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# The self-management for autism rating tool (SMART): a transition-readiness questionnaire for individuals with autism

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BOSTON UNIVERSITY  
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**THE SELF-MANAGEMENT FOR AUTISM RATING TOOL (SMART):  
A TRANSITION-READINESS QUESTIONNAIRE FOR  
INDIVIDUALS WITH AUTISM**

by

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Occupational Therapy

**ABSTRACT**

Youth with autism spectrum disorder (ASD) often have poor outcomes while transitioning to adulthood, such as experiencing low rates of employment, post-secondary education, independent living, and life-long friendships after high school graduation. Factors which may be contributing to these poor transition outcomes include the lack of understanding of their limitation and needs, and the lack of assessments designed specifically for the ASD population which address their abilities to manage the complex, multi-step life tasks of adult living. The Self-Management for Autism Rating Tool (SMART) is a clinical assessment designed for individuals with ASD, aged 16 to 35, to evaluate the self-management skills required to function successfully in adulthood. The tool was influenced by guiding theories, evidence, and assessments such as the Transition-Q and PEDI-CAT, and will be developed across three phases before clinical use. The SMART provides an increased understanding of the capabilities and needs of adolescents with ASD which can guide intervention efforts and better connect individuals with appropriate programs and supports. Addressing the self-management needs of young adults with ASD could lead to improved transition outcomes for this population, allowing

them to reach their potential to live independent and productive lives.

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## **CHAPTER ONE: INTRODUCTION**

### **Nature and Importance of the Problem**

Transitioning out of the secondary school system and into adulthood is often a decisive and critical change for any adolescent. During this time of transition, the adolescent identifies their personal goals following secondary education with respect to higher education, vocational training, employment, and/or independent living (Giarelli, Ruttenberg & Segal, 2013). For youth with autism spectrum disorder (ASD), learning to successfully manage the tasks of adulthood is often more challenging. (Gotham et al., 2015, Henninger and Taylor, 2013). Recent reviews of outcomes have indicated that individuals with ASD experience low rates of employment, post-secondary education, independent living, and life-long friendships after high school graduation (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011). Employment rates for young adults with ASD, regardless of intellectual or cognitive ability, reportedly range between 4.1% and 11.8% (Taylor & Seltzer, 2011). Even individuals with ASD who have completed postsecondary education have reported significant challenges with underemployment and chronic unemployment (Henninger & Taylor, 2012). Those with competitive employment are often working menial jobs, such as replacing dirty glasses at a hotel, and not working full-time. A majority are unable to support themselves financially. They continue to be dependent on their families to provide basic needs, financial support, housing, daytime supervision, and companionship (Taylor & Seltzer, 2011).

In addition, young adults with ASD have the poorest transition outcomes

compared to those from other disability categories. Across the spectrum, individuals with ASD have lower rates of independent living and participation in daytime activities compared to their peers with intellectual disabilities, developmental disabilities, and emotional disturbances (Newman et al., 2011; Taylor & Seltzer, 2011). Their functional challenges are not severe enough for them to qualify for adult day services, but severe enough for them to have difficulty functioning independently. Those without daytime activities also have an extremely high chance of developing comorbid psychiatric disorders, which may be a result of worsening symptoms due to less stimulating environments (Shattuck et al., 2012). These poor transition outcomes can result in decreased quality of life, increased risk for comorbid psychiatric disorders, increased dependence on social welfare, and increased caregiver burden for their families. Given the consistently rising prevalence of ASD in the U.S. (Centers for Disease Control and Prevention, 2019), there are large numbers of individuals with ASD entering the adult world, creating an urgent need for additional support during transition. Individuals with ASD are not reaching their potential to live independent and productive lives.

### **Contributors to the Problem**

One reason why individuals with ASD have poor outcomes may be because there is a lack of understanding of their limitations and needs, resulting in inadequate support during their transition out of secondary education. Students who are served in the general education classroom, in particular, receive fewer services to help them transition to the postsecondary environment (Taylor & Seltzer, 2011). Adolescents with ASD may also

benefit less from transition planning compared to students from other disability groups. Individuals with ASD struggle with self-initiation and goal-setting, which make them less likely than their peers with other types of disabilities to take leadership of their own transition planning (Shogren & Plotner, 2012). Because self-advocacy is challenging for these youth, their struggles are not made known. Their functional limitations are often overlooked because they typically perform well academically in secondary education settings (Wehman et al., 2014). This lack of understanding may lead to less efforts to coordinate post-secondary interventions and supports for adolescents with ASD. They are particularly vulnerable as they experience a shift in service provision after leaving high school. They are highly susceptible to service disengagement and instead are “falling through the cracks” during their transition to adulthood (Shattuck et al., 2011; Taylor & Seltzer, 2011).

The transition planning process is typically a joint effort of the education system, the family, and other involved services. One common need of all who are involved in transition planning and implementation is for assessments that identify the strengths and limitations of adolescents with ASD and help direct intervention efforts. A variety of standardized assessments of function, commonly known as “adaptive behavior” assessments, are available, which provide an overall indication of the young person’s progress in acquiring the skills needed for independent living (Sparrow, Cicchetti, & Balla, 2005). In general, however, these assessments are not designed to identify specific targets for intervention or training and may not cover all areas relevant to assuming adult roles. Often the items in the assessments address discrete skills, such as reading a menu

or cleaning up after one's self (Anderson-Loeb, 1996; Brigance, 1994; Bruininks, Hill, Weatherman, & Woodcock, 1986; Bruininks, Woodcock, Weatherman, & Hill, 1996; Lambert, Nihira, & Leland, 1993; Sparrow et al., 2005), and do not evaluate the ability to meet the more complex social and cognitive demands of adult roles. This represents a serious short-coming for transition planning for youth with ASD as it is often these demands that are most challenging for them. Individuals with ASD have difficulty with self-management skills, such as planning, managing time and emotions, responding to new demands, identifying and setting own goals, and adapting to changing contexts (Duncan & Bishop, 2015; Hedges et al., 2014; Pellicano, 2012; Rosenthal et al., 2013). There is a need for development of assessments, specifically for the ASD population, that evaluate these self-management skills required for adult living.

### **Approach to Address the Problem**

As one step to address this larger problem, this project will focus on developing an assessment tool for adolescents with ASD to evaluate the skills they need to manage the daily tasks of adulthood. An improved evaluation and understanding of their capabilities can guide intervention efforts and better connect individuals with appropriate programs, services, and resources. Addressing the self-management needs of young adults with ASD could lead to improved transition outcomes for this population.

The self-management tasks will be selected from the set of items included in the PEDI-CAT Responsibility domain, which were written specifically to measure the extent to which the youth takes responsibility for managing complex, multi-step life tasks



(Dumas et al., 2010). The assessment will also draw on the Transition-Q instrument as a model of a youth self-report tool that can be used to identify problem areas and set goals (Klassen et al., 2014). If a successful template can be developed, future work could include developing similar scales for other tasks.

## **CHAPTER TWO: THEORETICAL AND EVIDENCE BASE**

### **Theoretical and Conceptual Frameworks**

Theoretical and conceptual frameworks guide the proposed assessment for the identified problem described in Chapter One. Two appropriate and meaningful frameworks that address the needs of adolescents with autism spectrum disorder (ASD) transitioning to adulthood were determined through a thorough review of the literature. These models are the Life Course Theory (Elder & Shanahan, 2007) and the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001).

#### *Life Course Theory*

Life Course Theory examines an individual's life history and investigates how early events influenced future decisions and experiences. This approach argues that the sequence of events that lead an adolescent to adulthood is influenced by economic, social, and cultural factors (Elder & Shanahan, 2007). For individuals with ASD, both the underlying factors in ASD and extrinsic factors from structural, social, and cultural contexts are at play in determining their post-secondary outcomes. Intrinsic factors that are part of the clinical picture of ASD, such as communication and executive function difficulties, can be addressed with appropriate interventions and supports (Bellini, Peters, Benner, & Hopf, 2007; Bishop-Fitzpatrick, Minshew, & Eack, 2014). However, in order for adolescents with ASD to be referred to appropriate services and resources, external factors also need to be addressed, including beliefs of educators and parents, a lack of assessments that evaluate self-management capabilities for individuals with ASD, and

other systemic barriers in transition planning. Improving the understanding of the needs of youth with ASD amongst educators, families, and involved professionals may result in improved connection to suitable services and increased research efforts to develop assessments and interventions for this population. Addressing these sociocultural factors in adolescence may lead to improved function and independence in adulthood.

*International Classification of Functioning, Disability, and Health*

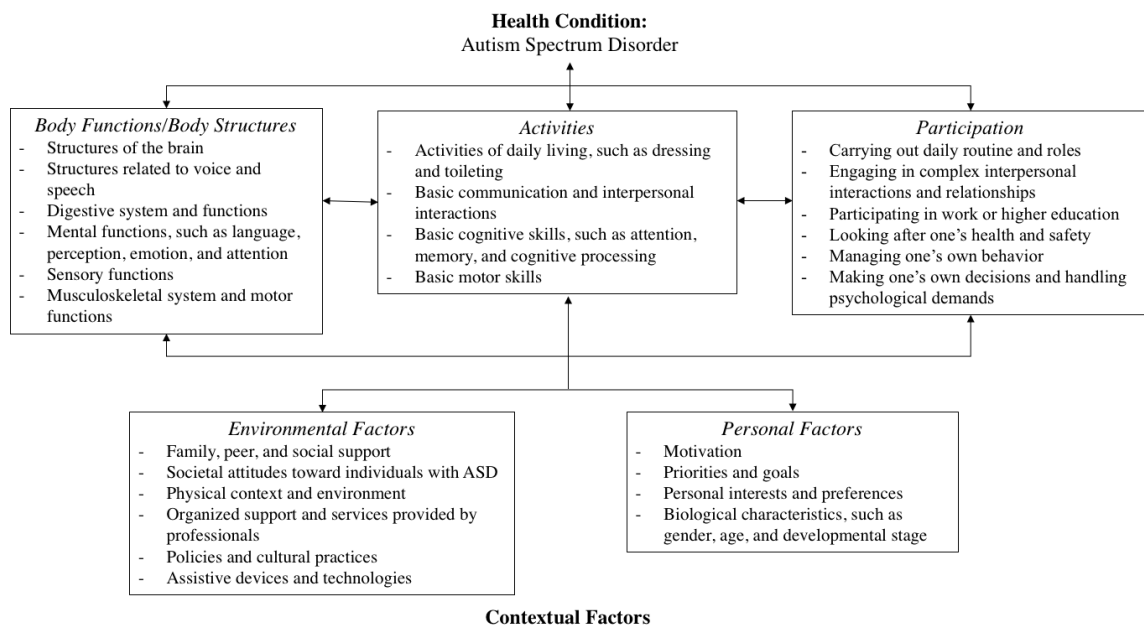
The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) is an effort based on a biopsychosocial model that is designed to standardize descriptions of function and disability. The ICF proposes that health and disability are complex, multi-dimensional constructs. The framework facilitates standardized assessment of functioning and health by providing detailed classifications in the areas of Body Function/Structure, Activity, and Participation. Body Functions are physiological functions of body systems, including psychological functions. Body Structures are anatomical parts of the body such as organs, limbs, and their components. Activity is the execution of a task or action by an individual, while Participation is involvement in a life situation. Although hierarchical in their degree of complexity, the framework asserts that the relation between these dimensions is not necessarily linear or pre-determined. In particular, the dimensions of Activity and Participation are affected by two contextual factors: personal characteristics and environmental features. Personal characteristics include gender, age, coping styles, social background, education, profession, past and current experience, overall behavior pattern, character, and other internal factors that influence how disability is experienced by the

individual. Environmental features include social attitudes, characteristics of the physical environment, legal and social structures, and other external factors (WHO, 2001).

Application of the ICF to characterize aspects of function and disability that are often associated with ASD may increase understanding of the strengths and needs of individuals with ASD and aid in improving transition outcomes. ASD is a complex condition encompassing many physical, environmental, and personal factors and areas of life. According to the literature, the primary relevant Body Structure is the structure of the brain, because of the consensus among experts of various professions that ASD is a brain-based condition. Other identified body structures closely related with ASD include structures related to voice and speech, movement, and digestive systems. The Body Functions identified with ASD comprise a variety of mental functions, such as language, perception, emotion, and attention. Other ASD-related functions are sensory functions, problems with speech, and with digestion (de Schipper, 2016). In the domains of Activity and Participation, individuals with ASD typically have difficulties with social relationships and communication, which constitute the core symptoms of ASD as described in the DSM-5 (American Psychiatric Association, 2013). Other categories that represent challenges include the ability to care for oneself and manage everyday life tasks; participation in school, work, and social life; and cognitive and motor skills. Environmental features to consider include individual support, common attitudes towards individuals with ASD, organized support and services provided by professionals, and the physical context and environment. And lastly, personal factors that are meaningful include the individual's motivation, goals, interests, preferences, and biological

characteristics (de Schipper, 2016). *Figure 2-1* illustrates the application of the ICF model for ASD, comprising common factors associated with the condition.

**Figure 2-1. Application of ICF of ASD**



### **Previous Attempts to Address the Problem**

Individuals with ASD typically have challenges with self-management of daily activities (Duncan & Bishop, 2015; Hedges et al., 2014; Pellicano, 2012; Rosenthal et al., 2013). The transition assessments available that evaluate daily living and functioning are known as adaptive behavior assessments. Adaptive behavior refers to the skills required for personal and social self-sufficiency across a variety of life situations including self-care (e.g. dressing and bathing), community mobility, home maintenance, establishing and maintaining relationships, and communicating needs and feelings (Sparrow, Cicchetti, & Balla, 2005). Adaptive behavior assessments are often used to help determine whether a student needs a post-secondary IEP goal in the area of independent

living, including the type and amount of assistance they may need to be successful in a given environment (e.g. residential, self-care, transportation, social communication, and community participation). These assessments typically rely on the parent, teacher, or caregiver as the informed respondent (National Technical Assistance Center on Transition, 2016).

Commonly used adaptive behavior assessments include the Vineland Adaptive Behavior Scales (VABS-II), Scales of Independent Behavior – Revised (SIB-R), and the AAMR Adaptive Behavior Scales (ABS-2). The Vineland Adaptive Behavior Scales (VABS-II) (Sparrow et al. 2005) is perhaps the most well-known measure of adaptive functioning in clinical and research contexts. It assesses adaptive behavior in the domains of communication, daily living skills, socialization, and motor skills. The Scales of Independent Behavior-Revised (SIB-R) (Bruininks, Woodcock, Weatherman, & Hill, 1996) is designed to measure functional independence and adaptive functioning in school, home, employment and community settings. This measure provides an assessment of four adaptive domains (motor skills, social interaction and communication, personal living and community living) and three maladaptive domains (internalized, social, and externalized). The AAMR Adaptive Behavior Scales (ABS-2) (Lambert, Nihira, & Leland, 1993) is intended to assess the personal and community independence, and personal and social performance of school-aged children. The scale is available in two forms, School and Residential/Community Settings, and both versions assess the manner in which individuals cope with the natural and social demands of their environment. The ABS-2 evaluates nine personal independence domains (independent

functioning, physical development, economic activity, language development, numbers and time, prevocational/vocational activity, self-direction, responsibility, and socialization) and seven maladaptive behaviors (social behavior, conformity, trustworthiness, stereotyped and hyperactive behavior, self-abusive behavior, social engagement, and disturbing interpersonal behavior). These measures are typically administered as questionnaires, but can also be implemented through structured interviews. Although these adaptive behavior assessments offer a valid and reliable method to evaluate deficits in adaptive behavior for diagnostic purposes, intervention planning, and research, they have their limitations. The limitations for these measures include the inconsistent operationalization of adaptive behavior, the cost and requirements for administration and scoring, and the broad and generalized examination of abilities.

There is a lack of clear definition of the construct of adaptive behavior, which has resulted in the varying mix of items included in adaptive behavior assessments. The items included involve behaviors believed to have clinical relevance for diagnostic purposes (e.g. making eye contact), behaviors that capture progress toward developmental milestones (e.g. holds pen/pencil properly), and behaviors that are culturally relevant activities of daily living (e.g. getting dressed). The items from these adaptive behavior measures were developed from a range of pragmatic experiences in an effort to document areas of daily life that presented challenges for people with developmental disabilities and which are not directly predictable from IQ score alone (Kramer et al., 2012). As a result, it is difficult to operationalize adaptive behavior and determine what is changing

over time or the underlying mechanisms affecting change.

Another limitation is the expense and extensive requirements for administration and scoring of these adaptive behavior assessments. The VABS-II, SIB-R, and ABS-2 all require trained professionals to administer and score the measure, and are costly (approximately \$150-400). These assessments can also be lengthy (e.g. 20 to 60 minutes), taking away time needed to plan effective interventions and services. These factors hinder their routine use, increase the burden placed on respondents and administrators, and raise research and clinical costs. In addition, a majority of adaptive behavior assessment implement norm-based scoring, which compares the performance of individuals with disabilities to that of those without disabilities. While norm-based scoring is beneficial for diagnostic purposes, these scores are not helpful as outcome measures to detect change in the context of individual performance.

Finally, these existing adaptive behavior assessments adopt a broad and generalized examination of an individual's capabilities. For example, the VABS-II would provide a summary of an individual's performance in the Daily Living Skills domain using a standard score that is compared with the scores of peers with similarly reported IQs. The items are rated with a scoring of 0 (never) to 2 (usually/often), and are often evaluating discrete skills, such as "keeps fingernails trimmed and clean" and "completes homework and turns it in on time." The measure indicates which behaviors and/or functional activities the individual has difficulty with but does not provide much direction in regards to what to prioritize for intervention. These assessments do not break down the steps needed to address the adolescent's problem areas, and the 3-point ordinal scale may



not be sensitive enough to detect change.

Furthermore, these well-known adaptive behavior assessments were developed for the general disabilities population and not specifically for individuals with ASD. According to the literature, the ASD population presents with unique problem areas compared to other disability groups, thereby warranting a need for an assessment designed specifically to identify skills relevant for this population. Young adults with ASD, including those with average or above average intellectual abilities, have the poorest transition outcomes out of all the disability categories (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011). These adolescents also often benefit less from the transition planning process compared to students from other disability groups. Individuals with ASD often struggle with self-initiation and goal-setting, which make them less likely than their peers with other types of disabilities to advocate for their needs and take leadership of their own transition planning (Shogren & Plotner, 2012). Because self-advocacy is challenging for these adolescents, their struggles are not made known. Their functional limitations are often overlooked because they typically perform well academically in secondary education settings (Wehman et al., 2014), and this lack of understanding may lead to less effort to connect adolescents with ASD with post-secondary interventions and services that could appropriately address their needs. A review of the literature indicated a need for transition assessments that evaluate self-management for adolescents with ASD. This population would benefit from an assessment that does not provide a broad evaluation of self-management of tasks, but assesses specific aspects of task management

that are most difficult for this population, such as executive functioning, emotional regulation, goal setting, and adapting to changing contexts.

## **CHAPTER THREE: DESCRIPTION OF THE PROPOSED ASSESSMENT**

### **Introduction**

The Self-Management for Autism Rating Tool (SMART) is a transition-readiness questionnaire designed for adolescents with autism spectrum disorder (ASD), starting at 16 years of age, to measure and track the development of skills they need to acquire in order to manage daily tasks of adulthood. The content of the tool was designed to include a range of skills, which are involved in completing a specific self-management task, and vary from those that even young adolescents should be able to do to skills that may require additional instruction or training. The use of this assessment in clinical practice would make it possible to identify the adolescents' strengths and areas in need of improvement in order to improve transition outcomes.

### **Intended Population**

The SMART is developed for use with adolescents and young adults, aged 16 to 35 years, with a diagnosis of ASD without an intellectual disability (i.e., with an IQ of 70 or higher), who are in the process of transitioning out of the secondary school system and into adulthood. As much as possible, the items were written to focus on essential self-management skills and tasks performed in adulthood that may be challenging for this population. The SMART may also be used to assess transition readiness for the general population or for youth with other disabilities, but the contents of this tool specifically target areas that are challenging for the ASD population and may not provide a comprehensive evaluation for individuals from other disability groups.

## **Applications**

The clinical uses of the SMART are to evaluate and monitor the presence or absence of relevant skills that are significant in key self-management tasks, to identify specific barriers in the transition to adulthood, to help set individualized goals and objectives, to guide the application of targeted interventions, and connect individuals with appropriate resources and services. The assessment can also be used in transition readiness research where studies are needed to document the outcomes of self-management interventions, and as a screening tool to identify individuals who may have difficulty transitioning to adulthood.

Self-management skills represent just one of an array of factors hypothesized to influence transition readiness for adolescents and young adults (Schwartz et al., 2011). For a more comprehensive evaluation, assessments to determine academic performance, self-determination, vocational interest and exploration, and other areas of adaptive behavior and independent living may be beneficial.

The SMART provides an increased understanding of the capabilities and needs of adolescents and young adults with ASD in the domain of self-management of daily living tasks. Adolescents with ASD could benefit from knowing their preparedness to manage crucial life tasks. A better understanding of their own difficulties and needs can motivate youth with ASD to learn self-management skills required to function successfully in their adult roles. The SMART also allows improved understanding of the needs of adolescents and young adults with ASD amongst educators, families, and involved professionals, which may guide intervention efforts, connect individuals with suitable services, supports

and resources, and increase research efforts for this population. The intended outcome for utilization of the SMART is to improve transition outcomes for youth with ASD, and improve their ability to achieve their life goals and experience success in adulthood.

### **Features**

There are two versions of the SMART: a self-report and a parent/caregiver report. The items in the self-report version are written in the first person or in I-statements (e.g. “I initiate next steps.”), while the items in the parent/caregiver report are written in the third person. The items are written in short sentences with everyday language and familiar words to improve readability and comprehension.

The SMART includes a selection of scales targeting individual self-management tasks. The evaluated self-management tasks were specifically selected because they are significant in achieving autonomy in adulthood and are often challenging for the ASD population. Individuals with ASD tend to struggle with more complex activities due to difficulties with emotion regulation, sensory information processing, and executive functions, such as cognitive flexibility, initiation, and planning (Hedges et al., 2014; Pellicano, 2012; Rosenthal et al., 2013). Self-management tasks such as “getting ready in the morning on time,” “keeping track of time throughout the day,” and “developing and following a plan to reach a specific goal” involve higher cognitive skills and ability to manage emotions under stress or unexpected circumstances. Addressing self-management tasks such as “maintaining cleanliness and upkeep of living space” and “managing food needs for the entire week” target perceptual and information processing

skills and executive function skills, such as organization and planning. The majority of youth with ASD also experience challenges with financial independence (Cheak-Zamora et al., 2017). Self-management tasks such as “tracking, spending, and managing money” and “paying bills and other accounts on time” are included in the assessment.

Each scale focuses on a single self-management task which was broken down into a set of individual items, discrete steps or skills required to manage the daily task. The items were determined based on their importance in completing the overall task and their perceived difficulty for the ASD population. Skills that require the individual to organize, plan, manage time and emotions, respond to new demands, set own goals, initiate tasks, and adapt to changing contexts were incorporated. Examples include breaking down activities into more manageable steps, staying focused on the primary task, asking for help when needed, initiating the next step, and managing emotions when dealing with pressure, inconsistencies, and setbacks. The set of items together map out a clinical hierarchy such that it can be used to track the mastery of skills over time. The items also focus on the individual’s ability to perform each functional activity in a manner that is effective given their abilities and challenges. They do not require the individual to perform the activity in a standardized manner for credit.

The SMART scores respondents only on items that are in their environment and/or are necessary for them to do. Items can be omitted if they are not clinically relevant for the individual. This allows for a client-centered and individualized assessment.

### **Administration of the SMART**

The SMART does not require any special environment, materials, or activities to administer. It can be completed independently by the adolescent/young adult and caregiver(s) through a written questionnaire or structured interview. The assessment focuses on performance at the present time. The SMART can be completed on multiple occasions for the same individual (e.g. initial evaluation, reassessment, discharge) and there is no minimum time that must pass between assessments.

Prior to administration, respondents should decide which self-management task(s) will be evaluated and select the corresponding scale. Then, they should identify and omit items that are not clinically relevant to the individual. It is recommended that the adolescent or young adult complete this step with their parent or caregiver.

The scale can be completed independently but the results should be interpreted by a professional with a background in education, pediatrics, and/or rehabilitation. The professional should also have an understanding of functional assessments and scoring to be able to understand and explain the intent of the individual items and meaning of different types of scores.

### **Assessment Scoring**

Each item is scored as follows: 1 – “Never,” 2 – “Sometimes,” 3 – “Often,” and 4 – “Always.”

TOTAL SCORE =  $\frac{\text{Sum of scores for each applicable item}}{4 \times (\text{Number of applicable items})} \times 100 = \underline{\hspace{2cm}} \%$

The total score does not represent a percentage of the norm. Rather, it provides a score which may facilitate comparing performance over time.

## **Development of the SMART**

### *Conceptual Model*

As mentioned in Chapter 2, the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) is a system designed to standardize descriptions of function and disability (WHO, 2001). Its application has been particularly notable in measurement development. The SMART was developed to be consistent with this conceptual framework. The framework describes the three dimensions of functioning that could be used to describe outcomes, Body Function/Structure, Activity, and Participation; and two contextual factors, personal characteristics and environmental features. The SMART's self-management skills, the items of each self-management task, address the Activity dimension, defined as the performance of discrete skills. The self-management tasks, the single constructs for each scale, address one aspect of the Participation dimension, which is defined as engagement in life situations. Participation involves engagement in complex sets of culturally typical activities and some degree of autonomy or personal choice. These scales aim to track and monitor the extent to which the adolescent or young adult is able to take control over organizing and managing major life tasks.

The "Personal factors" and "Environment factors" dimensions are not measured separately in the SMART. Instead, the response options allow respondents to indicate if a



skill is present but not applied consistently due to a variability of performance across environments and people. Individuals with ASD often have challenges adapting to changing contexts (Rosenthal et al., 2013). The “sometimes” or “often” rating can be useful to identify areas influenced by personal and/or environmental factors, and lead to exploration of how to improve the consistency of activity performance.

#### *Comparison with Measures of Adaptive Behavior*

The transition assessments available that evaluate daily living and functioning are known as adaptive behavior assessment, such as the Vineland Adaptive Behavior Scales (VABS-II) and the Scales of Independent Behavior (SIB-R) (Bruininks, Woodcock, Weatherman, & Hill, 1996; Sparrow, Cicchetti, & Balla, 2005). These measures evaluate the skills required for personal and social self-sufficiency across a variety of life situations including self-care (e.g. dressing and bathing), community mobility, home maintenance, establishing and maintaining relationships, and communicating needs and feelings (Sparrow et al., 2005). Adaptive behavior assessments are often used to help determine whether a student needs a post-secondary IEP goal in the area of independent living, including the type and amount of assistance they may need to be successful in a given environment (e.g. residential, self-care, transportation, social communication, and community participation).

The SMART is similar to these adaptive behavior assessments in their evaluation of discrete, functional skills that are clinically and culturally relevant to daily living. However, the SMART offers significant advantages compared to other measures of adaptive behavior. These advantages are as follows:

- Meaningful and individualized assessment: The SMART makes an important distinction between the performance of discrete activities and the ability to manage important life tasks. The measure allows for omission of items that are not meaningful or relevant to the individual, providing a client-centered and individualized evaluation.
- Assessment of an individual's optimal performance: Items on the VABS-II and SIB-R often require an individual to complete an activity in a certain way or require a particular method of performance. In contrast, the items on the SMART were carefully worded to allow individuals to complete activities using alternative methods. This lessens the extent to which individuals with disabilities are penalized in scoring due to use of adaptations or technology.
- Specific and explicit evaluation: Adaptive behavior assessments typically provide a broad and generalized examination of an individual's capabilities. They indicate which behaviors and/or functional activities the individual has difficulty with but do not provide much direction in regards to what to prioritize for intervention. These measures do not break down the steps needed to address the problem areas. Conversely, the SMART deconstructs key self-management tasks into a set of relevant skills, allowing for evaluation of what is changing over time and identification of the underlying mechanisms affecting change. This explicit information is helpful for guiding intervention efforts.
- Targeted to the autism population: The SMART was developed specifically for individuals with ASD. According to the literature, the ASD population presents

with unique problem areas compared to other disability groups and would benefit from measures and interventions tailored specifically to address their needs.

- Time efficient: Most commonly used adaptive behavior assessments are administered via interview, which can be time and resource consuming. The SMART offers a sound alternative that minimizes both examiner and respondent time while still yielding precise estimates of an adolescent or young adults' self-management capabilities.

#### *Content Development*

This project involves the first phase of instrument development — the development of constructs, scales, and items. Features of the SMART were influenced by the Transition-Q, a 14-item scale that measures self-management skills in health and healthcare in adolescents across a range of chronic health conditions, which was developed following internationally accepted guidelines for the development of a new patient-reported outcome instrument (Klassen et al., 2014). The SMART was created specifically for the ASD population and targets clinically relevant self-management tasks that are challenging for transition-aged adolescents with ASD. Identification of these key self-management tasks was completed through an in-depth research of the literature.

Based on the literature, individuals with ASD typically have difficulty with self-management skills, such as organizing and planning, managing time and emotions, responding to new demands, identifying and setting own goals, and adapting to changing contexts (Duncan & Bishop, 2015; Hedges et al., 2014; Pellicano, 2012; Rosenthal et al., 2013). Features from the PEDI-CAT were also used when developing the SMART. The

Pediatric Evaluation of Disability Inventory (PEDI), which was revised as a computer adaptive test (CAT), is an assessment that evaluates and detects changes in daily functioning for children and youth (birth through 20 years of age) with a variety of physical and/or behavioral conditions. It includes a Responsibility domain, which measures the extent to which the youth takes responsibility for managing complex, multi-step life tasks (Haley et al., 2012). A significant number of items from the Responsibility domain represent self-management tasks that are often difficult for individuals with ASD, such as “developing and following a plan to reach a specific goal,” and “tracking, spending, and managing money.” Therefore, items from the PEDI-CAT were referenced when determining relevant self-management tasks to be evaluated and deconstructed into a set of discrete skills.

A brief instruction and four response options labeled as follows: “never,” “sometimes,” “often,” and “always,” were developed to improve readability, comprehension, and accuracy. The scale was created to be consistent with a systematic review which recommended using a simple question format, fewer (four to five) response categories, and labeled categories (Khadka et al., 2012). Flesh-Kincaid grade level scores, an indicator of comprehension difficulty, were examined to reduce items to the lowest possible grade (Flesch, 1948). The scale was presented to an expert in the field, a professor and department chair of a reputable occupational therapy program. This expert had substantial research expertise on the topic of transition readiness, including three decades of research on the development of assessments to guide service planning, evaluate activity participation and performance for individuals with disabilities, and

support outcomes research. She provided written feedback on instructions, response options and items, which was used to revise the scales.

### **Sample of SMART Scale**

The current version of SMART addresses six self-management tasks: “getting ready in the morning,” “keeping your living space clean,” “preparing your meals for the week,” “tracking, spending, and managing money,” “paying bills on time,” and “managing daily expenses.” A sample of the scale for the self-management tasks of “getting ready in the morning” is included below in *Figure 3-1*. Additional scales for the self-report and caregiver report are included in *Appendix A* and *Appendix B*.

**Figure 3-1. Sample of SMART Scale**  
**The Self-Management for Autism Rating Tool**  
*Youth Version*

These questions are about <b>getting ready in the morning</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	I know what time I need to get up so that I can do everything I need to do before going to school or work.	1	2	3	4
2.	I set an alarm the night before.	1	2	3	4
3.	I go to sleep on time so that I get enough sleep to not feel tired.	1	2	3	4
4.	I wake up when my alarm rings and get out of bed.	1	2	3	4
5.	I perform my morning activities, such as grooming, dressing and eating breakfast, in an orderly fashion.	1	2	3	4
6.	I check my time as I do each task to make sure I am on track to leave on time.	1	2	3	4
7.	I choose the right clothes for the weather and activity (e.g., work, interview, meeting up with a friend).	1	2	3	4
8.	I check to make sure I have everything I need before I leave the house (e.g., keys, money, wallet, cell phone, lunch).	1	2	3	4
9.	I check and turn off all lights and appliances (e.g., oven, hair straightener, heater) before I leave.	1	2	3	4
10.	I lock the door or close the garage before I leave.	1	2	3	4

11.	I leave the house at the right time to get to school or work on time.	1	2	3	4
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### **Limitations and Considerations**

One limitation is that the SMART was developed through a western worldview, which emphasizes autonomy, individuality, and self-actualization. The contents in the assessment are influenced by these values, and aim to evaluate the person's ability to be independent and responsible for managing their own daily life. Therefore, the self-management skills and tasks that are targeted may not be relevant to individuals from other cultures. Particular self-management tasks and associated routines that must be learned are defined by a person's socio-cultural context, and reflect the typical roles and norms of adults in that community.

Another limitation of the SMART is that it evaluates the individual's capacity to execute steps or skills involved in a self-management task, but it does not assess the ability to understand the meaning and reasons underlying those steps. An individual's ability to understand the purpose of learning certain skills and tasks, as well as their motivation to learn, is associated with their self-determination. Self-determination is defined as the "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 1996). According to the literature, engaging in self-determined behaviors, such as making one's own decisions, being self-aware, and having an internal locus of control, is correlated with an enhanced quality of life (Lachapelle et al., 2005; White, Flanagan, & Nadig, 2018). It may be beneficial for interventions to guide adolescents to not only follow rules or

execute individual steps, but to also grasp the purpose of and motivation for learning these self-management skills.

One consideration is the potential for inconsistencies between the self-report and caregiver/parent report scales. Differences may reflect youth's degree of self-awareness of their capabilities or different interpretations of actions and performance. Caregivers and adolescents may also differ in their beliefs about which self-management skills and tasks matter and how much they matter. Disagreements between informants provide opportunities for involved parties to discuss what they believe to be most important, and therefore, what they might wish to target in intervention.

Currently, the SMART focuses on a limited number of self-management tasks. The development of self-management skills separate from the presented few, and assessment of other variables, such as the concept of self-efficacy (i.e. a person's belief in his or her ability to succeed in specific situations (Bandura, 1977)), may also be important to transition success. There is a scope for future research to develop additional clinically meaningful scales to measure other important self-management tasks and transition-related constructs.

### **Future Phases**

This project provides an initial design of the assessment tool, including its constructs, items, and scales. Future phases of development will need to occur in order to finalize the measure. This would involve (1) collaborating with experts and conducting online surveys with parents of adolescents with ASD to obtain feedback on the relevance,



wording, format, and presentation of items and to identify any missing content in order to revise the scale as necessary; (2) holding interviews with individuals, aged 16 to 35 years, with ASD to obtain their feedback on the wording and comprehensibility of the measure; (3) executing a pilot field test and a large-scale field test to collect data from a sample of adolescents and using the data to choose a subset of items that represent the best indicators of self-management skills, and (4) examining the assessment's psychometric properties to ensure reliability and validity.

## **CHAPTER FOUR: EVALUATION PLAN**

### **The Need for Assessment Evaluation**

Evaluating the merit of an assessment is an integral step in the development of an assessment to obtain evidence that the instrument accurately evaluates the concept it claims to measure. The Self-Management for Autism Rating Tool (SMART) will go through three phases of development before clinical use. The first phase involves the initial design of the assessment tool, in which the domains are identified and the items are generated. The evaluation of the SMART occurs in the second and third phases of development. During the second phase, an evaluation of content validity by experts and the parents of adolescents will take place. Pre-testing will also occur during the second phase, which will consist of cognitive interviews with adolescents with autism spectrum disorder (ASD), and a pilot field test with adolescents and their parents. The last phase involves the implementation of a large-scale field test and examination of the assessment's psychometric properties.

### **Evaluation of the SMART**

Phase 2 consists of the evaluation of content validity and pre-testing. Content validity, also known as “theoretical analysis,” refers to the “adequacy with which a measure assesses the domain of interest” (Hinkin, 1995). For an instrument to be effective, it is essential that the items measure what they are presumed to measure. Content validity is generally assessed through evaluation by experts and individuals from the target population (Boateng, Neilands, Frongillo, Melgar-Quiñonez, & Young, 2018).

The intended plan is to have at least three experts, who have experience with measure development and/or are knowledgeable about the capabilities of individuals with ASD, to evaluate the SMART. The measure will be distributed to experts who will evaluate each item to determine whether it represents the domain of interest. Their feedback will provide guidance for the modification of items. The goal for the evaluation by experts is to assess the content relevance, representativeness, and technical quality of the items constituting each scale. The outcome for the evaluation by experts is indication of the extent to which the existing items are viewed as appropriate, and suggestions for improvements, such as changes in wording and addition or removal of items.

The evaluation by the target population will be completed through the use of open-ended surveys distributed to parents of individuals with ASD. Evaluation by the target population assesses the face validity, which is the “degree that respondents or lay persons judge that the items of an assessment instrument are appropriate to the targeted construct and assessment objectives” (Haynes, Richard, & Kubany, 1995). Parents of adolescents with ASD were selected as the target population judges because they are knowledgeable about adult responsibilities and the daily needs of adolescents with ASD. The goal for the evaluation by the target population is to determine if the set of items represent the domain of interest. They will assess the items constituting each scale for representativeness of the actual experience for individuals with ASD and their caregivers. The survey will be created using a free online survey tool, such as Google Forms, and distributed to parents of adolescents of ASD who are willing to participate. A sample of the survey is provided in *Table 4-1*. The outcome for the evaluation by the target

population is selection of items for inclusion in the initial version of the instrument. Surveys will be conducted until saturation has been reached. Saturation is defined as the point in the research process at which no additional information is discovered in data analysis. Researchers can be reasonably certain that further data collection would yield similar results. The redundancy of results indicate that data collection may cease (Faulkner & Trotter, 2017). The final sample size for the survey will be determined by saturation, however a range of 5 to 15 surveys completed is anticipated.

**Table 4-1. Sample of the Open-Ended Survey to Parents**

<b>13. I clean out the fridge/freezer on my own and do not leave expired and moldy food.</b>		
Is this item relevant?	Yes ____	No ____
Is this item important?	Yes ____	No ____
Is this item clear and easy to understand?	Yes ____	No ____
<b>14. When I notice something needs to be fixed or replaced that I can't do on my own, I call a specialist or service on my own.</b>		
Is this item relevant?	Yes ____	No ____
Is this item important?	Yes ____	No ____
Is this item clear and easy to understand?	Yes ____	No ____
After reviewing the items in this set, is there anything missing?		
Is there anything you would add?		
Please explain:		

Pre-testing will include the implementation of cognitive interviews and a pilot field test. The cognitive interviews will be approximately one-hour meetings with

adolescents with ASD who are willing to participate. The purpose of the cognitive interviews is to assess the adolescent's understanding and comprehension of the items and whether this understanding is what was intended. This process minimizes misunderstanding and subsequent measurement error by eliminating poorly worded items, revising phrasing to be maximally understood, and reducing the cognitive burden on research participants. The outcome for the cognitive interviews is a revised set of items. Interviews are conducted iteratively, with revision made based on initial interviews that are tested during subsequent interviews, until saturation is reached. A range of 5 to 10 interviews is anticipated.

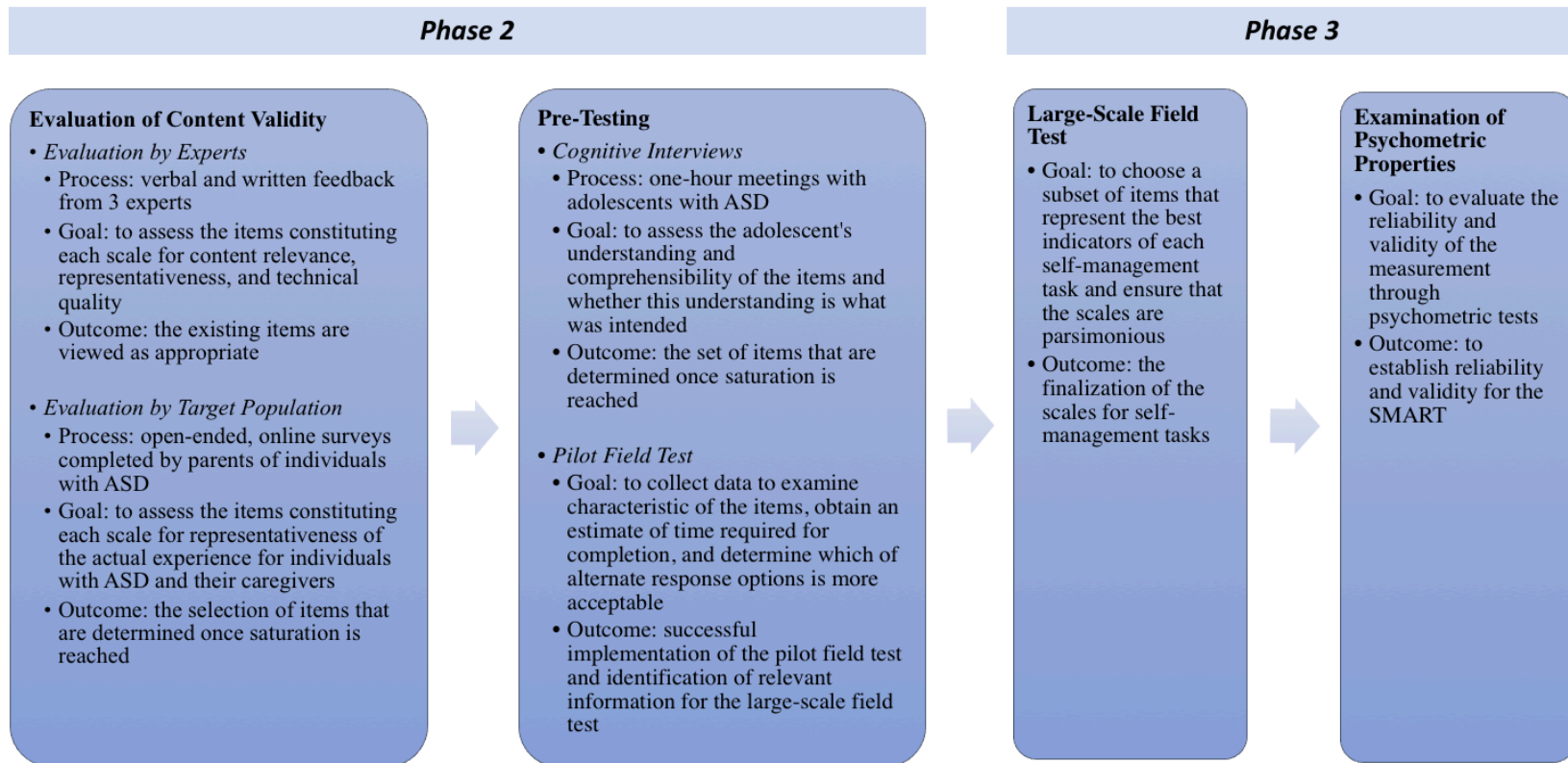
The purpose of a pilot field test is to collect data to examine characteristics of the items, such as range of scores and potential floor and ceiling effects, and obtain an estimate of time required for completion. A pilot field test can also be used to determine which of alternate response options is more acceptable. The typical sample for a pilot test would be 30–50 participants that span the full age range for which the instrument is intended. The outcome is successful implementation of the pilot field test and identification of relevant information required to design a large-scale field test.

Phase 3 consists of a large-scale field test and the examination of psychometric properties. The goal of the large-scale field test is to choose a subset of items that represent the best indicators of each self-management task and ensure that the scales are parsimonious. This includes processes such as item reduction and extraction of factors. The outcome of this field test is the finalization of the scales for self-management tasks. Following the completion of the scales, an examination of the psychometric properties

will be carried out. The goal is to evaluate the reliability and validity of the measurement through psychometric tests. The outcome of this step is to establish reliability and validity for the SMART.

A rigorous and thorough evaluation ensures that the SMART is a well-designed measure which accurately quantifies the self-management capabilities of individuals with ASD and advances understanding of the needs for this population. Details of Phase 3 will be solidified based on results from Phase 2. The summary of the evaluation plan is visualized in *Figure 4-1*.

**Figure 4-1. Visual Model of the Evaluation Plan**



## **CHAPTER FIVE: FUNDING PLAN**

### **Description of the Proposed Assessment Tool**

The proposed assessment tool, entitled the Self-Management for Autism Rating Tool (SMART), is a transition-readiness questionnaire designed to improve transition outcomes for adolescents and young adults with autism spectrum disorder (ASD) by measuring and tracking the development of skills required for managing the daily tasks of adulthood. The SMART includes a collection of rating scales, each targeting a single complex, multi-step self-management task. The selected self-management tasks are deconstructed into discrete skills, which are presented as a set of items for each scale. The SMART targets essential self-management skills and tasks that are often challenging for the autism population, and can be utilized to evaluate and monitor the presence or absence of relevant skills, to assist in setting individualized goals, to guide the application of targeted interventions, and to measure outcomes for research efforts or screen for at-risk individuals.

### **Funding Plan Objectives**

The development of the SMART requires resources that include significant time, personnel, and financial support. The purpose of this chapter is to examine the funding plan for the development of the SMART. The objectives of the funding plan are as follows:



- 1) Identify the necessary expenses associated with the first and second phases of assessment development
- 2) Identify state and federal funding resources available to support the first phase of assessment development

### **Prospective Expenses**

The expenses for the first phase of development of the SMART are associated with the initial design of the assessment tool, and the expenses for the second phase are related to the evaluation of content validity by parents of adolescents and pre-testing, which includes cognitive interviews and a pilot field test. The majority of expenses associated with these two phases include payment for personnel and compensation for study participants.

*Personnel:* The *assessment tool designer* is an expert in activity analysis with knowledge of the abilities and skills necessary for adolescents with ASD to transition into adulthood. The assessment tool designer, who is also the author, will be compensated for her time at a market-based hourly rate that is similar to an hourly rate of a per diem occupational therapist working in an outpatient setting (\$40/hour). The assessment tool designer must be compensated at a comparable rate as an occupational therapist working clinically, as time spent planning will be away from her standard paying clinical position. The number of hours spent on design of the content for the assessment is an estimated 100 hours, and includes time spent performing literature reviews to support the development of the measure; writing content; evaluating content comprehensibility,

format, and presentation; and participating in meetings. The number of hours spent on planning for and implementing the cognitive interviews and pilot field test is an estimated total of 100 hours. This includes time spent seeking funding sources, gathering necessary materials, instructing and meeting with other personnel, obtaining and organizing feedback data, and performing additional research.

The addition of an *assessment consultant* will yield greater success in the development of the measure. The assessment consultant should be well-versed in occupational therapy practice and have substantial expertise on transition readiness for individuals with ASD, and the development of functional assessments. The role of the assessment consultant will be to suggest resources, and provide insight and feedback for the content of the assessment tool. An honorarium payment of \$250 will be provided, noting approximately five hours of consultation at \$50/hour for mentorship.

A *research assistant* will be needed when planning for and implementing the cognitive interviews and pilot field test. The research assistant should be a student enrolled in an occupational therapy or occupational therapy assistant program. Their role will include:

- Marketing to recruit individuals for the cognitive interviews and pilot field testing (e.g., flyer, newsletter, online posting, email and phone correspondence, general promotion, etc.)
- Qualitative and quantitative data collection (e.g. interviews, surveys)
- Proofreading, editing, and preparation of manuscripts and reports
- Other logistical duties including booking spaces and coordination of research

participants

The research assistant will be paid at an hourly rate of \$15/hour for 10 hours a week during a 15-week semester.

*Compensation for Study Participants:* Incentives will be used to recruit adolescents with ASD and their parents to participate in phases of this project. The evaluation of content validity by parents of adolescents will be completed through the use of online surveys, which will be created by a free online survey tool, such as Google Forms. The sample size for the surveys will be determined by saturation. The anticipated number of surveys ranges from 5 to 15 surveys. On completion, parents will receive a \$15 gift certificate. The face-to-face cognitive interviews will be completed with adolescents with ASD to obtain feedback to ensure that the measure be optimally understood by respondents. The number of interviews will also be determined by saturation. The anticipated number of interviews is 5 to 10 interviews, each lasting up to an hour. On completion, adolescents will receive a \$15 gift certificate for participating. The pilot field testing will be used to collect data from a small sample of adolescents and their parents, and use the data to choose a subset of items that represent the best indicators of each self-management task. The goal is to have at least 15 parents and 15 adolescents. On completion, they will receive a \$10 gift certificate for their participation.

Additional expenses were considered. This includes supplies, such as paper and pens; equipment, such as a computer or laptop, and printer; internet access; and rental of facilities. For the first year, the assessment tool designer will be creating the measure on a computer or laptop, and has the flexibility of working at home or in other community

environments. At this point of the project, the designer has access to a personal laptop, printer, internet access, and writing materials. For the following year, the majority of the work will be done in a university setting, allowing for the use of available resources such as computers, printers, internet access, and rooms for meetings. A summary of the total expenses for the first phase of this project is listed in *Table 5-1*.

**Table 5-1. Summary of Expenses**

Item	Rate	Design Expense (Year 1)	Planning Expense (Year 2 – first 6 months)	Implementation Expense (Year 2 – last 6 months)	Rationale
Assessment Tool Designer	\$40/hr	\$4,000 (100 hours) - Research: 20 hours - Content: 40 hours - Evaluation: 20 hours - Meetings: 20 hours	\$2,000 (50 hours) - Seeking funds: 10 hours - Gathering materials: 10 hours - Meetings: 20 hours - Research: 10 hours	\$2,000 (50 hours) - Data collection: 15 hours - Meetings: 20 hours - Evaluation: 15 hours	To perform literature reviews, write content, evaluate content, seek funds, gather materials, organize data collection, evaluate data, and meet with personnel
Assessment Consultant	\$50/hr	\$250 for total of 5 hours - Honorarium, committed to ten 30-minute meetings	\$0	\$0	To suggest resources, provide insight and feedback to assessment content
Research Assistant	\$15/hr	\$0	\$2,250	\$2,250	To assist with marking, planning process, data collection, and other logistics
Incentives for Online Surveys	\$15 for parent	\$0	\$0	\$225 (15 surveys)	To compensate for study participation

Incentives for Cognitive Interviews	\$15 for adolescent	\$0	\$0	\$150 (10 interviews)	To compensate for study participation
Incentives for Pilot Field Test	\$10 for each participant	\$0	\$0	\$300 (30 participants)	To compensate for study participation
<b>TOTAL EXPENSES</b>		\$4,250	\$4,250	\$4,925	\$13,425 for design, planning, and implementation
Dissemination Expense (see Table 6-1)					\$1,319.92
<b>TOTAL OVERALL EXPENSE</b>					\$14,744.92

### Potential Funding Sources

Funding for this project can be provided by the author and obtained from outside sources, including local, state, and federal grants, foundations, and gifts. *Table 5-2* summarizes potential funding sources for the development of the SMART.

**Table 5-2. Potential Funding Sources for the Development of the SMART**

Funding Source	Amount	Description and Requirements
<i>Federal</i>		
National Institute of Mental Health “Career Enhancement Award”	\$2,000	Provides funding for “experienced investigators with the scientific competencies required to conduct research relevant to services for adults or transition-age youth with ASD” (NIH, 2020).  Website: <a href="https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-20-420.html">https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-20-420.html</a>
U.S. Department of Health & Human Services “Disability and Rehabilitation Research Program: Health and Function”	Up to \$500,000	Provides funding for research projects that are “aimed at improving health and function outcomes of individuals with disabilities” (Administration for Community Living, 2020).  Website: <a href="https://acl.gov/grants/disability-and-rehabilitation-research-projects-drrp-program-health-and-function-development">https://acl.gov/grants/disability-and-rehabilitation-research-projects-drrp-program-health-and-function-development</a>
U.S. Department of Education	Up to \$1,400,000 for	Provides funding for research on “the development, implementation, and evaluation of comprehensive school-based interventions intended to improve outcomes for

“Special Education Research Grants”	measurement project type	students identified with or at risk for ASD from kindergarten through Grade 12” (IES, 2019).  Website: <a href="https://ies.ed.gov/funding/pdf/2020_84324A.pdf">https://ies.ed.gov/funding/pdf/2020_84324A.pdf</a>
<i>University</i>		
Boston University Sargent College  “Student Research Grant”	Up to \$5,000	Provides funding for “Sargent students and postdoctoral fellows...completing ongoing research at Sargent” (Boston University Sargent College, 2020).  Website: <a href="https://www.bu.edu/sargent/research/research-funding-administration/funding-opportunities-for-sargent-faculty-and-students/student-research-grant/">https://www.bu.edu/sargent/research/research-funding-administration/funding-opportunities-for-sargent-faculty-and-students/student-research-grant/</a>
<i>Foundations</i>		
The American Occupational Therapy Foundation  “Implementation Research Grant”	\$100,000	Provides funding for “research that is focused on helping occupational therapists take evidence-informed practice from theory to reality in their practice setting” (AOTF, 2020).  Website: <a href="https://www.aotf.org/Grants/Implementation-Research-Grant">https://www.aotf.org/Grants/Implementation-Research-Grant</a>
The American Occupational Therapy Foundation  “Dr. Gary Kielhofner Doctoral Research Scholarship”	\$5,000	Provides funding for “an occupational therapist doctoral candidate in pursuing their research” (AOTF, 2020).  Website: <a href="https://www.aotf.org/Grants/Kielhofner-Doctoral-Research-Scholarship">https://www.aotf.org/Grants/Kielhofner-Doctoral-Research-Scholarship</a>
Organization for Autism Research  “2020 Research Grant”	\$2,000	Provides funding for “studies that will likely produce practical and clearly objective results that can help parents, families, professionals, and people with autism make more fully informed choices, leading to healthier and happier lives” (Organization for Autism Research, 2020).  Website: <a href="https://researchautism.org/2020-research-grant-applications-now-open/">https://researchautism.org/2020-research-grant-applications-now-open/</a>
Andrew Family Foundation	Not specified	Provides funding for “projects and organizations that foster individual growth and enhance communities through education, humanitarian efforts, and the arts” (Andrew Family Foundation, 2020)  Website: <a href="https://online.foundationsource.com/ws/index.jsp?site=andrewfamily">https://online.foundationsource.com/ws/index.jsp?site=andrewfamily</a>

The Roothbert Fund	\$5,000-7,000	Provides funding for “men and women in need of financial aid to further their education” (Roothbert Fund, 2020).  Website: <a href="http://www.roothbertfund.org/scholarshipsprogram.php?p=roothbert-fund-scholarships">http://www.roothbertfund.org/scholarshipsprogram.php?p=roothbert-fund-scholarships</a>
<i>Crowdfunding</i>		
Crowdsourcing	Not specified	Provides a platform for unrelated donors to contribute based on personal interest in the topic  Website: <a href="http://www.gofundme.com">www.gofundme.com</a>

### **Conclusion**

The proposed assessment tool, the SMART, will incur expenses during the first phase of development, which includes the initial design of the measure and the planning for and implementation of cognitive interviews and a pilot field test. It is anticipated that expenses will increase as the project moves onto the next phase due to higher costs involved in implementing a large-scale field test. The anticipated expenses for the first year total approximately \$4,250, and the anticipated expenses for the subsequent year total approximately \$9,200 (*see Table 5-1*). Potential funding sources to cover the anticipated expenses include federal, association, foundation, and crowdfunding options.

## **CHAPTER SIX: DISSEMINATION PLAN**

### **Description of the Proposed Assessment**

The Self-Management for Autism Rating Tool (SMART) is a transition-readiness questionnaire aimed to improve the transition outcomes of adolescents with autism spectrum disorder (ASD) by evaluating their capabilities to manage the daily life tasks of adulthood. Increased understanding of their strengths and needs will help guide intervention efforts and connect these adolescents with appropriate services and resources. Currently, individuals with ASD are struggling with the transition into their adult roles, as evident by the low rates of employment, post-secondary education, meaningful relationships, and independent living (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011). The goal of the SMART is to help young adults with ASD reach their potential to live independent and productive lives through improving their ability to manage the complex, multi-step daily tasks of adulthood.

### **Dissemination Plan Objectives**

Similar to the planning and evaluation stages of measure development, the dissemination of the SMART also requires resources that include significant time, personnel, materials, and financial support. The purpose of this chapter is to examine the dissemination plan for the proposed assessment. The objectives of the plan are as follows:

- Identify long and short-term dissemination goals for the proposed assessment
- Identify the target audiences for dissemination and their specific needs that could be addressed by the proposed assessment



- Describe dissemination activities to be performed that will deliver key messages to the target audiences
- Communicate the budget and evaluation plan for dissemination

### **Dissemination Goals**

Long-term Goal: Widespread knowledge and adoption of the SMART into practice by personnel involved in transition planning, interventions, and research aimed to improve transition outcomes for the ASD population.

Short-term Goals:

- Secondary school educators and professionals involved in transition planning will be knowledgeable about the SMART and utilize the assessment to coordinate appropriate post-secondary services and supports for students with ASD.
- Providers and developers of transition interventions will be knowledgeable about the SMART and utilize the assessment in their clinical practice to better target self-management skills in young adults with ASD and monitor changes in their capabilities.
- Researchers will be knowledgeable about the SMART and utilize the assessment in studies to understand the factors that influence transition readiness, which may result in the development of new interventions to target self-management for individuals with ASD.

### **Target Audiences, Key Messages, and Dissemination Activities**

There are two audiences that will require specific attention in order to

successfully disseminate the proposed assessment: special education case managers and intervention providers/developers.

*Primary Audience: Special Education Case Managers*

A case manager, in the secondary education setting, is responsible for organizing students' special education services and supports. They oversee the Individualized Education Programs (IEPs) and ensure that services and supports are being provided in the way that is described in the plans. The case manager could be a certified educator, school district representative, service provider, or another member of the IEP team (Morin, 2019).

The case manager and the IEP team help prepare adolescents with ASD for life after secondary education through a formal process called transition planning. A transition plan is critical for young people with ASD to be successful and participate to the fullest extent possible in society. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) requires that transition planning begin by the time the adolescent turns 16, or younger if determined appropriate by the IEP team or state education agency (IDEA, 2004). Key messages targeted to case managers will promote how the SMART can aid in the transition planning process and enhance their coordination of transition services.

Key Messages:

- Utilizing the SMART will increase understanding of a student's capabilities, which will improve coordination of services and supports.
- Utilizing the SMART will ensure that adolescents with ASD do not "fall through

the cracks,” and are connected with the appropriate interventions they need.

- The SMART provides an individualized and meaningful assessment that is cost-effective, quick, and easily administered and scored.

Sources/Messengers:

- *Assessment tool designer:* Jean Lin, MS, OTR is the assessment tool designer. She is also an occupational therapist treating geriatric patients in the community setting, and a student in the post-professional OTD program.
- *Assessment expert:* Wendy Coster, PhD, OT, OTR, FAOTA is a professor and chair of the Department of Occupational Therapy at Boston University’s College of Health and Rehabilitation Sciences: Sargent College. She is a renowned expert in occupational therapy, the development of children and youth with disabilities, and the development of functional measures. She co-authored the Pediatric Evaluation of Disability Inventory (PEDI) and the School Function Assessment (SFA), directed development and testing of the Participation and Environment Measure for Children and Youth (PEM-CY), and contributed to the development of the Late-Life Function & Disability Instrument (LLFDI) and Activity Measure for Post-Acute Care (AM-PAC).
- *Evaluation participants:* Individuals with ASD and parents who have participated in the evaluation processes (e.g. open-ended surveys, cognitive interviews, field test) can share their experiences using the SMART.

Dissemination Activities:

- Written Information

- Research Publication: Publishing a research article in a peer-reviewed journal is a prestigious method to gain recognition and credibility for submitted work and promote further research. Peer-reviewed journals that will be considered include, the American Journal of Occupational Therapy, Disability and Rehabilitation, Physical & Occupational Therapy in Pediatrics, and the Journal of Pediatric Rehabilitation Medicine. Additional research will be performed to identify the practice-oriented journals best suited for this audience. There are no charges for submitting to these journals.
  - OT Practice Advertisement: *OT Practice* is a monthly magazine that circulates via standard mail to more than 68,000 active readers. There is no cost to submit a written article to *OT Practice* magazine (AOTA, 2020c).
  - Email: An email will be drafted and distributed to the directors of Special Education or other administrators from local high schools. There is no financial cost for this activity.
  - Poster: A poster, which will be co-authored by Dr. Wendy Coster, will be printed and displayed at future AOTA conferences. The poster can also be used at various meetings. The cost to print a 48” x 36” poster is \$56.93 (MakeSigns.com, 2020).
- Electronic Media
- Website: A website will be created explaining the purpose, intended

population, applications, features, administration, scoring, and development of the SMART. Registering a top-level domain (.com) with GoDaddy costs \$11.99 for the first year, and then \$17.99 for the following years (GoDaddy.com, 2020).

- Person-to-Person Contact

- Personal Meetings: Meetings will occur with directors of Special Education or other personnel from local high schools. There is no financial cost for this activity.
- Invited lecturer: Jean Lin will present the SMART in lectures in accredited Occupational Therapy programs, such as Boston University. Additional promotion will occur with Dr. Wendy Coster in her academic courses. There is no financial cost for this activity.
- AOTA Conference: The 2021 AOTA Annual Conference is expected to have more than 10,000 occupational therapy professionals and more than 375 exhibitors (AOTA, 2020b). Face-to-face contact will be performed by the attending messengers. Conference registration for AOTA members is \$451 (AOTA, 2020a). The assessment tool designer will also present a poster at the conference.

*Secondary Audience: Intervention Providers or Developers*

There are various programs and services for young adults with ASD that aim to address social, academic, career, and life skills necessary for post-secondary success.

Examples include interventions such as the Stepped Transition in Education Program for

Students with ASD (STEPS), which is a multi-method program aimed to promote successful transition into postsecondary education through supporting students with ASD both prior to and during college (White et al., 2017). Another example is the Ivy Street School, located in Brookline, Massachusetts, which has a tailored transition curriculum focused on independent living, social skills, meaningful relationships, vocational choices, behavior management, life skills, and self-direction (Ivy Street School, 2020). Key messages targeted to intervention providers and developers will promote how the SMART can enhance their knowledge of the capabilities of their participants, and improve their ability to evaluate, address, and monitor the skills of their participants.

**Key Messages:**

- Utilizing the SMART will increase understanding of an individual's capabilities, which can guide intervention efforts.
- The SMART provides data which can be used for program evaluation and program development.
- The SMART offers unique features, such as the examination of challenges in daily life common to adolescents with ASD that are often not well-identified by usual instruments.

**Sources/Messengers:**

- *Assessment tool designer:* Jean Lin, MS, OTR is the assessment tool designer. She is also an occupational therapist treating geriatric patients in the community setting, and a student in the post-professional OTD program.
- *Assessment expert:* Wendy Coster, PhD, OT, OTR, FAOTA is a professor and

chair of the Department of Occupational Therapy at Boston University's College of Health and Rehabilitation Sciences (Sargent College). She is a renowned expert in occupational therapy, the development of children and youth with disabilities, and the development of functional measures. She co-authored the Pediatric Evaluation of Disability Inventory (PEDI) and the School Function Assessment (SFA), directed development and testing of the Participation and Environment Measure for Children and Youth (PEM-CY), and contributed to the development of the Late-Life Function & Disability Instrument (LLFDI) and Activity Measure for Post-Acute Care (AM-PAC).

- *Evaluation participants*: Individuals with ASD and parents who have participated in the evaluation processes (e.g. open-ended surveys, cognitive interviews, field test) can share their experiences using the SMART.

#### Dissemination Activities:

- Written Information
  - o Research Publication: Publishing a research article in a peer-reviewed journal is a prestigious method to gain recognition and credibility for submitted work and promote further research. Peer-reviewed journals that will be considered include, the American Journal of Occupational Therapy, Disability and Rehabilitation, Physical & Occupational Therapy in Pediatrics, and the Journal of Pediatric Rehabilitation Medicine. Additional research will be performed to identify the practice-oriented journals best suited for this audience. There are no charges for submitting

to these journals.

- OT Practice Advertisement: *OT Practice* is a monthly magazine that circulates via standard mail to more than 68,000 active readers. There is no cost to submit a written article to *OT Practice* magazine (AOTA, 2020c).
- Email: An email will be drafted and distributed to known programs and services for transition-aged youth with ASD, such as Ivy Street School. There is no financial cost for this activity.
- Poster: A poster, which will be co-authored by Dr. Wendy Coster, will be printed and displayed at future AOTA conferences. The poster can also be used at various meetings. The cost to print a 48” x 36” poster is \$56.93 (MakeSigns.com, 2020).
- Electronic Media
  - Website: A website will be created explaining the purpose, intended population, applications, features, administration, scoring, and development of the SMART. Registering a top-level domain (.com) with GoDaddy costs \$11.99 for the first year, and then \$17.99 for the following years (GoDaddy.com, 2020).
- Person-to-Person Contact
  - Personal Meetings: Meetings will occur with intervention providers and/or developers. There is no financial cost for this activity.
  - Invited lecturer: Jean Lin will present the SMART in lectures in accredited



Occupational Therapy programs, such as Boston University. Additional promotion will occur with Dr. Wendy Coster in her academic courses.

There is no financial cost for this activity.

- AOTA Conference: The 2021 AOTA Annual Conference is expected to have more than 10,000 occupational therapy professionals and more than 375 exhibitors (AOTA, 2020b). Face-to-face contact will be performed by the attending messengers. Conference registration for AOTA members is \$451 (AOTA, 2020a). The assessment tool designer will also present a poster at the conference.

In order to carry out these dissemination activities, the time of the assessment tool designer will be accounted for at a rate of \$40/hour for 10 hours (\$400 total). The dissemination expenses are further summarized in *Table 6-1*.

**Table 6-1. Dissemination Budget**

<b>Item</b>	<b>Primary Audience (Case Managers)</b>	<b>Secondary Audience (Providers &amp; Developers)</b>	<b>Rationale</b>
Time spent by the Designer	\$400 (\$40/hour for 10 hours)	\$400 (\$40/hour for 10 hours)	To plan and implement dissemination activities
<i>Written Information</i>			
Research Publication	\$0	\$0	To disseminate to the academic community, gain recognition and credibility for submitted work, and promote further research
<i>OT Practice</i> Article	\$0	\$0	To disseminate to 68,000 readers
Email	\$0	\$0	To disseminate to local high schools (primary), and intervention providers/developers (secondary)
Poster	\$56.93	\$0 (budgeted for primary audience)	To be used at conferences and meetings
<i>Electronic</i>			
Website	\$11.99 (for the first year)	\$0 (budgeted for primary audience)	To disseminated to a worldwide audience online
<i>Person-to-Person Contact</i>			
Personal Meetings	\$0	\$0	To disseminate to local high schools (primary), and intervention providers/developers (secondary)
Invited Lecturer	\$0	\$0	To disseminate to occupational therapy faculty and students
AOTA Conference	\$451 (registration fee)	\$0 (budgeted for primary audience)	To have access to over 10,000 attendees
<b>TOTAL EXPENSES</b>	\$919.92	\$400	For each audience
<b>TOTAL DISSEMINATION EXPENSE</b>	\$1,319.92		

### **Dissemination Evaluation**

The overall success of dissemination efforts will be evaluated according to the following criteria:

1. The utilization of the SMART in secondary education transition planning
2. The utilization of the SMART in transition interventions
3. The utilization of the SMART in research efforts

An assessment of the effectiveness of specific dissemination activities may include:

- *Research Publications*: The number of articles published or cited
- *Magazine Articles*: The number of articles published
- *Website*: The number of website visits
- *Meetings*: The number of meetings with case managers and intervention providers/developers
- *Invited Lecturer*: The number of presentations or the number of new invitations per word of mouth and other dissemination activities
- *AOTA Conferences*: The number of conference proposals accepted in future years

### **Conclusion**

The dissemination plan provides details of the dissemination messages and efforts to key personnel who work with transition-aged individuals with ASD. The primary goal for dissemination is to increase knowledge and adoption of the SMART in transition planning, interventions, and research. Utilization of the SMART improves transition outcomes for the ASD population by furthering the understanding of the self-

management abilities of adolescents with ASD amongst parents, educators, involved professionals, and the adolescents themselves.

## CHAPTER SEVEN: CONCLUSION

According to recent evidence, a majority of youth with autism spectrum disorder (ASD) experience poor outcomes as they transition from secondary education into adulthood. They have challenges with achieving and maintaining employment, higher education, independent living, and social connectedness (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011). A significant number of young adults with ASD are unable to support themselves financially, and often continue to depend on their families for basic needs, financial support, housing, daytime supervision, and companionship (Taylor & Seltzer, 2011). In addition, they have the poorest transition outcomes compared to their peers with other disabilities. Across the spectrum, individuals with ASD have lower rates of independent living and participation in daytime activities compared to those with intellectual disabilities, developmental disabilities, and emotional disturbances (Newman et al., 2011; Taylor & Seltzer, 2011).

One reason why individuals with ASD have poor outcomes may be because there is a lack of understanding of their limitations and needs, resulting in inadequate support during their transition out of secondary education. Because self-initiation, goal-setting, and self-advocacy is challenging for these youth, their struggles are often not made known. Their functional limitations may be overlooked because they typically perform well academically in secondary education settings (Shogren & Plotner, 2012; Wehman et al., 2014). This lack of understanding results in less efforts to coordinate post-secondary interventions and supports for adolescents with ASD. They are particularly vulnerable as

they experience a shift in service provision after leaving high school, and instead are “falling through the cracks” during their transition to adulthood (Shattuck et al., 2011; Taylor & Seltzer, 2011).

The transition planning process is typically a joint effort of the education system, the family, and other involved services. One common need of all who are involved in transition planning and implementation is for assessments that identify the strengths and limitations of adolescents with ASD and help direct intervention efforts. A variety of standardized assessments of function, commonly known as “adaptive behavior” assessments, are available, which provide an overall indication of the young person’s progress in acquiring the skills needed for independent living (Sparrow, Cicchetti, & Balla, 2005). In general, however, these assessments are not designed to identify specific targets for intervention or training and may not cover all areas relevant to assuming adult roles. Often the items in the assessments address discrete skills (Anderson-Loeb, 1996; Brigance, 1994; Bruininks, Hill, Weatherman, & Woodcock, 1986; Bruininks, Woodcock, Weatherman, & Hill, 1996; Lambert, Nihira, & Leland, 1993; Sparrow et al., 2005), and do not evaluate the ability to meet the more complex social and cognitive demands of adult roles. This represents a serious short-coming for transition planning for youth with ASD as it is often these demands that are most challenging for them. Individuals with ASD have difficulty with self-management skills, such as planning, managing time and emotions, responding to new demands, identifying and setting own goals, and adapting to changing contexts (Duncan & Bishop, 2015; Hedges et al., 2014; Pellicano, 2012; Rosenthal et al., 2013). There is a need for development of assessments,

specifically for the ASD population, that evaluate these self-management skills required for adult living.

The Self-Management for Autism Rating Tool (SMART) is one solution aimed at improving transition outcomes for adolescents and young adults with ASD. The SMART is a transition-readiness questionnaire designed specifically for individuals with ASD to measure and track the development of skills they need in order to manage the daily tasks of adulthood. The clinical uses of the SMART are to evaluate and monitor the presence or absence of relevant skills that are significant in key self-management tasks, to identify specific barriers in the transition to adulthood, to help set individualized goals and objectives, to guide the application of targeted interventions, and connect individuals with appropriate resources and services. The assessment can also be used in transition readiness research where studies are needed to document the outcomes of self-management interventions, and as a screening tool to identify individuals who may have difficulty transitioning to adulthood. The SMART provides an increased understanding of the capabilities and needs of adolescents and young adults with ASD in the domain of self-management of daily living tasks. Adolescents with ASD could benefit from knowing their preparedness to manage crucial life tasks. A better understanding of their own difficulties and needs can motivate youth with ASD to learn self-management skills required to function successfully in their adult roles. Features of the SMART include the utilization of both self-report and caregiver-report, the ease of administration, the ability to modify the measure for meaningful and individualized assessment, the identification of specific and explicit data, and the evaluation of problem areas unique for the ASD

population. The development of the assessment was influenced by guiding theories such as the Life Course Theory (Elder & Shanahan, 2007) and the World Health Organization's (WHO) International Classification of Functioning (ICF) (WHO, 2001), the Transition-Q (Klassen et al., 2014), and the PEDI-CAT (Haley et al., 2012).

The SMART will undergo three phases of development. This project completes the first phase of development, which was the initial design of the measure, and provides the foundation and reasoning for future phases. Future phases will involve (1) further evaluation by experts and conducting online surveys to parents of adolescents with ASD to obtain feedback on the relevance, wording, format, and presentation of items and to identify any missing content in order to revise the scale as necessary; (2) holding interviews with individuals, aged 16 to 35 years, with ASD to obtain their feedback on the wording and comprehensibility of the measure; (3) executing a pilot field test and a large-scale field test to collect data from a sample of adolescents and using the data to choose a subset of items that represent the best indicators of self-management skills, and (4) examining the assessment's psychometric properties to ensure reliability and validity. The current version of SMART addresses six self-management tasks: getting ready in the morning; keeping your living space clean; preparing your meals for the week; tracking, spending, and managing money; paying bills on time; and managing daily expenses. If a successful template can be developed, future work could include developing similar scales for other self-management tasks.

The SMART provides an improved evaluation and understanding of the capabilities and needs of transition-aged individuals with ASD which can guide



intervention efforts and result in better coordination of transition programs, services, and resources. Addressing the self-management needs of young adults with ASD can ultimately lead to improved transition outcomes, empowering and equipping them to live independent and productive lives in society.

## APPENDICES

### Appendix A: SMART (Youth Version)

## The Self-Management for Autism Rating Tool

*Youth Version*

These questions are about <b>getting ready in the morning</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	I know what time I need to get up so that I can do everything I need to do before going to school or work.	1	2	3	4
2.	I set an alarm the night before.	1	2	3	4
3.	I go to sleep on time so that I get enough sleep to not feel tired.	1	2	3	4
4.	I wake up when my alarm rings and get out of bed.	1	2	3	4
5.	I perform my morning activities, such as grooming, dressing and eating breakfast, in an orderly fashion.	1	2	3	4
6.	I check my time as I do each task to make sure I am on track to leave on time.	1	2	3	4
7.	I choose the right clothes for the weather and activity (e.g., work, interview, meeting up with a friend).	1	2	3	4
8.	I check to make sure I have everything I need before I leave the house (e.g., keys, money, wallet, cell phone, lunch).	1	2	3	4
9.	I check and turn off all lights and appliances (e.g., oven, hair straightener, heater) before I leave.	1	2	3	4
10.	I lock the door or close the garage before I leave.	1	2	3	4
11.	I leave the house at the right time to get to school or work on time.	1	2	3	4

These questions are about <b>keeping your living space clean</b> . For each question, please circle <b>only 1 answer</b> .		Never	Sometimes	Often	Always
1.	When I have to clean or organize a messy space, I can break up the task into smaller steps (e.g., organize one drawer at a time).	1	2	3	4
2.	I sort items into categories (e.g., clothing, books, trash) on my own.	1	2	3	4
3.	I have specific places in my home for my items (e.g., cleaning supplies are in the closet).	1	2	3	4
4.	After using something, I put it back where it belongs.	1	2	3	4
5.	When I see a mess, I clean it up and do not put it off.	1	2	3	4
6.	I do not let garbage pile up and empty the trash when it is full.	1	2	3	4
7.	I dust, vacuum, mop, and/or sweep regularly (at least once a month).	1	2	3	4
8.	I clean the bathroom regularly (at least once a month), including scrubbing the tub, sink, and toilet.	1	2	3	4
9.	I know how to use household machines (e.g., dish washer, washing machine, dryer) and set the right settings (washing cycle, temperature).	1	2	3	4
10.	When doing laundry, I pre-treat stains and separate my clothes according to color, special washing instructions, and/or fabric weight.	1	2	3	4
11.	I clean out the fridge/freezer on my own and do not leave expired and moldy food.	1	2	3	4
12.	When I notice something needs to be fixed or replaced that I can't do on my own, I call a specialist or service on my own.	1	2	3	4

These questions are about <b>preparing your meals for the week</b> . For each question, please circle <b>only 1 answer</b> .		Never	Sometimes	Often	Always
1.	I break down the task into smaller steps, like planning breakfast, lunch, and dinner for the next few days.	1	2	3	4
2.	I plan my meals to include all the food groups (vegetables, fruits, meats, dairy) for each day.	1	2	3	4
3.	For meals I do not know to make, I follow a recipe.	1	2	3	4
4.	I find recipes online, in cookbooks, or magazines on my own.	1	2	3	4
5.	I know how to follow the steps of a recipe, including gathering all items and ingredients I need.	1	2	3	4
6.	Before making a shopping list, I check the kitchen to see if I already have what I need.	1	2	3	4
7.	Before going to the store, I create a shopping list of things I need.	1	2	3	4
8.	I travel on my own to and from the store.	1	2	3	4
9.	I stay focused on what I need to buy and pick out the items that are on my shopping list.	1	2	3	4
10.	I find the items on my list at the store, and ask the grocery store worker if I need help.	1	2	3	4
11.	I check to make sure I am buying the item of the right size or amount.	1	2	3	4
12.	I check to make sure I am buying an item that is not expired, bruised, or blemished.	1	2	3	4
13.	I compare prices and buy the item that is the better deal.	1	2	3	4
14.	I pay for my groceries on my own at the cash register or self-checkout machine.	1	2	3	4

These questions are about <b>tracking, spending, and managing money</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	I know how to sign into my bank account and use the website on my own.	1	2	3	4
2.	I check my bank account and statements regularly to make sure there are not mistakes.	1	2	3	4
3.	I stay away from spending more money than what is in my account.	1	2	3	4
4.	I use the cash machine or ATM on my own.	1	2	3	4
5.	I talk to the bank staff at the counter or over the phone if I have any questions.	1	2	3	4
6.	I keep my credit/debit card, checks, and cash in a safe place.	1	2	3	4
7.	I keep my bank details to myself and do not share them with people I do not trust.	1	2	3	4
8.	I ask for help if I am unsure about someone contacting me to ask for money.	1	2	3	4
9.	I use a budgeting tool, such as an online application or a spreadsheet, to keep track of my money.	1	2	3	4

These questions are about <b>paying bills on time</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	I open and read my bills on my own.	1	2	3	4
2.	I write a check by myself.	1	2	3	4
3.	I know how to prepare the envelope and send the check through the mail.	1	2	3	4
4.	I mark on my calendar or checklist to keep track of my bills.	1	2	3	4
5.	I sort my bills into categories, such as by type, on my own.	1	2	3	4
6.	I know how to sign into my bank account and use the website on my own.	1	2	3	4
7.	I know how to log into the company's website to pay my bills.	1	2	3	4
8.	I use automatic payment to pay monthly bills, such as credit card or utility bills.	1	2	3	4
9.	I ask people I trust when I have questions about my bills or how to pay them.	1	2	3	4

These questions are about <b>managing daily expenses</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	I keep my credit/debit card, checks, and cash in a safe place.	1	2	3	4
2.	I remember to bring my wallet when I go out and keep it in a safe place.	1	2	3	4
3.	I make a shopping list before I go shopping.	1	2	3	4
4.	I set a budget, or the maximum amount, for what I will buy at the store.	1	2	3	4
5.	I stay focused on what is on my shopping list, and stay away from buying other items that I may not need.	1	2	3	4
6.	I check to make sure I bought the item of the right size or amount.	1	2	3	4
7.	I compare prices and buy the item that is the better deal.	1	2	3	4
8.	When I am paying at the cash register, I check to make sure I am paying the right amount.	1	2	3	4
9.	I do not go over my budget with what I buy in the store.	1	2	3	4
10.	I take the time to look up information or ask for help when buying something I don't normally buy each week, such as new shoes or devices.	1	2	3	4

**Appendix B: SMART (Parent Version)**

**The Self-Management for Autism Rating Tool**

*Parent Version*

These questions are about <b>getting ready in the morning</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	My child knows what time they need to get up so that they can do everything they need to before going to school or work.	1	2	3	4
2.	My child sets an alarm the night before without my help.	1	2	3	4
3.	My child goes to sleep on time so that they get enough sleep to not feel tired.	1	2	3	4
4.	My child wakes up when their alarm rings and gets out of bed.	1	2	3	4
5.	My child performs their morning activities, such as grooming, dressing and eating breakfast, in an orderly fashion.	1	2	3	4
6.	My child checks the time as they do each task to make sure they are on track to leave on time.	1	2	3	4
7.	My child chooses the right clothes for the weather and activity (e.g., work, interview, meeting up with a friend).	1	2	3	4
8.	My child checks if they have everything they need before leaving the house (e.g., keys, money, wallet, cell phone, lunch).	1	2	3	4
9.	My child checks and turns off all lights and appliances (e.g., oven, hair straightener, heater) before they leave the house.	1	2	3	4
10.	My child locks the door or closes the garage before they leave.	1	2	3	4
11.	My child leaves the house at the right time to get to school or work on time.	1	2	3	4



These questions are about <b>keeping the living space clean</b> . For each question, please circle <b>only 1 answer</b> .		Never	Sometimes	Often	Always
1.	When having to clean or organize a messy space, my child can break up the task into smaller steps (e.g., organize one drawer at a time).	1	2	3	4
2.	My child sorts items into categories (e.g., clothing, books, trash) on their own.	1	2	3	4
3.	My child has specific places in their home for items (e.g., cleaning supplies are in the closet).	1	2	3	4
4.	After using something, my child puts it back where it belongs.	1	2	3	4
5.	When there is a mess, my child cleans it up and does not put it off.	1	2	3	4
6.	My child does not let garbage pile up and empties the trash when it is full.	1	2	3	4
7.	My child dusts, vacuums, mops, and/or sweeps regularly (at least once a month).	1	2	3	4
8.	My child cleans the bathroom regularly (at least once a month), including scrubbing the tub, sink, and toilet.	1	2	3	4
9.	My child knows how to use household machines (e.g., dish washer, washing machine, dryer) and set the right settings (washing cycle, temperature).	1	2	3	4
10.	When doing laundry, my child pre-treats stains and separates my clothes according to color, special washing instructions, and/or fabric weight.	1	2	3	4
11.	My child cleans out the fridge/freezer on their own and does not leave expired and moldy food.	1	2	3	4
12.	When my child notice something needs to be fixed or replaced that they can't do, they call a specialist or service on their own.	1	2	3	4

These questions are about <b>preparing meals for the week</b> . For each question, please circle <b>only 1 answer</b> .		Never	Sometimes	Often	Always
1.	My child breaks down the task into smaller steps, like planning breakfast, lunch, and dinner for the next few days.	1	2	3	4
2.	My child plans their meals to include all the food groups (vegetables, fruits, meats, dairy) for each day.	1	2	3	4
3.	My child follows a recipe for meals they do not know how to make.	1	2	3	4
4.	My child finds recipes online, in cookbooks, or magazines on their own.	1	2	3	4
5.	My child knows how to follow the steps of a recipe, including gathering all items and ingredients they need.	1	2	3	4
6.	Before making a shopping list, my child checks the kitchen to see if they already have what they need.	1	2	3	4
7.	Before going to the store, my child creates a shopping list of things they need.	1	2	3	4
8.	My child travels on their own to and from the store.	1	2	3	4
9.	My child stays focused on what they need to buy and picks out the items that are on the shopping list.	1	2	3	4
10.	My child finds the items on the list at the store, and asks the grocery store worker if they need help.	1	2	3	4
11.	My child checks to make sure they are buying the item of the right size or amount.	1	2	3	4
12.	My child checks to make sure they are buying an item that is not expired, bruised, or blemished.	1	2	3	4
13.	My child compares prices and buys the item that is the better deal.	1	2	3	4
14.	My child pays for the groceries on their own at the cash register or self-checkout machine.	1	2	3	4

These questions are about <b>tracking, spending, and managing money</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	My child knows how to sign into the bank account and use the website on their own.	1	2	3	4
2.	My child checks their bank account and statements regularly to make sure there are not mistakes.	1	2	3	4
3.	My child stays away from spending more money than what is in the account.	1	2	3	4
4.	My child uses the cash machine or ATM on their own.	1	2	3	4
5.	My child talks to the bank staff at the counter or over the phone if they have any questions.	1	2	3	4
6.	My child keeps their credit/debit card, checks, and cash in a safe place.	1	2	3	4
7.	My child keeps bank details to themselves and does not share them with people they do not trust.	1	2	3	4
8.	My child asks for help if they are unsure about someone contacting them to ask for money.	1	2	3	4
9.	My child uses a budgeting tool, such as an online application or a spreadsheet, to keep track of their money.	1	2	3	4

These questions are about <b>paying bills on time</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	My child opens and reads the bills on their own.	1	2	3	4
2.	My child writes a check on their own.	1	2	3	4
3.	My child knows how to prepare the envelope and send the check through the mail.	1	2	3	4
4.	My child marks on their calendar or checklist to keep track of their bills.	1	2	3	4
5.	My child sorts the bills into categories, such as by type, on their own.	1	2	3	4
6.	My child knows how to sign into the bank account and use the website on their own.	1	2	3	4
7.	My child knows how to log into the company's website to pay the bills.	1	2	3	4
8.	My child uses automatic payment to pay monthly bills, such as credit card or utility bills.	1	2	3	4
9.	My child asks me or someone they trust when they have questions about their bills.	1	2	3	4

These questions are about <b>managing daily expenses</b> . For each question, please circle <b><u>only 1 answer</u></b> .		Never	Sometimes	Often	Always
1.	My child keeps their credit/debit card, checks, and cash in a safe place.	1	2	3	4
2.	My child remembers to bring their wallet when they go out and keeps it in a safe place.	1	2	3	4
3.	My child makes a shopping list before they go shopping.	1	2	3	4
4.	My child sets a budget, or the maximum amount, for what they will buy at the store.	1	2	3	4
5.	My child stays focused on what is on the shopping list, and stays away from buying other items that they may not need.	1	2	3	4
6.	My child checks to make sure they bought the item of the right size or amount.	1	2	3	4
7.	My child compares prices and buy the item that is the better deal.	1	2	3	4
8.	When they are paying at the cash register, my child checks to make sure they are paying the right amount.	1	2	3	4
9.	My child does not go over the budget with what they buy in the store.	1	2	3	4
10.	My child takes the time to look up information or ask for help when buying something they don't normally buy each week, such as new shoes or devices.	1	2	3	4

## **Appendix C: Executive Summary**

### **The Self-Management for Autism Rating Tool**

#### **Introduction**

Learning to successfully manage the tasks of adulthood is often challenging for youth with autism spectrum disorder (ASD) (Gotham et al., 2015, Henninger and Taylor, 2013). According to the evidence-based research, individuals with ASD experience low rates of employment, higher education, independent living, and life-long friendships after high school graduation (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011). Compared to their peers with other disabilities, young adults with ASD have poorer transition outcomes (Newman et al., 2011; Taylor & Seltzer, 2011). Given the rising ASD population in the U.S. (Center for Disease Control and Prevention, 2019), there will be larger numbers of youth with ASD entering into adulthood, creating an urgent need for additional support during transition. Young adults with ASD are not reaching their potential to live independent and productive lives.

One reason why individuals with ASD have poor transition outcomes may be because there is a lack of understanding of their limitations and needs, resulting in inadequate support during their transition out of high school. These individuals are particularly vulnerable as they experience a shift in service provision after graduating. Because adolescents with ASD are not being effectively connected with programs and resources to address their problem areas, they instead are “falling through the cracks” during their transition to adulthood (Shattuck et al., 2011; Taylor & Seltzer, 2011).

One solution to address this larger problem is the development of an assessment tool for adolescents with ASD to evaluate the skills they need to manage the daily tasks of adulthood. Assessments are used in the transition planning process to identify an individual's strengths and limitations and provide guidance for steps to address the needs. The currently available assessments that evaluate an individual's independent living skills, known as "adaptive behavior" measures, provide a general overview of a person's abilities and are not created specifically to target the problem areas for youth with ASD. There is a need for an assessment that targets specific self-management skills required for adult living that are problem areas for the ASD population.

### **Guiding Theories for the Proposed Solution**

The theoretical models that guide the development of the proposed assessment for the identified problem described in the introduction are the Life Course Theory (Elder & Shanahan, 2007) and the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001). Life Course Theory examines an individual's life history and investigates how early events influenced future decisions and experiences (Elder & Shanahan, 2007). For individuals with ASD, both the symptoms of the disorder and external factors, such as their surrounding environment or societal attitudes, are at play in determining their transition outcomes. The challenges that they face, such as difficulties with the more complex social and cognitive demands of adult roles, can be addressed with appropriate programs and supports (Bellini, Peters, Benner, & Hopf, 2007; Bishop-Fitzpatrick, Minshew, & Eack,

2014). However, in order for adolescents with ASD to be connected with these service and resources, changes will need to occur with external contributors, such as the misconstrued beliefs of educators and parents, the lack of assessments that evaluate self-management capabilities for individuals with ASD, and other systemic barriers in transitioning planning.

The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) is a model which provides a standard language and framework for the description of health and functioning. The model identifies three levels of human functioning: functioning at the level of the body or body part, the whole person, and the whole person in a social context. It assesses the interaction between the health condition and contextual factors, such as external environmental factors and internal personal factors (WHO, 2001). Application of the ICF to define aspects of ASD provides an overview of the strengths and needs of individuals with ASD and can be utilized to improve transition outcomes for this population.

### **The Proposed Assessment**

The proposed solution is the Self-Management for Autism Rating Tool (SMART), which is a transition-readiness questionnaire designed for individuals with autism spectrum disorder (ASD), aged 16 to 35, to measure and track the development of skills they need to acquire in order to manage daily tasks of adulthood. The uses of the SMART are to evaluate and monitor the presence or absence of relevant skills that are significant in key self-management tasks, to identify specific barriers in the transition to



adulthood, to help set individualized goals and objectives, to guide the application of targeted programs and services, and to connect individuals to these programs and services. The assessment can also be used in research in which studies are needed to document the effectiveness of programs, and as a screening tool to identify those who may have difficulty transitioning to adulthood.

### *Features*

There are two versions of the SMART: a self-report and a parent/caregiver report. The items are written in short sentences with everyday language and familiar words to improve readability and comprehension. The SMART includes a selection of scales targeting individual self-management tasks. Each self-management task is broken down into smaller steps or skills, resulting in a set of items for each scale. The evaluated self-management tasks and skills were specifically selected because they are significant in achieving autonomy in adulthood and are often challenging for the ASD population. The self-management tasks and skills evaluated through the SMART target more complex abilities such as organizing, planning, managing time and emotions, responding to new demands, setting own goals, initiating tasks, and adapting to changing contexts. The items also focus on the individual's ability to perform each functional activity in a manner that is effective given their abilities and challenges. They do not require the individual to perform the activity in a specific way for credit. The SMART scores respondents only on items that are in their environment and/or are necessary for them to do. Items can be omitted if they are not relevant for the individual. This allows for a client-centered and individualized assessment.

### *Administration*

The SMART does not require any special environment, materials, or activities to administer. It can be completed independently by the adolescent/young adult and caregiver(s) through a written questionnaire or structured interview. The assessment focuses on performance at the present time. The SMART can be completed on multiple occasions for the same individual and there is no minimum time that must pass between assessments. Although the scale can be completed independently, but the results should be interpreted by a professional with a background in education, pediatrics, and/or rehabilitation. The professional should also have an understanding of functional assessments and scoring to be able to understand and explain the intent of the individual items and meaning of different types of scores.

### *Development of the SMART*

The SMART was developed to be consistent with the ICF model (WHO, 2001), which provides a distinction between self-management skills, which address an individual's ability to function at the level of the person, versus self-management tasks, which address an individual's ability to function at the level of the person in society. In addition, personal and environmental factors were also considered. The response options allow respondents to indicate if a skill is present but not applied consistently due to a variability of performance across environments and people.

Features of the SMART were influenced by the Transition-Q (Klassen et al., 2014), a 14-item scale that measures self-management skills in health and healthcare in adolescents across a range of chronic health conditions, and the Pediatric Evaluation of

Disability Inventory (PEDI-CAT) (Haley et al., 2012), a computer adaptive assessment that evaluates and detects changes in daily functioning for children and youth (birth through 20 years of age) with a variety of physical and/or behavioral conditions. The measure was created to be consistent with a systematic review which recommended using a simple question format, fewer (four to five) response categories, and labeled categories (Khadka et al., 2012).

### **Development Phases and Evaluation**

The SMART will go through three phases of development before clinical use. The first phase involves the initial design of the assessment tool. The second phase involves an evaluation by experts, parents of adolescents with ASD, and individuals with ASD to provide feedback for changes, and a pilot field test to determine how a larger field test will be carried out. The last phase involves conducting a large-scale field test to formally evaluate the assessment in a larger population, and examining if the assessment is consistent and effective for its intended purpose. A rigorous and thorough evaluation will be performed to ensure that the SMART is a well-designed measure which accurately quantifies the self-management capabilities of individuals with ASD and advances the understanding of the needs for this population.

### **Funding Plan**

The development of the SMART requires resources that include significant time, personnel, and financial support. There are expenses associated with designing the initial

instrument, planning and implementing evaluation activities to enhance the measure, and disseminating the proposed assessment. The majority of expenses involve payment for personnel and compensation for study participants. Funding will be provided by the author and obtained from outside sources, including local, state, and federal grants, foundations, and gifts.

### **Conclusion**

The ultimate goal of the SMART is to improve transition outcomes for youth with ASD through enhancing understanding of their capabilities and improving coordination of services and supports that target problem areas related to managing the daily tasks of adulthood. Increased knowledge and adoption of the measure in transition planning, programs and supports, and research can help parents, educators, involved professionals, and the adolescents themselves, better address the needs of the ASD population. The SMART can contribute in helping adolescents with ASD reach their potential to live independent and productive lives in adulthood.

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## Appendix D: Fact Sheet



The Self-Management for Autism Rating Tool (SMART):  
 A Transition-Readiness  
 Questionnaire for Individuals with  
 Autism  
*Jean Lin, MS, OTR/L*

### The Problem:

- Young adults with autism spectrum disorder (ASD), regardless of intellectual ability, experience poor transition outcomes, such as low rates of employment, secondary education, and independent living after high school graduation (Eaves & Ho, 2008; Howlin & Moss, 2012; Gotham et al., 2015; Orsmond et al., 2013; Newman et al., 2011; Taylor & Seltzer, 2011).
- Given the rising ASD population in the U.S., there will be larger numbers of youth with ASD entering into adulthood, creating an urgent need for additional support during transition (Centers for Disease Control and Prevention, 2020).
- Adolescents are particularly vulnerable as they experience a shift in service provision after graduation, and therefore, are “falling through the cracks” during their transition to adulthood (Shattuck et al., 2011; Taylor & Seltzer, 2011).

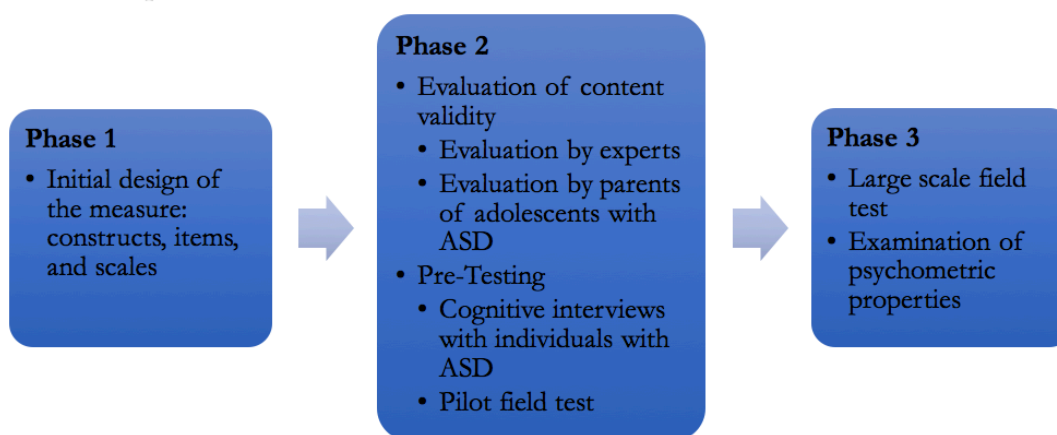
### The Proposed Solution:

- The Self-Management for Autism Rating Tool (SMART) is a clinical measure designed for individuals with ASD, aged 16 to 35, to measure and track the development of skills needed to manage the daily life tasks of adulthood.
  - *Developed specifically for ASD:* The ASD population presents with unique problem areas compared to other disability groups. The SMART was developed specifically to address areas that are challenging for individuals with ASD, such as complex tasks requiring emotion regulation, sensory information processing, and executive functioning.
  - *Meaningful and individualized assessment:* The SMART allows for omission of items that are not meaningful or relevant to the individual, providing a client-centered and individualized evaluation.
  - *Specific and explicit evaluation:* The SMART deconstructs key self-management tasks into a set of relevant skills, allowing for evaluation of what is changing over time and identification of the underlying mechanisms affecting change. This explicit information is helpful for guiding intervention efforts.



- *Time efficient and cost effective:* The SMART does not require any special environment, materials, or activities to administer. It can be completed independently by the adolescent/young adult or caregiver(s) through a written questionnaire or structured interview.
- The SMART can be utilized in transition planning to set individualized goals and connect adolescents with appropriate programs and services, in interventions to assess targeted areas and measure progress, and in research to determine the effectiveness of programs.

### The Development of the Assessment:



### Impact on Occupational Therapy:

- Occupational therapists (OT) are often key personnel in transition planning and services for individuals with ASD. Increased knowledge and adoption of the SMART can help OTs better address the needs of youth with ASD in order to help them reach their potential and live independent and productive lives in adulthood.
- The SMART can be utilized in clinical practice to identify specific problem areas to address, set individualized goals, guide application of interventions, monitor changes, and measure outcomes.

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