ORIGINAL PAPER

Developing a Measure of Key Adult Outcomes in Adults with Developmental Disabilities: Conceptual Model and Item Generation of the REALS (Relationships, Employment, Autonomy, and Life Satisfaction)

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Abstract

Employment, social relationships, and autonomy are priorities to people with intellectual and developmental disabilities (IDDs). However, few validated measures exist to systematically assess these key adult outcomes in this population. This research includes first steps to develop self- and proxy report measures of life outcomes for adults with IDDs—the Relationships, Employment, Autonomy, and Life Satisfaction (REALS). A literature search identified existing adult outcome measures, and comparison of their domains informed initial conceptual model development. External consultants revised the model, and items were generated. Autistic adults (n = 15), adults with other IDDs (n = 7), caregivers of autistic adults (n = 13), and caregivers of adults with other IDDs (n = 10) completed in-depth cognitive interviews to assess comprehension of items and response categories, factors influencing how participants respond to items, and the inclusiveness of the item pool. A final conceptual model was generated with three subdomains (social relationships, employment, and autonomy), including assessment of life satisfaction within each domain. Cognitive interviews revealed that response set restructuring and item-level revisions were needed to capture the complexity of adult life and make the measure more accessible across a range of abilities. This study developed a conceptual model of relationships, work, and autonomy specific to adults with IDDs. Future work will involve collecting data from 800 + self-reporters with IDDs and 800 + caregivers of adults with IDDs to conduct psychometric analyses. Improving measurement in this area is critical to better understanding the needs of adults with IDDs and improving services available to them.

Keywords Autism · Developmental disabilities · Adult outcomes · Measurement · Survey development

Intellectual and developmental disabilities (IDD), including autism, intellectual disability, Fragile X, Down syndrome, and similar conditions affect at least 1 in every 40 children in the United States, with similar prevalence estimates in adults (Brugha et al., 2011; Christensen et al., 2018; Sherman, 2002; Shin et al., 2009; Turner et al., 1996). IDDs are life course neurodevelopmental disorders and many individuals with IDD experience challenges in adulthood,

such as maintaining social relationships, employment, and independence. Such challenges are compounded by the societal barriers and inequities (Roy et al., 2021) commonly experienced by adults with disabilities (Hartley et al., 2011; Taylor & Hodapp, 2012; Taylor & Mailick, 2014). This is further exacerbated by the considerable decrease in services and supports once individuals age out of childhood school systems (Hewitt et al., 2013; Shattuck et al., 2018, 2020). Despite this, most research on IDDs has focused on youth, and we know little about important adult life outcomes in this population.

Employment, social relationships, and autonomy are all real-world, adult life outcomes that are priorities to the IDD community (Benevides & Cassidy, 2020; Benevides et al., 2020; Kramer et al., 2019; Raymaker et al., 2022).

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Employment is associated with greater financial stability, community participation, and higher quality of life; job satisfaction is correlated with higher self-esteem and physical and mental health wellness (Faragher et al., 2005). Further, employment is one key avenue for adults with disabilities to receive services and supports through state vocational rehabilitation systems (Martinis, 2015). Despite its importance, rates of unemployment among adults with IDDs frequently exceed 50% (Bush & Tassé, 2017; Howlin et al., 2004, 2013) with estimates of under-employment often higher (Gotham et al., 2015).

Meaningful interpersonal relationships are among the top ranked priorities by adults with IDDs (Benevides et al., 2020). Adults with IDDs want supportive friendships, romantic partners, and meaningful casual relationships in their lives (Benevides et al., 2020; Farley et al., 2017; Gilmore & Cuskelly, 2014; Hartley et al., 2011; Orsmond et al., 2004). Yet, many adults with IDDs are isolated and have limited opportunities to interact socially with people outside of their home (Gilmore & Cuskelly, 2014; Taylor & Hodapp, 2012). This isolation has only been exacerbated as a result of the COVID-19 pandemic (Embregts et al., 2022).

Finally, autonomy is also a critical life outcome for adults with any disability. This is a particularly important outcome given that many adults with IDDs still rely on the support from their aging parents for daily living (Esbensen et al., 2010; Fernández-Ávalos et al., 2020; Hartley et al., 2011; Hewitt et al., 2013; Hustyi et al., 2015). Aging parents of adult children with IDDs have worse health outcomes and have major concerns about the future planning for their adult children (Hewitt et al., 2013; Kropf, 1997; Seltzer et al., 2011), suggesting that autonomy and independence are urgent research and public health priorities.

Measures that capture real life outcomes that matter to adults with IDDs are critical to identifying gaps in service systems as well as evaluating the effectiveness of existing programs. However, measurement of these outcomes for adults with IDDs has been suboptimal, with either coarse measurement that has not been scientifically validated or adaptations from childhood measures with limited applicability to adults (Berry-Kravis et al., 2013; Esbensen et al., 2017; Hart et al., 2017; Henninger & Taylor, 2013; Koslowski et al., 2016). Landmark studies of adult outcomes have traditionally classified individuals as having good, fair, or poor outcomes (Magiati et al., 2014), a rating which has low reliability and is generally insensitive to treatment-related changes. Other studies have utilized adaptive behavior scales as outcome measures, even though they were not designed for that purpose, such as the Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 2016) or the Adaptive Behavior Assessment Scale-3 (Harrison & Oakland, 2015). Commonly used measures developed for IDD treatment trials as outcome measures, such as

the Aberrant Behavior Checklist (Aman et al., 1985), are more feasible and sensitive to change. However, many such measures were developed without input from people with lived experience, and their content does not span social, independent living, and employment domains. Ultimately, researchers lack the ability to systematically assess important adult life outcomes in this population. This absence of validated, dimensional measures is a methodological barrier to supporting positive outcomes for adults with IDDs.

In this study, we sought to develop and refine an item bank of key aspects of adult life among adults with IDDs using rigorous measurement development standards established by the Patient-Reported Outcome Measurement Information System (PROMIS®) NIH initiative (PROMIS®, 2013). PROMIS® has an open-access repository of over 300 brief, validated, and efficient measures of health and wellbeing for use with adults across a wide range of patient populations that adhere to PROMIS® Instrument Development and Validation Scientific Standards (PROMIS®, 2013). These standards provide a model for ensuring rigor at all phases of measurement development, including conceptual model generation, item pool construction, cognitive interviewing and testing, and assessing reliability, validity, and interpretability.

The item bank developed is called the Relationships Employment Autonomy and Life Satisfaction (REALS). The REALS is a self- and proxy-report questionnaire format with item content spanning relationships, employment, and autonomy among adults with IDDs. First, we generated a conceptual model using community input to inform item development. We then developed the item pool and initial REALS instrument structure. Finally, we conducted cognitive interviews (N = 43) with both self-reporters and caregivers to assess the comprehension of all items and response categories, factors that influence how participants respond to items, and the inclusiveness of the item pool in capturing pertinent concerns related to these constructs.

Methods

Development of Conceptual Model

PROMIS® standards require that conceptual models are informed by existing evidence and developed and reviewed by content, measurement, and clinical experts. The preliminary conceptual model was developed and formatted by the study team based on extant literature. The initial model was then reviewed by outside consultants and well-established experts in the field. All investigators and project consultants met multiple times to engage in scholarly debate and dialogue, and organized feedback to generate an updated conceptual model (see Fig. 1), which included the domain (adult
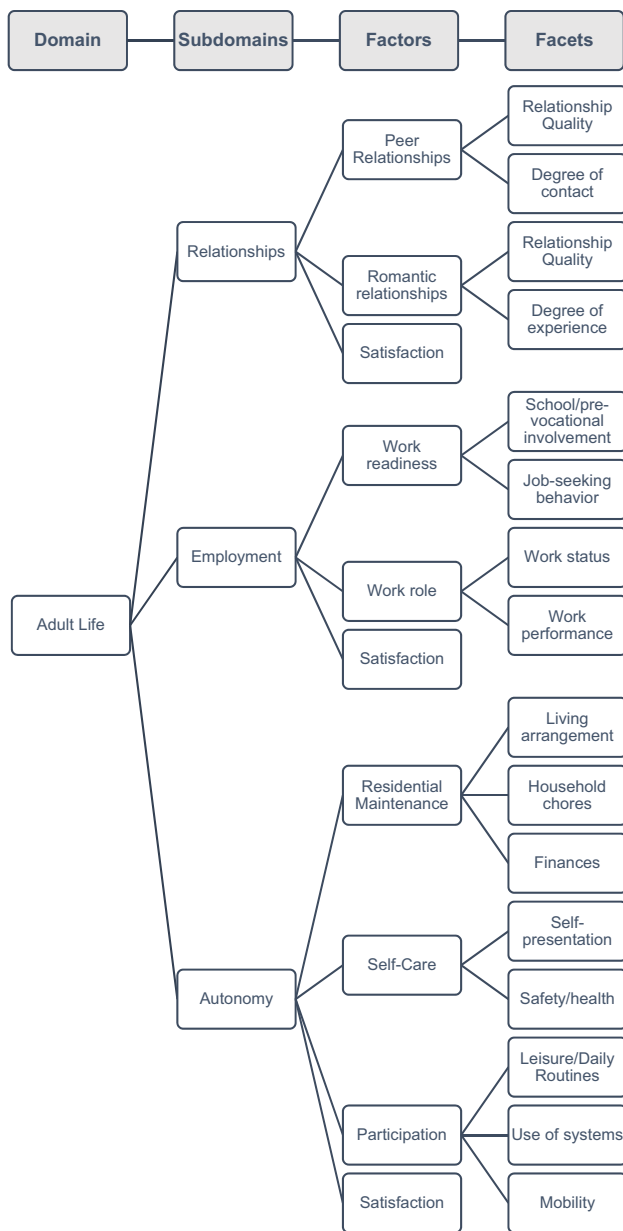
Fig. 1 Initial conceptual model used to generate REALS items for cognitive interviews

life), subdomains (relationships, employment, and autonomy), factors, and facets. The *Relationships* subdomain captures the quantity and quality of social relationships inside and outside of the family (e.g., friends, acquaintances), not social skills, or behaviors that may impact relationships. *Employment* captures the continuum from job preparation and readiness skills to aspects of one's employment role and volunteering. This domain also includes items relevant to being a student. *Autonomy* was intended to be broader than, but inclusive of, independent living skills, and covered residential maintenance, self-care, and participation in

personally meaningful activities. Based on participant input, a satisfaction factor was also added to each subdomain.

Item Pool Development and Instrument Structure

Per PROMIS standards, the item generation process includes reviewing items from existing measures with overlapping content and including and adapting high quality items that are relevant to the conceptual model in the new measure. A comprehensive literature search was conducted to identify all existing instruments that assess relationships, employment, and autonomy in adult IDD and psychiatric populations. Google Scholar, Medline, PsycInfo, and PubMed were utilized during this extensive search. Search terms included a measurement term (e.g., psychometric, reliability, validity) or "questionnaire", "scale", or "survey" together with a domain term (e.g., adaptive behavior, outcome, employment, independent living, social relationships). Over 50 measures were identified that contained overlapping content with a subdomain, factor, or facet of our conceptual model. For example, we considered measures developed for, or most commonly used in, IDD (i.e., Scales of Independent Behavior—Revised [SIB-R; Bruininks et al., 1996], Waisman Activities of Daily Living [W-ADL; Maenner et al., 2013]), as well as those primarily used in other populations [i.e., Specific Levels of Functioning Scale [SLOF; Schneider & Struening, 1983], Work Behavior Inventory [WBI; Bryson et al., 1997], as well as PROMIS measures in relevant domains. Per PROMIS standards, items from existing measures were incorporated into the item pool only if they could be mapped directly onto our preliminary conceptual model. Such items were typically heavily revised for clarity, readability, and grammatical consistency with the rest of the items. The number of items included verbatim from existing measures was small (n = 8), and so to ensure adequate content coverage of the model (i.e., at least four items per facet), the majority of items generated for the measure were novel.

All items were developed and revised with attention paid to: (1) possible basal and ceiling effects, particularly with regard to ensuring that the pool included items that could be endorsed positively even in the presence of severe intellectual disability; (2) inclusivity of language and pronoun use; (3) reading level (i.e., grade 6 or lower); (4) dimensional nature (i.e., avoiding categorical or dichotomous responses); (5) range of item difficulty (i.e., likelihood of being positively endorsed); and (6) items that could be theoretically responsive to change. A total of 128 items were generated to undergo cognitive interviews.

Finally, response options were generated based on other established PROMIS® measures (frequency, satisfaction) or new for this measure (degree of engagement, degree of independence) (See Table 1). Respondents were also

asked to rate each item within a 3-month timeframe, so that the final measure would be sensitive to change.

Self-Report and Proxy-Report Versions

Both the self-report and proxy-report versions of the REALS were developed concurrently, from the same conceptual model, with the same items. The only difference was that the self-report version was worded in first-person, and the proxy-report version was worded in third person.

Naming the REALS

The REALS was named by our participatory research group of community partners, the Pittsburgh Adult Autism Research Community Collaborative (PAARCC), which includes autistic adults, caregivers of autistic individuals, researchers, and community clinicians. The PAARCC group proposed several different names and voted on the REALS—Relationships, Employment, Autonomy, and Life Satisfaction.

Cognitive Interviews

PROMIS® standards include cognitive interviews as a necessary step in establishing the validity of a new instrument that occur after the initial item pool is developed and prior to psychometric testing. A cognitive interview is an evaluation of each individual item in the pool that assesses participant comprehension of items and response categories, factors influencing how participants respond to items, and the inclusiveness of the item pool in capturing pertinent concerns. Cognitive interviews are done across a diverse range of participants in order to understand how the items work across participants with different backgrounds and life experiences. PROMIS® guidelines for cognitive interviewing require a that minimum of five participants review each item (PROMIS®, 2013). We initially opted to recruit a much larger sample of interview respondents than PROMIS® recommends to better capture the immense heterogeneity among adults with IDDs and caregivers of adults with IDDs.

Participants

Participants were recruited from past research studies at the University of Pittsburgh, self-initiated and community/professional referrals, announcements in local and national

Table 1 Four initial REALS response sets to undergo cognitive interviews

Degree of Engagement
Never or rarely—Not something you do (no opportunity or cannot handle the activity)
Tolerates—Arranged by someone else and able to do it (generally get through the activity without major incidents)
Participates—Arranged by someone else and you are actively engaged and responsive
Initiates—Seeks the activity independently
Not enough information to rate
Degree of Independence
Never or rarely
Prompted by others and completes with assistance/support
Prompted by others but completes independently
Independently initiates and completes
Not enough information to rate
Frequency
Never or rarely—Not something you do (no opportunity or cannot handle the activity)
Sometimes—Do occasionally
Often—Is something you usually do
Almost always—Do almost all the time or consistently when there is an opportunity
Not enough information to rate
Satisfaction
Not at all
A little bit
Quite a bit
Very much
Not enough information to rate

online registries, recruitment flyers, and presentations to service providers in the community A total of 43 individuals were included who (1) were aged 18 years or older and (2) either had a professional diagnosis of autism or another IDD or were a support person for an autistic adult or adult with another IDD with at least weekly contact.

Cognitive interviews were conducted with autistic adults (n = 14), adults with other IDDs (n = 7), caregivers of autistic adults (n = 13), and caregivers of adults with other IDDs (n = 9). Self-reporting adults (n = 21) ranged in age from 19.25 to 50.56 years ($M = 32.16$, $SD = 9.65$). A total of 14 had a professional diagnosis of autism, one had Fragile-X, one had Cerebral Palsy, and five had Williams syndrome. Full scale IQ scores for self-reporters ranged from 51 to 122 (M = 92.65; SD = 20.98). Caregivers (n = 22) ranged in age from 24.75 to 80.79 ($M = 57.72$, $SD = 11.73$) and were caring for adults who were 19.74 to 39.78 years of age ($M = 27.13$, $SD = 6.57$). Of the 22 caregivers, 13 were the parents or caregivers of autistic adults, four Down syndrome, four Williams syndrome, and one was the parent of an adult with Prader-Willi syndrome. Over two-thirds of caregivers (N = 15, 68%) were parents whose adult children lived with them. Additionally, 27% (N = 6) reported that the person they cared for had a professional diagnosis of intellectual disability. Only one caregiver interviewed was a paid caregiver; the rest were parents of the adult with IDD about whom they answered questions. Full scale IQ scores for caregivers ranged from 84 to 126 ($M = 107.9$, $SD = 9.95$).

Ethical Approval

All participants provided written, informed consent prior to participation and the study was approved by the University of Pittsburgh Institutional Review Board. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Procedure

Prior to completing the cognitive interview, trained research staff administered both the Weschler Abbreviated Scale of Intelligence (WASI) and the Word Reading subtest of the Wide Range Achievement Test (WRAT). Most cognitive interviews (N = 41, 95%) were completed virtually using Zoom. Self-reporting adults with IDD were interviewed with the self-report version of the REALS and caregivers of adults with IDD were interviewed with the proxy report version. Participants reviewed all aspects of the new measure, including instructions, response sets, and individual items. Using a structured PowerPoint document,

trained research staff prompted participants to read each item, select a response, and discuss how they arrived at that response, all aloud. To minimize bias, interviewers were instructed to use exclusively open-ended questions, to avoid guiding questions, and to avoid reflecting or summarizing participant responses. Participants were also asked to provide general feedback on response options or items where appropriate (e.g., the applicability of items to lived experiences, inclusiveness of response choices, meaning of terms, confusing or vague wording), including any issues in content coverage (e.g., concepts that needed to be added or removed).

Total interview time ranged from 77 to 278 min ($M = 142.60$, $SD = 45.55$), often broken up into multiple one-hour sessions. Individual item responses were recorded, and interviewers took detailed notes on participant thought processes for each item, making sure to document challenges, such as instances of confusing terminology, difficulty choosing a response, unclear or non-applicable questions, etc. Upon completion of each session, interviewers also wrote detailed memos in which they documented notable patterns of participant responding across multiple items that would not otherwise be reflected in item-level notes (e.g., if a participant had difficulty answering a particular block of questions or consistently struggled to use a specific response set). All memos were aggregated and used in tandem with item-level notes to inform measure revisions.

Upon completion of cognitive interviews, study investigators, study coordinators, and research specialists met to discuss participant feedback and revise the measure. All item-level feedback was aggregated and organized by item (i.e., feedback from all participants was included under each respective item). The study team reviewed each item individually and discussed whether collective participant feedback indicated a need to revise or drop an item. Decisions on whether to revise or drop items were made on a case-by-case basis. Per PROMIS standards, the team looked closely for any participant feedback that indicated more common issues, such as difficulty orienting to and using the measurement time frame, difficulty answering questions with double negatives, and unintended interpretations of items (PROMIS®, 2013, p. 18). Memos included notable patterns of participant responding beyond item-level feedback (e.g., consistent difficulty understanding items within a specific facet), which were synthesized and categorized. This feedback was also reviewed by the entire study team and informed the restructuring of response options. When revising items and response sets, the team used verbatim language from participant feedback whenever possible. Additionally, parallel changes were made to both the self-report and proxy versions to cover all feedback from both groups and keep test forms consistent in anticipation of psychometric testing.

Once the final item pool was determined and the response sets revised, the measure was evaluated for readability and minor changes were made to make the measure readable at a sixth-grade level. The revised measure was then reviewed and approved by the investigator team and project consultants who contributed to the initial conceptual model development. PROMIS® guidelines require that if major revisions are necessary after initial interviews, the subsequent revised items undergo an additional 3–5 cognitive interviews (PROMIS®, 2013). Thus, after participant feedback was incorporated, two adult participants and one caregiver who participated in the first round of cognitive interviews were recruited again to complete a second cognitive interview with the revised measure. These participants provided minimal additional feedback, which was incorporated into final instrument revisions by the study team.

Results

Cognitive Interviews

Major participant feedback related to instrument structure and item content are shown in Table 2 with the corresponding revisions made.

Feedback Related to Instrument Structure

Response Options

Participant feedback revealed several structural issues related to the original response options. First, the original measure was broken into sections designated by the four separate response sets (degree of independence, degree of engagement, frequency, and satisfaction), with a collection of items from each subdomain (employment, relationships, autonomy) distributed across each response set. For example, of all the autonomy items, some were rated by frequency, some were rated by degree of independence, others still by degree of engagement, and some by satisfaction. However, participants expressed difficulty orienting to the different response sets. Both caregivers and self-reporters also had trouble using the independence and engagement rating scales, frequently reporting that no single answer choice applied fully to their lived experience. For example, multiple participants had difficulty choosing between the response options, "prompted by others but completes independently," and, "independently initiates and completes," often describing situations in which they (or their adult child) would independently initiate a task, but required some support to complete it. In addition, many caregivers had difficulty rating solely the frequency at which tasks

were completed when the frequency at which a task was completed was largely dependent on caregiver assistance. For example, when asked to rate the frequency of the item "arrives to appointments on time," one caregiver rated the item as "always," but explained that her son was always on time for appointments because she was responsible for managing the appointment and driving her son to the office. Self-reporters also expressed that items were difficult to rate unidimensionally (e.g., "I don't do that very often because I don't want to do it, not because I can't do it").

To address these concerns, several major changes were made to the response sets and measure structure (See Table 3). First, the degree of engagement response set was dropped entirely because it was challenging for participants to use and response choices were not mutually exclusive. The independence response option was revised and simplified to reflect the amount of support needed to complete each task. Participants did not report challenges using the frequency scale, and so it was retained. Next, the measure was restructured so that all items would be rated first on the frequency at which they occur, and then on the level of support needed to achieve them. Dropping the independence and engagement response sets addressed participants' reported challenges with these response choices. Restructuring the measure so that all items were rated on frequency and support addressed the difficulty participants had rating each item unidimensionally. Participants reported that the satisfaction response choices were straightforward, and so these were retained.

Three-Month Timeframe

Both caregivers and self-reporters expressed difficulty rating highly temporal items (i.e., items associated with specific times of the year) within the limitations of the 3-month timeframe. For example, items related to medical well visits, voting in elections, taking vacations, and filing taxes were often challenging to rate. In these instances, participants often qualified their responses with explanations that they could complete such tasks and/or had completed them in past, but simply had not had the chance to do so in the past three months. As a result, highly temporal items were either removed from the measure or revised to reflect tasks that would likely occur more consistently within a three-month timeframe.

Employment Ratings

Two changes were made to employment items and subdomain. First, self-reporters with stable employment responded with lower engagement, independence, and frequency ratings on seeking employment items because they had not engaged in any job seeking behavior in the past three

Table 2 Notable revisions made to REALS structure and response choices as a result of participant feedback

Feedback type	Given by*	Example	Revisions made
Assigning satisfaction ratings to others was awkward, especially when those adults were minimally or non-speaking	CG	**Instructions:** *Please rate how satisfied you think this person is with each of the following aspects of their life:* **Caregiver response:** "I mean, it's hard to say exactly. I think he enjoys his activities?"	Satisfaction items were removed from the proxy version
Rating frequency without consideration of independence was difficult in situations where frequency was largely dependent on caregiver assistance	CG	**Item:** *Comes to appointments on time* **Response options:** Never or rarely; Sometimes; Often; Almost always **Caregiver response:** "Well, I [always] take him to his appointments on time. But he would not be able to do that on his own."	All items are now assessed on both frequency and level of support needed
Participants were capable of completing many tasks probed by measure items but had not had the opportunity to do so in the past 3 months	CG SR	**Item:** *Votes in elections* **Self-reporter response:** "I haven't done that in the past three months. Typically, I would be independent, but never or rarely."	Highly temporal items were removed from the measure
Many individuals were not currently working but were attending school	CG SR	**Item:** *Finish given tasks at work* **Self-reporter response:** <u>"Can I just say, 'at school'?"</u>	All work items were revised to cover work <u>and</u> school
Stably employed respondents scored low on certain employment items because they were not actively seeking employment in the past 3 months	SR	**Item:** *Apply for jobs or seek job interviews* **Response options:** Never or rarely; Sometimes; Often; Almost always **Self-reporter response:** "Not in the last three months. So, I guess never or rarely?"	Work/school readiness and work/school performance items separated to be answered by unemployed and employed individuals, respectively

Table 3 Summary of REALS instrument before and after cognitive interviews

First draft of REALS	After cognitive interviews
12 background questions	8 background questions
128 total items	108 total items
38 relationships	31 relationships
15 employment	18 employment
75 autonomy	59 autonomy
Response set distribution	*Response set distribution*
38 degree of independence	61 frequency <u>and</u> level of support
23 degree of engagement	7 work/school readiness <u>or</u> 6 work/school performance
39 frequency	34 satisfaction
28 satisfaction	Independence and engagement dropped
Satisfaction items completed by self-reporters <u>and</u> caregivers	Satisfaction items completed by self-reporters <u>only</u>

Note: Item categories (relationships, employment, autonomy) are based on the REALS conceptual model; final scale content and structure will be determined based on later factor analysis

months. To address this, employment items were separated into two mutually exclusive sections, Work/School Readiness and Work/School Performance, to be filled out by unemployed and employed respondents, respectively. Second, both caregivers and self-reporters had questions about whether student status was considered employment. Many individuals were not currently employed but were attending school at least part-time. Thus, all work/school performance items were also revised to apply to both work and school, and student status was also added to the background items at the beginning of the measure.

Satisfaction Ratings

Caregivers expressed that assigning satisfaction ratings to the adults they cared for felt awkward, especially when the adults they cared for were minimally or non-speaking. The study team agreed that it was not appropriate for caregivers to rate another individual's own satisfaction. Thus, the satisfaction items were removed from the proxy-report version of the questionnaire.

Item-Level Feedback

To improve the accessibility of the measure, individual items were revised or dropped on a case-by-case basis in response to participant feedback. Examples of common item-level feedback and subsequent revisions are shown in Table 4.

Second Round of Cognitive Interviews

Feedback from the second round of cognitive interviews (n = 3) was favorable. Participants reported that measure flow was improved, items were clearer, and the streamlined response sets were easier to use than in the first cognitive interview. They appreciated the separation of employment

Table 4 Examples of REALS Item-level feedback and revisions from self-report version

Revision goal	Original item	Revised item
Simplified wording	"Meets performance expectations"	"Completes assigned tasks"
	"Are punctual at work"	"Arrive for work on time"
	"Living arrangement	"Where you live"
Separating compound questions	"Tolerate doctor and dental visits"	"Tolerate doctor visits" "Tolerate dental visits"
Unambiguous terms	"Make use of services that are available to you"	"Use disability or mental health services that are available to you"
	"Maintain personal space boundaries"	"Maintain personal physical space boundaries"
Inclusive language	"Walk safely in the community"	"Get around safely in the community"
	"Communicate a need for help when sick, hurt, or scared"	"Communicate, verbally or non-verbally, a need for help when sick, hurt, or scared"

items into the Work/School Readiness and Work/School Performance sections. They pointed out that some items should only be rated on frequency rather than frequency and support (e.g., items about romantic relationships). The team reviewed the measure for additional items that would be more appropriate to be rated on frequency alone.

Item Bank for Psychometric Testing

In summary, and as shown in Table 3, from the initial item pool of 12 background questions and 128 items, 8 background questions and 108 total items were retained for psychometric testing. Of those 108 items, the 34 satisfaction items were retained for psychometric testing with self-reporters only. Satisfaction items were rated on a 5-point Likert satisfaction scale. All other items were rated on *both* frequency and amount of support needed.

Discussion

This study developed a conceptual model of key aspects of adult life (relationships, employment, autonomy, and life satisfaction) for individuals with IDD utilizing community input and in-depth feedback from autistic adults, adults with other IDDs, and caregivers. The conceptual model was developed, and items were generated, field-tested, and revised using rigorous PROMIS® methodology. The results of this work will be used to further develop the REALS into a user-friendly and broadly applicable measures of key aspects of adult life, validated for use with adults with IDD. An additional goal of this initial phase of measurement development was to establish content and face validity of our conceptual model and item pool, which was achieved through expert review and in-depth interviews with our target population. Next steps will involve the collection of data from 800 self-reporters with IDD (e.g., autism, Down syndrome, Fragile X, Williams syndrome, etc.), and 800 caregivers of adults with IDD to conduct psychometric analyses.

The disability community has called for researchers to focus on real life outcomes that are important to adults with IDDs (Benevides & Cassidy, 2020; Benevides et al., 2020; Kramer et al., 2019). The development of the REALS directly addresses this call and also improves upon a number of ethical and methodological barriers in research and practice with these adults. First, the REALS was developed and tested, and will be psychometrically validated, in a population of adults with IDD, thus addressing methodological issues inherent in the use of measures that are not well validated in adults with IDD (Nicolaidis et al., 2020). Furthermore, prioritizing the development, testing, and validation of a self-report measure of adult

outcomes addresses further ethical issues surrounding the use of proxy-report, especially when it is used for adults who are capable of self-reporting (McDonald & Raymaker, 2013; Santoro & Constantine, 2022). Moreover, one of the biggest strengths of the new measure is that it also assesses adult life outcomes that directly matter to adults with IDDs (Benevides et al., 2020; Kramer et al., 2019). The REALS is not intended to be a unitary measure of all adult life outcomes; rather, it focuses on areas of adult life that are both important to the population and currently lacking in appropriate measurement options. Although psychometric analyses will be forthcoming, it is likely that the REALS will consist of several independent subscales that can be selected based on the context or need; it will not provide a "total score" of adult life outcome. We believe this is vital to shifting research and clinical care away from using functioning labels, which are dehumanizing to adults with IDDs (Kapp, 2023).

One of the larger challenges we faced developing this measure was negotiating the push and pull between the need for methodological simplicity and the need for practical relevance, especially given the heterogeneity of the IDD community and the general complexity of human life overall. Our initial REALS draft included four separate response sets with each REALS item rated unidimensionally on one of the four response sets. However, cognitive interviews revealed that there were different dimensions to these key aspects of adult life that we were not adequately capturing, which prompted us to restructure the REALS and measure all items on two different dimensions. Our task was to develop an empirically meaningful measure of relevant aspects of adulthood without oversimplifying or misrepresenting adult life for people with IDDs, and we believe we have achieved this balance with the REALS.

An important lesson learned from this process was the clear need for measures that are more accessible in order to be inclusive of the wide range of ability within the adult IDD community. Much of the feedback we received, particularly from our self-reporting adult participants, was consistent with the recommendations of other research in the development and adaptation of measurement instruments for adults with autism and other IDDs. The vast majority of item-level comments we received were related to simplifying, clarifying, and concretizing REALS items. Our subsequent revisions were in line with prior work suggesting that adapted items for individuals with IDDs be brief, unambiguous (e.g., with clear context and examples), and readable (e.g., plain language, simple sentence structure, without compound questions) (Beck et al., 2023; Bell et al., 2018; Cassidy et al., 2020; Nicolaidis et al., 2020). We believe the subsequent changes that were made as a result of this feedback are integral to the utility of the REALS for adults with IDDs.

The self-report option of the REALS is a major strength and self-report should be given strong preference whenever possible in both research and clinical settings. However, the proxy report version can be used if an individual cannot self-report and supports the eventual use of the REALS across the full spectrum of IDD. Furthermore, the life satisfaction section of the self-report measure gives researchers and clinicians the ability to assess participants' own satisfaction with different facets of their adult life, which can help to inform treatment priorities and intervention goals and facilitate better person-centered support.

The REALS has the potential to be used across a wide range of research and service settings. Following psychometric testing, the REALS will be a measurement option for clinical trials of interventions that target important adult life outcomes, such as social activity, work readiness, securing and maintaining employment, and life skills that are vital to independent living. While psychometric results are still forthcoming, we anticipate that the REALS will consist of many brief scales that measure different factors of adult life (for example, separate scales for peer relationships, work readiness, residential maintenance, self-care, etc.) which will enhance specialized treatment. Researchers and clinicians may opt to use just some, or all, of the different scales, as needed based on their research or clinical situation.

Future use of the REALS within clinical trials will help to assess test–retest reliability and determine whether the REALS is change-sensitive. It will also be freely available for clinicians to evaluate progress and program evaluation with IDD caseloads. The REALS also has applicability to service needs at an individual and population level, for example, if integrated into national registries, such as the Simons Powering Autism Research (SPARK) registry. The REALS may also be mapped onto insurance claims and service usage to evaluate the current service landscape and inform insurance policy.

Conclusion

People with IDDs face considerable challenges in adulthood, experiencing difficulty establishing and maintaining meaningful relationships, living independently, and maintaining competitive employment. Development of the REALS addresses researchers' inability to systematically assess outcomes in this population and removes methodological barriers to supporting positive outcomes and improving service provision for these adults. Lessons learned throughout the development of the REALS are consistent with other work in this area and contribute to a growing body of literature working to establish foundations for measurement development and adaptation in the IDD community. The REALS allows researchers and clinicians

to assess real life outcomes and better understand the needs of adults with IDD in key areas of adult life, guiding their successful transition to and through adulthood, and enhancing services available to them.

Declarations

Conflict of interest The authors report no relevant disclosures or conflicts of interest.

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