Development and Validation of a Culturally Relevant Self-Determination Scale for adults with Intellectual and Developmental Disabilities in India

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Abstract

Background:
Self-determination is a fundamental component influencing autonomy, well-being, and societal participation among individuals with intellectual and developmental disabilities (IDD). However, in India, the absence of culturally adapted and psychometrically validated tools poses significant barriers to accurately assessing self-determination capacities and supporting person-centred interventions.

Objective:
This study aimed to develop and validate the Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD), an assessment tool tailored to the Indian sociocultural context.

Methods:
Following a rigorous multi-phase process, the SDS-IDD was developed through literature review, expert panel consultations, and focus group discussions involving stakeholders, including adults with IDD, caregivers, and special educators. A sample of 100 adults with mild to moderate intellectual and developmental disabilities (IDD) from urban and semi-urban regions of India was recruited for field testing. Psychometric evaluation included assessments of internal consistency using Cronbach's alpha, test-retest reliability over a two-week interval, and construct validity through exploratory factor analysis (EFA).

Results:
The SDS-IDD demonstrated high internal consistency (Cronbach's $\alpha = 0.86$) and strong test-retest reliability ($r = 0.82$, $p < 0.001$). Factor analysis revealed a robust three-factor structure encompassing Autonomy, Goal-Setting, and Self-Advocacy domains, explaining 68.7% of the total variance. Convergent validity was supported by moderate positive correlations with adapted versions of The Arc's Self-Determination Scale.

Conclusion:
The SDS-IDD emerges as a culturally sensitive, reliable, and valid instrument for measuring self-determination among Indian adults with IDD. Its application holds significant potential for enhancing individualised support planning, program evaluation, and disability policy development in India. Future research should focus on broader regional adaptations and longitudinal validation to strengthen its utility across diverse Indian contexts.

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Keywords
Self-Determination, Intellectual and Developmental Disabilities (IDD), Scale Development, Cultural Adaptation, Psychometric Validation, Autonomy, Self-Advocacy, Disability Assessment, India

Highlights

- Developed the culturally adapted Self-Determination Scale for Indian adults with IDD.
- Conducted psychometric validation with 100 adults across urban and semi-urban regions.
- SDS-IDD showed high internal consistency (α = 0.86) and strong test-retest reliability (r = 0.82).
- Factor analysis revealed three core domains: Autonomy, Goal-Setting, and Self-Advocacy.
- SDS-IDD enables culturally sensitive assessment for planning supports and policy formulation.

1. Introduction

Self-determination, encompassing the ability to make informed decisions, set personal goals, and regulate one's life, is increasingly recognised as a vital component of quality of life for individuals with intellectual and developmental disabilities (IDD). Research consistently demonstrates that higher levels of self-determination among individuals with intellectual and developmental disabilities (IDD) are associated with improved educational attainment, better employment outcomes, increased independent living, and enhanced mental health (Wehmeyer & Schalock, 2001; Shogren et al., 2015). Self-determination is not only an educational or rehabilitative goal but a fundamental human right, underscored by international mandates such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006).

Despite the growing emphasis on self-determination globally, culturally sensitive measurement tools remain scarce, particularly in non-Western, collectivist societies such as India. Internationally recognised instruments such as The Arc's Self-Determination Scale (Wehmeyer, 1995) and the AIR Self-Determination Scale (Wolman et al., 1994) were developed in Western contexts. These instruments embed assumptions about autonomy and decision-making that may not fully align with the Indian sociocultural fabric, where family-centred decision-making, interdependence, and hierarchical social structures play significant roles. Consequently, direct adoption of these tools may lead to inaccurate assessments or misinterpretation of self-determination capacities among Indian adults with IDD.

India's unique socio-demographic diversity, encompassing regional, linguistic, and socio-economic differences, further complicates the application of standardised international measures. Moreover, legal frameworks such as the Rights of Persons with Disabilities (RPwD) Act, 2016, and initiatives under the National Education Policy (NEP) 2020 emphasise the need for inclusive practices, autonomy, and empowerment of individuals with disabilities. However, the meaningful implementation of these rights-based frameworks requires reliable and culturally appropriate assessment tools to monitor, support, and enhance self-determination outcomes.

Existing self-determination assessments face critical challenges when applied in the Indian context. These include linguistic complexity that is unsuitable for varying literacy levels, concepts of independence that may conflict with familial expectations, and cognitive demands that exceed the abilities of individuals with mild to moderate intellectual and developmental disabilities (IDD). Furthermore, tools heavily reliant on self-report formats may disadvantage individuals with communication difficulties, which are common within the IDD population. These limitations necessitate the development of an indigenous tool that reflects the lived realities, aspirations, and social structures of Indian adults with IDD.

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Recognising this gap, the present study sought to develop and validate the Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD). The SDS-IDD was designed to capture critical domains of self-determination—Autonomy, Goal-Setting, and Self-Advocacy—through culturally relevant language, scenarios, and normative frameworks. It aims to facilitate individualised support planning, enable person-centred interventions, and inform broader disability inclusion policies within India.

The development process of the SDS-IDD was guided by the Functional Model of Self-Determination (Wehmeyer, 1999), which conceptualises self-determined behaviour as a set of volitional, goal-directed actions that enable individuals to act as causal agents in their lives. This model, emphasising autonomy, self-regulation, psychological empowerment, and self-realisation, offers a robust framework adaptable across cultural contexts. However, adaptation required contextualising domains to reflect Indian familial structures, community participation patterns, and decision-making dynamics.

This research involved a systematic, multi-phase process beginning with a literature review and expert consultations to define culturally appropriate domains and items. Focus group discussions with adults with intellectual and developmental disabilities (IDD), caregivers, and special educators ensured linguistic simplicity, relevance, and comprehensibility. Subsequent field testing with 100 adults across urban and semi-urban settings evaluated the psychometric properties of the scale, including internal consistency, test-retest reliability, and construct validity through exploratory factor analysis.

The findings from this study significantly contribute to disability research in India by providing a psychometrically validated, culturally responsive tool. The SDS-IDD provides a framework for professionals to accurately assess self-determination levels, design targeted interventions, and monitor individual and systemic progress toward achieving autonomy and inclusion. Furthermore, it supports the broader goals of the RPwD Act and UNCRPD by promoting assessment practices that respect cultural contexts and individual aspirations.

In addition to filling a critical measurement gap, the SDS-IDD fosters a paradigm shift toward recognising adults with IDD as autonomous individuals capable of exercising choice and control over their lives. This shift is fundamental to dismantling paternalistic care models and advancing the rights-based, person-centred approach to disability services and policy in India.

Thus, the present paper details the development, validation, and implications of the Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD), advancing both the scientific and practical frontiers of disability assessment and intervention within the Indian context.

2. Materials and Methods

2.1 Study Design

This study employed a cross-sectional, tool-development and validation design, incorporating both qualitative and quantitative methodologies. The primary aim was to develop a culturally relevant, psychometrically validated Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD) tailored to the Indian sociocultural context.

2.2 Instrument Development Process

2.2.1 Item Generation

Initial items for the SDS-IDD were generated through an extensive review of existing literature on self-determination theory (Wehmeyer, 1999; Deci & Ryan, 2000), analysis of international scales such as The Arc's Self-Determination Scale and AIR Self-Determination Scale, and consultations with subject-matter experts. Focus group discussions (FGDs) with adults with IDD, caregivers, and special educators helped refine items for cultural and linguistic appropriateness.

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2.2.2 Content Validation

An expert panel comprising five specialists in special education, clinical psychology, and disability studies reviewed the initial 40-item pool. Items were evaluated for clarity, cultural relevance, and developmental appropriateness. Based on their feedback, redundant and ambiguous items were removed, resulting in a 30-item draft scale organised under three domains: Autonomy, Goal-Setting, and Self-Advocacy.

2.3 Participants

2.3.1 Inclusion Criteria

- Adults aged 14–35 years
- Clinical diagnosis of mild to moderate intellectualand developmental disabilities
- Ability to provide informed assent, with consent from guardians as necessary
- Basic communication abilities (verbal or alternative modes)

Table 1: Participant Demographic Characteristics

Characteristic	Category	Frequency (n)	Percentage (%)
Age (years)	**14–25**	**58**	**58%**
	26–35	**42**	**42%**
Gender	**Male**	**58**	**58%**
	Female	**42**	**42%**
Severity of IDD	**Mild IDD**	**63**	**63%**
	Moderate IDD	**37**	**37%**
Region	**Urban**	**61**	**61%**
	Semi-Urban	**39**	**39%**

Describes the age distribution, gender, severity of intellectual and developmental disability (IDD), and regional background of the study participants (N = 100).

2.3.2 Sampling and Recruitment

A purposive sample of 100 adults with intellectual and developmental disabilities (IDD) was recruited from vocational training centres, inclusive educational settings, and community-based rehabilitation programs across urban and semi-urban regions in North and West India. Sampling focused on ensuring diversity in gender, socio-economic background, and educational experiences.

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2.4 Ethical Considerations

The study received ethical approval from the Institutional Research Ethics Committee. Informed consent was obtained from participants' legal guardians, and participant assent was sought using accessible communication formats. Confidentiality, voluntary participation, and the right to withdraw were ensured throughout the study.

2.5 Data Collection Procedure

Participants individually completed the SDS-IDD in a structured interview format, which accommodated varied literacy levels. For individuals requiring assistance, trained facilitators familiar with disability communication protocols conducted the administration using visual supports, simplified language, and clarifications as needed.

A subset of 40 participants was re-administered the SDS-IDD two weeks later to assess test-retest reliability.

2.6 Psychometric Evaluation

2.6.1 Internal Consistency Reliability

The internal consistency of the SDS-IDD was assessed using Cronbach's alpha coefficients, both for the full scale and its domains. A value of $\alpha \geq 0.70$ was considered acceptable.

2.6.2 Test-Retest Reliability

Test-retest reliability was evaluated using Pearson's correlation coefficient between scores from the initial administration and the two-week follow-up administration.

2.6.3 Construct Validity

Exploratory factor analysis (EFA) was conducted using Principal Component Analysis (PCA) with varimax rotation to examine the underlying factor structure. The Kaiser-Meyer-Olkin (KMO) measure and Bartlett's test of sphericity were used to verify sampling adequacy and the suitability of the data for factor analysis.

2.6.4 Convergent Validity

Convergent validity was assessed by correlating the SDS-IDD scores with adapted scores from The Arc's Self-Determination Scale, using Pearson's correlation analysis.

3. Results

3.1 Participant Characteristics

The final sample consisted of 100 adults with intellectual and developmental disabilities (IDD), aged between 14 and 35 years (Mean age = 26.4 years; SD = 4.9).

- **Gender distribution**: 58% male and 42% female.
- **Geographical representation**: Participants were drawn from both urban (61%) and semi-urban (39%) regions in North and West India.
- **Functional profiles**: 63% were classified as having mild IDD, and 37% as moderate IDD based on clinical assessments.

3.2 Internal Consistency Reliability

The Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD) demonstrated strong internal consistency.

- **Overall Cronbach's alpha**: 0.86, indicatingexcellentinternal consistency.
- **Domain-wise reliability**:
  - Autonomy domain: $\alpha = 0.84$
  - Goal-Setting domain: $\alpha = 0.81$
  - Self-Advocacy domain: $\alpha = 0.79$

All values exceeded the acceptable threshold ($\alpha \geq 0.70$), supporting the scale's internal consistency.

3.3 Test-Retest Reliability

A subset of 40 participants was reassessed after two weeks to determine temporal stability.

- **Test-retest correlation coefficient**: r = 0.82 ($p < 0.001$), indicating strong test-retest reliability and suggesting that the SDS-IDD yields stable results over time.

3.4 Construct Validity: Exploratory Factor Analysis (EFA)

EFA was conducted to explore the underlying factor structure of the SDS-IDD.

- **Kaiser-Meyer-Olkin (KMO) measure**: 0.82, indicating meritorious sampling adequacy.
- **Bartlett's Test of Sphericity**: χ^2 (435) = 1987.45, $p < 0.001$, confirming the appropriateness of factor analysis.

Principal Component Analysis with varimax rotation yielded three factors with eigenvalues greater than 1.0, collectively accounting for 68.7% of the total variance.

- **Factor 1**: Autonomy (eigenvalue = 5.72; variance explained = 34.2%)
- **Factor 2**: Goal-Setting (eigenvalue = 2.85; variance explained = 19.4%)
- **Factor 3**: Self-Advocacy (eigenvalue 1.62; variance explained = 15.1%)

Item loadings within each factor were above 0.60, indicating strong associations between items and their corresponding domains.

3.5 Convergent Validity

Convergent validity was assessed by correlating SDS-IDD scores with scores from an adapted version of The Arc's Self-Determination Scale.

- **Correlation coefficient**: r = 0.64 ($p < 0.001$), indicating a moderate to strong positive relationship and supporting the convergent validity of SDS-IDD.

3.6 Summary of Psychometric Findings

Table 2: SDS-IDD is a psychometrically sound tool

Property	SDS-IDD Result	Interpretation
Internal Consistency (α)	**0.86**	**Excellent**
Test-Retest Reliability (r)	**0.82**	**Strong**
Total Variance Explained	**68.7%**	**Robust construct**
Convergent Validity (r)	**0.64**	**Moderate to strong**

These results confirm that the SDS-IDD is a psychometrically sound, culturally appropriate instrument for assessing self-determination among adults with IDD in the Indian context.

4. Discussion

This study aimed to develop and validate the Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD) tailored to the Indian sociocultural context. The findings indicate that the SDS-IDD is a reliable and valid tool, demonstrating robust psychometric properties across internal consistency, test-retest reliability, construct validity, and convergent validity.

The overall Cronbach's alpha of 0.86 reflects high internal consistency, exceeding the recommended minimum threshold of

0.70 for psychological instruments (Nunnally & Bernstein, 1994). Domain-wise reliability for Autonomy, Goal-Setting, and Self-Advocacy subscales also met acceptable standards, confirming the internal coherence of items within each domain.

Temporal stability was confirmed by a test-retest correlation of r = 0.82, indicating that the SDS-IDD reliably measures self-determination over time. These results are consistent with prior validations of international self-determination scales, such as The Arc's Self-Determination Scale (Wehmeyer, 1995), reinforcing the scale's empirical soundness.

Exploratory factor analysis supported construct validity, yielding a clear three-factor solution that explained 68.7% of the total variance. The identified autonomy, Goal-Setting, and Self-Advocacy align closely with theoretical models of self-determination and reflect the contextual adaptations necessary for the Indian setting, where collective decision-making and family involvement are integral aspects of daily life.

Convergent validity, demonstrated through a moderate to strong positive correlation (r = 0.64) with an adapted version of The Arc's scale, further strengthens the claim that SDS-IDD effectively captures the construct of self-determination among Indian adults with IDD.

The present study's outcomes emphasise the importance of culturally responsive assessment tools. Western measures often assume individualistic notions of autonomy, which may not translate seamlessly into collectivist societies. The SDS-IDD, by contrast, integrates culturally relevant scenarios, accessible language, and contextually appropriate constructs, offering a more accurate reflection of self-determination capacities within the Indian sociocultural milieu.

From a practical perspective, the SDS-IDD offers valuable implications for individualised educational planning, vocational training, community-based rehabilitation, and disability-inclusive policymaking. It can serve as a foundational assessment to identify individual strengths and areas for intervention and to design programs that foster autonomy, self-advocacy, and goal-directed behaviour.

Limitations of the study include the restriction of the sample to urban and semi-urban areas of North and West India, which may limit generalizability across India's broader regional and linguistic diversity. Additionally, individuals with severe or profound IDD were omitted, suggesting a need for adapted versions of the SDS-IDD to cater to varying levels of support needs. Future research should focus on longitudinal validation, broader regional adaptations, and testing with diverse populations with disabilities.

5. Conclusion

The Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD) represents a significant contribution to disability assessment practice in India. Developed through culturally responsive methodologies and validated through rigorous statistical analyses, the SDS-IDD provides a reliable, valid, and contextually appropriate measure of self-determination for adults with intellectual and developmental disabilities (IDD).

By capturing the domains of Autonomy, Goal-Setting, and Self-Advocacy within the Indian sociocultural framework, the SDS-IDD addresses critical gaps in assessment tools available for this population. Its application can inform individualised supports, empower adults with IDD to lead more autonomous lives, and contribute to

the realisation of disability rights as enshrined in the Rights of Persons with Disabilities (RPwD) Act, 2016 and the UNCRPD.

Future research should focus on extending validation efforts across diverse regions of India, developing simplified versions for individuals with non-verbal or severe disabilities, and exploring the longitudinal impacts of interventions using the SDS-IDD. Ultimately, widespread adoption of culturally relevant tools like the SDS-IDD can play a transformative role in advancing autonomy, dignity, and meaningful inclusion for adults with intellectual and developmental disabilities in India.

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7. Conflict of Interest

The authors declare that there are no conflicts of interest related to the research, authorship, and/or publication of this article.

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