UNIVERSITY OF CALIFORNIA

Los Angeles

Personalized Assessment for Youth with Autism:

Evaluating the Psychometric Properties

of a Semi-Structured Interview

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Education

by

Amanda Rose Johnson

© Copyright by

Amanda Rose Johnson

ABSTRACT OF THE DISSERTATION

Personalized Assessment for Youth with Autism:

Evaluating the Psychometric Properties

of a Semi-Structured Interview

by

Amanda Rose Johnson

Doctor of Philosophy in Education

University of California, Los Angeles, 2024

Professor Jeffrey J. Wood, Chair

Abstract

Personalized assessment measures focusing on caregiver-reported problems have been found to be psychometrically robust and useful in monitoring the clinical response of typically developing children in psychological interventions due to the high sensitivity to change of such measures (e.g., Weisz et al., 2011). However, until recently, these measures have not addressed autism-related challenges, and there is still a need for a personalized assessment of children and youth with autism that 1) is broadly inclusive of the heterogeneity of autism-related needs, 2) addresses the critical perspective of caregivers, and 3) facilitates intervention monitoring for

specific children. This project explores the development and psychometric properties of a newly developed personalized semi-structured interview for caregivers of children with autism drawing from the ratings methodology used in the Top Problems Assessment (TPA) developed by Weisz and colleagues (2011) in two phases. The newly developed semi-structured interview (known namely as the YTP-Interview) protocol addresses multiple autism-related clinical areas and identifies the top problems salient to the caregivers, allowing for rapid repeated administration throughout intervention. Through qualitative exploration, the pilot study (Phase 1) of the project found that extensive clinical information can be obtained from this personalized semi-structured interview. Caregivers reported individualized problems in relation to six clinical domains (e.g., externalizing behavior, peer engagement), demonstrating rich insight into their child's specific challenges and needs. Phase 2 of the project examined the test-retest reliability, convergent and discriminant validity, sensitivity and specificity, and face validity of the YTP-Interview across six domains: Dysregulated and Disruptive Behavior, Anxiety and Depression, Restricted and Repetitive Behaviors, Peer Engagement in School and Community, Conversation and Friendship, and Self-Care Skills. Data was collected from 31 caregivers of children with autism at three time points: Baseline, Week 1, and Week 2 of intervention. Spearman's rho correlations indicated strong test-retest reliability for all domains, with particularly high correlations for the Peer Engagement and Conversation and Friendship domains. The ROC curve analysis provided valuable insights into the utility of the YTP-Interview for identifying clinically significant problems in children with autism. The analysis revealed that the optimal cut-scores demonstrated acceptable levels of sensitivity and specificity across five of the six clinical areas. The face validity results demonstrated high accuracy across all domains, with percentages ranging from 98% to 100%. Furthermore, caregiver satisfaction with the YTP-Interview was overwhelmingly

positive, with 100% of participants indicating they were very satisfied with the process. Overall, the findings suggest that the YTP-Interview is a reliable and valid tool for identifying and monitoring the top problems in children with autism as reported by their caregivers, demonstrating strong psychometric properties that support its use in clinical practice and research applications. The results from this study are promising, suggesting that this new measure has the potential to align assessment and intervention foci with the needs and aspirations of families.

Keywords: autism, idiographic assessments, personalized care, measurement-based care, caregiver goals, top problems

The dissertation of Amanda Rose Johnson is approved.

Catherine Lord Morrison

Minjeong Jeon

Bryce D. McLeod

Jeffrey J. Wood, Committee Chair

University of California, Los Angeles

2024

Table of Contents

Introduction	1
Methods	14
Results	22
Discussion	27
Tables	36
Supplementary Materials	45
Appendix	48
References	58

List of Tables, Figures, and Supplementary Materials

Table 1 – Areas of Clinical Need for Autistic Youth	5
Table 2 – Demographic Characteristics of Child and Caregiver (N=31)	7
Table 3 – Descriptive Statistics	3
Table 4 – Total Number of Top Problems Reported and Average Severity Scores39)
Table 5 – Spearman's Rho Correlation for Interview Domains Across Time Points40)
Table 6 – Spearman's Rho Correlation Coefficients	l
Table 7 – ROC Curve Analysis for YTP-Interview Domains	2
Table 8 – Face Validity43	3
Table 9 – Post-Interview Survey Data44	1
Table 10 – Phase 1: Demographic Characteristics of Child and Caregiver	5
Table 11 – Phase 1: Total Number of Top Problems Reported and Average Severity Scores46	5
Table 12 – Phase 1: Brief Attitudinal Survey Data	7
Appendix A – Interview Protocol	3
Appendix B – Clinical Area Parent Rating Cards55	5

Acknowledgements

As I'm writing this I'm filled with such joy and gratitude thinking of all the wonderful people who helped me reach this point. First and foremost, thank you, Dr. Jeffrey Wood, for shaping me as a researcher and academic, for playing such a pivotal role in this research, and for encouraging me to explore every idea. Your significant influence and unwavering support have been invaluable, and I couldn't have asked for a better advisor.

I would like to express my deepest appreciation to my dissertation committee, Dr. Catherine Lord Morrison, Dr. Minjeong Jeon, and Dr. Bryce McLeod, who dedicated their time to getting this project to this stage. Your support and feedback throughout this project have been instrumental in shaping this research. Learning from you all is something I will forever cherish. To my other mentors along the way, Dr. Sunny Kim, Drs. Robert and Lynn Koegel, Dr. Karen Sze Wood, your guidance has been incredibly valuable, and I will always appreciate everything you've done for me. Thank you to Kashia and Billy who showed me the ropes and demonstrated how to work hard while balancing life outside of academia. To Ginny & Lauren, who constantly reminded me that you're never alone on this journey. To Tommer, who has been by my side since day one and has made exploring the wonders of LA an unforgettable experience. To the other members of the Wood Lab who continually spark my intellectual curiosity and push our research to new heights, thank you Jolie, Katherine, Ingrid, Samara, and Keenan. I am so excited to see what you all accomplish next.

To my partner, Jen, who has been the biggest support I could have ever asked for. Thank you for enduring the late nights and early mornings with me, and for standing by my side through all the highs and lows. I want to be a better person every day because of you. And to Rylee, our amazing pup, who has been with us every step of the way and makes every day

brighter. You two are my world. To partner's parents, Nancy and Joel, your kindness and support have been incredibly meaningful to me, and I am truly grateful for your presence in my life.

I am beyond blessed to have the most supportive group of college friends who have turned into lifelong friends. I am so grateful for the squad trips that made this journey tolerable and all the other things you all do to bring so much joy into my life. Although I have my bruin pride, I'll forever be a UCSB gaucho. A heartfelt shout out to Veronika and Jenny for constantly boosting my confidence and reminding me every moment possible of how special our friendship is. To my Culver City crew, Leigh, Madi, Jordan, Ben & Quinn, I'll forever be grateful for the golf, pickleball, trivia nights and all the chit chats. To my oldest friends Tara and Amanda, thank you for growing up next to me, and growing with me. You two will always hold such a special place in my heart.

To my family who has helped me get to this place: Adam and Katie, you two have been the biggest rock and support for me, providing a safe place to land and a family to lean on – that sense of security has meant the world to me. To my parents, who always did the best they could and accepted me for exactly who I am. Your unconditional love and support have been my foundation. Daniel, who without you I wouldn't have started my grad school fund at the age of 10 or known I wanted to pursue higher education. To my brave and curious nephew Byron, thank you for inspiring me to explore this field. To my nieces and nephews, watching you grow up has been one of the biggest blessings. And to the rest of my family who provided nothing but good times and laughs, I feel so fortunate to have you all supporting me. I love you all so much.

You have all brought so much light to my grad school journey, and I'm incredibly grateful for your support. To those I couldn't name, I appreciate you more than words can express.

VITA

EDUCATION	
2024	University of California, Los Angeles Ph.D. Candidate Graduate School of Education & Information Studies
2016	University of California, Santa Barbara B.A. Communication Studies Emphasis: Applied Research Methods Minor in Applied Psychology & Minor in Education
SELECTED C	ERTIFICATES & AWARDS
2021	Leadership in Education and Neurodevelopmental Disabilities Certificate $Fellow$ (500+ hours completed) UCLA
2021	Center for the Integration of Research, Teaching and Learning Practitioner UCLA
2018 & 2019	Graduate Summer Research Mentorship (x2) & Graduate Research Mentorship
2018 – 2019	Robert Levine Scholarship Recipient
2017 - 2020	UCLA GSE&IS Merit-Based Academic Scholarship
RESEARCH E	XPERIENCE
2017 – 2023	UCLA Developmental Diversity Lab (WoodLab), Graduate Student Researcher
2021 - 2022	UC Davis MIND Institute, Cognitive Behavioral Therapist (Research Setting)
2019 –2021	ABC Child Partial Hospitalization Program, Graduate Student Researcher
2018 – 2019	KidsConnect Autism Program, Graduate Student Researcher
TEACHING E	XPERIENCE
2023 – 2024	Grader - University of California, Los Angeles TCL Master's Program in Department of Education: Philosophy of Coaching
2019 – 2021	Teaching Associate – University of California, Los Angeles Psychiatry 79: Applied Positive Neuroscience
2018 – 2021	Teaching Associate – University of California, Los Angeles Psychology 130: Developmental Psychology Psychology 131: Research in Developmental Psychology Psychology 134A & B: Applied Developmental Psychology Psychology 134J: Dynamics of Parenting Psychology 188B: Adversity in Early Childhood Development

SELECTED PUBLICATIONS

Total Publications = 10

- **Johnson, A. R.***, Wolpe, S.*, Kim, S., (2024) Navigating the Transition to Adulthood: Insights from Caregivers of Autistic Individuals. *Journal of Autism and Developmental Disorders*.
- Tien, I. S., **Johnson, A. R.,** Kim, J., & Wood, J. J. (2023). Examining Diagnostic Trends and Gender Differences in the ADOS-II. *Journal of Autism and Developmental Disorders*, Advance online publication.
- Wood, J. J., Wood, K., Rosenau, K., **Johnson, A. R.,** Cho, A., Herschell, A., Muscatello, V. S., & McLeod, B. D. (2023) Practitioner Adherence and Competence in MEYA, a Free Online Self-Instruction Program in Modular CBT for Children's Autism-Related Clinical Needs and Mental Health Challenges. *Journal of Autism and Developmental Disorders*.
- **Johnson, A. R.,** Wolpe, S., Straus, J., Wood, K., & Wood, J., (2022) Cognitive Behavioral Therapy for Youth with Autism: Review and Recommendations for Treatment Development. *Evidence-Based Practices in Autism Spectrum Disorder Second Edition* (in press).
- **Johnson, A. R.,** Wolpe, S., Tien, I. S., Muscatello, V. S., & Wood, J. J. (2023). Cognitive-behavioral therapy for children with autism and anxiety. In *Handbook of Lifespan Cognitive Behavioral Therapy* (pp. 181-191). Academic Press.
- Wood, J. J., Kuhfeld, M., Sturm, A., Cai, L., Wood, K. S., Cornejo Guevara, M. V., Galán, C. A., **Johnson, A. R.**, Cho, A., & Weisz, J. R. (2022). Personalized Autism Symptom Assessment with the Youth Top Problems Scale: Observational and parent-report formats for clinical trials applications. *Psychological Assessment*, *34*(1), 43–57.

SELECTED PRESENTATIONS

Total Presentations = 18 | First Authored = 8

- **Johnson**, A.R. & Wolpe, S. (2022). Navigating the Post-High School Service Landscape: Reflections from Caregivers of Autistic Young Adults. In A. Kuo (Chair), *AIR-P Research Day at AUCD 2022*. Poster Symposium presented at Association of University Centers on Disabilities 2022 Annual Conference, Washington, D. C.
- **Johnson, A. R.,** Cho, A., Rosenau, K. (2022). A Free, Open-Access, Internet-Based CBT Training Platform for Clinicians Working with Children on the Autism Spectrum: Development and Initial Evaluation. In J. J. Wood (Chair), A Free, Open-Access, Internet-Based CBT Training Platform for Clinicians Working with Children on the Autism Spectrum: Development and Initial Evaluation.

 Symposium presented at the Association for Behavioral and Cognitive Therapies Annual Convention.

SELECTED SERVICE

2023	Infrastructure for Collaborative Research – AIR-P Network: Committee Member
2023	Cureus – Part of Springer: Manuscript Reviewer
2022	The ACM CHI Conference on Human Factors in Computing Systems: Student Volunteer

Autism is highly heterogeneous, creating a need for personalized measures and resources to inform the course of clinical care based on the individual's needs (Lord et al., 2020). While diagnostic instruments are often used by practitioners to systematically identify individuals with autism (Lord et al., 2022), there is a paucity of informant-based measures that account for multiple areas of autism-related challenges for children with autism. The growing awareness that autism-related characteristics transcend multiple diagnostic classifications lends itself to the critical need for a personalized tool that assesses these as part of a comprehensive evaluation (Lai et al., 2019). Personalized symptom assessments (e.g., Weisz et al., 2011) have features that are sensitive to behavioral changes over time for youth with autism (Wood et al., 2022) and could be implemented in various contexts, including community-based care, at little to no financial cost. Therefore, the goal of this project is to provide a comprehensive evaluation of a brief semi-structured interview, including its reliability, convergent validity, and sensitivity to treatment-related changes. Building upon the initial development and pilot phase, the study focuses on the personalized semi-structured interview that addresses multiple autism-related traits and captures the primary concerns reported by caregivers of youth on the spectrum.

Literature Review

Autism & Assessment in Community Mental Health

Autism is a complex neurodevelopmental condition characterized by differences in social communication and rigid and repetitive behaviors (APA, 2013). These can vary significantly from person to person, demonstrating the heterogeneity of autism (Masi et al., 2017; Ozonoff et al., 2010). Individuals with autism may experience a variety of autism-related challenges (Kaat & Lecavalier, 2015), including dysregulated and challenging externalizing behaviors (Laugeson

et al., 2012), anxiety or emotional dysregulation (Wood & Gadow, 2010; Lai et al., 2019), rigid or repetitive behavior (Lord et al., 2000; Gabriels et al., 2005; Golya & McIntyre, 2018), social communication difficulties (Sandbank et al., 2021), challenges engaging in school and community settings (Weiss & Harris, 2001), and difficulties with adaptive living skills (Palman et al., 2012; Neely et al., 2016). For example, children with autism have an increased likelihood of having co-occurring anxiety disorders, as up to 80% of children with autism meet the criteria of a clinical diagnosis of anxiety (Simonoff et al., 2008), in comparison to the approximately 7% of typically developing children who have clinical anxiety (Ghandour et al., 2018).

Assessment is essential to understanding an individual's needs and goals during clinical care (Lai et al., 2019). However, traditional comprehensive evaluations are time-consuming and expensive, and test selection can be arbitrary (Kaat & Lecavalier, 2015). Frequently, clinicians opt for a rushed assessment because time and cost concerns are often a barrier (Adams et al., 2021). Overall, the assessment process can be a tumultuous experience for families. This is unfortunate because it can prevent individuals and families from accessing needed services.

While numerous instruments designed to measure autism-related traits have been developed over the past two decades and have significantly influenced the field (Havdahl et al., 2016), they are not without shortcomings. First, many brief standardized measures ask individuals to respond to fixed questions (e.g., the Social Responsiveness Scale (SRS); Constantino & Gruber, 2012), the Child Behavior Checklist (CBCL; Achenbach & Ruffle, 2000), and the Adaptive Behavior Assessment System (ABAS; Harrison & Oakland, 2003). Although this approach is valuable in that it is short and easy to administer, it may fail to address the heterogeneity of autism as these assessments often only target one domain of development (i.e., the SRS measures social-communication difficulties and RRBs). Consequently,

standardized questionnaires may lead to misguided estimates of presenting challenges (Wood & Gadow, 2010). The structure of questions and input from caregivers typically limits the caregivers(s) and encourages them to use clinical jargon that does not closely match their child's clinical needs. Bannon and McKay (2005) found that families whose care did not match the caregiver's requested goals ended treatment earlier than those who received care aligned with their targets. There is a clear need for a validated assessment tool that takes into consideration how autistic-related challenges and other co-occurring mental health conditions may present in people with autism in their own unique ways (Lai et al., 2019; Kaat & Lecavalier, 2015).

Personalized / Idiographic Assessments

Assessment measures for youth with autism have been primarily nomothetic (Ung et al., 2015; Norris et al., 2022) with a focus on broad-based and singularly focused symptom presentations. The benefit of this approach is that it provides an assessment of how an individual's characteristics and challenges compare to a broader population (Haynes & O'Brien, 2000; Haynes et al., 2009). However, there is emerging evidence suggesting that idiographic measures, in which individual clients are compared to themselves over time (Haynes et al., 2009; Weisz et al., 2011), have the potential to capture improvement in personalized treatment targets throughout care (Christon et al., 2015). Idiographic assessments are unique to the individual and their experiences. Research is beginning to reflect the importance of individualized care for children enrolled in psychotherapy (West et al., 2016; Hume et al., 2021).

In early efforts, Weisz and colleagues developed the Youth Top Problems Assessment (TPA) scale, a personalized assessment administered after a structured diagnostic interview (2011). The rationale for the TPA was to provide a structured way for collecting caregiver's main areas of concern through a psychometrically sound, client-guided approach. When

implementing the TPA, caregivers are asked to state in their own words the top three problems their child was experiencing that would be important to address in clinical care (details of the interview procedure are provided below). The TPA (Weisz et al., 2011) is sensitive to capturing change over the course of treatment while also providing personalized information on problems faced by the youth rather than nomothetic measures like the Pediatric Anxiety Rating Scale and Child Behavior Checklist which may characterize aspects of anxiety rather than a full clinical profile. Through utilizing the TPA as an outcome measure, there are opportunities to address specific treatment goals that align with the family's needs and priorities (Wood et al., 2019; 2022). The findings from the initial study found the TPA measure to be a psychometrically sound tool sensitive to invention response and supplements empirically derived assessment (Weisz et al., 2011) however, it is not without its limitations. First, the TPA interview requires a lengthy structured interview like the Anxiety Disorders Interview Schedule (Brown & Barlow, 2014) to take place prior to collecting youth top problems, which requires an extensively trained clinician to administer and which is costly and inefficient from a services perspective. Additionally, the TPA focuses on just three clinical challenges across any domain of clinical need, potentially limiting its assessment scope for many children. Furthermore, it was not developed for children with autism, suggesting that autism-specific revisions should be considered.

In short, there is a need for personalized psychological assessment of children on the spectrum that is broadly inclusive of the heterogeneity of autism-related need, addresses the critical perspective of caregivers, and facilitates intervention monitoring for specific children (Christon et al., 2015; Weisz et al., 2011; Wood et al., 2015b; Wood et al., 2022). Currently,

there is no personalized assessment tool of this sort for children with autism (Wood et al., 2015b; Wood et al., 2022).

Need for Accessible, Low-Cost, and Free Evidence-Based Assessment Resources in School and Community Environments

Youth with autism and their caregivers often seek services in multiple settings; however, reports indicate that the primary setting for services is in school and community contexts (Pickard et al., 2018; Zablotsky et al., 2015). A study by Zablotsky et al. (2015) found that 61.7% of children with autism in their sample received only community-based services (i.e., physical therapy, social skills training, occupational therapy, and speech or language therapy). with that percentage rising to 72.2% when examining children with autism and ID (intellectual disability). Given that much of the youth autistic community is exclusively utilizing communitybased mental health services (such as, early intervention programs, ABA services, social skills training, parent training and support, community mental health center), it is imperative that resources are available to support their students and clients. Conversely, it is vital that these measurements are validated in community-based care settings to ensure generalizability. Further, future assessment research should prioritize the needs of community-based contexts as these are the most likely settings where individuals on the spectrum will be addressing their reported autism-related challenges. One aspect to this pursuit that has to date received little attention is evidence-based assessment (EBA), a foundational component of evidence-based practices (EBP; APA, 2013; Hunsley & Mash, 2007).

Phase 1: Development & Pilot of the Personalized, Semi-Structured Interview

The first phase of this program of research endeavored to build from the Youth Top Problems Assessment (TPA) developed by Weisz and colleagues (2011) and apply it for use by community practitioners without specialized training serving youth on the spectrum in healthcare or mental health practice settings. First, the original TPA methodology is summarized, and then, the process for the adaptations devised for this project are described.

Background: The Top Problems Assessment

The Top Problems Assessment (TPA) is an idiographic instrument designed to identify and monitor youth problems that are especially important from the caregiver's perspective (Weisz et al., 2011). The TPA approach was created to individualize treatment outcome assessment while also being a psychometrically sound procedure. The original study by Weisz and colleagues explored whether the Children's Interview for Psychiatric Syndromes (The ChIPS; Rooney et al., 1999; Weller et al., 2000) could be administered as the first step of an idiographic interview about a youth's specific clinical needs. The ChIPS diagnostic interview is a structured interview based on the DSM-IV criteria widely used in clinical practice that spans multiple internalizing and externalizing disorders, found to be common in youth outpatient settings (Rooney et al., 1999); however, autism is not included. The TPA is then administered after the structured ChIPS interview to obtain severity ratings of the top 3 clinical problems the caregiver identifies. Caregivers were encouraged to list the problems they were most concerned about in their own words. Once a preliminary list of concerns was discussed, the interviewer would first probe to see if any additional problems were not covered in the interview. The interviewer would recite the list of problems endorsed by the caregiver while asking questions such as "which one is the biggest problem right now? Which of these is giving [youth's name] the most trouble right now? Which one is the most important to work on?" Once the three top problems were decided upon, severity ratings were obtained for each top problem using a 0-10

scale, with 10 being the most severe. Although brief, the interview procedure for identifying top problems requires clinical skill and procedural guidelines (Herren et al., 2018).

An additional component of the TPA measure is that once top problems are identified in an initial interview, the caregiver's top problem can then be repeatedly assessed via a brief, progress-monitoring rating scale on a weekly basis during treatment. In the original TPA clinical sample (N = 178), the psychometric properties of the TPA were shown to have strong reliability, validity, and sensitivity to change during treatment (Weisz et al., 2011). These findings suggest that the TPA measure may have the psychometric properties needed to make it a valuable tool for clinical research and practice to complement standardized measures. A standardized measure may show that a youth "worries," but top problem identification shows what the youth worries about, adding specificity to the problem rather than the general information provided by standardized measures. Idiographic assessments have the ability to serve as a complementary tool to existing strategies and not as a replacement for families seeking comprehensive diagnoses that include important aspects such as language level, nonverbal cognition, academics, autism characteristics, and family functioning.

The Youth Top Problems – Interview (YTP-Interview)

The novel semi-structured interview developed for this project aimed to ensure that the assessment would capture the current challenges and concerns of parents of children and youth with autism. The a priori goals of the new semi-structured clinical interview were to create a measure that would 1) be brief enough to fit within the parameters of a single-hour intake therapy session (typical of community-based care settings), 2) address all major areas of autism-related clinical needs (including common co-occurring mental health concerns), and 3) automatically and reliably classify each top problem into an appropriate clinical domain (the six

identified clinical areas noted previously, e.g., externalizing behavior, social-communication, etc.). While this measure integrates similar principles of the original TPA, such as caregivers having the opportunity to report in their own words and the basic format of the TPA problem inquiry model, it differs from the original since it does not require a lengthy and routinized structured interview to be administered first in favor of an efficient and conversational single-hour interview that is intended to accomplish all three goals.

The semi-structured interview follows an overall structure but allows for discussion within the interview to develop a supportive connection with the caregiver. Semi-structured interviews are a sensitive and reliable form of measurement (Lord et al., 1999; Lord et al., 1994). When administered, responses can be followed with probes and prompts to enhance the precision and accuracy of responses. The advantage of using semi-structured interviews is that they collect responses of greater precision, scope, and specificity than brief self-report inventories. The methods of constructing and designing the semi-structured interview included: evaluating conceptual articles regarding domains of interest (i.e., evaluating construct relevance), reviewing relevant scales and their factor loadings such as the SRS and CBCL (Constantino & Gruber, 2012; Achenbach & Ruffle), and multiple rounds of expert feedback. Previous research has identified six main areas of potential clinical need for autistic youth: externalizing problems, internalizing problems, repetitive behavior, peer social engagement, social communication, and self-care (Wood et al., 2015a). Therefore, this personalized (idiographic) semi-structured interview focuses on these six primary areas titled as: 1) Dysregulated and Disruptive behavior, 2) Anxiety and Depression, 3) Restricted and Repetitive behaviors (RRBs), 4) Peer Engagement in School and Community (Peer Engagement), 5) Conversation and Friendship, and 6) Self-Care Skills (Self-Care) (see Table 1 for full details and definitions).

Interview Design

The interview consists of two components, 1) instructions to guide the clinician through the interview and 2) visual supports to help support informative responses from caregivers. The instructions for the clinician outline the purpose of the interview and how to guide the caregiver through each topic. Instructions for each of the six clinical areas are customized with exact wording or suggested paraphrasing that corresponds with six visual support pages (referenced as cue cards) that the caregivers view simultaneously with the interviewer. The interviewer is instructed to show one cue card at a time to help convey the concepts being addressed comprehensively, and the interviewer helps highlight the critical elements of the cue card verbally (see Clinical Area Cards, Appendix B). For example, for the second clinical area, internalizing behaviors (known as the Anxiety and Depression domain), the interviewer may present the cue card to the caregiver in the following way, (while pointing to the words on the Cue Card to the caregivers) "Some children tend to become [read boldfaced words first, such as 'Anxious'], about different things. They may [read the non-bold words like 'have many fears']." The six clinical areas are accompanied by a set of descriptors (the bold-faced words in the clinician instructions and script and two to three items that immediately follow). Many clinical area cards also address several subdomains; for example, the 'internalizing clinical area' (card 2) addresses both anxiety and depression.

One of the goals of the interviews is to encourage specificity of reported challenges; therefore, the interviewer may need to help the caregivers describe the child's specific problems or behaviors within that area in as specific a way as suits the situation. The instructions outline examples to support the interview with this goal, such as "for example, if the child often hits peers at school as well as siblings, the problem can be worded that way; if the child hits

indiscriminately across situations, the wording of the problem should reflect that." The descriptors were developed as proxies of higher-loading items from the reviewed trait inventories. Furthermore, the semi-structured format allows for the interview to integrate follow-up questions which may help to clarify contextual details, address ambiguous responses, and confirm the frequency or intensity of the reported concern.

This personalized assessment elicits multiple problems or challenges per each clinical area described in the caregivers' own words (e.g., "he doesn't know how to start playing with other kids"). During the interview, once the caregiver describes all their unique challenges and problems for each clinical area, the caregiver is asked to rate each problem in terms of its severity on a 0-10 Likert-type scale, with a 0 being 'not a problem and 10 being 'a very, very big problem.' The cue cards presented to the caregivers correspond with the six clinical areas and include a scale at the bottom for obtaining severity ratings for each reported concern. Once this process has been completed, the two problems with the highest severity rating are identified as high-priority goals or problems for tracking across the course of treatment. This assessment generates up to 12 top concerns (goals or problems) across the six clinical areas for such repeated monitoring (up to 2 per clinical area, see Table 1) although at baseline, no explicit limit is placed on the number of problems endorsed per area, allowing us to assess typical patterns of problem endorsement at the onset of intervention. This measure aims to translate the challenges children and youth are experiencing into defined and measurable goals that caregivers can rate weekly throughout treatment to help monitor outcomes.

Pilot Study: Qualitative Exploration of the Personalized Semi-Structured Interview

In the pilot study, qualitative methods were employed to explore and categorize the challenges associated with autism as reported by caregivers. The study had two primary aims.

The first aim was to identify emerging themes and characteristics within the problems reported by caregivers and classify the most significant challenges within six clinical areas. The second aim was to generate preliminary data on caregivers' satisfaction with the brief, semi-structured format. Participants for the pilot study were recruited through two different integrated day treatment programs located at a Tier 1 research institution and included eight caregivers (seven mothers and one father; average age 40.13, range 32-48 years old) of children with autism (seven males; average age 6.1, range 3 – 13 years old; see Supplementary Materials: Table 10).

Findings

The problems described by caregivers mapped onto the prompts from the six clinical domains surveyed in the YTP-Interview, offering compelling evidence of face validity: that is, because parents provided problem descriptions concurrent with each of the six clinical areas during the expected section of the interview, the automatic categorization of parent-reported problems into broader clinical domains (e.g., externalizing, social communication) was highly successful and could be expected to produce relevant evidence based practice allocation by clinicians during intervention (e.g., intervention components addressing externalizing difficulties for a child whose top problems were classified as externalizing) (see Supplementary Materials: Table 11). Another promising finding was that the attitudinal data collected suggests that caregivers enjoyed this interview format, with all participants expressing that they would take part in this style of interview again (see Supplementary Materials: Table 12). Post-interview survey data indicated that caregivers were satisfied with the assessment process.

The pilot study was the first step in the larger scope of this project to evaluate the psychometric properties of the YTP-Interview in conjunction with traditional measures.

Phase 2: Psychometric Evaluation Study

Therefore, this study aimed to assess the reliability and validity of a brief, personalized semi-structured interview for parents of youth on the spectrum in community mental health and school settings.

Aim 1: Explore the test-retest reliability of the brief semi-structured interview by examining correlations over time (during intervention).

Hypothesis 1: YTP-Interview scores will exhibit strong test-retest reliability over a 1-week timeframe during the first two sessions of intervention.

Aim 2: Assess the convergent and divergent validity of a brief semi-structured, clinically guided interview for caregivers of youth with autism in community mental health and school settings.

Hypothesis 2: The YTP-Interview scores will show moderate to strong correlations with scores obtained from established measures assessing similar constructs, and weaker correlations with scores obtained from established measures assessing non-aligned constructs.

Aim 3: Evaluate the sensitivity of a brief, personalized, semi-structured interview to clinically significant scores on traditional symptom rating scales.

Hypothesis 3: It is hypothesized that the YTP-Interview scores will exhibit adequate sensitivity and specificity for detecting clinically significant scores on traditional symptom rating scales.

Aim 4: Assess the face validity of the YTP-Interview by evaluating the accuracy of total problems reported in each domain as perceived by caregivers.

Hypothesis 4: The YTP-Interview will demonstrate high face validity, with a high percentage of problems rated as belonging in the automatically assigned clinical domain,

indicating that the interview effectively categorizes the problems of concerns described by caregivers.

Aim 5: To evaluate caregivers' satisfaction with the brief, semi-structured interview process and gather qualitative feedback to support and enhance the development of the interview methodology.

Hypothesis 5: Caregivers will report a high level of satisfaction with the brief, semistructured interview, as evidenced by Likert scale ratings and qualitative feedback indicating that the interview captured relevant information and was a positive experience overall.

Within this conversational assessment approach, we can utilize caregivers' descriptions to find what the parents feel are the main challenges their autistic child faces, making this tool person-centered, efficient, and accessible for various contexts.

Theoretical Framework

Two theoretical perspectives informed this research. First, the theory of "the autisms," the primary conceptual model, suggests that autism is a heterogeneous disorder with multiple etiologies (Geschwind & Levitt, 2007), meaning individuals' experiences can vary significantly in their clinical presentation. Studies conducted by Geschwind and Levitt (2007) and Maximo et al. (2014) suggested that autism is unlikely to be associated with the differences in one specific brain region alone or universally associated with any genetic pattern but rather linked to the differences of multiple, spatially distributed neural systems. Therefore, research efforts should attempt to appropriately account for the differing needs of autistic individuals while attempting to understand the specific and non-specific factors that influence the variability in relative risk, trait expression, treatment responsiveness, and in the co-occurrence of medical and mental health symptoms.

Second, the methodology for this study is guided by the theoretical framework of nomological networks, as established by Cronbach and Meehl (1955) and Kane (1980). This theoretical construct encompasses fundamental principles that pertain to observable properties and the nomological validity of scales, specifically how they correlate with measures of different yet related constructs. The application of this framework emphasizes the practical utility of assessments in providing evidence-based practices for clinicians and professionals involved in designing comprehensive early intensive behavioral intervention programs for children with autism. By aligning with the theoretical framework of nomological networks, this study seeks to establish a solid foundation for the validity of the personalized, semi-structured interview assessment employed. It ensures that the assessments are reliable, relevant, and possess the necessary psychometric properties to accurately capture and measure the key constructs associated with autism. This approach aims to enhance the overall quality and usefulness of the assessment tools in facilitating evidence-based practices for clinicians and professionals working with children on the spectrum.

Methods

This study received Institutional Review Board approval.

Participants

The participants for this study were recruited due to their involvement in a larger study examining emotional and behavioral needs for children aged 6-14 years with autism, which compared cognitive behavioral therapy (CBT) and usual clinical care. The study sample for this phase of the YTP-Interview project comprised 31 caregivers of children on the spectrum, recruited from community mental health clinics and school settings (*see below*). The inclusion

criteria for participation were 1) be a caregiver of a child or adolescent between the age of 5-17 years, 2) for that child to have an autism diagnosis or meet research criteria for inclusion (SRS; t-score > 60), and 3) the child must possess verbal abilities, demonstrated by a Vineland expressive communication score above 8, to participate to the broader study. Additionally, for this project, the caregiver must be proficient in English and have reliable internet access to participate in the ZoomTM interview component. Eligibility was determined through a brief screening phone call with a study team member, which assessed all exclusion criteria. Upon initial eligibility confirmation, caregivers schedule their ZoomTM interview with a study team member. Upon completion of the interview, caregivers received the remaining surveys, including the SRS, to further assess inclusion criteria.

As mentioned, the participants were caregivers (29 mothers and two fathers; average age 44;3, (range 27-58 years old; SD 6.67)) of children with autism. The study captured relevant demographic information regarding the caregiver's and their children, the demographic information is reported below in Table 2. The sample demographics of the children included, 77.4% reported as male with an average age of the sample of children reported 10;1 years old (range 6 – 14; SD 2.07), their children as 67.7% White, non-Hispanic, 16.1% Asian, 9.6% Black, 16.1% Latino (Table 2).

Recruitment Process & Informed Consent

The recruitment process involved various strategies to reach potential participants for the original treatment study. A convenience sampling method was employed to select a diverse sample of parents representing different demographic characteristics. Recruitment materials, such as flyers and online advertisements, were distributed through community centers, schools, autism support organizations, and online platforms dedicated to autism-related topics. Interested

individuals were instructed to contact the study team via email or phone to express their interest and request further information. Upon expressing interest in the study, potential participants were provided with detailed information about the study's purpose, procedures, risks, and benefits.

Informed consent was obtained from all participants prior to their involvement in the study.

Incentives

To incentivize participation, participants were offered a monetary incentive for participation in this assessment-related additional study. Upon completion of the study, families received \$75 as compensation for their time and effort.

Setting

The study was conducted remotely using ZoomTM video conferencing. After obtaining informed consent, participants were provided with a secure Zoom link from a member of the study team. The interview portion with the participants was scheduled at mutually convenient times. The interviews were conducted with the participants in a private office by the study's primary investigator located on the campus of the Tier 1 research institution. The interviews were audio recorded and stored on a secure server.

Procedures

There are five main procedures to the study. The survey data was collected using a combination of HIPAA-compliant RedCapTM, Google FormsTM, and Pearson Q-Global SystemTM.

First, once participants, the caregivers, provided consent, participants were asked to complete a pre-survey that collected demographic information and their thoughts on the clinical assessment process. Next, the participants were scheduled for the semi-structured interview designed to capture personalized information about their child's autism-related traits and

challenges. The interview was conducted by one of two study team members using the semi-structured protocol. During the interview, participants were presented with rating cards during the interview to use as a guide and partial structure for the interview (*see Appendix A and B for complete interview material*). To minimize potential bias and ensure the statistical rigor of our comparisons, participants first completed the semi-structured personalized interview before engaging in the standard measures. This sequence was specifically designed to prevent any influence from the standard measures on the responses given during the interview.

Third, upon completing the aforementioned procedures, participants were sent the remaining study surveys, which included measures assessing various aspects related to their child's autism traits, behaviors, and functional abilities. The surveys are listed below and were expected to take 40-60 minutes to complete in total.

Fourth, along with the study surveys, participants were also sent the Vineland Adaptive Behavior Scales through a link provided directly from Q-Global. Q-global is an online platform developed by Pearson Clinical AssessmentTM that allows for easy and digital administration of the Vineland.

Lastly, participants were invited to complete a post-survey that collected a small amount of information regarding their satisfaction with the interview process. The survey included three key questions on a 5-point Likert scale: (1) "Do you feel this interview captured all the relevant information you wanted to share?" (1=strongly disagree; 5=strongly agree), (2) "Would you participate in this type of interview again? (If yes, please elaborate on the strengths of this interview and rating process. If no, please elaborate on the weaknesses you see of this interview and rating process)" (1=strongly disagree; 5=strongly agree) and (3) "How satisfied were you with this interview?" (1=very dissatisfied; 5=very satisfied). Participants were encouraged to

provide feedback, and responses were anonymized to ensure candidness. Comment boxes were included to elicit qualitative feedback. The post-survey was emailed to participants following the interview's conclusion and was presented as an optional part of study participation; all participants except one completed this portion. Moreover, in an attempt to eliminate potential bias, the survey did not collect identifiable information, and all ratings were only viewed after data collection. Additionally, responses were scored in a random order to further disconnect a specific response to a specific participant. These procedures were outlined prior to the participant completing the post-survey. This attitudinal data was collected to gather caregivers' first-hand feelings about the interview experience. To encourage a higher response rate, the post-survey only contained three questions regarding their experience with the interview process. In the end, the pre-and post-survey measures took approximately 5 – 10 minutes for participants to complete.

Throughout the various study steps, participants had the opportunity to ask questions and seek clarification from the study team. Total participation in this study was expected to take 1 to 2 hours. The study procedures were conducted in a manner that respected every participant's privacy and confidentiality.

Measures

Social Responsiveness Scale (SRS). The SRS (Constantino & Gruber, 2005) is a widely used questionnaire that assesses social communication and interaction deficits associated with autism spectrum disorder (ASD). It consists of 65 items that capture various aspects of social behavior, including social awareness, social cognition, social motivation, and autistic mannerisms. Participants rate each item on a four-point Likert scale, ranging from "Not true" to "Almost always true." The SRS provides a quantitative measure of social responsiveness, with

higher scores indicating greater impairment in social functioning. The SRS has demonstrated good reliability and validity, with high internal consistency (Cronbach's $\alpha > .90$) and test-retest reliability (r > .80) (Constantino & Gruber, 2005). It is a widely used tool for assessing social deficits in individuals on the spectrum and can inform treatment planning and monitoring of social development. The SRS typically takes approximately 15 to 20 minutes to complete. The raw DSM-Social and DSM-Repetitive scales derived for the SRS were used to evaluate convergent and discriminant validity for Aim 2, and the total T-score was used to evaluate sensitivity and specificity for Aim 3.

Brief Problem Monitor (BPM). The BPM (Achenbach, 2011) is a brief measure designed to assess the presence and severity of various behavioral and emotional problems in children and adolescents. It consists of 15 items that cover a range of problem areas, including aggression, anxiety, and attention difficulties. Participants rate each item on a four-point Likert scale, ranging from "Not at all" to "Very much." The BPM has demonstrated good construct validity and internal consistency, with high correlations with other established measures of child psychopathology (Achenbach, 2011; Pedersen et al., 2021). Higher scores on the BPM indicate a greater presence and severity of behavioral and emotional problems. The BPM typically takes 5 minutes to complete. The raw BPM-Externalizing and BPM-Internalizing scales were used to evaluate convergent and discriminant validity for Aim 2, and the corresponding T-scores were used to evaluate sensitivity and specificity for Aim 3.

Vineland Adaptive Behavior Scale. The Vineland (Sparrow, et al., 2005) is a standardized norm-referenced assessment tool that measures the personal and social skills of individuals and assesses adaptive behavior. The assessment is conducted through Q-Global using the Comprehensive Parent/Caregiver Form, which covers three main domains: Communication

(including receptive, expressive, and written communication), Daily Living Skills (encompassing personal, domestic/numeric, and community/school skills), and Socialization (including interpersonal relationships, play and leisure, and coping skills). It provides standard scores and age equivalents, allowing for a comprehensive evaluation of adaptive behavior across different developmental stages. The Vineland has demonstrated good reliability and validity, with high internal consistency coefficients (Cronbach's α ranging from 0.84 to 0.96 for the Communication domain, 0.80 to 0.95 for the Daily Living Skills domain, and 0.88 to 0.94 for the Socialization domain) and test-retest reliability (ranging from .80 to .95) (Sparrow et al., 2005; de Bildt et al., 2005; de Bildt et al., 2021). The completion time for the Vineland may vary depending on the individual, but it typically takes approximately 30 to 45 minutes to complete. Standard Scores for Communication and Socialization, and the Personal Daily Living Skills (DLS) v-scale score were used to evaluate Aims 2 and 3. The Personal DLS (v-score) was chosen over the DLS standard score for this study as it provides a more specific emphasis on personal care, which more closely aligns with the focus of the YTP-Interview.

Repetitive Behavior Questionnaire (RBQ-2): The RBQ-2 (Leekam et al., 2007) is a widely used questionnaire that assesses repetitive behaviors in individuals on the spectrum. It consists of 15 items that capture different aspects of repetitive behaviors, including motor stereotypes, rituals, and restricted interests. Scores for these items are summed into a total score. Participants rate each item on a four-point Likert scale, ranging from "Not true" to "Almost always true." The RBQ-2 has demonstrated good reliability and validity, with high internal consistency (Cronbach's $\alpha = .84$) and test-retest reliability (r = .81) (Leekam et al., 2007). Higher scores on the RBQ-2 indicate a greater presence of repetitive behaviors in individuals on the spectrum. The RBQ-2 typically takes 5 minutes to complete.

Personalized, Brief, Semi-structured Interview (YTP-Interview). See Background, above, for full description. The initial pilot indicated that the interview takes approximately 30 minutes to one hour to complete. Following the interview results, a weekly tracking form was developed for participants focusing on the top two problems identified within each clinical area, resulting in a total of up to 12 problems. Participants were asked to rate these identified problems on a weekly basis during treatment using the same scale presented to them during the interview. This approach allowed for continuous monitoring of the specific challenges highlighted during the interview and enable tracking of any changes or progress over time. To test for convergent and divergent validity, the scores for all problems endorsed at baseline were summed to create a total problem score for each of the six YTP-Interview domains. Because the intention of the YTP-Interview for clinical monitoring over the course of treatment is to focus on the top two problems from each domain for repeated assessments, test-retest reliability and sensitivity and specificity analyses focused on just the top two items per domain (individual items for the former and summed scores for the latter).

Demographics. In addition to the measures described above, the study collected demographic data, including information about caregivers and their children. The demographic survey gathered a range of background information, such as service receipt, current services, comprehensiveness of services, and family satisfaction of services. This survey was expected to take 5-10 minutes to complete.

<u>Survey-Caregiver Satisfaction</u>. As mentioned above (*see Procedures*), the post-interview survey was administered to gather caregivers' firsthand feedback and attitudes regarding their experience with the interview process. This survey was expected to take 3-5 minutes for participants to complete.

Analysis

In this study, we aimed to evaluate the psychometric properties of the YTP-Interview through a series of statistical analyses. These analyses included the calculation of descriptive statistics, correlation analyses to assess test-retest reliability, convergent and discriminant validity, sensitivity and specificity, and an examination of face validity. To evaluate the interview domains, correlations were calculated between the interview and existing standardized measures, and between scores at different time points. This approach provided a robust assessment of the interview's reliability and validity. Additionally, the post-survey data was analyzed using descriptive statistics to summarize participants' responses and the data from the free response comment boxes were analyzed qualitatively analyzed using thematic analysis to identify common themes (Braun & Clark, 2006).

Results

Descriptive Statistics

Descriptive statistics for the semi-structured interview and the behavioral and adaptive measures are presented in Table 3. The table presents the number of valid cases (N), minimum and maximum values, mean, and standard deviation for each measure. These descriptive statistics provide insights into the range, central tendency, and variability of the ratings across different measures. For instance, Dysregulated and Disruptive Rating had a mean of 27.87 (SD = 16.24) with scores ranging from 9 to 93, indicating considerable variability in the ratings.

Test- Retest Reliability

The test-retest reliability of the YTP-Interview was evaluated for each interview domain and for the top two problems summed together associated in each domain across two timepoints:

Week 1 and Week 2. The choice of Week 1 to Week 2 was deliberate, given the fixed and stable nature of these time points across participants, as opposed to the highly variable timing from Baseline to Week 1, which often spanned a month or more. Table 5 presents the Spearman's rho correlation coefficients and their significance levels. The results demonstrated high and significant correlations across all domains, indicating strong test-retest reliability. The high correlation coefficients indicate that scores are relatively stable over time.

Convergent and Discriminant Validity

The baseline ratings across all items for each YTP-Interview domain were summed and Spearman's Rho (r_s) was used due to the skewed distributions and presence of outliers in the YTP-Interview variables. Negative correlations with the Vineland were expected since higher Vineland scores indicate more adaptive behavior, whereas higher YTP-Interview scores indicate more severe difficulties. The analysis revealed several significant correlations, suggesting meaningful relationships between the interview ratings and the external measures. The correlation analysis provided evidence of convergent and discriminant validity for the YTP-Interview domains. The YTP-Interview Dysregulated and Disruptive Behavior domain showed a large and significant positive correlation with the BPM Externalizing Raw Score ($r_s = .667, p < .667, p$.001) indicating convergent validity. It had a stronger correlation with BPM Externalizing than with other measures, supporting discriminant validity. The YTP-Interview Conversation and Friendship domain correlated significantly with Vineland Communication ($r_s = -.617, p < .001$), Vineland Socialization ($r_s = -.474$, p = .004), and the SRS DSM-Social Domain scale ($r_s = .444$, p = .007), indicating strong convergent validity and highlighting its relevance to communication and social behaviors. The YTP-Interview Peer Engagement domain had a significant correlation with SRS Social Responsiveness ($r_s = .364$, p = .029), slightly higher than its correlations with

other scales, supporting convergent and discriminant validity. The Vineland Communication and Socialization scales were also moderately correlated with the YTP-Interview Peer Engagement domain. The YTP-Interview RRB domain was significantly correlated with the SRS Repetitive Behavior scale ($r_s = .378$, p = .029), as expected, but also with the BPM Externalizing scale ($r_s = .621$, p < .001), suggesting some overlap with externalizing behaviors. The YTP-Interview Anxiety and Depression domain and Self-Care domain did not exhibit predicted correlations with the BPM or Vineland measures (Table 6).

Sensitivity and Specificity

Receiver Operating Characteristic (ROC) analyses were utilized to assess the 6 YTP-Interview domains in relation to clinically significant cut-scores on the BPM, SRS, and Vineland (see Table 7). As with the convergent validity analyses above, baseline ratings across all items for each YTP-Interview domain were summed for these analyses. Sensitivity to clinically significant cut-scores (T>63, v-scale score<11) on corresponding traditional normed measures was in the mid-.80 range for Dysregulated and Disruptive Behavior, Peer Engagement, Conversation and Friendship, and RRB domains, while it was in the mid-.70s for the Anxiety and Depression and Self-Care domains. Specificity plus sensitivity was around 1.50 for all YTP-Interview domains except for Anxiety and Depression, signifying an acceptable level of classification capacity for an instrument of this type for the other five domains. Using these optimal cut-score points that maximally balance sensitivity and specificity, sensitivity (ruling in true positives) to clinically significant challenges was adequate to good for all scales, and specificity (ruling out true negatives) was reasonable in all cases except for Anxiety and Depression, a sensible approach in a setting in which it is more problematic to overall or minimize a clinically meaningful problem (e.g., depressive symptomatology) than it is to offer

brief treatment for a mild or benign manifestation of the problem. Taking a different approach, following the method in which the MEYA therapy training algorithm (Wood et al., 2024) currently recommends intervention modules to practitioners (in which a YTP of 5 or greater for either YTP item determines if an intervention for that clinical area should be mounted), sensitivity ranged from .88 to 1.0, meaning that almost all true positive cases were identified across the six areas with this cut-score. However, specificity was very poor, ranging from .17 to 0 (there was 0 specificity for Dysregulated and Disruptive Behavior because all children had scores above 5 for at least one item at baseline, but not all of them had T-scores \geq 63 for the BPM Externalizing scale).

Face Validity

Face validity was assessed by evaluating the convergence between the automatic categorization of each problem reported by caregivers and an expert rater's independent judgment of the problem's clinical category. The results showed high agreement across all domains (Table 8). Specifically, 58 out of 60 problems automatically categorized in the Dysregulated and Disruptive Behavior domain were categorized by the expert rater as belonging in the Dysregulated and Disruptive Behavior domain. the Anxiety and Depression domain had 51 out of 52 problems categorized as belonging in the correct domain (98.08%), the RRB domain had 54 out of 55 problems categorized as belonging in the correct domain (98.18%), the Peer Engagement domain had 48 out of 48 problems categorized as belonging in the correct domain (100%), the Conversation and Friendship domain had 57 out of 57 problems categorized as belonging in the correct domain (100%), and the Self-Care domain had 47 out of 47 problems categorized as belonging in the correct domain (100%). These high percentages indicate that the

domains captured the problems as intended, supporting the face validity of the personalized semi-structured interview (YTP-Interview).

Participant Satisfaction with the Personalized Semi-Structured Interview

Quantitative analysis of the post-interview survey revealed that 93.3% of participants 28 out of 30) strongly agreed, while 6.7% (2 out of 30) agreed that the interview captured all relevant information (Table 9). 100% of participants indicated they would participate in a similar interview again. Furthermore, 100% of participants (30 out of 30) were very satisfied with the interview. Qualitative analysis identified a few key themes: 1) Noticing Improvement and Progress, 2) Self-Reflection and Awareness, and 3) Time Efficiency.

- Noticing Improvement and Progress: Tracking progress and seeing improvements over time are significant strengths noted by participants.
- Self-Reflection and Awareness: The process aids in self-reflection for parents, helping them understand and identify triggers and areas of progress.
- Time Efficiency: The process is seen as time efficient and manageable, which is a positive aspect for parents.

These themes suggest that participants find the interview and weekly check in process beneficial, particularly in terms of monitoring progress, facilitating self-reflection, and being time efficient. Participants praised the interview structure and clarity of questions but noted areas for improvement, including one participant who indicated that most of the responses were experienced during the course of the study, but some responses were limited as they were too specific.

Discussion

The diversity of clinical presentations in autism is vast, with unique challenges for every individual. While many measures can help guide clinical practice and intervention planning, these often come at a cost in terms of demands on expertise and training, clinical time spent, and, therefore, financial investment (Bannon & McKay, 2005; Havdahl et al., 2016). This project attempted to develop and test an interview measure that is free of cost, can be integrated into a single session of standard clinical practice, and can automatically categorize top problems reported by caregivers to help guide the allocation of specific corresponding evidence-based practices during intervention. A qualitative approach supported the exploratory aims of the pilot study and highlighted that the interview allowed the richness of caregiver-reported problems and processes to be captured. The aim of this present study was to provide a preliminary analysis of the psychometric properties of a new semi-structured, personalized interview, the YTP-Interview. The findings from phase 2 provide support for the convergent, discriminant, and face validity of the YTP-Interview domains and demonstrate the essential role caregivers play in case formulation and the value of personalized assessments.

Regarding Aim 1, the strong test-retest reliability for all domains indicates that the YTP-Interview can reliably measure key areas of concern in children with autism over short periods. All domains showed high and significant correlations between Week 1 and Week 2, highlighting the strong reliability of the YTP-Interview over short intervals of time. These correlations indicate that the interview reliably measures the intended constructs, providing confidence in its use for ongoing assessment and evaluation in children with autism. This relative stability is crucial for its use in clinical settings to track changes and outcomes over time. Future research

should examine the interview's reliability over more extended periods and in larger, more diverse samples to validate these findings further.

For Aim 2, Dysregulated and Disruptive behavior, Conversation and Friendship, Peer Engagement, and RRBs YTP-Interview domains showed evidence of convergent validity, particularly Dysregulated and Disruptive behavior and Conversation and Friendship domains, which demonstrated strong correlations with relevant behavioral and adaptive measures. However, the Anxiety and Depression and Self-Care YTP-Interview domains did not exhibit significant correlations, possibility due to the sample's homogeneity or the broad nature of the self-care construct. Overall, the results suggest that while some YTP-Interview domains align well with established measures of similar constructs, others may require further refinement or may be influenced by specific sample characteristics. These findings highlight the importance of considering the context and specific characteristics of the population when evaluating psychometric properties. For instance, the sample was recruited for this study for high mental health need, including internalizing and externalizing behavioral needs, this in turn may restrict the range of variability seen in the validating measures (i.e., BPM), therefore, limiting the degree to which meaningful correlations may be detectable. Future research should continue to explore this correlation in a broader sample of youth with autism to determine whether the Anxiety and Depression domain would benefit from further refinement.

Caregivers described many top problems related to classic conceptualizations of autism, including RRBs, difficulties with social engagement and social-communication, and friendship-related challenges. Specificity in problem description was notable, offering potential directions for intervention focus; for example, "he has a hard time with changes in routine" may lead a practitioner to opt for a CBT-based EBP that can be focused around a specific area of "exposure

therapy" (i.e., novelty and transitions). The ROC curve analysis provided valuable insights into the utility of the YTP-Interview for identifying clinically significant problems in children with autism (Aim 3). The optimal cut-scores for each domain varied, reflecting the diverse nature of the clinical areas assessed by the YTP-Interview. The analysis revealed that the optimal cutscores demonstrated acceptable levels of sensitivity and specificity across five of the six clinical areas. For anxiety and depressive feelings, there can be challenges in precisely capturing this domain based on parent-reported measures (Dirks et al., 2014; Freitag et al., 2023). There was some age-dependent variability in top problems in this domain; caregivers of younger children highlighted challenges with sensory sensations at a much higher rate than other caregivers, for example. Severity ratings of these problems were generally very high and suggested that the challenges and difficulties associated with autism specifically were often high-priority foci for addressing in intervention from the caregivers' perspective (Table 4). Overall, the ROC curve analyses show that the YTP-Interview is likely able to serve as a good starting point for indicating clinical areas that may need intervention focus at the onset of treatment; decisions pertaining to which areas to focus on and when to switch from one area to another are unlikely to be an automated process in psychological interventions, when stakeholder input is critical to these decisions; nonetheless, in helping to provide a roadmap or first draft of a clinical plan and to help with recognizing when to switch between clinical foci in therapy, the YTP-Interview used at baseline and repeatedly during treatment is likely to offer meaningful empirical support.

The mental health needs associated with autism were also frequently represented in the caregiver's responses, for example, externalizing behavior (e.g., aggression) and internalizing symptoms (e.g., depression). In this domain, caregivers reported a range of challenges distinguishable from core autism-related challenges that showed high face validity as mental

health needs. The reported challenges not only represent the variability of mental health symptom presentation that can only be captured by a personalized measure but also the potential to guide the implementation of an individualized EBP program to target these specific goals (e.g., parent training for aggression; behavioral activation for depression).

Furthermore, the interview captured many goals regarding adaptive behavior reported by the caregivers. These problems ranged from self-care skills, such as "he struggles with teeth brushing and washing himself," to organizational abilities, such as "he doesn't organize things and leaves everything a mess." Interestingly, for the younger participants, the interview uncovered that many caregivers did not prioritize the Self-Care domain, with significantly lower overall ratings. In contrast, for the older children, caregivers reported self-care challenges as severe, with many of the goals falling under the themes of "organization" and "independence." Relatedly, caregivers with children with younger children (under the age of 7) did not report many goals in this area. This finding reflects prior literature (Estes et al., 2009) as caregivers with younger children expect to be responsible for many self-help routines, while caregivers of older children experience considerable challenges transferring responsibility for adaptive skills.

Additionally, the interview seemed to capture a fair degree of similar experiences among caregivers regardless of the age or gender of their child: most families reported numerous problems as being "a very, very big problem" across several clinical domains, and most families reported close to the maximum 12 top problems, usually with severity scores above the midpoint of 5 (see Table 4 and Table 11). While some variation was attributable to individual differences in children's behavior and specific challenges, ultimately, all the top problems reported by caregivers corresponded to one of the six core clinical areas. The notable patterns reported in the results (i.e., caregivers reporting the greatest number of problems in the externalizing domain)

underscore the importance of individualized assessment, as narrowly focusing on one clinical area in a subsequent intervention may not support the overall functioning of children with autism.

Personalized assessments have many advantages; as highlighted by the data above, a personalized assessment approach can elicit relevant data specific to each child (Christon et al., 2015; Haynes et al., 2009; Weisz et al., 2011). The problems described by caregivers in this study reflected the heterogeneity of problems and goals typically associated with autism. Notably, the problems described by caregivers mapped onto the prompts from the six clinical domains surveyed in this interview, offering compelling evidence of face validity (Aim 4). The face validity of the interview was evaluated by assessing whether the items generated by caregivers for each clinical domain (externalizing, internalizing, personal care and related behaviors, etc.) were representative of relevant clinical issues for each domain. While grouping "conversation and friendship" together may not seem immediately intuitive, these two areas are highly interrelated and often overlap in observers' behavioral lexicon (i.e., sharing interests, providing emotional support, and engaging in friendly chats). Whereas the more activity-based "social engagement" domain involves participating in group activities, following rules, and being accepted or admired for one's skills. One can be socially engaged in activities and still not have the deeper, more personal interactions that characterize friendships and meaningful conversations (Bauminger & Kasari, 2000; Parker et al., 2015). Face validity results indicated that the YTP-Interview domains captured the problems as intended at a high level of convergence (range 98-100%) between the automatic categorization of each problem reported by caregivers and an expert rater's independent judgment of the problem's clinical category across all domains. This supports the conclusion that the YTP-Interview effectively identifies and

categorizes the problems it aims to measure ensuring that the assessment was comprehensive and aligned with real-world observations.

One of the main goals of qualitative analysis's main goals in the Phase 1 pilot study was to better understand caregivers' experience, particularly in relation to the challenges and how they believe clinical care would ideally support them and their goals. These findings highlight that caregivers can play an essential role in case formulation, given the opportunity as caregivers have expert knowledge of their child, and they can further inform our understanding of autism and, specifically, how it impacts their life and family system. The findings from the initial pilot (N=8) study and the Phase 2 qualitative analysis indicated that participants were very satisfied with the interview process, highlighting its comprehensiveness and effectiveness. These findings were again replicated in this larger exploration of the psychometric properties through the postinterview survey (N=31; Aim 5). Minimal feedback regarding the interview structure, interface, or design was discussed. Moving forward, it is recommended to include more specific questions aimed at identifying areas for improvement. This approach would provide additional insights into how the interview process can be refined. These insights can inform future interview designs, thereby enhancing participant satisfaction and improving the overall quality of the data collected. From these results, it may be inferred that the interview accurately captures the challenges that these children are facing and are able to target these problems in therapy.

The findings suggest that a brief semi-structured, personalized assessment approach that addresses a range of challenges may better characterize the holistic clinical needs of the child and can complement existing strategies in community mental health and school settings. This idiographic assessment, used at the onset of intervention, can promote rapport and collaboration with caregivers while being informative for intervention planning and tracking.

Implications and Limitations

This research has implications for families of children who experience disparities in access to autism-related assessments (e.g., Durkin et al., 2017), consequently leading to inequalities in access to essential clinical care (Kaufman, 2022). Access to evidence-based assessment may help reduce the disparities seen in mental health service use by helping make evidence-based practices more available to consumers who seek treatment in community-based mental health service settings. This assessment tool was created with "real-world" community practitioners in mind. This means providing tools that can be feasibly implemented while being accurate in real-world situations and contexts. Additional research will clarify if this instrument can facilitate such goals.

Although this study offers potential promise in the form of a new instrument and new findings, it also has limitations. While the measurements selected for comparing psychometric properties have significant empirical support, there are still questions around the psychometric properties of the Vineland, which has recently received scrutiny around its online administration, with researchers urging caution in interpreting domain or overall adaptive behavior composite scores in autistic individuals and emphasizing the need for careful consideration of the administration format (Wilkinson et al., 2024). Furthermore, regarding assessing test-retest reliability, it is important to note that interpretations can be challenging when an intervention is administered during the test-retest period, as the intervention might influence the results. However, in this study we chose to focus on the period from Week 1 to Week 2, which represents the very beginning of the treatment, and thus aimed to minimize the impact of the intervention.

As noted throughout this paper, the YTP-Interview can capture an individual's specific needs and challenges, to hopefully be addressed in clinical treatment; however, another limitation is that in clinical practice, it may still be difficult for many practitioners to map specific evidence-based techniques to specific problems. Additionally, another heavily cited limitation with this type of research is that reliance on caregiver reports of problems and challenges may be vulnerable to bias (Nauta et al., 2004) and this measure does not yet consider the child's perspective of their problems. Future research will work on incorporating a portion of the interview into the child's report of their top challenges. Another limitation of this study is that the interview was primarily tested with more able, verbal children with autism, which may limit the generalizability of the findings to less verbal children; however, with appropriate adaptations, the interview could potentially be applicable to a broader range of verbal abilities. Overall, the sample size was relatively small, which may also affect the generalizability of the findings. Future studies with larger and more diverse samples are recommended to validate these results.

Conclusion

In conclusion, these findings suggest that an idiographic assessment may be a beneficial method to gain insight into the children's specific challenges. As demonstrated, the current study found that an extensive breadth of information can be obtained from this personalized semi-structured interview. Furthermore, the findings suggest that the YTP-Interview is a reliable and valid tool for identifying and monitoring the top problems in children with autism as reported by their caregivers, demonstrating strong psychometric properties that support its use in clinical practice and research applications. The results from this project are promising, suggesting that this new measure has the potential to align assessment and intervention foci with the needs and

aspirations of caregivers and the family system as a whole while being an important step towards providing a psychometrically sound, personalized assessment that is free and accessible for community health settings, enhancing the ability to accurately identify and address the unique needs of children with autism.

Table 1.Areas of Clinical Need for Autistic Youth

Clinical Areas	Description	YTP-Interview Domain Name
Externalizing Behavior	(i.e., dysregulated and disruptive behavior) refers to a grouping of behavior problems that are manifested in children's outward behavior and reflect the child negatively acting on the external environment	Dysregulated and Disruptive behavior
Internalizing Behavior	(i.e., anxiety and depression) are problems that more centrally affect the child's internal psychological environment rather than the external world	Anxiety and Depression
Rigid & Repetitive Behaviors	restricted, repetitive patterns of behavior, interests, or activities	RRBs
Social Communication	(i.e., social-emotional reciprocity, nonverbal communicative behaviors): one's ability to communicate socially.	Conversation and Friendship
Social (Interaction & Engagement)	(i.e., social orienting with peers in school and community settings; developing, maintaining, and understanding relationships) refers to one's degree of participation in a community or society	Peer Engagement
Adaptive Living Skills	(i.e., self-help or self-care skills): are the everyday tasks undertaken so children are ready to participate in life activities (including dressing, eating, cleaning teeth).	Self-Care

Table 2.Demographic Characteristics of Child and Caregiver (N=31)

Characteristics	n	%
Child Gender		
Male	24	77.4
Female	7	22.6
Child Race		
White	21	67.7
Asian	5	16.1
Black	3	9.6
Latino	4	12.9
Native American	2	6.5
Hispanic	5	16.1
Caregiver Gender		
Male	2	6.5
Female	29	93.5
Caregiver Race		
White	22	71
Asian	4	12.9
Black	2	6.5
Latino	3	9.7
Hispanic	4	12.9
Caregivers' Highest Level of Education	Completed	
High School	7	22.6
Bachelor's Degree	10	32.3
Post-Bachelor's Degree	10	32.3
Trade School	3	9.7
Caregiver Martial Status		
Married, domestic partnership	25	80.6
Separated, single, widowed	6	19.4
Household Income		
Less than \$25,000	2	6.5
\$25,000 - \$50,000	2	6.5
\$50,000 - \$100,000	6	19.4
\$100,000 - \$200,000	12	38.7
More than \$200,000	7	22.6
Prefer not to answer	2	6.5

Table 3.Descriptive Statistics

YTP-Interview Scales	N	Minimum	Maximum	Mean	Std. Deviation
Dysregulated and	11	IVIIIIIIIIIIII	WithAmitain	IVICUII	Std. Deviation
Disruptive Behavior	30	9	93	27.87	16.24
Anxiety and Depression	29	3	36	16.03	8.57
RRBs	30	5	64	20.9	14.26
Peer Engagement	28	2	47	14.75	9.61
Conversation & Friendship	30	1	54	16.8	9.51
Self-Care	26	5	47	19.54	12.15
Valid N (listwise)	23				
Measures & Scales					
BPM Externalizing Raw					
Score	31	0	14	7.58	3.63
BPM Internalizing Raw					
Score	31	1	12	5.84	2.97
RBQ-2 Total Repetitive					
Behavior Score	31	24	51	36.52	7.04
Vineland - Communication					
(Standard Score)	30	70	105	84.63	10.22
Vineland - Personal Daily					
Living Skills (v-Score)	30	8	17	12.50	1.87
Vineland - Socialization	• •				
(Standard Score)	30	64	101	79.9	8.88
SRS Total Score	31	0.58	2.05	1.49	0.35
SRS Social Responsiveness	31	0.48	2.22	1.4	0.43
Valid N (listwise)	30				

Table 4.Total Number of Top Problems (TP) Reported and Average Severity Scores (N=31)

	Average Number	Average		Average of	
Clinical Areas	of TP Reported	TP Score	SD	Top 2 TPs	SD
Dysregulated and					
Disruptive					
Behaviors	3.52 (range: 1–9)	7.67	2.09	8.57	1.51
Anxiety and					
Depression	2.16(range: 0–4)	6.94	2.47	7.34	2.30
Rigid and Repetitive					
Behavior	2.87(range: 0–5)	7.30	2.62	7.73	2.26
Peer Engagement	1.90 (range: 0–5)	7.51	2.37	7.61	2.38
Conversation &	1.90 (range. 0–3)	7.51	2.37	7.01	2.30
:	2.12 (1.4)	7.64	1.02	7.04	1.04
Friendship	2.13 (range: 1–4)	7.64	1.93	7.84	1.94
Self-Care Skills	2.48 (range: 0–6)	7.82	2.08	8.30	1.71

 Table 5.

 Spearman's Rho Correlation Coefficients for Interview Domains Across Time Points

YTP-Interview Domains	Week 1 vs. Week 2
Dysregulated and Disruptive Behavior	0.869** (<0.001)
Anxiety and Depression RRB	0.903** (<0.001) 0.898** (<0.001)
Peer Engagement	0.912** (<0.001)
Conversation and Friendship	0.940** (<0.001)
Self-Care	0.906** (<0.001)

Note. Correlation coefficients are Spearman's rho. Significance levels (2-tailed) are in parentheses. *p < 0.05, **p < 0.01.

Table 6.Spearman's Rho Correlation Coefficients

		Y	TP-Intervi	ew Domains		
Measures	Dysregulated and Disruptive Behavior	Anxiety and Depression	RRB	Peer Engagement	Conversation & Friendship	Self- Care
BPM		•			1	
Externalizing Raw Score BPM	0.667**	0.027	0.621**	0.215	0.359*	0.436*
Internalizing Raw Score Total Repetitive	-0.060	0.077	-0.029	0.323*	0.004	0.090
Behavior Score Communication	0.404*	0.075	0.257	0.236	0.183	.0378*
(Standard Score) Personal Daily	-0.160	-0.168	-0.067	-0.247	-0.617**	-0.219
Living Skills (v- Score) Socialization	-0.224	0.009	-0.297	-0.266	-0.388	-0.259
(Standard Score) SRS Total	0.025	-0.029	-0.129	-0.221	-0.474**	-0.197
Score	-0.173	0.284	0.139	0.364*	0.444**	0.033

Note. *p < .05, **p < .01 (based on one-tailed tests).

Table 7.ROC Curve Analysis for YTP-Interview Domains

	Optimal YTP-Int			Total Sensitivity +
Clinical Areas	Cut-Score	Sensitivity	Specificity	Specificity
Dysregulated and				_
Disruptive				
Behaviors	20.5	.81	.78	1.59
Anxiety and				
Depression	9	.74	.33	1.07
RRB	12.5	.82	.62	1.44
Peer Engagement	7.5	.84	.67	1.51
Conversation &				
Friendship	13.5	.84	.80	1.64
Self-Care	20.5	.75	.78	1.53

Table 8.Face Validity

	Total	Total Problems	A
Domain	Problems Reported	Accurately Reported	Accuracy (%)
Dysregulated and Disruptive	Reported	Керопец	(70)
Behavior	60	58	96.67%
Anxiety and Depression	52	51	98.08%
RRBs	55	54	98.18%
Peer Engagement	48	48	100%
Conversation & Friendship	57	57	100%
Self-Care	47	47	100%

Table 9.Post-Interview Survey Data

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
				n (%)	n (%)
Do you feel this interview captured all relevant					
information you					28/30
wanted to share?	-	-	-	2/30 (6.7)	(93.3)
Would you participate					
in this type of					30/30
interview again?	-	-	-	-	(100)
	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
					
					n (%)
How satisfied were you					30/30
with this interview?	-	-	-	-	(100)

Supplemental Materials (Tables from Phase 1: Pilot Study)

 Table 10.

 Phase 1: Demographic Characteristics of Child and Caregiver

Characteristics	n	%
Child Gender		
Male	7	87.5
Female	1	12.5
Child Diagnosis		
Autism	8	100
ADHD	3	37.5
Anxiety Disorder	2	25
Speech Language Delay	4	50
Global Development Delay	1	12.5
Medication		
Stimulant	1	12.5
Anti-depressant	2	25
Services		
Applied Behavioral Analysis (ABA)	4	50
Occupational Therapy	1	12.5
Speech Services	2	25
Individual Counseling	1	12.5
Psychiatry	1	12.5
Caregivers' highest level of education comp	leted	
High School	2	25
Some College	1	12.5
Bachelor's Degree	2	50
Post-Bachelor's Degree	3	37.5
Caregiver Martial Status		
Married	4	50
Separated, single, widowed	4	50

Table 11.Phase 1: Total Number of Top Problems Reported and Average Severity Scores (N=8)

Clinical Areas	Total TP reported	Average TP Score	SD	Average Top 2 TPs	SD
Dysregulated and Disruptive Behaviors	43	7.44	2.28	9.19	1.38
Anxiety and Depression	36	7.36	2.3	9	1.18
Rigid and Repetitive Behavior	41	7.05	2.8	7.5	2.83
Peer Engagement Conversation &	27	8.12	2.4	9.07	1.49
Friendship	28	8.14	2.34	8.64	2.17
Self-Care Skills	23	5.96	2.6	6.31	2.14

Table 12.Phase 1: Brief Attitudinal Survey Data

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
				n (%)	n (%)
Do you feel this interview captured all relevant information you wanted to share?	-	-	-	1/8 (12.5)	7/8 (87.5)
Would you participate in this type of interview again?	_	-	_	_	8/8 (100)
	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied n (%)
How satisfied were you with this interview?	-	_	-	_	8/8 (100)

Appendix A. Interview Protocol

Interview Protocol 1

Use this form in conjunction with the Clinical Area Cards

During the Interview, you will show each Card to the parents, one at a time, and review the problems on the Card. Each Card will consist of 2 or 3 boxes. In each of these boxes, you will find a bold-faced word followed by non-bold descriptions that correspond to the bold-faced word at the top of the box.

Interview Protocol

You will read each Clinical Area Card in the following way while pointing to bold-faced and non-bold words on the Card to the parents:

Example: "Some children tend to become [read the bold-faced word, such as "Aggressive"]. This may include: [read the non-bold words like "Hitting, Insulting, and Threatening"].

Remember to go through each of these areas one at a time with the family. It is OK to adjust the wording of the interview to make it understandable to the family you are working with.

Following each bold-faced word and non-bold word, you will ask the parent(s):

Example: "Have you noticed if your child has problems acting [read the bold-faced word, such as "Aggressively"]."

**IF the parent endorses the problem behavior, help them describe the child's specific behaviors descriptively as suits the situation. For example, if the parent endorses aggressive behavior and states that the child often hits peers at school, the problem can be worded precisely that way; if the child hits people in most situations, the wording of the problem should reflect that. This is much more precise than the simple word "Hits." Be sure to use as much of the parent's own wording on the problem description as possible and write it below in the Problem List at the bottom of each page.

To begin the interview, have the Clinical Area Cards ready for the parent(s) to follow along with. This will help guide accurate and informative responses from the parents.

Say: "We are now going to begin the Clinical Interview, and we will go over six Clinical Area cards. Are you ready to begin?"

Present Card 1 (Dysregulated and Disruptive Behavior) to the parent and turn to page 2 of this interview outline. Begin by reading the bold-faced text and then the non-bold words. Follow the instructions to proceed through the remainder of the interview.

.

Clinical Area 1: Dysregulated and Disruptive Behavior

Say: Some children tend to become Aggressive. This may include: Hitting, Insulting, and Threatening. Have you noticed if your child has problems acting Aggressively?"

Be sure to use as much of the parent's own wording on the problem description and write it below on the blank lines provided at the bottom. It's okay to adjust the language on the cards to make them understandable for the parent(s).

Continue this process with the other bold-faced keywords in this clinical area; if the parent endorses the general bold-faced area, help them develop wordings for the specific problems.

Say: Some children tend to become Frustrated. This may include: Acting Disobedient, Having Tantrums, and Being Easily Angered. Have you noticed if your child has problems getting Frustrated? (...if so, get specific problem descriptions as exemplified in the paragraph marked with ** on page 1).

Say: Some children tend to become Restless and Distractible. This may include: Being Uncomfortable While Sitting Still, Having a Hard Time Focusing, and Having Difficulty Completely Homework or Classwork. Have you noticed if your child has problems being Restless and Distractible? (Write down parent(s) responses).

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

1.	Dysregulated and Disruptive Behavior	YTP Score (0-10)

Clinical Area 2: Anxiety and Depression

Say: "Some children tend to become Anxious. This may include: Having Many Fears, Feeling Tense or Panicked, Being Afraid of New People and Situations, and Clinging to Parents. Have you noticed if your child has problems acting Anxious?

Write down problems, as described by parents, below. Continue with this same process with the other bold-faced key word in this clinical area:

Say: Some children tend to get Depressed. This may include: Feeling Sad or "Blue," Having Low Energy, Lacking Interest in Things, and Having Easily Hurt Feelings. Have you noticed if your child has problems with Depression?

Remember: If the parent endorses problems with being Anxious or getting Depressed, help them describe the child's specific behaviors in a descriptive way that suits the situation. Be sure to use as much of the parent's own wording on the problem description as possible and write it below.

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

2.	Anxiety and Depression		(0-10)
		· ·	

Clinical Area 3: Rigid and Repetitive Behavior

Show the Rigid and Repetitive Behavior Card to the parent(s) and review the problems on the Card in the following way while pointing to the boldface word "Conversations" on the Card to the parents.

Say: "Some children tend to have Habits. This may include: Repeating Movements and Repeating Phrases (echolalia). Have you noticed if your child has problems having habits?"

Write down problems, as described by parents, below. Continue with this same process with the other bold-faced key word in this clinical area:

Say: Some children tend to have Rigid Behavior. This may include: Having to do Things in a Certain Way, and Getting Upset When Things go Differently Than Expected. Have you noticed if your child has problems acting Rigid?

Say: Some children tend to have Obsessions. This may include: Having Very Intense Interests in Just a Few Things, and Having Unwanted Thoughts "Stuck" in their Head. Have you noticed if your child has problems having Obsessions? (...if so, get specific problem descriptions as exemplified in the paragraph marked with ** on page 1).

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

3.	Rigid and Repetitive Behavior	YTP Score (0-10)

Clinical Area 4: Peer Engagement in School and the Community

Show the Peer Engagement in School and Community Card to the parent(s) and review the problems on the Card in the following way:

Say: "Some children tend to be Not Engaged with Peers. This may include: Not Joining Play or Having Difficulty Playing with Peers When Required to, and Not Responding When Invited to Play. Have you noticed if your child has problems Not Engaging with Peers?"

Write down problems, as described by parents, below. Continue with this same process with the other bold-faced key word in this clinical area:

Say: Some children tend to Only Play on their Own Terms. This may include: Only being Willing to Play a Small Number of Games (Even if Those Games are not available), and Insisting that Games are Played by Rules That Cannot Change. Have you noticed that your child tends to Only Play on their Own Terms?

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

4.	Peer Engagement in School and the Community	YTP Score (0-10)

Clinical Area 5: Conversation and Friendship

Show the Conversation and Friendship Card to the parent(s) and review the problems on the Card in the following way while pointing to the boldface word "Conversations" on the Card to the parents.

Say: "Some children tend to have problems with Conversations. This may include: Not Knowing What to Say to Keep the Conversation Going, Talking Too Much About Own Interests, and Not Showing Interest in Others' Topics. Have you noticed if your child has problems with Conversations?"

Write down problems, as described by parents, below. Continue with this same process with the other bold-faced key word in this clinical area:

Remember: If the parent endorses problems with Conversations, help them describe the child's specific behaviors in a descriptive way that suits the situation. Be sure to use as much of the parent's own wording on the problem description as possible and write it below.

Say: Some children tend to have problems with Making Friends. This may include: Having Few "Get-Togethers" With Peers Out of School, Having Few Friends in School, and Having Difficulty Acting Flexibly or "Nice" to Make and Keep Friends. Have you noticed if your child has problems with Making Friends?

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

5.	Conversation and Friendship	YTP Score (0-10)

Clinical Area 6: Self-Care Skills

Show the Self Care Skills Card to the parent(s) and review the problems on the Card in the following way while pointing to the boldface word "Self-Help Skills" on the Card to the parents.

Say: "Some children tend to have problems with Self-Help Skills. This may include: Having Difficulty Doing Self-Care Routines Independently, and Having Poor Personal Hygiene. Have you noticed if your child has problems with Self-Help Skills?"

Write down problems, as described by parents, below. Continue with this same process with the other bold-faced key word in this clinical area:

Say: Some children tend to have problems with Being Organized. This may include: Not Keeping Toys and Possessions Organized, Having Difficulty Living up to Responsibilities (Like Chores or Family Obligations), and Having Difficulty Planning Ahead. Have you noticed if your child has problems with Being Organized?

Say: "Ok, now, on a scale from 0 to 10, where 0 is not a problem at all to you, 5 is a problem, and 10 is a very, very big problem, how much would you say [problem as described by the parent] is a problem for your child?

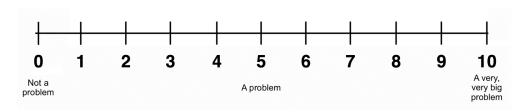
6.	Self-Care Skills	YTP Score (0-10)
		 -

Appendix B. Clinical Area Parent Rating Cards

Clinical Area Parent Rating Cards

Card 1: Dysregulated and Disruptive Behaviors

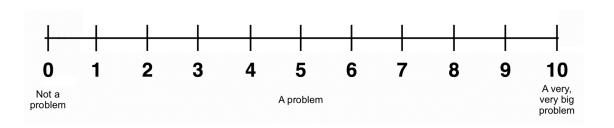
Aggressive	Frustrated or	Restless and Distractible
Hits	Angry	Feels uncomfortable sitting still
Insults	Acts disobedient	Has a hard time focusing
Threatens	Has tantrums	Has difficulty completing
	Gets irritated	homework or classwork
	easily	



Clinical Area Parent Rating Cards

Card 2: Anxiety and Depression

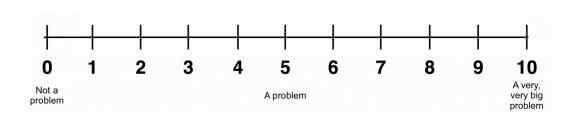
<u>Anxious</u>	<u>Depressed</u>
Has many fears	Feels sad or "blue"
Feels tense or panicked	Has low energy
Feels afraid of new people and	Lacks interest in things
situations	Feelings get hurt easily
Clings to parents	



Clinical Area Parent Rating Cards

Card 3: Rigid and Repetitive Behavior

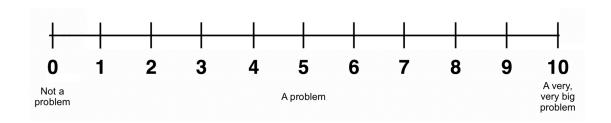
<u>Habits</u>	Rigid Behavior	<u>Obsessions</u>
Repeats movements (tics)	Has to do things a certain way	Has intense interests in just a few things
Repeats phrases (echolalia)	Gets upset when things go differently than expected	Has unwanted thoughts "stuck" in his/her head



Clinical Area Parent Rating Cards

Card 4: Peer Engagement in School and the Community

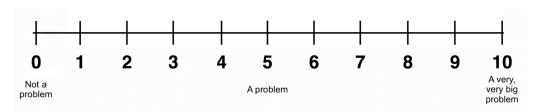
Not Engaged with Peers	Only Play on Own Terms
Doesn't join in play	Only willing to play a small
Reluctant to play or work in	number of games
groups when required to	Insists games are played by rules
Doesn't respond when invited to	that cannot change
play	



Clinical Area Parent Rating Cards

Card 5: Conversation and Friendship

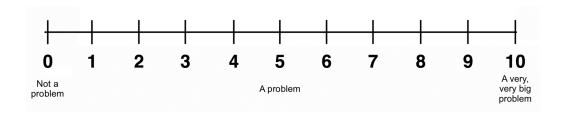
<u>Conversations</u>	Making Friends
Difficulty in keeping conversations going	Has few "get-togethers" with peers outside of school
Talks too much about own interests Doesn't show interest in others' topics	Has few friends in school Has difficulty acting flexible or "considerate" in order to have friends



Clinical Area Parent Rating Cards

Card 6: Self Care Skills

Self-Help Skills	Being Organized
Difficulty doing self-care routines independently	Doesn't keep toys and possessions organized
Has poor personal hygiene	Difficulty with responsibilities (like chores or family obligations)
	Difficulty with planning ahead



References

- Achenbach, T. M., & Ruffle, T. M. (2000). The child behavior checklist and related forms for assessing behavioral/emotional problems and competencies. *Pediatrics in Review, 21*(8), 265–271.
- Adams, D., & Young, K. (2021). A systematic review of the perceived barriers and facilitators to accessing psychological treatment for mental health problems in individuals on the autism spectrum. *Review Journal of Autism and Developmental Disorders*, 8(4), 436-453.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Anagnostou, E., Jones, N., Huerta, M., Halladay, A. K., Wang, P., Scahill, L., Horrigan, J. P., Kasari, C., Lord, C., Choi, D., Sullivan K., & Dawson, G. (2015). Measuring social communication behaviors as a treatment endpoint in individuals with autism spectrum disorder. *Autism*, 19(5), 622-636.
- Bannon Jr, W. M., & McKay, M. M. (2005). Are barriers to service and parental preference match for service related to urban child mental health service use? *Families in Society*, 86(1), 30-34.
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development*, 71(2), 447-456.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77-101.
- Centers for Disease Control and Prevention. (2018). Data and statistics on autism spectrum disorder. Retrieved from https://www.cdc.gov/ncbddd/autism/data.html.

- Christon, L. M., McLeod, B. D., & Jensen-Doss, A. (2015). Evidence-based assessment meets evidence-based treatment: An approach to science-informed case conceptualization.

 Cognitive and Behavioral Practice, 22(1), 36-48.
- Constantino, J. N., & Gruber, C. P. (2012). *Social responsiveness scale: SRS-2*. Western Psychological Services.
- Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., Metzger, L. M., Shoushtari, C. S., Splinter, R., & Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness scale with the autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders*, 33(4), 427–433.
- Creswell, J. W., & Creswell, J. D. (2017). Research design: Qualitative, quantitative, and mixed methods approaches. Sage Publications.
- Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee,
 L. C., Schieve, L. A., Van Naarden Braun, K., Wingate, M. S., & Yeargin-Allsopp, M.
 (2017). Autism spectrum disorder among US children (2002–2010): Socioeconomic,
 racial, and ethnic disparities. *American Journal of Public Health*, 107(11), 1818-1826.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375-387.
- Freitag, G. F., Grassie, H. L., Jeong, A., Mallidi, A., Comer, J. S., Ehrenreich-May, J., &
 Brotman, M. A. (2023). Systematic review: questionnaire-based measurement of emotion dysregulation in children and adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 62(7), 728-763.

- Gabriels, R. L., Cuccaro, M. L., Hill, D. E., Ivers, B. J., & Goldson, E. (2005). Repetitive behaviors in autism: Relationships with associated clinical features. *Research in Developmental Disabilities*, 26(2), 169-181.
- Geschwind, D. H., & Levitt, P. (2007). Autism spectrum disorders: Developmental disconnection syndromes. *Current Opinion in Neurobiology*, *17*(1), 103-111.
- Ghandour, R. M., Jones, J. R., Lebrun-Harris, L. A., Minnaert, J., Blumberg, S. J., Fields, J., Bethell, H., & Kogan, M. D. (2018). The design and implementation of the 2016 National Survey of Children's Health. *Maternal and Child Health Journal*, 22(8), 1093-1102.
- Gould, E. R., Dixon, D. R., Najdowski, A. C., Smith, M. N., & Tarbox, J. (2011). A review of assessments for determining the content of early intensive behavioral intervention programs for autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 990-1002.
- Golya, N., & McIntyre, L. L. (2018). Variability in adaptive behavior in young children with autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 43(1), 102-111.
- Harrison, P. L., & Oakland, T. (2003). Adaptive Behavior Assessment System manual (2nd ed.).

 Western Psychological Services.
- Havdahl, K. A., Hus Bal, V., Huerta, M., Pickles, A., Øyen, A.-S., Stoltenberg, C., Lord, C.,
 Bishop, S. L. (2016). multidimensional influences on autism symptom measures:
 Implications for use in etiological research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 55(12), 1054-1063.e3.
- Haynes, S. N., & O'Brien, W. H. (2000). *Principles and practice of behavioral assessment*. Springer Science & Business Media.

- Haynes, S. N., Mumma, G. H., & Pinson, C. (2009). Idiographic assessment: Conceptual and psychometric foundations of individualized behavioral assessment. *Clinical Psychology Review*, 29(2), 179-191.
- Herren, J., Garibaldi, P., Evans, S. C., & Weisz, J. R. (2018) Youth Top Problems assessment manual. [Unpublished Manual]. Retrieved from https://weiszlab.fas.harvard.edu/files/jweisz/files/top_problems_assessment_manual_0
 https://weiszlab.fas.harvard.edu/files/jweisz/files/top_problems_assessment_manual_0
- Hunsley, J., & Mash, E. J. (2007). Evidence-based assessment. *Annual Review of Clinical Psychology*, *3*(1), 29–51.
- Kaat, A. J., & Lecavalier, L. (2015). Reliability and validity of parent- and child-rated anxiety measures in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(10), 3219–3231.
- Kanne, S. M., Mazurek, M. O., Sikora, D., Bellando, J., Branum-Martin, L., Handen, B., Katz,
 T., Freedman, B., Powell, M. P., & Warren, Z. (2014). The Autism Impact Measure
 (AIM): Initial development of a new tool for treatment outcome measurement. *Journal of Autism and Developmental Disorders*, 44(1), 168-179.
- Kaufman, N. K. (2022). Rethinking "gold standards" and "best practices" in the assessment of autism. *Applied Neuropsychology: Child*, 11(3), 529-540.
- Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S.
 H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population:
 A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819-829.

- Laugeson, E. A., Frankel, F., Gantman, A., Dillon, A. R., & Mogil, C. (2012). Evidence-based social skills training for adolescents with autism spectrum disorders: the UCLA PEERS program. *Journal of Autism and Developmental Disorders*, 42(6), 1025–1036.
- Lord, C., & Jones, R. M. (2012). Annual Research Review: Re-thinking the classification of autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *53*(5), 490-509.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659-685.
- Lord, C., Rutter, M., & DiLavore, P. C. (1999). Autism diagnostic observation schedule--Generic. *Dissertation Abstracts International Section A: Humanities and Social Sciences*.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205-223.
- Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience Bulletin*, 33(2), 183-193.
- Maximo, J. O., Cadena, E. J., & Kana, R. K. (2014). The implications of brain connectivity in the neuropsychology of autism. *Neuropsychology Review*, 24(1), 16-31.
- Minuchin, S., & Fishman, H. C. (1981). Family therapy techniques. Harvard University Press.
- Nauta, M. H., Scholing, A., Rapee, R. M., Abbott, M., Spence, S. H., & Waters, A. (2004). A parent-report measure of children's anxiety: psychometric properties and comparison

- with child-report in a clinic and normal sample. *Behavior Research and Rherapy*, 42(7), 813-839.
- Norris, L. A., Rabner, J. C., Storch, E. A., Wood, J. J., Kerns, C., Lewin, A. B., Small, B. J., & Kendall, P. C. (2022). Idiographic coping outcomes in youth with autism spectrum disorder and co-occurring anxiety: Results from the TAASD study. *Journal of Autism and Developmental Disorders*, 1-8.
- Ozonoff, S., Iosif, A. M., Baguio, F., Cook, I. C., Hill, M. M., Hutman, T., Rogers, S. J., Rozga, A., Sangha, S., Sigman, M., Steinfeld, M. B., & Young, G. S. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(3), 256-266.
- Parker, J. G., Rubin, K. H., Erath, S. A., Wojslawowicz, J. C., & Buskirk, A. A. (2015). Peer relationships, child development, and adjustment: A developmental psychopathology perspective. *Developmental Psychopathology: Volume one: Theory and Method*, 419-493.
- Pickard, K., Reyes, N., & Reaven, J. (2018). Short report: Examining the inclusion of diverse participants in CBT research for youth with ASD and anxiety. *Autism*, 23(4), 1057–1064.
- Rooney, A. L., & Van Ostenberg, P. R. (1999). *Licensure, accreditation, and certification:*approaches to health services quality. Bethesda: Center for Human Services, Quality

 Assurance Project.
- Rosenfeld, C. S. (2015). Microbiome disturbances and autism spectrum disorders. *Drug Metabolism and Disposition*, 43(10), 1557-1571.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and

- associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921–929.
- Storch, E. A., Wood, J. J., Guzick, A. G., Small, B. J., Kerns, C. M., Ordaz, D. L., Schneider, S. C., & Kendall, P. C. (2022). Moderators of response to personalized and standard care cognitive-behavioral therapy for youth with autism spectrum disorder and comorbid anxiety. *Journal of Autism and Developmental Disorders*, 52(2), 950–958.
- Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods*. (3rd ed.). John Wiley & Sons, Inc.
- Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing*, 16(2), 151–155.
- Ung, D., Selles, R., Small, B. J., & Storch, E. A. (2015). A systematic review and meta-analysis of cognitive-behavioral therapy for anxiety in youth with high-functioning autism spectrum disorders. *Child Psychiatry & Human Development*, 46(4), 533-547.
- Weiss, M. J., & Harris, S. L. (2001). Teaching social skills to people with autism. *Behavior Modification*, 25(5), 785-802.
- Weisz, J. R., Chorpita, B. F., Frye, A., Ng, M. Y., Lau, N., Bearman, S. K., Hoagwood, K. E. (2011). Youth top problems: Using idiographic, consumer-guided assessment to identify treatment needs and to track change during psychotherapy. Journal of Consulting and *Clinical Psychology*, 79(3), 369-380.
- Weisz, J. R., Chorpita, B. F., Palinkas, L. A., Schoenwald, S. K., Miranda, J., Bearman, S. K., & Research Network on Youth Mental Health. (2012). Testing standard and modular designs for psychotherapy treating depression, anxiety, and conduct problems in youth: A randomized effectiveness trial. *Archives of General Psychiatry*, 69(3), 274–282.

- Weller, E. B., Weller, R. A., Fristad, M. A., Rooney, M. T., & Schecter, J. (2000). Children's interview for psychiatric syndromes (ChIPS). *Journal of the American Academy of Child & Adolescent Psychiatry*, 39(1), 76-84.
- Wilkinson, E., Farmer, C., Kleiman, E., & Bal, V. H. (2024). Factor structure of the VABS-3

 Comprehensive Parent/Caregiver form in autistic individuals: Poor fit of three-factor and unidimensional models. *Autism*, 28(3), 616-626.
- Wood, J. J., Ehrenreich-May, J., Alessandri, M., Fujii, C., Renno, P., Laugeson, E., & Storch, E.
 A. (2015a). Cognitive behavioral therapy for early adolescents with autism spectrum disorders and clinical anxiety: A randomized, controlled trial. *Behavior Therapy*, 46(1), 7–9.
- Wood, J. J., & Gadow, K. D. (2010). Exploring the nature and function of anxiety in youth with autism spectrum disorders. *Clinical Psychology: Science and Practice*, 17(4), 281–292.
- Wood, J. J., Kendall, P. C., Wood, K. S., Kerns, C. M., Seltzer, M., Small, B. J., Lewin, A. B., & Storch, E. A. (2019). Cognitive behavioral treatments for anxiety in children with autism spectrum disorder: a randomized clinical trial. *JAMA Psychiatry*, 77(5), 474-483.
- Wood, J. J., Kuhfeld, M., Sturm, A., Cai, L., Wood, K. S., Cornejo Guevara, M. V., Galan, C.
 A., Johnson, A. R., Cho, A.-C., & Weisz, J. R. (2022). Personalized autism symptom assessment with the Youth Top Problems Scale: Observational and parent-report formats for clinical trials applications. *Psychological Assessment*, 34(1), 43–5.
- Wood, J. J., McLeod, B. D., Klebanoff, S., & Brookman-Frazee, L. (2015b). Toward the implementation of evidence-based interventions for youth with autism spectrum disorders in schools and community agencies. *Behavior Therapy*, 46(1), 83-95.

- Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015).

 Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 36(2), 98-105.
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey.