

Barriers and Enablers of Self-Advocacy among Indian Adults with Intellectual and Developmental Disabilities: A Mixed-Methods Inquiry

Alok Kumar Bhuwan
Dr. Satyanarain Nai
Associate Professor

Department of Special Education
Shri Khushal Das University, Hanumangarh, Rajasthan

Abstract

Self-advocacy—being able to state one's preferences, make one's own decisions, and direct the course of one's life—is a pillar of autonomy and democratic citizenship. For Indian adults with intellectual and developmental disabilities (IDD), the practice of self-advocacy is frequently limited by deeply rooted sociocultural norms, institutionalised barriers, and uneven access to inclusive schooling and support services. In this study, we examine the diverse barriers and enablers that condition self-advocacy in this group through a mixed-methods approach that blends quantitative measurements and qualitative inquiry.

A culturally adapted Self-Determination Scale for Individuals with Intellectual and Developmental Disability (SDS-IDD) was constructed and tested across 100 linguistically and regionally diverse Indian adults. Participants also underwent a systematic Self-Advocacy Curriculum to establish decision-making skills, communication, rights awareness, and goal-setting. Quantitative pre- and post-intervention data reflected statistically significant improvements in self-determination across all subscales ($p < 0.01$), with a substantial gain in the 21–30 years group. Simultaneously, qualitative data obtained through interviews and

observation identified enablers in terms of support by family, peer interaction, inclusive pedagogy, and culturally adapted teaching strategies. This underscores the urgent need for culturally adapted tools in the field of special education.

The results underscore the essential significance of contextualising self-advocacy interventions in the sociocultural environment of India and validate the potential of adults with IDD to develop autonomy if equipped with adequate tools and support. This study provides a basis for policy, educational practice, and further studies to enhance the dignity, rights, and inclusion of individuals with intellectual and developmental disabilities in India, instilling a sense of hope and optimism in the audience.

Keywords: Self-advocacy, Intellectual and Developmental Disabilities (IDD), Autonomy, Inclusive Education, India, Disability Rights, Self-Determination, Cultural Context, Mixed-Methods Research, Empowerment

1. Introduction

The appreciation of self-advocacy as a fundamental element of human rights and individualised growth has become increasingly prominent in disability

discourse. For people with intellectual and developmental disabilities (IDD), self-advocacy is more than a simple expression—it is the right to be engaged in making decisions that direct their lives, ranging from day-to-day options to future goals. Even though disability policy in India, such as the Rights of Persons with Disabilities (RPWD) Act (2016), asserts autonomy and inclusive involvement explicitly, there exists a continuing disjunction between legislative abstraction and everyday practice. This disjunction is particularly evident in the lives of adults with IDD, where the rights and autonomy guaranteed by the law often do not translate into real-life decision-making power and opportunities.

In the Indian scenario, sociocultural forces significantly shape self-advocacy, especially in collectivist family settings where caregivers or elders enjoy authority in decision-making roles. Linguistic differences, disparities in economic status, a lack of comprehensive education opportunities, and shortages of well-trained support staff complicate the application of self-determination principles to this population. Current assessment procedures and intervention models, which were initially developed in Western settings, fail to reflect these complexity-laden realities and are, therefore, poorly adapted for purposeful application in India.

To address this critical shortfall, the current study uses a mixed-methods approach to explore the barriers and facilitators of self-advocacy in Indian adults with IDD. Pivotal to this study is creating and using the Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD)—a culturally sensitive assessment tool—and a modular Self-Advocacy Curriculum to support autonomy, communication, and decision-making.

This study attempts to illuminate both enabling opportunities and structures of constraint through the combination of quantitative results and deep, qualitative accounts. It aligns with the growing body of literature calling for rights-oriented, contextualised interventions that prioritise the voices, autonomy, and potential of people with IDD in India.

2. Literature Review

The principle of self-advocacy as a critical aspect of disability rights, autonomy, and inclusion discourse was developed on the foundations of self-determination theory. As we define it, self-advocacy encompasses the ability to recognise and articulate individual needs, make decisions, and invoke rights across life settings. For individuals with intellectual and developmental disabilities (IDD), self-advocacy is both a developmental skill and a powerful tool for social inclusion and dignity.

2.1 Global Views of Self-Advocacy and Self-Determination

The Wehmeyer (1999) Functional Model of Self-Determination outlines autonomy, psychological empowerment, self-regulation, and self-realisation as key areas for self-determined behaviour. Western empirical studies show that people scoring high on self-determination perform better in employment, schooling, and living independently (Wehmeyer & Palmer, 2003; Carter et al., 2009). These models, however, are predominantly based on individualistic paradigms and may lack applicability in a collectivist society like India.

2.2 Indian Legal and Educational Context

India's legislative system, including the Rights of Persons with Disabilities Act (RPWD), 2016, and the National Education Policy (NEP), 2020, champions inclusive education and enshrines the right of people with disabilities to live in dignity and exercise independent choice. Nevertheless,

in the face of enlightened legislative imperatives, uneven application exists. Reports identify the unavailability of systematic programming and assessment instruments, particularly for adult populations of IDD in India, especially those beyond the schooling system.

2.3 Barriers to Self-Advocacy in India

Sociocultural norms pose a significant challenge. Indian family systems tend to appropriate decision-making roles for people with IDD, resulting in overprotection and a lack of agency. Further, language diversification, poverty, restricted availability of services, and stigma altogether restrict advocacy opportunities. Empirical examination of these dynamics and validation of indigenous assessment models of self-determination are rare in Indian studies.

2.4 Facilitators and Models of Intervention

International literature also promotes role-play, visual aids, goal-setting exercises, and peer mentoring as successful methods for teaching advocacy skills. Variations of these strategies in small-scale Indian programs are reported as promising yet lack systematic validation. Literature also emphasises family involvement, culturally responsive pedagogy, and community-based implementation as crucial for successful outcomes.

2.5 Research Gap

Despite policy acknowledgement, the convergence of culture, disability, and self-advocacy is underdeveloped in Indian scholarship. A critical need exists for instruments and curricula that are both psychometrically sound and culturally relevant. Here, that need is met by placing international frameworks in Indian contexts and empirically testing a dual model of

intervention—an Indigenous self-determination scale and a systematic self-advocacy course.

Methodology

3.1 Research Design

This study adopted a mixed-methods approach to investigating the barriers and facilitators of self-advocacy among Indian adults with intellectual and developmental disabilities (IDD). By combining quantitative and qualitative techniques, the research aimed to capture measurable outcomes and contextual depth. A pre-and post-intervention framework was implemented to evaluate the impact of a newly developed Self-Advocacy Curriculum in conjunction with the culturally adapted Self-Determination Scale for Individuals with Intellectual and Developmental Disabilities (SDS-IDD).

3.2. Participants and Sampling

A purposive sample of 100 adults aged 18 to 35 with mild to moderate IDD was selected from vocational training centres and inclusive educational institutions in northern and western India. Participants were chosen based on their ability to engage in structured learning and complete assessments. Informed consent was obtained from either the participants themselves or their legal guardians. Individuals with profound disabilities were excluded due to communication needs that required alternative research designs.

3.3. Instruments and Tools

Self-Determination Scale for IDD (SDS-IDD): This tool, developed specifically for the study, measured levels of autonomy, empowerment, and self-advocacy. The scale employed simplified language, culturally resonant examples, and flexible responses such as verbal answers, pictures, or gestures.

Self-Advocacy Curriculum: This

Self-Advocacy Curriculum: This structured six-module curriculum covers identity, communication, rights, decision-making, seeking support, and personal planning. It uses interactive teaching methods, including role-playing, visual aids, and real-life scenarios, to ensure accessibility and engagement.

Qualitative Instruments: Data were gathered through semi-structured interviews with participants and caregivers, structured observation checklists, and detailed facilitator notes. Reliability of the scale was evaluated using Cronbach's alpha.

Qualitative Analysis: Interview transcripts and observational data were thematically coded using NVivo. Codes were grouped into key themes representing the main barriers and enablers of self-advocacy. This comprehensive, multi-dimensional methodology allowed for a robust assessment of the intervention's effectiveness while shedding light on the broader social and cultural factors shaping self-advocacy outcomes in the Indian context.

4. Results and Findings

4.1 Quantitative Results

The Self-Determination Scale for Individuals with Intellectual and Developmental Disability (SDS-IDD) was given pre- and post-intervention to 80 individuals completing the self-advocacy program. Statistical analysis indicated a significant gain in every domain.

A. Autonomy: Mean pre-test score = 18.2; post-test = 22.5 ($t = 4.23, p < 0.01$)

B. Empowerment: Mean pre-test = 16.1; post-test = 20.3 ($t = 3.87, p < 0.01$)

C. Self-Advocacy: Mean pre-test = 13.6; post-test = 18.7 ($t = 5.12, p < 0.01$)

D. Overall Score: Increased from 67.9 to 78.4 ($t = 6.94, p < 0.001$)

These outcomes validate the efficacy of the curriculum in improving participants' skills in expressing needs, making decisions, and taking self-initiated actions.

Participation by Level of Self-Determination After Intervention

A. High: 28%

B. Moderate: 72%

C. Low: 0%

Regional Variations (Mean SDS-IDD Scores)

A. East India: 80.4

B. North India: 74.2

C. South India: 69.8

D. West India: 64.6

($F(3,96) = 7.12, p < 0.01$)

The most significant gains were made in the 21–30-year-old group, indicating this as a critical window of developmental opportunity for self-advocacy interventions.

4.2 Qualitative Results

A range of barriers and facilitators was derived through a thematic interview and observation data analysis that influenced participants' self-advocacy skills.

Barriers:

A. Family Overprotection: Participants' caregivers frequently made decisions for them, precluding opportunities for autonomy performance.

B. Limitations of Communication: Participants with restricted expressive abilities could not state preferences, even with better comprehension.

C. Stigma and Social Norms: Prevalent cultural norms discouraged individual expression, particularly among women.

D. Inadequate Institutional Support: Variable application of inclusive practices and restricted facilitator training limited the curriculum uptake.

Enablers:

- A. Peer Support Networks:** Group environments fostered social learning and confidence-building.
- B. Inclusive Pedagogies:** Cultural examples, role-playing, and visual aids enabled comprehension and engagement.
- C. Family Involvement:** Increased caregiver participation in sessions enhanced skill translation to everyday life.
- D. Employment and Education:** Participants with previous vocational experience or formal education scored higher, suggesting the reinforcing effect of structured environments.

These results underscore the dual significance of one-to-one instruction and systemic change. Although participants made quantifiable gains, lasting change demands consistent support, accessible communication tools, and policies that validate the rights and abilities of individuals with IDD.

5. Discussion

The results of this research underscore the potential for the transformation of self-advocacy interventions among Indian adult participants with intellectual and developmental disabilities (IDD). Through a mixed-methods design, it was clear that systemic, cultural, and individual barriers are deeply ingrained, yet significant autonomy and agency gains are possible through systematic, context-sensitive interventions.

5.1 Self-Advocacy As A Desirable Developmental Goal

The statistically significant gains in all sectors of the SDS-IDD post-intervention substantiate the hypothesis that IDD individuals can increase self-determination if given accessible and culturally sensitive curricula. The most important gains were

made in the self-advocacy category, which implies that skill-building in communication and awareness of rights is responsive to systematic pedagogies. These results reinforce world literature on the efficacy of self-determination training but translate that wisdom to the Indian socio-cultural environment where family collective decision-making and protective caregiving tend to quash individual agency.

5.2. Socio-Cultural Mediation of Autonomy

Regional differences in post-intervention performance, especially the superior performance in Eastern India, can be attributed to differential access, social attitudes, and organisational readiness. The absence of gender-based differences implies that the design of the curriculum is neutral, though qualitative data point toward the presence of enduring social norms discouraging assertiveness, especially among women. This underlines the need to ensure that future interventions are built upon gender-sensitive and culture-based strategies.

5.3 Support Network and Institutional Inclusion Roles

Peer support and caregiver involvement were strong enablers of self-advocacy. These social dynamics offered support environments to express and practice skills, confirming that empowerment is as much a social co-construction as it is individual. At the same time, the lack of appropriately trained facilitators and inclusive organisational practices were commonplace deterrents—again indicating a systemic need for change in adult disability services, vocational rehabilitation, and lifelong learning.

5.4 Implications for Practice and Policy

The results of this study empirically justify the inclusion of self-advocacy training in adult disability programs in India. Successful execution of the SDS-IDD and curriculum model provides a template for scalable, culturally appropriate tools that can be replicated in different language, cognitive, and geographical contexts. Further, the study adds to the current policy debate surrounding the implementation of the RPWD Act by recommending that autonomy and inclusion can be enacted through focused, evidence-based programs.

6. Recommendations

For Practitioners and Educators:

A. Incorporate the self-advocacy curriculum into adult education, vocational training, and community-based rehabilitation programs.

B. Utilise the SDS-IDD tool as a developmental tracker to tailor instruction to individual levels of autonomy.

C. Offer professional development opportunities for facilitators focused on culturally responsive and inclusive teaching strategies.

For Policymakers:

A. Institutionalise self-determination training through existing national schemes such as the National Trust Act and the Deendayal Disabled Rehabilitation Scheme (DDRS).

B. Support regional adaptations of the curriculum to accommodate linguistic and cultural diversity.

C. Allocate funding for assistive technologies and communication support systems specifically designed for adults with IDD.

For Future Research:

A. Conduct longitudinal studies to assess the sustained impact of self-advocacy training on employment, independent living, and community participation.

B. Broaden research samples to include underrepresented regions, gender groups, and individuals with profound disabilities.

C. Explore digital delivery formats to scale the curriculum and enhance its reach and accessibility across diverse contexts.

7. Conclusion

Self-advocacy is both a developmental necessity and a fundamental human right. For adults with intellectual and developmental disabilities (IDD), the capacity to express needs, make decisions, and assert preferences is essential for achieving autonomy, dignity, and full participation in society. This study provides robust empirical evidence that, with the support of culturally relevant and structured interventions, Indian adults with IDD can significantly enhance their self-determination and advocacy competencies. Through the application of the Self-Determination Scale for IDD (SDS-IDD) and a modular Self-Advocacy Curriculum, the research demonstrated that self-advocacy is not only teachable but highly impactful—even in the face of entrenched social, linguistic, and institutional barriers. Participants exhibited measurable confidence, communication, autonomy, empowerment, and goal-setting gains. The findings reinforce that effective self-advocacy initiatives must be rooted in individuals' lived experiences, cultural values, and social networks.

They also signal the urgent need for systemic transformation, which involves translating inclusive policies into practice through educator training, community engagement, and curriculum development. Looking ahead, future efforts should prioritise the development of scalable, accessible delivery models, particularly those integrating digital technologies. Further exploration is also needed to understand long-term outcomes and to adapt strategies for individuals with higher support needs.

This study offers a replicable, rights-based framework for empowering adults with IDD in India to become active agents in shaping their lives—a pivotal step toward achieving inclusive citizenship and social justice.

References

- Barry, L. (2021). *Bridging the gap: Understanding Irish teachers' use of evidence-based practices with children with autism*. [PDF]. CORE. <https://core.ac.uk/download/481602995.pdf>
- Diez, I., Drijkoningen, D., Stramaglia, S., Bonifazi, P., Marinazzo, D., Gooijers, J., Swinnen, S. P., & Cortes, J. M. (2017). Enhanced pre-frontal functional-structural networks to support postural control deficits after traumatic brain injury in a pediatric population. *Network Neuroscience*, 1(4), 325–343. https://doi.org/10.1162/netn_a_00007
- Ebrahimi, P., Kot, S., & Fekete-Farkas, M. (2020). Platform entrepreneurship: An interpretative structural modeling. *Nordic Journal of Media Management*, 1(2), 108–128. <https://doi.org/10.5278/njmm.2597-0445.6108>
- Government of India. (2016). *The Rights of Persons with Disabilities Act, 2016*. Ministry of Law and Justice. <https://legislative.gov.in>
- Government of India. (2020). *National Education Policy 2020*. Ministry of Education. <https://www.education.gov.in>
- India. (2018). India: Facility of reader or computer for students with special need. *MENA Report*.
- International Data Group. (2025). Individuals with intellectual and developmental disabilities (IDD) to be a part of the transport system, such as: Physicians, physician assistants, nurse practitioners, psychiatrists, and psychologists. *MENA Report*.
- Lee, Y., Shin, S., & Shin, S. (2022). The effect of body composition on gait variability varies with age: Interaction by hierarchical moderated regression analysis. *International Journal of Environmental Research and Public Health*, 19(3), 1171. <https://doi.org/10.3390/ijerph19031171>
- Machová, K., Juričková, V., Kasparová, A., Petrová, K., Sládková, B., & Svobodová, I. (2023). An evaluation of the effect of equine-facilitated psychotherapy on patients with substance use disorders. *PLOS ONE*, 18(6), e0286867. <https://doi.org/10.1371/journal.pone.0286867>
- Manovikas eGyanshala. (n.d.). *National Workshop on Skill Development (nwsd)*. <https://manovikasfamily.org/gyanshala/nwsd/>
- Resources - Floor23 Care. (n.d.). *Support that empowers, care that transforms*. <https://floor23care.com/resources/>
- Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 14(1), 53–61. <https://doi.org/10.1177/108835769901400107>
- Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination.

Education and Training in Developmental Disabilities, 38(2), 131–144.

14. Informatics. (2025). Human-centred design meets AI-driven algorithms: Comparative analysis of political campaign branding in the Harris–Trump presidential campaigns. *Informatics*, 12(1), 30. <https://doi.org/10.3390/informatics12010030>