purpose, relations with others, and autonomy (Ryff, 2014). When these six constructs are present, an individual has an overall high level of well-being. This conceptualization of well-being better reflects the causal conditions for the positive emotions and life satisfaction outlined in the traditional SWB theories. With eudaimonic SWB, the emphasis is on the individual's reciprocal relationships with the community; where one "find[s] fulfillment as a contributing member of society" (Hazel, 2016, p. 23). Furthermore, eudaimonic SWB refers to the deeper needs of an individual as opposed to simply examining what an individual wants and desires (Ryff, 2014; Seligman, 2011).

Subjective well-being and intellectual disability. SWB for individuals with ID has historically been an underexplored construct (Dykens, 2006; Shogren, 2014). While researchers have examined the SWB of parents and overall family well-being of children with ID (e.g., Werner & Shulman, 2013), tools for measuring and understanding how individuals with ID experience SWB are limited due to language and cognitive constraints (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013). Researchers have begun using adapted assessments with visual prompts and tablet computer technology to elicit information on the SWB of individuals with ID (Bostrom & Broberg, 2017). Additionally, systematic caregiver behavioral observations of mood and emotions have been used to measure SWB in those with severe and profound ID and significantly limited communication skills (Vos et al., 2013). A few qualitative researchers have also explored the topic of SWB in the ID community, bringing the voices of participants into the conversation about what the phenomenon of SWB means to those living with ID (Foley et al., 2012; Haigh et al., 2013; Scott; Foley, Bourke, Leonard, & Girdler, 2014).

Initial research indicates that SWB for this population is characterized by a joyful attitude, positive relationships, meaningful participation, and autonomy (Bostrom & Broberg, 2017; Scott et al., 2014; Foley et al., 2012). Individual characteristics such as emotional competency (Rey, Extremera, Duran, & Ortiz-Tallo, 2014), a positive sense of self (Foley et al., 2012) or a hope for the future (Scott et al., 2014) are associated with SWB, while advanced age, medical problems, and compromised adaptive behaviors may detract from SWB (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010). Contextual factors such as access to safe and inclusive settings are also associated with higher levels of SWB (Haigh et al., 2013).

Developmental Growth. Developmental growth can be defined as the process of changing with age, building new skills, gaining new knowledge, and transforming into something new (Trawick-Smith, 2014). Developmental growth does not stop at a certain age; aside from temporary plateaus, humans develop continually over the lifespan, sometimes steadily, sometimes with sudden transformations (Shonkoff, Phillips, & National Research Council, 2000). In TET-M, continued developmental growth must accompany SWB in order to achieve a state of thriving.

For school psychologists, student developmental growth is traditionally characterized and measured by academic progress as well as social, emotional, and behavioral development (NASP, 2010). The wide range of ages covered by school psychological services (birth to 21) requires any consideration of developmental growth to be grounded in a strong understanding of cognitive and psychosocial developmental theories (see Erikson, 1950; Piaget, 1954) with knowledge of developmental milestones and expectations across the life span as well as evidence-based strategies for supporting development (NASP, 2010). Again, it is important to note that the developmental growth axis of TET-M is not a measure of normative development. Students with ID, who may be functioning well below same-aged peers, may still fall in the high range of the developmental growth continuum. The emphasis is on the *trajectory* of development. Therefore, students who are making progress and moving toward individualized goals that are lower than expected based on grade-level standards or developmental stages can still be considered thriving.

Stage theories of development break down an individual's growth into measurable chunks, following a biological process, over time (Trawick-Smith, 2014). Developmental

stage theorists were concerned with capturing the typical or “normative” process of human development over the lifespan, and typically failed to capture the developmental experience of those with disabilities (Smart, 2012). However, school psychologists can still utilize stage theories of development when assessing a student’s growth trajectory and setting goals, while making sure to consider the unique aspects of a student’s developmental profile related to ID.

Erikson’s (1950) psychosocial development theory and Piaget’s (1954) theory of cognitive development are particularly salient in a discussion about developmental growth and thriving. Erikson (1950) laid out eight stages of psychosocial development, in which an individual resolves a series of personal crises as he or she ages (see Table 4). Satisfactory resolutions to the developmental crises result in the development of major new social and emotional skills and moving on to the next life stage.

Piaget’s (1954) theory on cognitive development outlined the stages in which a child constructs knowledge (see Table 5). Piaget (1954) asserted that the process of assimilation allows children to fit new information into their pre-existing understanding of the world, whereby accommodation is the process in which the child’s cognition develops to adapt to the new information. School psychologists can reflect on these critical stage theories as they consider a student’s placement on the developmental growth axis of TET-M. Furthermore, a deep understanding of developmental stage theories allows the school psychologist to set appropriate and meaningful goals for growth based on developmentally appropriate stages.

Table 4

Erikson's Stages of Psychosocial Development (Erikson, 1950)

Age	Stage	Developmental task
0-18 months	Trust vs. Mistrust	Building trusting relationships with caregivers
18 months-3.5 years	Autonomy vs. shame	Building independence to separate from caregivers and explore surroundings
3.5 years-6 years	Initiative vs. guilt	Taking risks, expressing thoughts and feelings
6 years- 12 years	Industry vs. inferiority	Developing skills, acquiring competence, learning to work
Adolescence	Identity vs. identity confusion	Working out one's place in the world, identifying personal values and beliefs
Young adulthood	Intimacy vs. isolation	Learning to relate closely with other people
Adulthood	Generativity vs. stagnation	Contributing to society and nurturing the next generation
Older adulthood	Integrity vs. despair	Contemplating one's life

Table 5

Piaget's Stages of Cognitive Development (Piaget, 1954)

Age	Stage	Developmental task
0-18 months	Sensorimotor	Using movement and senses to understand the world
18 months-7 years	Preoperational	Beginning of internal thought and use of symbols, concrete reasoning
8 years-12 years	Concrete operational	Early logical reasoning, continue to benefit from the use of concrete materials
12 years-adulthood	Formal operational	Abstract reasoning and hypothetical thinking

Developmental growth and intellectual disability. Research indicates that students with ID can and do experience the stages outlined above (Smart, 2012). However, a strict or rigid adherence to the normative linear progression through the stages is unlikely to prove valid in a population of people with limitations imposed from both biological and societal factors. Thus, while stage theories are useful for understanding typical human development, they fail to acknowledge the influence of the individual/context interaction that is so critical for the ID population.

The concept of plasticity may be more useful when considering developmental growth for those with ID. Development need not be stagnant or predetermined by society or genetics; rather development can be encouraged and advanced. In developmental psychology, the concept of plasticity refers to the notion that adequately supportive environments can move individuals toward healthy developmental outcomes (Lerner et al., 2006). Further, in neuroscience, plasticity refers to the brain's capacity to change, grow, and adapt, especially with exposure to enriched learning environments (Bryck & Fisher, 2012). For example, the life expectancy, IQ scores, and developmental outcomes of those with some genetic conditions that cause ID have drastically improved over the past half-century due to historical changes in the ecological systems of support (e.g., advances in the medical community and an inclusive public education system; Roizen, 2013). A supportive environment can drastically impact development for many with ID; it is impossible to predict potential when outcomes change over time with historical advances. Rather, it is more useful to consider the plasticity of each individual's development, and work to promote growth in all developmental areas over the lifespan.

In the QOL concept, personal growth for people with disabilities is a key domain in the category of independence (Schalock & Alonso, 2014). The personal growth domain is operationalized as having valid assessment data about present levels of performance, learning new skills that are of interest to the individual, accomplishing individualized academic goals, and obtaining educational degrees (Gomez, et. al., 2015; Schalock & Alonso, 2014). This domain aligns well with school psychologists' professional responsibility to promote learning for all students regardless of disability status (NASP, 2010). School psychologists can advocate for students with ID by continuing to encourage academic, social, and behavioral growth regardless of stereotypes or documented phenotypes for a disability. A strong understanding of developmental stage theories, individual characteristics of the student, as well as the student and family's particular desires for social inclusion can guide the formation of appropriate goals and interventions to support student advancement in multiple domains and at all levels of functioning.

Quadrants

In TET-M, the intersecting axes of SWB and developmental growth create four quadrants for consideration: thriving, static, suffering, and taxed. Each quadrant represents general "modes of being." Students will identify with each of these four conditions at different times, depending on the systems of support and unique life circumstances. Furthermore, school psychologists can provide consultation, intervention, and advocacy services within the systems of support to move students upward on the axis of SWB and forward on the axis of developmental growth in order to promote student thriving.

Thriving. A state of thriving falls in the upper right quadrant, when both SWB and developmental growth are in the elevated range. Thriving is the ultimate goal for students with ID. A thriving student is satisfied with his or her life conditions, enjoys a positive mood, while also exhibiting continued personal growth and development. Developmental levels need not be high when compared with developmental expectations for the student's chronological age. Rather, the focus is on learning and progress – an upward trajectory toward individualized goals (Benson & Scales, 2009; Schalock & Alonso, 2014; Spreitzer et al., 2005). The systems of support address student needs, and students contribute meaningfully to their communities with the use of personal strengths and self-determination (Schalock et al., 2010; Peterson & Seligman, 2004). Bidirectional arrows between the thriving quadrant and the systems of support indicate high levels of social justice, self-determined social inclusion, meaningful contribution to the broader society, as well as enjoyable and reciprocal personal relationships.

For example, a student who is thriving may be a twenty-year-old student with ID and ASD in the transition program of his public-school district. Three days a week, he participates in a job-training program at a local electronics-recycling center. The work involves systematically breaking down computer motherboards and properly disposing of the materials. The student enjoys the predictable and stable work expectations, the quiet individual workstation, and the interaction with technology. The student's supervisor and job coach have developed a visual schedule for his daily activities so that he knows exactly what is expected of him at each point of the day and when he will be able to take a break. In addition to learning specific job skills that will benefit him when he is seeking future employment, as well as new vocabulary related to the work, the student has also

developed some valuable new adaptive skills. With the help of his transition teacher, the student has learned to navigate the regional transportation system application on his phone so that he can independently and successfully ride a bus to work for each shift.

Static. The upper left quadrant is titled static and refers to students with high levels of SWB but halted development. This state of being neglects the innate capacities of a student to grow, learn, and contribute to society in meaningful and self-directed ways. Students in the static quadrant may be students who are happy and well behaved but are failing to make adequate growth or are even regressing in their skills. Here, stereotypes of low developmental potential, a desire to maintain SWB at the expense of growth, inadequate curricula, or a lack of appropriate academic interventions may keep students from thriving.

For example, a high school student with Down syndrome (DS) may be in the static state. She may present with a cheerful mood and a pleasant disposition, enjoying her days at school and forming friendships with peers and educators. However, a close examination of her development indicates that she plateaued academically with a first-grade reading level at the end of elementary school. The student and her family may assert that this reading level is inadequate to help her navigate the community for post-secondary employment and educational opportunities. In order to promote thriving for this student, the school psychologist may advocate for the student's developmental growth in her individualized education program (IEP) with some specific academic goals in addition to functional life skills.

Suffering. In the lower left quadrant, students with low levels of SWB and stagnant development or regression can be classified in a state of suffering. Students with

ID who are suffering are of particular concern for school psychologists and will require a high level of support. In retrospect, individuals with disabilities living in institutionalized settings in the late 19th and early 20th centuries may have spent vast amounts of their lives in the suffering quadrant. The goal set for these individuals was complete removal from society through systematic warehousing, as opposed to a focus on personal satisfaction or growth (Wehmeyer, 2013). For students in the suffering quadrant, school psychologists can provide evidence-based strategies at all levels of the students' bioecological systems to first increase SWB and then developmental growth. Basic neurological development suggests starting with strategies to improve SWB before improving developmental growth. Students who are more regulated emotionally will be better equipped to access interventions aimed at developing higher-level thinking and learning tasks (Perry, 2009).

An example of a student in the suffering quadrant may be a middle school student with ID who spends a significant portion of her day in the school's time-out room due to persistent aggressive behaviors. When she is not in seclusion, the student is in a self-contained classroom where she receives small group and one-on-one instruction from a special educator or paraprofessional. With a lack of valid and current assessment results, in part due to the student's lack of verbal communication skills, the teacher knows little about her present levels of academic ability. Therefore, the student has some general IEP goals related to self-management and communication, but she has failed to make progress over the course of the year. The school psychologist can use data-based decision making to address both the student's SWB as well as the student's developmental growth in order to move her closer toward a state of thriving.

Taxed. Taxed is the name of the lower right quadrant, and is characterized by continued developmental growth with low levels of SWB. The taxed quadrant indicates a condition where the focus is on student growth but mental health and well-being are neglected; progress is prioritized at any cost. Students with ID who are taxed may be referred to the school psychologist for concerns with internalizing conditions (e.g., self-injurious behaviors or withdrawal) or externalizing behaviors (e.g., disruptive behaviors in the classroom). The student is making adequate growth toward IEP goals. However, he or she presents with general life dissatisfaction and a pervasive negative mood; personal strengths, needs, preferences, and SWB are largely sacrificed for the sake of development.

For example, a taxed state may occur when a first-grade student with fragile X syndrome (FXS) is engaged in an educational program aimed at teaching reading in a loud, unpredictable, and busy inclusive classroom environment. The student may make some progress on his phonemic awareness per his IEP goals, but individual needs related to sensory processing sensitivities and a preference for a predictable routine likely detract from his SWB (Hagerman, 2006). The student may engage in hand-biting or explosive behaviors in the classroom, indicating a taxed state. The school psychologist will need to address SWB through supportive systems that address individual strengths and needs in order to encourage this student to thrive.

Implications for School Psychology

Students with ID face unprecedented challenges upon graduation, and are less likely than any other students receiving IEP services in the schools to have had many of the key experiences linked to positive post-school outcomes (Lipscomb et al., 2017). A

focus on thriving provides the field of school psychology with a holistic approach to improving school supports for this unique student population. The shift in the disabilities field from a medical model to a social ecological model is largely theoretical. The TET-M provides school psychologists with an avenue to operationalize and actualize this theoretical shift within the school setting by applying principles of positive psychology and best practices in school-based mental health supports to encourage thriving for all students with ID.

Application of Thriving in School Systems

Working within the framework of a multi-tiered system of supports (MTSS), school psychologists can apply TET-M to a data-based decision-making process to determine intervention needs and promote thriving (hereafter called the Thriving Tree; see Figure 2). Practitioners can utilize the TET-M and the Thriving Tree to determine which quadrant best describes a student's functioning (by considering biological systems of support, SWB, and developmental trajectory) and how support services can help to move the student toward a state of thriving. Implementation of evidence-based consultation, intervention, and advocacy strategies in any or all levels of the student's ecology can directly and indirectly enhance student QOL. School psychologists are well positioned for this work with expertise in meaningful assessment, school-based intervention, and systems restructuring to enhance learning and well-being for all students (NASP, 2010).

Measuring systems. School psychologists can assess and document a student's relevant bioecological systems using a wide variety of assessment instruments (see Table 6). Psychoeducational assessments provide data on individual variables that a student

brings to the school setting such as cognitive ability, communication skills, and sensory needs (NASP, 2010; Salvia, Ysseldyke, & Witmer, 2013). Furthermore, school psychologists can directly assess a student's character strengths with the *Values in Action (VIA) Inventory of Strengths for Youth* (VIA-Youth; Park & Peterson, 2006), using cognitive accommodations for students with ID such as providing definitions and context for complex survey questions (Shogren, Wehmeyer, Forber-Pratt, & Palmer, 2015).

Table 6

Measuring Systems of Support

Instrument/Strategy	Bioecological Systems Level
Psychoeducational assessment (NASP, 2010; Salvia et al., 2013)	Individual
Values in Action (VIA) Inventory of Strengths for Youth (Park & Peterson, 2006)	Individual
Clinical assessment interviews with students, parents, and teachers (Sattler & Hoge, 2006)	Micro, Meso, Exo, Macro
Review of school records (Sattler & Hoge, 2006)	Micro, Meso, Exo
Classroom observation (NASP, 2010; Volpe et al., 2005)	Micro, Meso, Exo
Classmaps surveys (Doll et al., 2010)	Exo
School climate surveys (Klotz, 2016)	Exo
Resource mapping (Adelman & Taylor, 2013)	Exo
Review of relevant political and legal issues for students (http://www.nasponline.org/research-and-policy/current-law-and-policy-priorities)	Macro

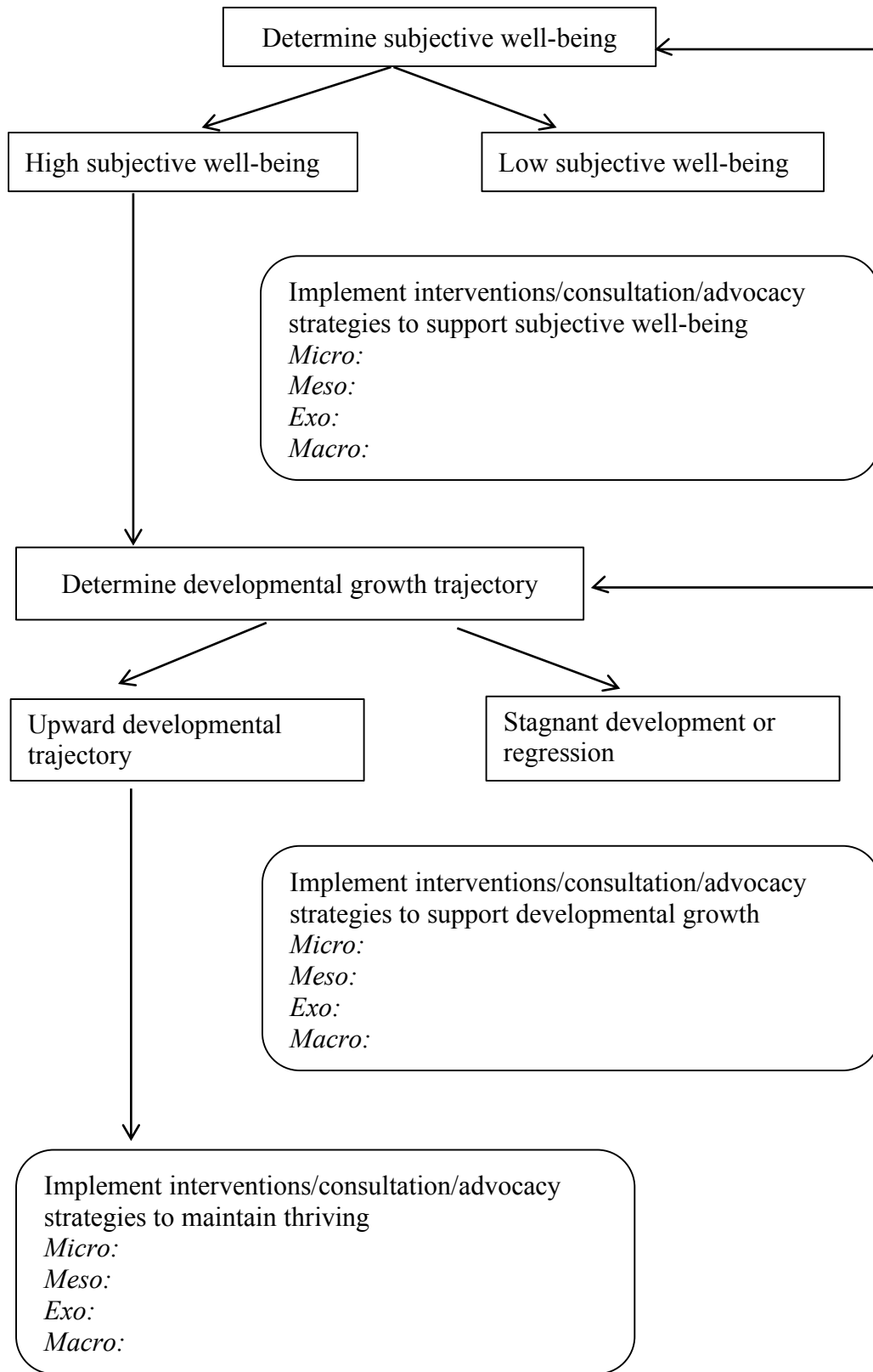


Figure 2. Thriving Tree: Data-based decision-making process to promote thriving.

Using a bioecological systems lens in a clinical assessment interview (Sattler & Hoge, 2006) can provide insight to a student's micro and meso systems and the quality of reciprocity in those relationships. Furthermore, the clinical assessment interview will provide data regarding a student's quality and frequency of self-determined social inclusion in the community or society at large. Reviewing the student's records for social history data may reveal critical changes in a student's systems of support over time. Using direct classroom observations (Volpe, DiPerna, Hintze, Shapiro, 2005) and student surveys (Doll et al., 2010), a school psychologist can assess the class climate. A thorough documentation and analysis of the student's school disciplinary system, overall school climate (Klotz, 2016), the student's school and neighborhood resources (Adelman & Taylor, 2013), and current cultural, legal, and political issues that may impact an individual student and his or her family (e.g. immigration policies, court case decisions regarding transgender students, high-profile acts of violence) can be useful for understanding a student's exo and macro systems.

Measuring subjective well-being. In order to maintain its subjective quality, SWB must be measured through self-reporting (Huebner & Furlong, 2016). Survey scales have been developed to directly assess a student's current perceptions of life satisfaction and mood (see Table 7). Further, student clinical assessment interviews can inform the school psychologist about more eudaimonic aspects of SWB, including questions about the student's quality of relationships, when the student feels most engaged in life or loses track of time, what the student is most proud of in terms of accomplishment, and how the student perceives his or her role in the school or broader community.

Table 7

Measuring Subjective Well-Being

Thriving Element	Assessment Instrument
Subjective well-being	Students' Life Satisfaction Scale (Huebner, 1991)
	Multidimensional Students' Life Satisfaction Scale (Huebner, Zullig, & Saha, 2012)
	Student clinical assessment interview (Sattler & Hoge, 2006)

Measuring developmental growth. School psychologists are particularly well trained and suited for measuring the developmental growth trajectories of students. Table 8 provides suggested assessment instruments. In terms of academics, school psychologists can review academic records and progress monitoring data to analyze the growth trajectory for a variety of academic subjects (Parker, Vannest, Davis, & Clemmens, 2012). Comprehensive psychoeducational assessments can provide data on present levels of performance (NASP, 2010; Salvia et al., 2013) and, when coupled with a review of records, will reveal the trajectory of the student's development and whether or not the student is making adequate progress toward individualized goals. A developmental history interview (Sattler & Hoge, 2006) provides the family's perspectives on present developmental levels and whether or not the student is growing or at a period of stagnancy or developmental regression.

Table 8

Measuring Developmental Growth

Thriving Element	Assessment Instrument
Developmental Growth	Progress monitoring (Parker et al., 2012)
	Psychoeducational assessment (Salvia et al., 2013)
	Developmental history interview (Sattler & Hoge, 2006)
	Review of school records (Sattler & Hoge, 2006)

Future Directions

In order to maintain their dedication to all marginalized students, the school psychology research community must further the exploration of the thriving construct. In-depth qualitative studies aimed at better understanding the phenomenon of SWB and the developmental growth trajectories for the ID, and other, student populations would add the voices of those who currently thrive to the scholarly literature. This would support the QOL domains of social inclusion and self-determination and fulfill the NASP (2016) commitment to social justice for all students. Furthermore, researchers can investigate factors, both individual and contextual, that facilitate thriving in different populations, perhaps leading to the development of more evidence-based strategies for school-based MTSS interventions. While there are several evidence-based strategies to promote thriving by increasing SWB and developmental growth in the school psychology literature (see Table 9), few have been validated with specific populations of students (e.g., Down syndrome, social-emotional disability, cerebral palsy). There is a need for high quality research to inform practitioners on promising service-delivery models that produce optimal outcomes for students with disabilities, including those with ID.

Conclusion

Until now, the field of school psychology has yet to define what it means for students with ID to thrive in our schools. This new framework acknowledges that thriving with ID is a multi-faceted construct that includes elevated levels of SWB and a state of continued developmental growth within a series of inclusive and supportive systems. A history of marginalization, coupled with substantial dependence on a fair and just socio-cultural and political system, compels school psychologists to advocate for this community. Our profession has long viewed the work of social justice through the lens of cultural diversity (Shriberg et al., 2008). It is time to add a focus on neurodiversity to our field's work for and with disenfranchised populations, placing a priority on building supportive school communities for students with ID and their families. This model provides focus for school psychologists to build both student learning and mental health and to promote students with ID who thrive in school, at home, and in life.

Table 9

Evidence-Based Strategies for Promoting Thriving in Schools

Thriving Element	Grade(s)	Strategy	Bioecological Systems Level
Subjective well-being	Elementary, Secondary	The well-being promotion program (Suldo, Savage, & Mercer, 2014)	Micro
	Elementary	Awesome Us (Quinlan, Swain, Cameron, & Vella-Broderick, 2015)	Micro, meso
Developmental growth	All	Multi-tiered systems of support (MTSS; Utley & Obiakor, 2015)	Micro, exo, macro
	All	Problem-solving consultation (Hurwitz, Kratochwill, & Serlin, 2015)	Micro
	All	Social-emotional learning (Schonfeld et al., 2015)	Micro, meso, exo
	All	Family-school partnership (Miller, Lines, & Flemming, 2014)	Meso
	All	School-wide positive behavior supports (SWPBIS; Horner & Sugai, 2015)	Exo
	Secondary	Positive youth development multi-tiered system of supports (PYD-MTSS; Hazel, 2016)	Exo
	Transition	Self-advocacy (Kramer, 2015)	Exo, Macro
	Transition	Transition Planning, Implementation, and Evaluation (TPIE; Talapatra, Roach, Varjas, Houchins, & Crimmins, 2017)	Micro, meso, exo

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THRIVING WITH DOWN SYNDROME: A MULTIPLE CASE STUDY

The vision of the National Association of School Psychologists (NASP) is that all students will thrive in school, at home, and in life (NASP, n.d.). This professional responsibility for school psychologists includes students with significant, pervasive, and lifelong disabilities, such as Down syndrome (DS). Students with DS can benefit from the support of school psychologists through assessments and direct intervention (Davis, 2008), as well as systems-level change and broad advocacy efforts. Further, our field's commitment to social justice (NASP, 2016) and prevention and wellness promotion (NASP, 2014) make school psychologists a natural fit to promote thriving for this student population.

DS is a chromosomal abnormality that is the most common known genetic cause of intellectual disability (ID; Roizen, 2013). In addition to cognitive delays, the disorder is associated with adaptive delays and serious medical complications (Perlman, 2014). Due to the genetic cause and the documented medical complications for individuals with DS, a great deal of information exists concerning the needs and pathology associated with the disorder. These findings often come from a medical deficit, or needs-based model (Dykens, 2006; Roach, 2003). There is markedly less information on those individuals with DS who thrive, or the factors that contribute to well-being and growth in this population.

Thriving is a multi-faceted positive psychology construct that refers to a state of growth and well-being (Benson & Scales, 2009; Lerner et al., 2010; Prilleltensky, 2012; Weiss & Riosa, 2015). Positive psychology is the scientific study of what enables

individuals and communities to thrive (International Association of Positive Psychology [IAPP], n.d.). A positive psychology orientation is transformational in nature, allowing practitioners and researchers to recognize assets within a community, thus shifting the focus away from merely fixing problems and more toward building resilience and enhancing outcomes (Mertens, 2009).

The lack of attention given to thriving in the DS population is unfortunate as it ignores a population of people who lead healthy, happy, and fulfilling lives with DS (Alderson, 2001; Skotko, Levine & Goldstein, 2011). Indeed, the lack of research may even be harmful to the DS population and their families because it can lead to a reduction in educator expectations for achievement, false limitations placed on long-term life goals, and even uninformed termination of pregnancies due to a lack of accurate information (de Graaf, Buckley, Skotko, 2015; Gilmore, Campbell, & Cuskelly, 2010). Thus, it is critical that research on DS addresses the range of possibilities for life outcomes, including a thorough documentation and analysis of those who are thriving.

Down Syndrome

Dr. John Langdon Down first identified DS as a specific condition in 1866 (Manfredini, 1988); however, scientists did not discover the underlying genetic cause until the late 1950s. Since then, prenatal screening has enabled doctors to identify the risk of a DS diagnosis as early as the first trimester of pregnancy (Roizen, 2013). However, the disorder is hardly a modern phenomenon. In fact, archeological excavations have produced skulls of humans with DS dating as far back as the 7th century (Roizen, 2013). DS has been around for a very long time and is relatively common. Prevalence rates of 1 in 700-800 births in the U.S. indicate that most school psychologists will work with

students with DS at some time in their career (de Graaf et al., 2015). To best meet the needs of this student group, it is critical to understand the genetics that cause the disorder, the characteristic strengths and needs associated with the syndrome, and the systems of support relevant to this population.

Genetics

There are three primary causes of DS, all three of which involve extra chromosomal material (Perlman, 2014). Ninety-five percent of all individuals with DS have trisomy 21, in which a third copy of human chromosome 21 is formed by nondisjunction (a failure to separate) during mitosis (Bornstein et al., 2010). Far fewer (1-3% for each type) cases of DS are caused by translocation or mosaic DS. In translocation, the long arm of the 21st chromosome attaches itself to another chromosome, thereby resulting in extra genetic material and a diagnosis of DS (Batshaw, Gropman, & Lanpher, 2013). Mosaicism occurs when some of the individual's cells possess the extra 21st chromosome and others do not. For example, an individual may have trisomy 21 in his or her blood cells, but not in his or her skin cells. Those with mosaic DS may demonstrate higher cognitive ability, yet tend to have similar medical outcomes to those with translocation and trisomy 21 (Batshaw et al., 2013). Further, the risk of having a baby with DS increases significantly with maternal age (Roizen, 2013).

Phenotype

A phenotype is the outward expression, or observable traits, of the interaction of genetics and environment (Batshaw et al., 2013). Characteristics such as behavior patterns, learning styles, communication abilities, growth and motor development, and social and emotional profiles all make up a disability phenotype. In DS, as with many

disabilities, the phenotype has variation. Individual characteristics, comorbid conditions, the family and community setting, as well as broad societal influences all impact the profiles of individuals with DS. It is important to note that individuals with DS may closely follow the phenotypic expectations in some domains, yet differ significantly in other ways (Fidler, Hodapp, & Dykens, 2002; Reilly, 2012). Just as a pathological approach alone will be of little good (Roach, 2003), an overreliance on phenotypic characteristics may result in overgeneralization of DS. It is important for service providers to guard against assuming universality and instead remember each individual brings his or her own strengths and preferences, life circumstances, and relationships to the table.

Physical Attributes. Although there are a wide variety of physical features associated with DS, two attributes are present in all individuals with DS. First, individuals with DS have a developmental delay, resulting in a decreased rate of bone growth (Perlman, 2014). This typically causes individuals with DS to have a shorter stature and decreased size of the head (microcephaly) as compared to others their age. Second, individuals with DS have low muscle tone (hypotonia), causing loose ligaments and hyperextension of the joints (Perlman, 2014). Additional physical features that may be present include upward slanting, almond shaped eyes, a flat nasal bridge, extra skin around the neck, and a wide gap between the toes (Perlman, 2014). Individuals with DS also frequently have significant medical needs, such as congenital heart disease, gastrointestinal disorders, thyroid conditions, and autoimmune diseases (Perlman, 2014; Roizen, 2013). Many children with DS will spend a considerable amount of time in hospitals starting at a very young age for corrective heart or gastrointestinal surgeries

(Miodrag, Silverberg, Urbano, & Hodapp, 2013).

Cognitive/Learning Profile. The developmental course of cognitive abilities is unique in the DS community. While infants typically present with average cognitive functioning, skills tend to decline within the first year of life. The average intelligence quotient (IQ) score for an adult with DS is 55, while the average score in the general population is 100 (Perlman, 2014). More specifically, many individuals with DS possess personal cognitive strengths in the areas of visual-spatial processing (Fidler, 2005). This strength appears to be most prominent in skills related to visual memory, visual motor integration, and visual imitation. Further, a pattern of significant relative weaknesses in the areas of verbal processing skills and auditory working memory is common for individuals with DS (Fidler, 2005). A cognitive decline is present in most individuals with DS, with the onset of Alzheimer-like neuropathy by age 45 (Carr, 2012; Fidler, 2005).

Adaptive Skills. In terms of daily functioning, individuals with DS tend to require more assistance than others of a similar age (Roizen, 2013; van Diujn, Dijkxhoorn, Scholte, & van Berckelaer-Onnes, 2010). Adaptive functioning tends to develop at a rate slower than age equivalent peers and peak at a lower level for individuals with DS (van Diujn et al, 2010). While the range of adaptive functioning is broad with the DS community, and varies drastically based on the individual as well as opportunities and supports in the family, school, and community, some specific trends have been noted in the literature. Multiple studies examining adaptive behaviors in individuals with DS have indicated a profile of relative strengths in social skills and daily living skills, as well as relative deficits in communication and motor skills (Fidler,

Hepburn, & Rogers, 2006; van Diujn et al., 2010).

Communication. Individuals with DS tend to have significant communication delays in early childhood, and many do not speak their first words until after 18-months-of-age (Roizen, 2013). As children gain communication skills, they continue to struggle with articulation and expressive language. For many children with DS, receptive communication skills are a relative strength compared with expressive communication skills (Abbeduto et al., 2003; Fidler, 2005; Kumin, 2001). Additionally, nonverbal communication is a relative area of strength for young adults with DS (Fidler, 2005). However, there is significant variation in communication skills for individuals with DS, and exposure and environment play a significant role in language expression (Deckers, Van Zaalen, Stoep, Van Balkom, & Verhoeven, 2016). For example, adults with DS in professional and community routines with more complex and novel verbal requests frequently acquire a variety of new vocabulary terms. Furthermore, inconsistencies in speech and language intervention services available in adulthood make it difficult to generalize the receptive/expressive communication gap that is more common during childhood (Kumin, & Schoenbrodt, 2016).

Social Skills and Behavior. Individuals with DS tend to have personal strengths in social functioning, especially when compared to individuals with other genetic causes of ID (Fidler, Most, Booth-LaForce, & Kelly, 2008). Specifically, results from studies using parent behavior rating forms have indicated higher levels of engagement with caregivers (Fidler et al., 2008), more developed play and leisure skills (Fidler et al., 2006), and higher quality relationships (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004) when compared to same-aged peers with ID caused by other genetic disorders.

That is not to say that individuals with DS do not exhibit behavior problems. In fact, social strengths may actually impede on-task behaviors for children with DS. Fidler (2006) noted a “social motivation profile” whereby individuals with DS may compensate for deficits in problem solving abilities with their strengths in sociability. Resulting behaviors have been described as “party trick behaviors” where individuals with DS engage in distracting social behaviors to avoid task completion (Wishart, 1996). Furthermore, although aggression is relatively low for individuals with DS, behavioral concerns associated with rigidity and cognitive inflexibility such as stubborn disobedience, attention seeking, and arguing are relatively common (Dykens et al., 2002). Additionally, more externalizing behaviors (e.g., hyperactivity) are seen in childhood and more internalizing concerns (e.g., social withdrawal) arise in adolescence (Dykens, 2007).

Mental Health. There is a historic and persistent stereotype that individuals with DS are pervasively cheery and pleasant (Gilmore et al., 2003; Roizen, 2013). However, research indicates that this stereotype neglects reality; the mental health of those with DS is more nuanced. Parents of children with DS *do* consistently report higher levels of joy and happiness in their children than the parents of children with other genetic causes of ID (Rosner et al., 2004). Further, several studies measuring the self-esteem and life satisfaction for individuals with DS have found that a sizable proportion of those living with DS enjoy their lives, feel competent, and think highly of themselves (Begley, 1999; Glenn & Cunningham, 2001; Skotko, et al., 2011). Higher levels of happiness and life satisfaction with DS may be correlated with living situations (e.g., more satisfaction when living with family, independently, and/or with roommates, than when living in a

group home), the influence of religion, certain states of residency, and how many parents live in the home (Skotko et al., 2011). However, studies also show that as individuals with DS age, occurrences of smiling decrease (Fidler, Barrett, & Most, 2005) and parents rate their children as less cheerful and affectionate (Hodapp et al., 2003).

Recent research indicates that individuals with DS have an increased risk of comorbid autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) compared with the general population (Oxelgren et al., 2017; Moss, Nelson, Richards, Oliver, 2013). Furthermore, age increases the risk for individuals with DS developing mental health problems (Dykens, 2007). Early onset of Alzheimer's disease is common for adults with DS, starting in the mid-forties (Carr, 2012; Fidler, 2005). Additionally, clinical depression is a particular concern in the DS population. Specific factors associated with DS – high risks of dementia, specific neurological attributes (e.g., reduced levels of neurotransmitters and lower hippocampal volumes), communication deficits, working memory difficulties, and attachment issues with caregivers – place them at an increased risk for developing clinical levels of depression (Walker, Dosen, Buitelaar, & Janzing, 2011).

To summarize, the positive mental health for those with DS is particularly salient in childhood and adolescence. Dykens (2007) reported that while approximately 30-40% of children with ID have significant signs of psychopathology, only 18-23% of children with DS have the same levels of mental health problems. While this is an increased risk in comparison with typically developing peers, those with DS are at significantly less risk than those with ID caused by other genetic conditions (Dyken, 2007). The onset of age is a significant risk factor in mental health issues, and service providers must consider

mental health supports as individuals with DS enter adulthood.

Systems of Support and Down Syndrome

The Association for Intellectual and Developmental Disabilities (AAIDD) puts forth a social ecological model for disability, emphasizing the significance of support from an individual's surrounding systems on general human functioning, as a method for contextualizing service delivery models (Buntinx, 2014; Schalock et al., 2010). Outcomes for those with DS can be greatly enhanced by supportive systems that address individual needs adequately and build on strengths (Schalock et al., 2010). Understanding those who thrive with DS requires an understanding of research related to relevant systems of support, including family, friends, school, work, and the community at large.

Home. Within the home context, an individual with DS receives critical supports from parents and immediate family members (Bronfenbrenner, 1979). For many families of children with disabilities, stress levels are higher than those of parents of typically developing children (Peer & Hillman, 2014). One way researchers have examined the family functioning of children with significant disabilities (e.g. ID) is by measuring the expressed emotion (EE) of parents. EE is a measure of the emotional climate for a family, including the quality of relationship between parent and child and the parent's attitudes about the child (Magana-Amato, 2015). High EE in parents of children with ID may interfere with treatment and be associated with negative child behavioral outcomes (Beck, Daley, Hastings, & Stevenson, 2004; Coleman & Riley, 2014). Research indicates that over one-third of parents of children with developmental disabilities (DD) have high EE, or an emotionally charged home environment (Thompson, Coleman, & Olmos, 2017). There is no data at this time regarding EE specific to the population of parents of

children with DS.

In terms of family functioning with DS, studies have documented a “DS advantage,” in which children with DS are reportedly easier to rear than those with other genetic causes of ID (Hodapp, Ly, Fidler, & Ricci, 2001; Hodapp, 2007). Research shows that families of children with DS report higher levels of well-being than families of children with other forms of ID (Fidler, Hodapp, & Dykens, 2000). However, critics of the “DS advantage” call attention to troubles with the metrics used to assess family levels of well-being, the importance of analyzing parent age and support systems when assessing well-being, and the necessity to consider the ages of the children at the time of assessment (Ebensen & Seltzer, 2011; Glidden, Grein, Ludwig, 2014). Overall, families of children with more developed adaptive behaviors and parents who use adaptive coping strategies for stress (e.g., positive reappraisal of the circumstances) have higher levels of well-being (Abbeduto et al., 2004; Rooke, Pereira-Silva, 2016; van der Veek, Kraaij, & Garnefski, 2009).

Over the course of the lifespan, parents of children with DS tend to report their highest levels of coping abilities during their children’s school aged and adolescent years (Goff et al., 2016). The combination of having time to accept a child’s diagnosis of DS coupled with supportive resources from the schools and community during these years may contribute to parents’ perceived coping abilities. Furthermore, multiple studies have documented that adults with DS may develop additional medical problems and begin significant cognitive declines in their mid-40s (Bittles, Bower, Hussein, & Glasson, 2006; Carr, 2012; Hodapp, Burke, Finley, & Urbano, 2016; Tsao, Kindlberger, Freminville, & Bussy, 2015). This places an increased caregiving burden—both emotional and

economic—on elderly parents. There is a clear need for a supportive system of public services to assist the entire family unit in the elder years of individuals with DS.

Social. In terms of friendships, limited research indicates that young children with DS can and do form true friendships, characterized as reciprocal, warm, and parent validated (Freeman & Kasair, 2002). In adulthood, limited communication skills, difficulty reading social cues, and challenges with empathy and identifying emotions in others can impact friendships (Watt, Johnson, & Virji-Babul, 2010; Wishart, 2007). In general, diminished social skills and behavior issues in children with disabilities can lead to long-term social isolation, reduced levels of well-being, and increased mental health problems throughout the lifespan (Guralnick, 2006). Thus, targeted skill building in the development of friendships for children with DS is imperative to encourage the development of mental health and long-term well-being.

Schools. Federal laws support service provision for young children (birth – age three) with disabilities through an Individualized Family Service Plan (IFSP; Individuals with Disabilities Education Act [IDEA], 2004). These early intervention services can start as soon as a diagnosis is made at birth for many children with DS. Indeed, starting early with an individual with DS allows interventionists to target skills that are still developing, and have not begun to differ significantly from peers without disabilities (Roberts & Richmond, 2014). The focus of early intervention is to support the family as primary caregivers. Therefore, therapies and assessments are frequently conducted in the home, with parents learning the methods to support their children in areas relevant to their daily lives. For those with DS, the frequency of early intervention can be critical; children receiving services more frequently demonstrate more significant growth in

development (Yoder, Woynaroski, Fey & Warren, 2014).

At age three, children with DS typically enter their community's school system in preschool settings. Provisions under IDEA (2004) ensure students with DS can be educated in the "least restrictive environment" (LRE) alongside their nondisabled peers per their individualized education program (IEP). Educational inclusion has a rich body of literature to support its use in the school systems (Gargiulo & Bouck, 2018). Several studies have documented that students with DS who attend school in an inclusive setting demonstrate higher levels of academic achievement than those in segregated learning environments (Turner, Alborz, & Gayle, 2008). Inclusion practices vary, based on the child's needs and the school's resources. Inclusion outcomes tend to be most successful for children with DS when classroom teachers are active partners in the educational program, working together with the special education team and the family (Fox, Farrell & Davis, 2004). Successful practices include positive behavior supports (e.g., praise for desired behavior), individual and small group learning arrangements, peer tutoring, and the use of assistive technology (Wolpert, 2001). These provisions and supports are documented in the child's IEP and reviewed on an annual basis.

Starting at age 16, the public schools are responsible for supporting students with disabilities, including DS, as they transition out of public schools and into the community through transition services (IDEA, 2004). Transition programming for students with DS must adequately assess and document student needs, strengths, interests, preferences, and goals for after graduation. Furthermore, the plan must document necessary support services, mapping out the coursework, community partnerships, and vocational training that will be implemented to facilitate the student's post-school success (Talapatra, Roach,

Varjas, Houchins, & Crimmins, 2017). For students with DS, the transition plan is a critical path toward independence in adulthood. Many students with DS remain on a transition plan through the age of 21, receiving supportive transition programming services in the community through the public school districts.

Recently, postsecondary education (PSE) opportunities have become an option for those with ID, including individuals with DS (Grigal, Hart, & Weir, 2012; Papay & Bambara, 2011; Plotner & Marshall, 2016). Some individuals with DS attend PSE programs on a college campus between the ages of 18 and 21 while still enrolled in the K-12 education system, and some individuals attend PSE programs later in adulthood (Grigal et al., 2012). PSE programs tend to differ significantly from traditional postsecondary college programs for students without disabilities. Rather than a traditional degree program, PSE for a student with DS may focus more on specific training for practical employment opportunities (Papay & Bambara, 2011) and independent living skills (Grigal et al., 2012). Thus, while academic skills are part of the programming, less than one quarter of PSE programs for students with disabilities highlight academic coursework as their primary goal (Grigal et al., 2012). Still, despite modifications to these college curriculums and the lack of traditional degree programs, the inclusion of individuals with DS in the PSE system is a moral imperative (Uditsky & Hughson, 2012). After all, postsecondary inclusion brings people with DS out of the margins of society and into their age appropriate natural settings in the community.

Community. Upon exiting public school services at age 21, adults with DS are faced with a far less inclusive environment than that found in the public schools (Gargiulo & Bouck, 2018). For many, a self-sustaining and satisfying professional life is

hard to come by (Kumin & Schoenbrodt, 2016). In fact, as of 2012, only 32% of Americans with ID ages 22-30 were employed, with a mean annual salary of less than \$15,000 (Butterworth, Migliore, Sulewski, & Zalewska, 2014). Specific to the DS community, a recent nationwide survey showed that a significant number of adults with DS are unemployed (Kumin & Schoenbrodt, 2016). Those who do have jobs, tend to work in a very limited pool of vocational areas, including food services, landscaping, office work, and janitorial services. Very few report full-time employment, but many are engaged in part-time work and part-time unpaid volunteer work in the community. In fact, over 40% of respondents indicated they volunteer in their community (Kumin & Schoenbrodt, 2016).

Limits on paid employment options make it difficult for those with DS to afford independent living without significant support from public services. In addition, reduced capacity in the areas of communication, cognitive problem solving, and adaptive development also impact an individual with DS's ability to live without the support of a family member or caregiver who can provide help with decision making and planning required in daily living (Van Gameraen-Oosterom et al., 2013). Although the scholarly literature does not currently detail the lives of those living independently with DS, rather merely captures deficits that make it difficult, there are accounts in the popular press media of adults with DS successfully living in the community (Bulman, 2017; Garber, 2013). Clearly, there is a need for more academic research into the topic of independent living with DS.

Outcomes

Life for individuals with DS has improved drastically in the last half century

(Roizen, 2013). As mentioned above, early intervention coupled with inclusive educational practices have enabled those with DS to develop many of the skills required for healthy functioning in our community. Medical advances, such as life-saving heart surgeries, have extended the life expectancies of people with DS several decades (Roizen, 2013). The inclusion of students with DS in public education, with early interventions starting at birth, has resulted in many people with DS developing a number of skills that were not previously thought possible for those with this condition. Opportunities in the community, including inclusive post-secondary options, are beginning to open some job options and are improving the quality of life for adults with DS.

However, despite these improvements in the lives of those with DS there remain significant challenges for adults with DS to pursue independent living in the community. Furthermore, there is a persistent tendency toward termination when prenatal results indicate a child will be born with DS (de Graaf et al., 2015; Natoli, Ackerman, McDermott, & Edwards, 2011). In fact, current studies in the US estimate that approximately 67% of women will choose termination when they receive a prenatal diagnosis of DS (Natoli et al., 2011). This has resulted in a reduction of the population of those living with DS in our country by approximately 30% (de Graaf et al., 2015).

The AAIDD social ecological model for disability asserts that adequate social supports can improve human functioning for all individuals with disabilities (Buntinx, 2014; Schalock et al., 2010). Perhaps outcomes for those with DS would improve further with more supportive systems of service-delivery that better address the unique phenotypic profiles of strengths and needs of this population. Working within the principles of positive psychology and using a thriving orientation may help school

psychologists to operationalize the social ecological model. This information can inform practice and policy, ultimately promoting thriving for all students with DS.

Thriving with Down Syndrome

The significant majority of individuals with DS report that they are generally happy and satisfied with their lives (Skotko et al., 2011). Perhaps many are, indeed, thriving with DS, however, thriving is a more complex construct than mere happiness. Thriving theory is informed by positive psychology (Peterson & Seligman, 2004; Seligman & Csikszentmihalyi, 2000; Seligman, 2011), bioecological systems theory (Bronfenbrenner, 1979), positive youth development (PYD; Benson & Scales, 2009; Lerner et al., 2013), the social ecological model for human functioning (Buntinx, 2014; Schalock et al., 2010), and quality of life (QOL) concept (Schalock & Alonso, 2014). Thriving is subjective, in that the individual reports satisfaction and enjoyment of life. Yet thriving is also objective, requiring measurable growth and positive life outcomes. Thriving occurs when an individual's unique personal characteristics are adequately supported by environmental factors in a series of inclusive and transactional systems of support (see Manuscript 1, Figure 1). Thriving encompasses a variety of concepts and factors. Briefly, one must consider subjective well-being (SWB), or an individual's self-reported life satisfaction and affective state or mood (Diener et al., 2016). Thriving also involves an upward developmental trajectory; progress and personal growth in meaningful areas of life (Schalock & Alonso, 2014). Finally, a series of supportive systems (e.g., family, school, community, and broader societal influences) as well as contribution through meaningful, self-determined social inclusion must be accounted for in the thriving discussion (Lerner et al., 2013; Schalock & Alonso, 2014). Thus, while

simple happiness in the population of those with DS has been documented (Skotko et al., 2011), the field has yet to fully explore the lives of those who truly thrive.

A systematic literature review in the psycINFO and ERIC academic databases revealed a significant gap in the literature in the area of individuals thriving with DS. An initial search with the subject fields “thriving” and “Down syndrome” resulted in zero articles, books, or theoretical papers on this highly specific topic. The addition of other positive psychological research topics related to thriving, including well-being, well being, wellbeing, eudaimon*, happiness, passion, optimal functioning, flourish*, character strengths, and positive youth development significantly expanded results (42 in psycINFO and 46 in ERIC). However, most of these articles referred specifically to the well-being of the mothers, fathers, and siblings of individuals with DS, and did not address the perspectives or experiences of those living with DS themselves.

Those few studies that did specifically examine thriving, happiness or well-being in the population of those with DS have identified a number of important themes and associations. Thriving and well-being in DS appear to be related to contextual factors such as higher levels of community participation (Lyons, Brennan, & Carroll, 2016; Scott, Foley, Bourke, Leonard, & Girdler, 2014; Wuang & Su, 2012), supportive government policies (Jiar, Handavani, & Xi, 2014), opportunities for physical activity (Love & Agiovlasitis, 2016), positive interpersonal relationships, independence in the community (Scott et al., 2014), geographic location, and living situations (Skotko et al., 2011). Thriving and well-being may also be related to individual characteristics, such as cognitive and motor abilities (Wuang & Su, 2012) or unique personal attitudes about life (Robison, 2000; Scott et al., 2014).

Another source of data comes from detailed and compelling narrative accounts on those who thrive with DS. Several memoirs (Bérubé, 1996 & 2016; Estreich, 2011; Kinsgley & Levitz, 1994; Wyllie, 2012), children's stories (Kahn, 2016), and documentaries (e.g., films *Monica and David* and *Up Syndrome*, and A & E television series *Born This Way*) put forth by individuals with DS and their friends and families document rich and meaningful lives, full of purpose, joy, and struggles. Many of those documented in these narratives would likely identify themselves as thriving based on the Transactional Ecological Thriving Model (TET-M; Manuscript 1, Figure 1). However, while one of these narrative authors (Bérubé, 1996 & 2016) also includes contextual information about historical, theoretical, political, and socio-cultural influences on his son's life, most focus primarily on textural and emotional descriptions of life with DS. These accounts artfully provide the reader with access to personal experiences and promote empathy. Perhaps a deep scholarly investigation relating this type of narrative data to previous research and contemporary theory may contextualize the information and improve utility for service provision and policy development.

Purpose of Study

The current study will fill some critical gaps in the disability, school psychology, and positive psychology literature bases with in-depth case studies of people who are currently thriving with DS. This focus on those with the highest levels of QOL will broaden the phenotype for the disability, alerting service providers (including school psychologists) to the potential of students with DS in our schools and how we can use data-based decision making and design supportive environments to help them thrive in school, at home, and in life (NASP, n.d.). The following research questions guide this

study:

1. How do individuals with DS and their families define thriving with DS?
2. What are the individual characteristics that influence thriving, as defined by the TET-M, for individuals with DS?
 - a. What are the individual psychosocial profiles of those who thrive with DS?
 - b. How do individuals with DS who thrive experience SWB?
 - c. In what ways do thriving individuals with DS demonstrate developmental growth?
3. What are the environmental factors that influence thriving, as defined by the TET-M, for individuals with DS?
 - a. What are the major systems of support for individuals who thrive with DS and how do they participate in these systems?
 - b. What facilitates thriving for individuals with DS?
 - c. What are some of the barriers to thriving for individuals with DS?

It is important to note that research question one aims to inductively define thriving directly from the participants' experience with the phenomenon. Questions two and three use an *a priori* definition for thriving outlined in the TET-M (Manuscript 1, Figure 1).

Methodology

This exploratory research study will use a case study methodology. Case study is a form of research in which a phenomenon is studied in depth within its natural context (Creswell, 2013; Stake, 1995; Yin, 2014). The target phenomenon in this case is thriving in individuals with DS. The overarching focus of the study is to describe the lives of

individuals with DS who are thriving.

Case study research is particularly useful for studying those who thrive with DS for three main reasons. First, case study allows for research on both individual and contextual factors (Yin, 2014) related to thriving. Personal characteristics and opinions of those who are thriving with DS have been vastly under examined in the scholarly literature. Indeed, thriving is, in part, a subjective and individual experience (Diener et al., 2016; Seligman, 2011). Thus, it is critical to initiate an in-depth inquiry eliciting the voices of those who are thriving to understand their lived experiences and perspectives on what contributes to their SWB and how they experience a good life (Roach, 2003). Thriving is also contextual in that it involves successful navigation of relationships and systems of support (Bronfenbrenner, 1979; Lerner et al., 2013; Prilleltensky, 2012). The case study method will also enable me to collect data from real-life contexts through observations, assessments, interviews with caregivers, and a review of records. This methodology is uniquely suited to a study of thriving in that it allows for a holistic inquiry of key individual and environmental variables related to the phenomenon.

Second, case study will allow for a deep, thorough, and detailed examination of the phenomenon of thriving. Several data collection methods, including interviews, naturalistic observations, documents and other artifacts, and even the use of some quantitative and standardized methods, exist in case studies (Creswell, 2013; Yin, 2014). This broad array of data collection allows for data triangulation, where information from multiple sources is combined to inform the findings of the study, thereby increasing validity of results (Park & Peterson, 2007; Yin, 2014). In my study, it is critical that I gather information directly from the participants, but also indirect and more objective

data, such as educational records. An examination of these artifacts may provide important information about the participants' life experiences that they are unable to articulate or are unaware were acting in their lives. Methods that solely use interviews (e.g., phenomenology) or quantitative data (e.g., surveys) would fail to capture the rich data available in artifact analysis and direct observation.

Third, case study is useful in that it can provide naturalistic generalizations, or “vicarious experiences” that help the reader connect with the participants and place themselves in the settings being studied (Stake, 1995, p.85). This is particularly useful when working within a transformative framework (Creswell, 2013; Mertens, 2009), as this study aims to do. A transformative paradigm for research is one that focuses on power inequities and the strengths of a community (Mertens, 2009). My hope is that this study will enable me to advocate for and with the population of individuals with DS by highlighting their assets and strengths. The case study approach allows for the creation of detailed descriptions that will provide the reader with a visceral experience and, therefore, an empathic understanding of these thriving individuals. I will use thick descriptions of settings, individuals, and interactions to thoroughly describe each case and what it looks and feels like to thrive with DS (Stake, 1995).

Procedures

Ethics. I will request approval for this study through the University of Denver's Institutional Review Board (IRB). As part of the IRB review, I will submit consent and assent forms for participants, parents, and others being observed or interviewed. Depending on participants' legal guardianship status, I will seek consent and/or assent from both participants and their parents to ensure that both parties understand the

research and willingly agree to the process (see Appendix A for consent and assent forms). Historically, many individuals with ID have been left out of research studies due to concerns with their ability to willingly consent (Horner-Johnson & Bailey, 2013), and this results in a lack of direct participation and voice from those with ID (Roach, 2003).

In working directly with a vulnerable population, I will take special care to ensure participants truly understand the consent process and make an informed choice to engage in the research. For example, best practices in obtaining informed consent from individuals with ID include using a conversational approach and checking for understanding of key components of the research process prior to actually requesting consent (Horner-Johnson & Bailey, 2013). If participants demonstrate misunderstandings, I will use a variety of accommodations, including having a caregiver present to assist with comprehension, adapting the consent form, and using more simple language (e.g., shorter sentences and phrases in easy-to-read formats). Participants who are unable or unwilling to provide clear assent (according to legal guardians and myself) will not be included in the study. In this way, I will guarantee ethical standards are used in the consent process, as well as the entire research study.

Sample

Cases. This investigation will specifically utilize a multiple case study design (Creswell, 2013; Yin, 2014; Stake, 1999 & 2006). Experts in case study research recommend that research teams conducting multiple case studies should include between three and ten cases to allow for adequate cross-case analysis without overwhelming the reader (Creswell, 2013; Stake, 2006). For this study, I will aim to recruit a minimum of four participants; a maximum of six participants will be considered to allow for

participant diversity (e.g., age, gender, family environment, socio-economic status). This range allows for a manageable solo and high-quality investigation within a reasonable amount of time.

Bounding the cases for this inquiry is critical for planning the scope of data collection (Yin, 2014). In case study, each case is an “integrated system” with clear predetermined boundaries surrounding a collection of working parts (Stake, 1995; p. 2). Therefore, cases in this study will include the individual participants themselves as well as their systems of support, including immediate families, community connections, schools or places of employment, systems of transportation, and even broader socio-political influences that may arise in the investigation (see Manuscript 1, Figure 1). In terms of chronological boundaries (Yin, 2014), I will be taking a retrospective account, investigating back to each participant’s birth and even to their prenatal status when possible through interviews with parents and a review of educational, medical, and community records when available.

Inclusion criteria will be that participants have a diagnosis of DS, are between the ages of 21 and 40, and are thriving. A definition for thriving will be based on the TET-M (see Manuscript 1, Figure 1) as a state of being where SWB is high and the individual demonstrates continued developmental growth. Exclusion criteria includes inability or unwillingness of the participant to assent or consent to participate.

Purposely drawing a varied sample that includes diversity is useful for an intensive study of a complex topic such as thriving (Stake, 2006). I will strive for diversity in my sample in terms of gender, race, ethnicity, and socio-economic status. This will be critical in light of the power and social justice issues related to thriving

(Prilleltensky, 2012). Furthermore, I will look for cases that are accessible, data-rich, and are conducive to learning more about the phenomenon (Stake, 2006). Practical logistics, such as location, willingness and ability to participate fully in the study, availability of records for review, and timing will all determine my final selection of cases (see Appendix B for screening questions).

A screening process with potential participants and families will ensure participants meet the thriving criteria. A brief interview of the individual with DS will ensure that the potential participant possesses high levels of SWB (see Appendix B). Sample questions will include asking participants to rate their satisfaction with life (Diener, Emmons, Larson, & Griffin, 1985) and general mood (Lyubomirsky & Lepper, 1999). Overall the participant must express both satisfaction with his or her life (option a or b on first screening question- see Appendix B) and a general positive mood (option a or b on second screening question- see Appendix B) to qualify with high SWB. Further, brief questions for both the participant and family will screen for continued developmental growth. This includes inquiry about whether or not current activities allow the potential participants to learn new skills, what specific skills have been learned in the past two years, and whether or not the new skills facilitate increased independence (Gomez, Arias, Verdugo, Tasse, & Brown, 2015; Schalock & Alonso, 2014). The individual and his or her family must indicate that the potential participant is continuing to grow and develop in ways that are meaningful to him or herself (affirmative response to third participant screening question and first family screening question- see Appendix B).

Recruitment. Recruitment for this study will be purposeful in order to provide

rich data regarding the phenomenon of thriving for individuals with DS (Stake, 2006). I will initiate recruitment through professional networking (convenience sampling) and then use snowball sampling to identify additional cases of interest through these connections (Creswell, 2013). I will reach out to families with whom I already have a relationship, as well as DS support organizations in the local area, and ask for recommendations of individuals with DS, ages 21 to 40, who are thriving.

I focus this study on the 21-40 age group for two reasons. First, young adults can provide a retrospective account of their educational experiences. My role as a school psychologist and my goal to contribute to the school psychology literature, calls me to investigate what experiences in school may facilitate or hinder the thriving of students with DS. This older age ensures that the participants can report on their lives as individuals who have completed their K-12 education, including transition programming. I am limiting the upper age range to 40 so that the participants and their families are not so far removed that they have no memory or written records from their time in the educational system.

The second reason for focusing on young adults is that I want to provide an account of what is possible for students when they complete their education. This will help to broaden the literature on possible outcomes for students with DS and inform educators and families about what it can mean to thrive with DS after completing school and entering adulthood. As educators create education plans and set goals for post-high school, they should understand the broad range of possibilities for individuals with DS in the community.

Data Collection

Data collection will be collaborative, and will elicit the thoughts, beliefs, experiences, and opinions of those who thrive with DS through interviews, observations, document reviews, and assessments. See Appendix C for a timeline of the data collection process for each case and Appendix D for a visual depiction of the ways each piece of the data collection process provides data for the research questions. In order to document the data collection process as whole, I will also keep a methodological journal in which I note my thinking and choices regarding methodological processes and decision-making throughout the study (e.g., reconciling barriers to data retrieval; Ortlipp, 2008).

Interviews. This study will involve at least four interviews for each case, beyond the screening interview: one with the participants (using photo-elicitation), two with parents (including one standardized interview and one open-ended case study interview), and an interview with one other significant adult in the participant's life (e.g., boss, friend, spouse, partner, teacher, community provider, social worker, minister, etc.). Case study interviews must inform the research questions in an approachable and nonthreatening manner (Yin, 2014). Therefore, questions for respondents will be open-ended and conversational in tone (Yin, 2014). I will engage in frequent reflective journaling, including directly before and after interviews, so that I maintain an awareness of my own subjectivities in the interviewing process and avoid influencing what participants choose to share (Ortlipp, 2008; Tracy, 2010). In particular, I will be careful to avoid using "assessments," in which I claim to have knowledge that I actually don't have access to (e.g., "I bet that made her feel really proud!") or "formulations," in which I selectively paraphrase, deleting key information and subsequently transform the

interviewee's meaning (Roulston, deMarrais, & Lewis, 2003).

Case study interviews. The primary interviews with parents will be open-ended, prolonged case study interviews (Yin, 2014). Here, I will speak with parents for extended periods of time, possibly over multiple sessions. Interviews with other adults in the participant's systems of support will be shorter case study interviews (Yin, 2014) that are more focused on topics related to their role in the participant's life. I will ask interviewees about their interpretations of what thriving means for the participant, and their thoughts on what facilitates thriving and what has acted as a barrier to thriving. Appendix E provides the open-ended interview protocol I plan to use with parents and other adults in the support system, including a table outlining how each interview question addresses the research questions and the literature to support each probe. Interviews with the participants will be open-ended and probe-based (Stake, 2006) to encourage friendly inquiry into a complex topic. Probe-based interviewing uses texts, videos, photos, or artifacts to evoke comments and meaning from participants and to elicit deeper discussion (Stake, 2006).

Five-Minute Speech Sample. In addition to the open-ended case study interviews, parents will also take part in brief standardized five-minute speech sample (FMSS) interviews to measure their EE (Expressed Emotion, or the emotional climate for the dyad). One goal of this study is to examine the systems of support for those who thrive with DS. A measurement of parent EE will provide useful data on the quality of relationships in the microsystems (Bronfenbrenner, 1979) of each participant. The FMSS (Magana-Amato, 2015) will be used to measure EE for this study. The FMSS consists of a brief structured interview, in which the parent responds to a prompt requesting a five-

minute uninterrupted monologue about the child and their relationship. The author (Magana-Amato, 2015) suggests starting any battery of interviews and assessments with the FMSS, therefore this interview will be the first in each case study. A systematic coding process is used to analyze a transcription of the interview for both content and tone. The coding system measures five areas of EE: initial statement, relationship, criticism (CRIT), dissatisfaction, and emotional over involvement (EOI).

I have been trained by the instrument author in the coding system and will personally transcribe and code each FMSS for the case studies. Additionally, another individual, also trained and experienced in coding FMSS, will code each sample in order to ensure inter-rater reliability and allow for consensus ratings for analysis. This data will provide information on the warmth of parent relationships for each participant in the study, as well as the parent's emotional involvement with the participant. My hope is that measuring the EE of parents of children with DS who thrive may indicate potential protective factors for families of children with DS.

Photo-elicitations. In this study, I will use the method of photo-elicitation as a probe for participant interviews (Guillemin & Drew, 2010). Photo elicitation is a method that involves participant-generated visual data to be utilized in the interview process (Guillemin & Drew, 2010; Povee, Bishop, & Roberts, 2014). Participants take photographs of the phenomenon of interest and an interview follows the photographs to elicit meaning from the participants. Photo-elicitation is both empowering and enabling (Guillemin & Drew, 2010). The method is empowering for participants in that it allows them a voice in the research process. Participants themselves can direct the attention of the researcher and initiate conversations about topics they believe are relevant during the

interview process. The method is enabling as it can allow the researcher “a different way in” to the phenomenon of interest (Guillemin & Drew, 2010, p.178). Visual methods may allow the researcher to gather data on a topic that is difficult to express with words, or with a population who struggles to communicate verbally.

Photo elicitation has historically been used in research about chronic illness with youth (Guillemin & Drew, 2010). This method has been described as a “communicative bridge” for speaking about a sensitive topic with a population of youth who may not have the vocabulary or cognitive maturity to adequately express their thoughts and feelings (Guillemin & Drew, 2010, p. 178). The participants in this study all have DS; a syndrome associated with deficits in abstract reasoning and expressive communication abilities (Fidler, 2005). Considering the DS phenotype, photo-elicitation may be particularly useful for extracting meaningful and data-rich interviews about the abstract topic of thriving. In fact, visual prompts are frequently used to elicit verbal communication for students with DS in educational settings (Kumin, 2001).

First, participants will be provided with iPhone 5s. The phones will not have a data plan or the ability to connect to the Internet; they will only have camera functionality. This has been used in prior studies with individuals with ID as a method to provide participants with cameras that fit in with their natural environment and are unlikely to draw any unusual attention (Grimmet, 2016). Participants will be given 1-2 weeks to photograph the people, places, and things that they believe help to “make their lives good.” The term “good life” has been used successfully in focus group research on well-being with adults with DS (Scott et al., 2014). The term is useful because it is easy to understand as well as open to interpretation by the individual being interviewed. In

particular, this phrase makes an abstract concept such as “thriving” more concrete and accessible to participants with limited communication and abstract reasoning skills. The 1-2 week timeframe allows enough time to capture key elements in their lives, without the interference of memory concerns that may happen with a longer time span. Participants will also be trained to use a photo notes app to quickly type a caption or note to help them recall why they took the photograph and explain the meaning behind the photo during the interview.

After each participant has completed taking photos, I will meet with them to discuss the pictures (see Appendix F for interview protocol). We will upload the photos to a laptop computer and scroll through each photo with accompanying notes to engage in a conversation about what contributes to their “good life.” This method was successfully used in a large-scale research study with adults with ID titled ‘This is Me’ (Povee, Bishop, & Roberts, 2014). In this project, the authors asked participants, “What made you take this photograph, and what is happening in this photograph?” to elicit meaning about visual data (Povee et al., 2014, p. 899). I will use these same two questions for interviewing participants, adding a third question: “How does [*item in picture*] help to make your life good?” Participants will have the choice of who to have present in their interviews. They will be offered the option of interviewing independently with myself, or bringing along any family members or peers of their choosing to help them communicate their thoughts and ideas. Notably, the interview portion of the photo-elicitation will take place after the observation and assessment portions. My intent is that this will help participants build rapport and feel more comfortable expressing their thoughts.

Direct Observations. I will also conduct observations of the participants’ daily

lives, including routines and unique special events. Observations will provide data necessary to better understand the individual characteristics that influence thriving for people with DS (research question #2) and how thriving individuals interact and participate within their systems of support (research question #3). Although observations will be guided by the research questions and the supporting literature (see Appendix G), I will also be open to noticing any recurring behaviors and patterns that may reflect underlying emergent themes about thriving with DS (Wolcott, 1995). Observations of each participant will take place over a 2-week period, allowing for natural fluctuations in mood and behavior, as well as any rapport building necessary for participant comfort.

My presence will undoubtedly affect the setting (Creswell, 2013); it will be impossible to blend in for a blind observation. Therefore, I will engage in “participant observation” in which I will join participants in three key life settings, including the home, a work/school/day program setting, and a community setting (e.g., places worship, community recreation center, homes of friends or family). Community settings will be chosen in partnership between the participant, the family, and myself that are data-rich, meaningful to the participant, and feasible for observation (e.g., accessible to a researcher, my presence will not disturb or harm anyone in the setting). I will participate alongside the participants, as appropriate, while also observing the environment (Wolcott, 1995; Yin, 2014). I will observe for a total of 2-4 hours per setting for a total of 6-12 hours of observation per case, over the course of 2 weeks. I will utilize field notes (See Appendix H) to capture what I see in these settings, including aesthetic details that may be useful in analysis and representation (Creswell, 2014; Stake, 1995; Yin, 2014). Descriptive “bursts,” or short vignettes in the field, will provide rich detailed data to use

in analysis and representation of what it looks and feels like to thrive with DS (research question #1; Wolcott, 1995, p. 98).

Admittedly, I am not an existing member of each community I am studying, and a two-week period of time does not truly allow me to be accepted into them. Thus, I will embed myself into the settings, helping out as needed and engaging as much as is appropriate. Further, recording data in the moment may distract the participants or remove me from full participation (Creswell, 2013). Therefore, at times I will need to write retroactive field notes and use memo writing (Creswell, 2013) or new narrative writing (Yin, 2014) to capture my thoughts on themes and ideas immediately after my time in observation data collection to supplement brief field notes that were taken in the moment of the observation.

Document Review. A review of available and important health and educational documents will also contribute to the data collection process by providing insights into the participants' medical and educational histories. In case study, reviewing existing documents and records allows the researcher access to historical information that may be critical to the topic of study, but impossible to observe at the current time (Stake, 1995). In the proposed study, educational and medical records provided by the family may shed light on academic growth over time, levels of inclusion in the educational history, medical procedures, behavioral history, personal strengths, and relative weaknesses. Documents and other artifacts may provide me with information about systems or organizations that I can probe further in interviews. Using my research questions, I can analyze these documents for codes and themes related to thriving with DS. In cases where documents are completely unavailable, I will probe further into educational and

medical histories during parent interviews.

Standardized Individual Assessments. Any examination of thriving must involve an examination of what the individual brings to the situation. This allows for a richer understanding of how the systems of support interact and support the individual's needs and how the individual uses his or her profile of strengths to contribute to relationships and the community at large (Buntinx, 2014; Gilman, Huebner, & Furlong, 2014; Lerner et al., 2013). In order to understand and communicate each individual's profiles of strengths and weaknesses, I will conduct psychoeducational assessments with each participant. I will include an assessment of cognitive abilities, adaptive functioning, mental health, communication skills, academic achievement, and strengths. This data will also allow for a comparison of scores with prior school and clinical assessment results to examine their growth trajectory at this point in early adulthood. Data from assessments completed within one year of this study will be used, as appropriate, with permission from the participant and his or her guardian (see Appendix I for Release of Information form)

Psychoeducational assessment data will include a current measure of IQ using the *Stanford-Binet 5* (SB5; Roid, 2003). The SB5 has strong psychometric properties and has been shown to be a useful and valid measure of IQ for individuals with DS (Hessl et al., 2016). Furthermore, the SB5 can be used with an alternate scoring method using a z-deviation score that reduces floor effects that are common when testing individuals with ID, and allows for a more accurate profile analysis of an individual's cognitive strengths and weaknesses when they score in the lower ranges of the test (Sansone et al., 2014). By using both z-deviation scores and traditional standard scores, I will be able to assess the

manner and extent to which cognition might influence each participant's thriving.

I will use the *Vineland Adaptive Behavior Scales, Third Edition* (Vineland-3; Sparrow, Saulnier, Cicchetti, & Doll, 2016) as a measure of each participant's levels of independence in the community. Vineland-3 data will be collected through a semi-structured interview with a parent or caregiver. Results will elucidate each participant's communication skills, daily living skills, socialization (including emotional coping skills), motor and maladaptive behaviors, as well as their overall adaptive functioning. A standardized measure of adaptive skills allows for an analysis of each participant's functioning in comparison to both the general public, as well as the subpopulation of individuals with DS, and a personal pattern of strengths and weaknesses.

Measures of mental health will indicate each participant's current levels of SWB. I will use the *Subjective Happiness Scale* (SHS; Lyubomirsky & Lepper, 1999; see Appendix J) as a global measure of happiness, and the *Satisfaction with Life Scale* (SWLS; Diener, Emmons, Larsen, & Griffen, 1985; see Appendix K) as an indicator of participant life satisfaction. Both measures are well-validated brief surveys for the measurement of SWB, and both have been used successfully in prior research with the population of adults with ID (Rey, Extremera, Duran, Ortiz-Tallo, 2013).

I will directly measure each participant's communication skills with the *Peabody Picture Vocabulary Test, Fourth Edition* (PPVT-4; Dunn & Dunn, 2007) and the *Expressive Vocabulary Test, Second Edition* (EVT-2) (Williams, 2007). Both have been used extensively with individuals with DS in both research and clinical settings (Finestack, Sterling, & Abbeduto, 2013; Loveall et al., 2016). These two measures combined will allow for a deeper understanding of the language abilities of each

participant and will inform analysis of how communication skills may impact thriving.

A brief measure of academic achievement will allow me to understand and describe each participant's basic academic skills and how they might influence each individual's ability thrive. I will use the *Woodcock-Johnson Tests of Achievement (Brief Achievement Cluster), Fourth Edition* (WJ-4; Schrank, McGrew, Mather, 2014) to measure basic reading, writing, and math skills for each participant. Academic achievement data will be useful for analysis of developmental growth trajectories as well as individual characteristics that may or may not allow the individual to participate and contribute to the systems of support.

Finally, I will conduct an analysis of each participant's individual strengths based on the principals of positive psychology (Peterson & Seligman, 2004). In order to measure strengths, I will administer the online *Values in Action (VIA) Inventory of Strengths for Youth* (VIA-Youth; Park & Peterson, 2006) using recommended accommodations and cognitive supports for enhancing validity with individuals with ID (Shogren, Wehmeyer, Forber-Pratt, & Palmer, 2015). This assessment will provide an overview of each participant's self-assessment of personal strengths of character and will inform an analysis of how the systems of support and individual strengths interact to impact thriving for each participant.

Data Analysis

There are a number of recommendations for best practices in case study data analysis (Creswell, 2013; Stake, 1995 & 2006; Yin, 2014). All involve an inductive and iterative process in which meaning is derived from raw data collected from each case. Detailed descriptions of the cases and the settings are critical for analysis. Stake (1995)

recommends looking for meaning in both individual instances of an event and an aggregation of occurrences. Further, he recommends looking for meaning via patterns that are identified through coding the data. Finally, he recommends the creation of naturalistic generalizations involving thick, rich descriptions that place the reader in the context of the case. Yin (2014) suggests “playing with the data” to aid in analysis, for instance creating charts, placing data in chronological order, and comparing and contrasting interview data between participants (p. 135).

For this study, I will transcribe audio recordings of interviews and field notes into a Microsoft Word document. Transcribing will allow me to become fully immersed in the data and conduct analysis throughout each stage of the project. Stake (1995) states, “There is no particular moment when data analysis begins. Analysis is a matter of giving meaning to first impressions as well as to final compilations” (p. 71). The act of transcription itself can be a useful mode of data analysis, and will allow me to listen carefully and critically to the interview data one more time. For ease of data analysis, I will intersperse photos from the photo elicitation process with the narrative interview data for each transcribed interview document. All data will be uploaded into a qualitative data analysis software program (ATLAS.ti) to assist in organization, storage, and analysis.

After data is transcribed and compiled with field notes from observations and document review and photographs, I will use open coding to identify basic categories related to the research questions (Creswell, 2013, p. 86). Next, I will look for patterns in the codes as well as categorical aggregations, or repeated instances of occurrences (Stake, 1995). From these patterns, I will first create broader categories and then several themes related to each case and also between cases. A table with open codes, categories, and

broad themes for all of the cases will provide transparency and allow the readers to reach their own conclusions about the research interpretations (Anfara, Brown, & Mangione, 2002). Finally, I will write several vignettes about each case to provide the reader with a detailed understanding of what it looks and feels like to thrive with DS.

Participants will be asked to review transcripts, field notes, and data analysis to assure that it was collected accurately, and that their beliefs and opinions are correctly expressed (Creswell, 2013). This member-checking will honor the experience and perspectives of a population of individuals who have been historically marginalized (Wehmeyer, 2013). This qualitative approach will give voice to those who are frequently absent from both the school psychology (Roach, Wixson, Talapatra, & LaSalle, 2009) and positive psychology (Dykens, 2006) literature bases. This form of qualitative research adheres to the quality of life (QOL) concept by using a mode of inquiry that promotes dignity, equality, inclusion, and empowerment for those with DS (Schalock & Alonso, 2014).

Author's Biography

Qualitative researchers are the “key instrument” in a qualitative study (Creswell, 2013, p. 45). In qualitative research, rather than striving to be an objective and unbiased, invisible researcher, the voice and perspectives of the researcher are openly disclosed. Sincerity is a noteworthy criterion for excellent qualitative research and entails “honesty and transparency about the researcher’s biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research” (Tracey, 2010, p. 841). Therefore, it is appropriate for me to provide an honest appraisal of my own subjectivities that affect the ways in which I design this study, interact with participants,

and interpret data. By positioning myself in this study, readers will be better able to interpret and evaluate my findings. I will examine reflexivity during data collection and analysis through personal journaling to document the ways in which I believe my subjectivities influenced my researcher role in the conclusion of this dissertation, as well as questions that arise and critical decision-making processes throughout the research process (Ortlipp, 2008; Tracy, 2010).

Professionally, I am a licensed school psychologist who has worked in public schools, charter schools, and private schools. Throughout my career, I have supported the mental health and well-being of many students, including those with ID. In my own practice, I worked from a positive psychology framework, building capacity by focusing on student strengths and healthy school communities. A major part of my work with students with ID, including those with DS, was to conduct psychoeducational assessments to support their learning. I have conducted, scored, and analyzed the data from countless IQ tests, parent rating forms, and student observations with the goal of identifying each student's strengths and needs to inform the placement and intervention decision-making process.

For the past two years, I have been working as a research assistant on a National Institutes of Health (NIH) funded grant research project (Hessl et al., 2016). Our goal is to validate a new cognitive assessment in the population of individuals with ID, including a sub-population of participants with DS. As part of the study, I have had the opportunity to meet over 40 individuals with DS and their families through two-day visits and one-month follow up visits to our university clinic. I have interviewed many of the parents of these individuals with DS, and have heard personal accounts of their lives. I have also

conducted many hours of cognitive assessments with these individuals and provided feedback sessions with test results to their families. The families who have participated in our research have openly shared some of the most poignant stories I have ever heard about living with a disability.

Some of the most intriguing stories have been from those individuals whom I began to consider were “thriving with DS.” Dozens of individuals entered our clinic and immediately brightened the days of our entire staff by sharing their joys with our team. These participants described meaningful lives, filled with healthy interpersonal relationships and personal growth. Some of these individuals were learning lines for theater productions or song lyrics for choir performances, others were in college programs earning certificates in athletic training or early childhood teaching, some were dating, others were leading church youth groups, some had successful jobs, and others were learning to drive. I was impressed by their life stories and surprised that I had not considered such positive outcomes before for students with DS when I was working in the schools. In particular, I was startled to notice that whenever I provided feedback sessions, there was an almost complete dismissal of these standardized results by parents of our participants. Many explained to me that these results meant little to them. They understood that quantitative assessment results almost always placed their children at or below the 1st percentile when compared with their chronological aged peers (Roizen, 2013). However, they were more concerned with understanding their child’s unique profile of strengths so they could help them navigate their school and the community. These interactions with individuals who were thriving with DS inspired me to more thoroughly investigate this phenomenon. I wanted to understand what thriving was like

for those individuals with DS and why they were able to thrive.

On a personal level, I am a white, heterosexual woman. I am married to a public-school art teacher who has been working in inclusive teaching settings for over 15 years. Our two children attend a local, inclusive public elementary school. While both of my children have unique learning needs in the classroom, neither receives specialized instruction at this time. I do not have any family members or close friends with significant disabilities. My interest and relationships with this population began entirely through my professional life. Through the year, working in this community, I have begun to form friendships with the parents of children with a variety of disabilities.

It is important, however, that I make clear my own personal distance from DS. I enter this community as an outsider with a professional interest and warmth. However, I have never personally experienced the struggles or joys related to DS. When I hear parents describe their infants' open-heart surgeries, watching their child finally learn to walk, the social stigma of not getting invited to birthday parties, or teachers saying they are scared to have their child in their class, I can only muster empathy and compassion. While I cannot ever truly know the experience of these families as an insider, I hope to use my status as an outsider to notice patterns and processes that might be overlooked by those living within the system. Perhaps my distance will allow me to reveal some nuances and assets that would be taken for granted by those living the phenomenon.

Assumptions

While assumptions are present in any research, a key assumption is present in this study. Criteria for determining a status of thriving will be based on the definition of thriving from the TET-M: high levels of SWB coupled with a state of continued

developmental growth (Manuscript 1, Figure 1). Purposeful recruitment and individual screening will be used to ensure participants demonstrate the phenomenon in question (Creswell, 2013; Stake, 2006). However, the screening process is inherently subjective, and does not involve a pre-determined standardized assessment or checklist.

Determining the presence of DS is a simple and concrete process, easily proven with results from karyotype testing or by simply noting the presence of the physical features most commonly associated with the phenotype (Roizen, 2013). However, thriving is a more subjective term that can be more difficult to measure than the presence of DS. Few studies have used standardized measures of thriving with the population of individuals with DS, and no validation studies to this date have proven the utility of such measures in this population (Weiss & Riosa, 2015). Furthermore, the act of determining whether or not someone is thriving is fraught with power dynamics. Having strict, quantitative cut-off scores for meeting the criteria of thriving may interfere with an authentic initial investigation of the phenomenon. This might narrow the scope of inquiry, thereby ignoring critical information about the processes involved with thriving (Massey, Cameron, Oulette, & Fine, 1998). Therefore, while participants will be recruited for this study via referrals based on a clear set of indicators of thriving (SWB and developmental growth trajectory), the final determination of thriving status will come from each participant and his or her family and is highly subjective in nature.

Limitations

There are some recognized limitations to this study. First, there are a limited number of cases in this analysis. This small sample size allows for an in-depth and rich description and analysis; however, it precludes the reader from generalizing data to all

others with DS. The cases will also be limited to a single geographic location – one state in the mountain west region of the United States. While there may be some diversity in terms of gender, socioeconomic status, race, and/or ethnicity, all six cases will be from the same geographical region. Thriving is contextual and dependent on systems of care (Prilleltensky, 2012). Therefore, an investigation limited to a single region will not be able to compare and contrast the impact of certain systems on thriving for individuals with DS. Future research can extend this study by broadening the number of individuals studied and the areas in which they reside.

Furthermore, the subjectivity mentioned in the assumptions section above can also be considered a potential limitation to the study. Much of the data gathered will come directly from the participants and the families (e.g., rating forms, interviews). This is intentional to bring the voices of those who thrive with DS directly into the scholarly discussion concerning their well-being (Roach et al., 2009). However, a history of persistent marginalization for individuals with ID (Dykens, 2006; Wehmeyer, 2013), as well as statistics regarding termination rates after a prenatal diagnosis of DS (Natoli et al., 2011) may (intentionally or subconsciously) cause participants and their families to want to skim over challenges and highlight successes. After all, the DS advocacy community has put forth a concerted effort to change public perceptions of the disability and highlight progress (Global Down Syndrome Foundation, n.d.; GDS & National Down Syndrome Congress, 2017). Further, self-reporting in research can result in social desirability bias, in which participants prefer to present themselves in a positive light regardless of the accuracy of their responses (Paulhus, 2002).

A number of methods will be employed to triangulate data and represent each

case as truthfully and comprehensively as possible, including direct observation and document review for a more objective perspective. Further, my status as an outsider allows me insight without the personal subjectivities that can present for those living with DS. However, a key element of qualitative research is to understand a phenomenon from the perspective of those most impacted, including the subjective, multiple truths that can emerge from this type of inquiry (Creswell, 2013). Therefore, all self-reporting in this study will be examined from multiple perspectives, using triangulation to expand, elucidate, and clarify the data. Ultimately the subjective self-reporting on thriving with DS will be documented, analyzed, and represented in this study in order to share a perspective that has historically been sidelined in the DS literature and merits the attention of researchers and practitioners.

Next Steps

Table 1 delineates the timeline for my proposed research. Dates will be dependent on passing my proposal and receiving IRB approval. Appendix L provides a logic model depicting the resources, processes, and expected outcomes for this study.

Table 1

Timeline of Dissertation

Month	Activity
Early November, 2017	Propose to committee
Late November	Submit proposal to IRB upon approval, recruit participants
December	Consent, photo elicitation training, collect records for review
January – March, 2018	Data collection, within case analysis
April	Cross-case analysis, writing
Late April	Submit first draft to Dr. Talapatra
May	Revise and edit
June	Submit final draft to committee
Late June	Oral defense
July	Edits
August, 2018	Graduate

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APPENDIXES

APPENDIX A- PARENT CONSENT FORM

University of Denver Consent Form for Participation in Research

Title of Research Study: Thriving with Down Syndrome: A Multiple Case Study

Researcher(s): Talia Thompson, EdS, Dr. Talapatra, University of Denver

Study Site: University of Denver

Purpose

You are being asked to participate in a research study. The purpose of this research is to understand what it means to thrive with Down syndrome, and the individual and environmental factors that facilitate thriving for people with Down syndrome. The end goal of this study is to inform service providers and families about the possibilities for living with Down syndrome, and inform the development of effective programming and policy.

Procedures

If you participate in this research study, you will be invited to:

- Provide educational and medical records for the researchers to review.
- Participate in 1-2 hours of interviewing about your child and your relationship. The interview will be audio recorded for transcription purposes.

Your child will be asked to:

- Take photos of things that “make his or her life good” and then share those photos in an interview with the researchers. The interview will be audio recorded for transcription purposes.
- The researchers will also observe your child for 6-12 hours during daily life activities in three different settings (home, school, work, community, church, etc.). You and your child will decide with the researcher where observations will take place.
- Finally, your child will also take part in approximately 4-6 hours of cognitive and educational testing, split up over 1-2 test sessions. Testing can take place in your home, a quiet setting of your child's choice, or the clinic at the University of Denver.

The researcher will also interview one other important adult (chosen by you and your child) about your child's life, and what facilitates his or her thriving. In all, your family will have contact with the researchers for a two-week period of time. You and your child may also be asked if you would like to review the findings from the study so you can give input about accuracy and any missing data.

Voluntary Participation

Participating in this research study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer interview questions, provide access to records, or allow observations for any reason without penalty or other benefits to which you are entitled.

Risks or Discomforts

Potential risks and/or discomforts of participation may include following: fatigue from participating in interviews or emotional discomfort when observed or confronted with questions that may probe personal information and breaches of confidentiality.

Benefits

Possible benefits of participation include: improving our understanding of what it means to thrive with Down syndrome, what helps to facilitate thriving, and how we might support others with Down syndrome so they can also thrive.

Incentives to participate

Your child will receive a \$25 gift card to a store of choice for participating in this research project.

Confidentiality

The researcher will take measures to keep your and your child's information safe throughout this study. These measures will include password protection of electronic data and keeping hard copies of personal information in a locked file cabinet behind a locked door. All research records will be destroyed five years after the study has ended. Your individual identity will be kept private when information is presented or published about this study.

However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. The research information may be shared with federal agencies or local committees who are responsible for protecting research participants.

Questions

If you have any questions about this project or your participation, please feel free to ask questions now or contact **Talia Thompson at 303-746-2226** or **talia.thompson@du.edu** at any time. You can also contact the faculty sponsor for this study, **Dr. Devadrita Talapatra at (303) 871-3352** or **devadrita.talapatra@du.edu**.

If you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by **emailing IRBAdmin@du.edu** or **calling (303) 871-2121** to speak to someone other than the researchers.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

Participant Signature

Date

Print Name

Please take all the time you need to read through this document and decide whether you would like your child to participate in this research study. Your child will also be asked to sign an assent form to participate in this study.

If you agree for your child to participate in this research study, please sign below. You will be given a copy of this form for your records.

Participant Signature

Date

Print Name

PARTICIPANT CONSENT/ASSENT FORM

University of Denver Consent/Assent Form for Participation in Research

Title of Research Study: Thriving with Down Syndrome: A Case Study

Researcher(s): Talia Thompson, EdS, Advisor: Dr. Talapatra, PhD, University of Denver

Study Site: _____

What is a research study?

A research study is a way to find out new information about something. We would like to learn more about how some people with Down syndrome thrive, or live good lives, and what helps them to thrive and live a good life.

Why are you being asked to be part of this research study?

You are being asked to join the research study because you have Down syndrome and you have told us that you are living a good life; you are thriving.

If you join the research study, what will you be asked to do?

If you agree to join this study, you will be asked to take a variety of tests, be observed in your daily life, participate in an interview, and take photos of things that make your life good. Also, your parent and another important adult in your life will take part in interviews.

- Take pictures of things that make your life good.
- Show your pictures to the researchers and tell us why you took these pictures and what makes your life good. You can choose to have another adult with you for any, or all, of the interview.
- Be observed in your daily life for about 12 hours, over the course of 2 weeks as you go about your normal everyday life. This will be at work, school, home, or in the community. We will choose where the observations will take place together with you and your parent/s. You can choose if you do or do not us to observe in a setting.
- Your parents and one other important adult in your life will speak with us about you and your life in an interview.
- Finally, you will complete some psychological and educational tests as part of this study. We can complete the tests in your home, another quiet setting of your choice, or in a clinic room at the University of Denver. You can also choose to have another adult with you for any, or all, of the

testing. The testing will take about four to six hours altogether. It can be broken up into two or more sessions if needed.

- You will be in the study for a total of two weeks.
- We will want to audio record you during the study as you answer questions in the interview.

Do you have to be in the study?

You do not have to be in this study. It is up to you. You can say okay now to be in the study and change your mind later. All you have to do is tell us when you want to stop. No one will be upset if you don't want to be in the study or if you change your mind later. You can take time to think about being in the study before you decide.

Will any part of the study hurt or be uncomfortable?

We do not think that you will be hurt or upset during the study.

We think that taking the tests will take up some of your time, and may be hard or make you tired.

Will the study help you or others?

We may learn something in this study that will help other people with Down syndrome some day. Maybe we will learn about what helps you to thrive, and how we can support others so they can thrive too.

Do your parents or legal guardian know about the study?

This study is also being explained to your parent or legal guardian. You can talk this over with your parent or legal guardian before deciding to participate if you want. You do not have to be in this study even if your parent or legal guardian thinks it is a good idea. It is up to you.

Will anyone else know that you are in this study?

We will not tell anyone else that you are in this study. You do not have to tell anyone about the study or your answers to the interview questions.

Who will see the information collected about you?

The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research.

The study information about you will not be given to your parents/guardians, teachers, friends, doctors, or boss. The researchers will not tell your friends about the study or your answers to the questions.

Your individual identity will be kept private when we write our final report.

What do you get for being in the study?

You will receive a \$25 gift card to a store of your choice for participating in the research study.

What if you have questions?

You can ask any questions that you have about the study at any time. Just tell the researcher or your parent/guardian that you have a question. You or your parent/guardian can contact the researchers anytime during the study by calling, **Talia Thompson at 303-746-2226 or emailing talia.thompson@du.edu** or by contacting her faculty advisor **Dr. Tanya Talapatra at 303-871-3352 or devadrita.talapatra@du.edu**.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

Participant Signature

Date

Print Name

- ☐ Participant is a consenting adult
- ☐ Participant is unable to consent and provided assent
- ☐ Participant did not consent/assent

Please take all the time you need to read through this document and decide whether you would like your child to participate in this research study.

If you agree for your child to participate in this research study and you agree that your child willingly consented/ assented to participate in this study, please sign below. You will be given a copy of this form for your records.

Parent/Guardian Signature

Date

Print Name

CONSENT FORM FOR ADULT IN SUPPORT SYSTEMS INTERVIEW

University of Denver Consent Form for Participation in Research

Title of Research Study: Thriving with Down Syndrome: A Multiple Case Study

Researcher(s): Talia Thompson, EdS, Dr. Talapatra, University of Denver

Study Site: _____

Purpose

You are being asked to participate in a research study. The purpose of this research is to understand what it means to thrive with Down syndrome, and the individual and environmental factors that facilitate thriving for people with Down syndrome. The end goal of this study is to inform service providers and families about the possibilities for living with Down syndrome, and inform the development of effective programming and policy.

Procedures

If you participate in this research study, you will be invited to:

- Participate in 1 hour of interviewing about _____ and what you see as the barriers and facilitators to his/her thriving. The interview will be audio recorded for transcription purposes.

Voluntary Participation

Participating in this research study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer any questions during the interview.

Risks or Discomforts

Potential risks and/or discomforts of participation may include following: fatigue from participating in interviews or emotional discomfort when confronted with questions that may probe personal information.

Benefits

Possible benefits of participation include improving our understanding of what it means to thrive with Down syndrome, what helps to facilitate thriving, what are the barriers to thriving, and how we might support others with Down syndrome so they can also thrive.

Confidentiality

The researcher will take measures to keep your information safe throughout this study. These measures will include password protection of electronic data and keeping hard copies of personal information in a locked file cabinet behind a locked door. All research records will be destroyed five years after the study has ended. Your individual identity will be kept private when information is presented or published about this study.

However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. The research information may be shared with federal agencies or local committees who are responsible for protecting research participants.

Questions

If you have any questions about this project or your participation, please feel free to ask questions now or contact **Talia Thompson at 303-746-2226** or **talia.thompson@du.edu** at any time. You

can also contact the faculty sponsor for this study, **Dr. Devadrita Talapatra** at **(303) 871-3352** or **devadrita.talapatra@du.edu**.

If you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by **emailing IRBAdmin@du.edu** or **calling (303) 871-2121** to speak to someone other than the researchers.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

Participant Signature

Date

Print Name

APPENDIX B

SCREENING INTERVIEW QUESTIONS

Participant Questions:

1. Can you tell me how often you feel satisfied or happy with your life?
 - a. All the time
 - b. Most of the time
 - c. Sometimes
 - d. Never
2. Some people generally feel happy most of the time. How true do you think that is for you lately?
 - a. Very true
 - b. Kind of true
 - c. Not true
3. Do you do things in your life that help you to learn new skills?
4. What are some of the new things you've learned to do recently?

Family questions:

1. Does _____ participate in activities where s/he has the opportunity to learn new skills?
2. What are some of the new skills that _____ has learned in the past two years?
3. How have those skills helped him/her to build independence?
4. What is _____ general mood on a daily basis?
5. Does _____ ever express to you his/her feelings about how satisfied s/he is with his/her life?
6. What records do you have available from _____'s education and medical history?
7. What is the feasibility of me observing _____ in his/her daily life?

Screening Question	Inclusion Criteria	Support from Literature
Participant questions 1-2 Family member questions 4-5	High levels of SWB	SWB is defined as self-identified life satisfaction coupled with positive mood (Diener et al., 1985; Diener et al., 2016)
Participant questions 3-4 Family member questions 1-3	Upward developmental growth trajectory	Personal development is measured by growth in skills that are meaningful to an individual with ID (Gomez, Arias, Verdugo, Tasse, & Brown, 2015; Schalock & Alonso, 2014)

APPENDIX C

DATA COLLECTION PROCESS

Activity	Week 1							Week 2							Week 3						
Consent																					
Document Review																					
Five Minute Speech Sample																					
Open-ended parent interview																					
Adult interview (Other)																					
Photo-elicitation interview																					
Participant observation																					
Standardized assessments																					
Transcription, within-case unit analysis																					

APPENDIX D

DATA COLLECTION PROCESS AND RESEARCH QUESTION ALIGNMENT

Research question	Interviews	Observation	Document Review	Assessment
1. How do individuals with DS and their families define thriving with DS?	X			
2. What are the individual characteristics that influence thriving for individuals with DS?				
a. What are the individual psychosocial profiles of those who thrive with DS?	X			X
b. How do individuals with DS who thrive experience SWB?	X	X	X	X
c. In what ways do thriving individuals with DS demonstrate developmental growth?	X	X	X	

Research question	Interviews	Observation	Document Review	Assessment
3. What are the environmental factors that influence thriving for individuals with DS?				
a. What are the major systems of support for individuals who thrive with DS and how do they participate in these systems?	X	X	X	
b. What facilitates thriving for individuals with DS?	X	X	X	
c. What are some of the barriers to thriving for individuals with DS?	X	X	X	

APPENDIX E

INTERVIEW PROTOCOL FOR PARENTS AND SUPPORTIVE ADULTS

1. How would you describe ____?*
2. What are some of his/her strengths?*
3. What is particularly challenging for him/her?*
4. Please tell me a little about your relationship with ____.*
5. Who are some other important people in his/her life?
6. How do you get along/partner/collaborate/work together with these people?
7. What are some important places or organizations for ____?
8. How does ____ interact with those settings? How do you interact with those settings?
9. How can you tell when ____ is happy or satisfied with life?
10. What do you think contributes most to ____'s life satisfaction?*
11. When is ____ most engaged in his or her life? Does he or she ever lose track of time or get lost in enjoyable tasks?
12. What is most meaningful for ____?
13. In what ways does ____ contribute to his/her community?
14. What are some barriers to ____'s happiness?*
15. In what ways do you think ____ is growing and developing at this stage of life?
16. What are some of ____'s best accomplishments/achievements?
17. What do you think facilitates his/her development and personal growth?*
18. What are some barriers to ____'s development and personal growth?*
19. Your family reports that ____ is currently thriving. Were there some times in his/her life when he/she was not thriving? What was different then?
20. Are there any large systems, political/social/cultural, that you think influence ____'s life for better or for worse?
21. What does it mean for a person with DS to thrive?*

* Indicates questions that will be asked for interviews with the additional adults in the participants' systems of support. Parents will be asked all of the interview questions.

Interview Question	Research Question	Support from literature
1. How would you describe ____?	2	General open-ended question in conversational tone to engage the interviewee (Yin, 2014)
2. What are some of his/strengths?	2.a	Consideration of strengths as valuable individual characteristics (Peterson & Seligman, 2004; Wehmeyer et al., 2010)
3. What is particularly challenging for him/her?	2.a	Critical to consider the individual characteristics that contribute to

		thriving (Gilman et al., 2014) and general human functioning with disabilities (Wehmeyer et al., 2010)
4. Please tell me a little about your relationship with ____.	3.a	Influence of microsystem (Bronfenbrenner, 1979; Lerner et al., 2013; Scott et al., 2014; Seligman, 2011; Wehmeyer et al., 2010).
5. Who are some other important people in his/her life?	3.a	Influence of microsystem (Bronfenbrenner, 1979; Lerner et al., 2013; Scott et al., 2014; Seligman, 2011; Wehmeyer et al., 2010).
6. How do you get along/partner/collaborate/work together with these people?	3.a	Influence of mesosystem (Bronfenbrenner, 1979)
7. What are some important places or organizations for ____?	3.a	Influence of exosystems (Bronfenbrenner, 1979; Lerner et al., 2013; Wehmeyer et al., 2010)
8. How does ____ interact with those settings? How do you interact with those settings?	3.a	Importance of meaningful social inclusion and supportive systems (Bronfenbrenner, 1979; Lerner et al., 2013; Wehmeyer et al., 2010)
9. How can you tell when ____ is happy or satisfied with life?	1 & 2.b	SWB is a critical component of thriving (Prillleltensky, 2011; Schalock & Alonso, 2014; Seligman, 2011)
10. What do you think contributes most to ____'s life satisfaction?	2.b & 3.b	SWB is influenced by multiple factors, including inherited temperament, but also life circumstances (Diener, 2016)
11. When is ____ most engaged in his or her life? Does he or she ever lose track of time or get lost in enjoyable tasks?	2.b	Engagement and flow have been associated with SWB in the general population (Seligman, 2011)
12. What is most meaningful for ____?	2.b	Contribution and meaningful social inclusion are associated with SWB/QOL (Hazel, 2016; Lerner et

		al., 2013 Schalock & Alonso, 2014; Seligman, 2011)
13. In what ways does _____ contribute to his/her community?	2.b & 3.b	Contribution and meaningful social inclusion are associated with SWB/QOL (Hazel, 2016; Lerner et al., 2013 Schalock & Alonso, 2014; Seligman, 2011)
14. What are some barriers to _____'s happiness?	2.b & 3.c	Literature on facilitators and barriers to SWB for individuals with DS is limited but may include relationships, independence, hopeful disposition, and inclusion (Scott et al., 2014)
15. In what ways do you think _____ is growing and developing at this stage of life?	2.b	Personal growth is associated with QOL for those with ID (Schalock & Alonso, 2014), learning and developmental progress are associated with thriving (Benson & Scales, 2009; Lerner et al., 2013)
16. What are some of _____'s best accomplishments/achievements?	2.c	Personal growth is associated with QOL for those with ID (Schalock & Alonso, 2014), learning and developmental progress are associated with thriving (Benson & Scales, 2009; Lerner et al., 2013)
17. What do you think facilitates or has facilitated in the past his/her development and personal growth?	2.c & 3.b	Research indicates early intervention (Yoder et al., 2014), inclusive education (Turner et al., 2008), and supportive community settings (Wehmeyer et al., 2010) support the developmental growth of people with DS.
18. What are some barriers to _____'s development and personal growth?	2.c & 3.c	Support systems inability to meet the unique personal needs of an individual can impact development and growth (Wehmeyer et al., 2010)
19. Your family reports that _____ is currently thriving. Were there some times in his/her life when	1, 3.c	Barriers to thriving with DS may include unique individual characteristics or comorbid

	he/she was not thriving? What was different then?		conditions as well as contextual factors (Weiss & Riosa, 2015)
20.	Are there any large systems, political/social/cultural, that you think influence ____'s life for better or for worse?	3.a	Influence of macrosystems and social justice on thriving (Bronfenbrenner, 1979; Prilleltensky, 2012)
21.	What does it mean for a person with DS to thrive?	1	It is critical to document the lived experiences of those thriving with DS and their families in order to document the strengths of the DS community and broaden the phenotype of the disorder (Creswell, 2013; Dykens, 2006; Mertens, 2009)

APPENDIX F

PARTICIPANT PHOTO ELICITATION INTERVIEW PROTOCOL

1. What is happening in this photograph?
2. What made you take this photograph?
3. How does [*item in picture*] help to make your life good?

APPENDIX G

OBSERVATION PROTOCOL

Setting (choose 3) and focus areas for observation	Research Question	Support from literature
<input type="checkbox"/> Home <input type="checkbox"/> School <input type="checkbox"/> Work <input type="checkbox"/> Religious setting <input type="checkbox"/> Community agency <input type="checkbox"/> Transitions between settings <input type="checkbox"/> Other	2.b&c, 3.a-c	Bioecological systems theory and the social ecological model for human functioning emphasizes the key role of an individual's systems of support (Bronfenbrenner, 1979; Buntinx, 2014; Wehmeyer et al., 2010)
Social inclusion/ participation	3.a-c	Meaningful social inclusion is a key aspect of QOL concept (Schalock & Alonso, 2014)
Access	3.b&c	Issues of statutory rights and access to supportive systems impacts development and QOL (Bronfenbrenner, 1979; Schalock & Alonso, 2014)
Relationships	2.b, 3.a	Relationships have been determined as key elements of SWB, QOL, and thriving (Lerner et al., 2010; Schalock & Alonso, 2014; Seligman, 2011)
Self-determination/ Choice-making	2.c, 3.b&c	Autonomy and choice-making are key aspects of QOL concept (Schalock & Alonso, 2014)
Emergent themes	1-3	Qualitative research is exploratory and allows for themes to emerge from the data to better understand a phenomenon (Creswell, 2013; Wolcott, 1995)

APPENDIX H

OBSERVATION FIELD NOTE PROTOCOL

Date		
Time		
Activity/setting		
Participants		
Research Question		
<u>Descriptive Notes</u>	<u>Reflective Notes</u>	
Physical Layout (draw plan)	Reflective comments: researcher questions to self, observations of nonverbal behavior, Interpretations, etc.]	
Description of participants Description of activities Description of individuals engaged in activity Sequence of activity over time Interactions Unplanned events Participants' comments (i.e., quotes)	Reflective comments: questions to self, observations of nonverbal behavior, my interpretations]	
The researcher's observation of what seems to be occurring]		

APPENDIX I - RELEASE OF INFORMATION



UNIVERSITY of
DENVER

MORGRIDGE COLLEGE OF EDUCATION

Authorization to Release/Request Information

University of Denver – Morgridge College of Education

I, _____, born _____,
hereby authorize the Educational Services Clinic of the University of Denver to:

☐ Release the following information to:
from:

☐ Request the following information

Talia Thompson and Dr. Devadrita Talapatra

University of Denver

Person/Agency

Person/Agency

1999 E. Evans Ave.

Address

Address

Denver, CO 80208

City/State/Zip

City/State/Zip

(303) 871-2379

Phone

Phone

Information to be released: Educational history, records, assessment data (please circle) for:

Participant's Name (please print)

Date

Purpose of release/request: Research

I understand that I may revoke this authorization at any time by giving written notice to the University of Denver, Morgridge College of Education. Without such a revocation, this authorization shall expire on ____/____/____ (If not date is specified, this authorization shall expire one year from the date of the signature.) I also herewith release the University of Denver, Morgridge College of Education from all liability for releasing such information.

Signature of participant or Legal Guardian

Date

Witness

NOTICE: The information disclosed by this authorization comes from records whose confidentiality is protected by federal law. Federal regulations prohibit you from making further disclosures of this information without the specific written consent of the person to whom it pertains.

APPENDIX J

SUBJECTIVE HAPPINESS SCALE (SHS; Lyubomirsky, & Lepper, 1999)

For each of the following statements and/or questions, please circle the point on the scale that you feel is most appropriate in describing you.

1. In general, I consider myself:

1	2	3	4	5	6	7
not a very happy person						a very happy person

2. Compared with most of my peers, I consider myself:

1	2	3	4	5	6	7
less happy						more happy

3. Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at all						a great deal

4. Some people are generally not very happy. Although they are not depressed, they never seem as happy as they might be. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at all						a great deal

APPENDIX K

THE SATISFACTION WITH LIFE SCALE (Diener et al., 1985)

The Satisfaction with Life Scale

By Ed Diener, Ph.D.

DIRECTIONS: Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Slightly Disagree
- 4 = Neither Agree or Disagree
- 5 = Slightly Agree
- 6 = Agree
- 7 = Strongly Agree

- _____ 1. In most ways my life is close to my ideal.
- _____ 2. The conditions of my life are excellent.
- _____ 3. I am satisfied with life.
- _____ 4. So far I have gotten the important things I want in life.
- _____ 5. If I could live my life over, I would change almost nothing.

APPENDIX L

LOGIC MODEL

