

ISSN: 2574 -1241 DOI: 10.26717/BJSTR.2025.63.009947

Social Status of Individuals with Autism Spectrum Disorder in Nepalese Society

Surendra Bajracharya*

Director, Autism Care Nepal Society, Godawari, Nepal

*Corresponding author: Surendra Bajracharya, Director, Autism Care Nepal Society, Godawari, Nepal

ARTICLE INFO

Received: dim October 24, 2025 Published: November 06, 2025

Citation: Surendra Bajracharya. Social Status of Individuals with Autism Spectrum Disorder in Nepalese Society. Biomed J Sci & Tech Res 63(5)-2025. BJSTR. MS.ID.009947.

ABSTRACT

This study explores perceptions of Autism Spectrum Disorder (ASD) in Nepal by mapping qualitative data to the Perceptual Stages of Autism Spectrum Disorder (3AR) Framework, which was created in conjunction with World Autism Awareness Day (WAAD) 2024. Using a hermeneutic phenomenological approach, I performed case studies (n = 4) with persons diagnosed with ASD, one focus group discussion (FGD; n = 9) with parents of children with ASD, and semi-structured interviews (n = 8) with religious and political leaders. Participants were purposively sampled to ensure diverse insights into ASD perceptions across immediate caregivers and broader community stakeholders. Data were transcribed verbatim, reflexively bracketed to mitigate researcher bias, and analyzed using Framework Analysis aligned with the 3AR stages. Findings reveal that parents possess nuanced, experiential awareness and strong acceptance of ASD, yet community leaders often exhibit limited knowledge and persistent misconceptions. Appreciation of Persons with Autism (PWA) remains conditional, with strengths overlooked in favor of sympathetic yet welfare-oriented attitudes. Recognition, manifested as policy support and rights-based inclusion, proved underdeveloped due to ambiguous disability classification criteria and weak implementation of ASD-specific legislation.

I discuss implications for inclusive education reforms, targeted awareness campaigns, and rights-based policy implementation, and propose actionable recommendations for Nepali policymakers, religious institutions, educational stakeholders, and community health workers.

Keywords: Autism Spectrum Disorder; Social Status; Low- and Middle-Income Countries; Nepal

Abbreviations: ASD: Autism Spectrum Disorder; WAAD: World Autism Awareness Day; FGD: Focus Group Discussion; PWA: Persons with Autism; ICFDH: Classification of Functioning, Disability, and Health; LMICs: Lowand Middle-Income Countries; UNCRPD: United Nations Convention on the Rights of Persons with Disabilities; MOWCSC: Ministry of Women, Children, and Senior Citizens; MOHP: Ministry of Health and Population; MOEST: Ministry of Education, Science, and Technology

Introduction

People with disabilities are the most disempowered and the most at-risk groups. In addition to that, they also have a small range of access to health services, education, and job opportunities, and they also suffer from prejudice and stigma. The World Health Organization characterizes disability as "a limitation or absence (as a result of an injury) of the ability to carry out an activity in the same way or within the scope that is considered normal for a human being" (1980). The Convention on the Rights of Persons with Disabilities states that disability is a human rights-based perspective which focuses on the intersection of personal and societal barriers that hinder people with disabilities from fully and equally participating in society (UN, 2006).

Disability is a generic term that covers a lot of impairments, limitations of activities, or restrictions of participation that are results of the relationship of a person who has a health condition with personal factors (such as age or gender) and environmental factors (such as the physical environment, attitudes), according to the International Classification of Functioning, Disability, and Health (ICFDH) (WHO, 2001). There is a strong need for the definition of disability to be changed and for the situation to be changed at every level for the disabled community, from the family to the government, society, and the workplace.

According to the new law on disability, the Social Welfare Act 2074 (2017), as a result of a study conducted in Nepal, the Act still contains

little information and lacks the inclusion of autism spectrum disorder (ASD) as the cause of the government's limited commitment to autism service development. Also, the law outlines the rights of persons with disability but does not address the issue of stigma and discrimination that are the root causes of the violation of the rights of persons with disability. Globally, public awareness and health responses to autism have improved markedly over the past decade, contributing to earlier diagnoses and increased prevalence estimates (Botha, et al. [1]). However, in low- and middle-income countries (LMICs) like Nepal, systemic barriers rooted in traditional belief systems, poverty, and weak health infrastructure continue to hinder accurate screening and acceptance (Laitila [2]). Research from South Africa's Autism Western Cape Organization similarly underscores that although awareness and acceptance are rising among engaged families, broad societal attitudes remain reticent, constrained by stigma and socio-economic challenges (Laitila [2]). The Perceptual Stages of Autism Spectrum Disorder (3AR) Framework, Awareness, Acceptance, Appreciation, and Recognition, was developed in the context of World Autism Awareness Day (WAAD) 2024's theme ("#Awareness #Acceptance #Appreciation: Moving from Surviving to Thriving: Autistic individuals share regional perspectives").

This stage-based model offers a structured lens through which to examine how autism is perceived and experienced at multiple socio-cultural levels (Botha, et al. [1]). While Awareness captures initial understanding of ASD, Acceptance describes familial and societal embracement of autistic identities. Appreciation highlights recognition of autistic individuals' abilities and contributions, and Recognition encompasses policy, rights-based inclusion, and long-term support mechanisms. Research on perceptions of autism has predominantly focused on Euro-American contexts, where advocacy by self-identified autistic adults has reshaped narratives from deficit-based to strengths-based paradigms (Botha, et al. [1]). Conversely, in South Asia, limited studies reveal that family's shoulder substantial caregiving burdens amid pervasive stigma, delayed diagnoses, and insufficient support systems (Al-Farsi, et al. [3,4]). For instance, Bhandari [4] documented that siblings play vital roles in socializing children with ASD in Nepal's Jhapa and Sunsari districts, yet pervasive community unawareness limits broader inclusion. Furthermore, policy analyses indicate that although Nepal's constitutional framework and disability legislation align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), enforcement weakens due to lack of measurable criteria for disability classifications and inadequate dissemination among stakeholders (Ability Manch [5]).

Research Questions

Building on these gaps, the present study examines following research questions:

1) How do caregivers perceive ASD across the stages of Awareness, Acceptance, Appreciation, and Recognition?

- 2) What are the views of religious and political leaders with regard to autism and in what ways are their perspectives similar or different from those of caregivers?
- 3) How do these stakeholders perceptions collectively influence the social status and inclusion of Persons with Autism (PWA) in Nepali society?

Methods

Study Design and Philosophical Underpinnings

This research employed a hermeneutic phenomenological design to explore lived experiences and perceptions of ASD in Nepal. Hermeneutic phenomenology is particularly suited for capturing the meanings individuals ascribe to their experiences while acknowledging researcher reflexivity (Van Manen, 2014). To structure data collection and analysis, I integrated the Perceptual Stages of Autism Spectrum Disorder (3AR) Framework, Awareness, Acceptance, Appreciation, and Recognition, developed in alignment with WAAD 2024's theme. Framework Analysis (Ritchie, et al. [6]) provided a systematic approach to organizing and interpreting qualitative data, ensuring that themes could be directly mapped onto each 3AR stage. A pragmatic philosophical stance underpinned our mixed-methods orientation (Creswell & Plano Clark, 2018), although this paper focuses exclusively on qualitative findings. Pragmatism bridges interpretative and realist paradigms by prioritizing practical outcomes and multiple methods to address research questions (Tashakkori & Teddlie, 2010). In this study, while positivist elements (e.g., quantifiable frequencies in a broader survey) informed contextual understanding, hermeneutic phenomenology guided in-depth qualitative exploration. Reflexive bracketing (Gearing, 2004) was adopted throughout to minimize researcher bias; co-authors maintained reflexive journals to document assumptions and positionality relative to ASD research in Nepal.

Participants and Sampling

This study targeted adults with ASD (n = 4; ages 18-35, recruited via local ASD support organizations and clinics in Kathmandu), parents of children with ASD (n = 9; members of the AutismCare Nepal Society support network from diverse socio-economic backgrounds), religious leaders (n = 4; community influencers in rituals and values), political leaders (n = 4; officials from UML, Maoist, Nepali Congress, and a local deputy mayor), and neighbors/relatives/siblings (n = 30; identified via snowball referrals from ASD families, who completed a complementary questionnaire to triangulate qualitative insights). I employed purposive (judgmental) sampling to identify participants with direct experiences or influence regarding ASD. Inclusion criteria for adults with ASD required: formal ASD diagnosis by a registered Nepali clinician, ages 18-35, and the capacity for verbal communication. Parents needed at least one child aged 5-18 with a confirmed ASD diagnosis. Religious and political leaders were required to hold official roles and oversee constituencies or congregations within Kathmandu

Valley [7-31]. This purposive approach ensured maximum variation across stakeholder roles and socio-cultural contexts. While sample sizes were modest, they aligned with hermeneutic phenomenology's emphasis on depth over breadth (Guest, Bunce, & Johnson, 2006). Detailed recruitment procedures included initial contact via phone or email, verbal explanation of study aims, and formal informed consent. Explainable trust and rapport were prioritized: researchers had prior collaborations with the ACNS, facilitating participant engagement.

Ethical Considerations

All participants provided written informed consent. For adults with ASD, additional assent procedures were used: simplified information sheets and verbal confirmations ensured understanding. Confidentiality was maintained by assigning pseudonyms. Digital audio files were encrypted, and transcripts de-identified prior to analysis.

Data Collection Procedures

Data were collected from February to April 2020 in private settings, community centers, and participants' homes to ensure open dialogue. First, four adults with autism spectrum disorder participated in one-on-one, semi-structured interviews lasting 45-60 minutes. These case studies, guided by Yin's (2018) methodology, offered indepth insights into the 3AR stages as perceived by individuals with autism themselves. Audio recordings (encrypted) and field notes captured verbal and nonverbal cues. Second, a two-hour focus group discussion with nine parents, balanced by gender and socio-economic backgrounds, elicited communal reflections on initial diagnosis reactions, evolving family roles, acknowledgment of children's abilities, and policy concerns. A trained qualitative researcher moderated the session at AutismCare Nepal Society, with audio recording and notes on nonverbal dynamics. Third, semi-structured interviews (45-60 minutes) with eight community leaders, four religious and four political, explored their conceptualizations of autism, doctrinal or party stances toward disability, roles for people with autism, and policy knowledge. Interviews occurred in offices or homes, with audio recording and detailed contextual field notes.

Reflexivity and Bracketing

Throughout data collection and analysis, researchers engaged in reflexive bracketing to acknowledge and mitigate their positionality. The author maintained reflexive journals documenting preconceived notions, e.g., assuming widespread community stigma, and logged moments when interpretations shifted.

Data Analysis

Transcription

All audio recordings were transcribed verbatim in Nepali and then translated into English by a bilingual transcriptionist experienced in qualitative research.

Framework Analysis (3AR)

I employed Ritchie and Spencer's (1994) five-step Framework Analysis, aligning codes and themes with the 3AR Framework. First, I familiarized myself by repeatedly reading transcripts and noting initial observations. Next, I identified a thematic framework through open coding, generating codes such as "sources of ASD information," "religious belief influences," "educational barriers," and "policy gaps." For indexing, I used Microsoft Excel to create a matrix with participants as rows and 3AR domains as columns, placing coded excerpts under the appropriate domain. During charting, I condensed data within each column into subthemes, such as "diagnosis via Google search" and "misconceptions as mental illness" under Awareness, and "unclear ID card criteria" and "lack of ASD-specific policy" under Recognition. Finally, mapping and interpretation involved iteratively examining the matrix to identify patterns, cross- group comparisons (e.g., parents versus leaders), and contrasting narratives, such as parents lived experiences of acceptance versus community leaders' superficial sympathy.

Rigor and Trustworthiness

I applied the four criteria for qualitative rigor: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

- Credibility: Prolonged engagement (two-month fieldwork), member checking (participants reviewed preliminary themes), and peer debriefing bolstered credibility.
- Transferability: Thick description of context and purposive sampling provide sufficient detail for readers to assess applicability to similar settings.
- Dependability: An audit trail, including transcripts, codebooks, reflexive journals, and analysis memos, was maintained.
- Confirmability: Triangulation across methods (case studies, FGDs, interviews) and stakeholder groups minimized researcher bias.

Findings

Awareness

Among four Persons with Autism (PWA) interviewed in a 2020 case study, three understood their diagnosis, while one young adult, though acknowledging having ASD, could not fully grasp its implications. High-functioning individuals displayed deeper insight, with one stating, "I'm really fine with autism. I can tell that it is a real task for parents; they have to put in even more work than regular individuals." Others had only vague awareness and could not elaborate on what autism involved (Source: Case Study of Person with Autism, 2020).

Parents emerged as the most informed group, yet misconceptions persisted. In a focus group discussion (FGD), highly educated parents

admitted they had not heard of autism before their child's diagnosis. One mother recalled that, at her daughter's second birthday party, her grandmother jokingly remarked that the child "seems just like an autism," but no one took it seriously because her daughter maintained good eye contact. Curious after noticing her daughter's repetitive behavior of pouring water between glasses at age two, the mother searched online. The images she found were "dreadful," as many symptoms matched her daughter's behavior. Although her husband downplayed the concern, she could not sleep and sought help from Autism Care Nepal Society. Upon consulting specialists, she learned that her daughter's repetitive pouring was also an autistic behavior.

Initially shocked, she soon realized, "every child with autism has some positive aspects though it's very severe," and chose to focus on her child's strengths rather than solely on deficits (Source: FGD of Parents of Children with Autism, 2020). Despite parents becoming increasingly informed post-diagnosis, their initial lack of awareness underscores a broader societal gap. Misinterpretation of early signs, such as attributing repetitive play to typical toddler curiosity, delays intervention and heightens parental anxiety. Many families only recognize autism when confronted with clinical information, rather than through community education or primary-care screening.

Acceptance

Acceptance among Religious Leaders

Semi-structured interviews with four religious leaders in 2020 revealed that three had heard the term "autism" for the first time during the interview, often conflating it with mental illness. A Buddhist monk, who regularly conducts meditation, puja offerings, and teaches Pali at Therbad Buddhism School, said he believed autism might be a mental disease, noting some students "do not concentrate at all and just stare or be in their own world." Another Buddhist leader, also a medical doctor, recognized autism as distinct, explaining that he knew it as "a disorder which starts from childhood. The child behaves differently, is socially different, learns slowly, needs special training and care at an early age and throughout life" (Source: Semi-Structured Interview of Religious Leaders, 2020). A Christian leader admitted, "I have no idea at all" when asked about autism, while a Hindu (Sanatan Dharma) woman attributed autistic behavior to karma: "I just thought it might be disease due to sin of past life." These responses demonstrate low baseline awareness among religious figures, with many viewings autism through lenses of mental illness or spiritual causation rather than as a neurodevelopmental condition.

Acceptance among Political Leaders

Political leaders also exhibited limited comprehension. A UML Communist Party member stated, "I think autism and Intellectual Disability are the same." A Maoist Party leader with a doctorate in Health Education described autism as "a disease caused due to genetic problems. They have physical and mental difficulties. They can be changed as time goes on." In contrast, the Deputy Mayor of Kirtipur Munici-

pality displayed greater awareness: "I have heard about Autism. It is a condition where persons are physically fine but have difficulty in daily living activities, delay in learning, look normal and have difficulty in communication" (Source: Semi- Structured Interview of Political Leaders, 2020).

Appreciation (Status and Abilities of People with Autism)

Most society members view disability with sympathy, assuming PWA are abnormal, unable to work, and forever dependent. Yet, interactions with autistic individuals reveal distinct interests and abilities alongside challenges. One adult said, "I like playing video games, Legos and I'm not really interested in others. I like creating things, both from Legos and in Minecraft. Minecraft is a wonderful video game that gives people the platform to create many interesting and innovative ideas." Another shared, "I am interested in drawing and arts. I like making art, reading English books, I have good memory power, I like cleaning rooms, making my bed, and washing hands." A third noted, "I like gadgets, play computer games and listen to music. I am especially good at computers, going to the grocery shop" (Source: Case Study of Person with Autism, 2020). Participation in household, religious, cultural, and social activities reflects how society appreciates PWA. One adult explained: "I am not much involved in household work. I also don't participate in religious activities unless it's a very important festival like Dashain and Tihar. I just meet my relatives and have fun. I don't do cultural works like prayers, I don't really do that, and I'm an atheist." In contrast, another said, "I am involved in cleaning rooms, recite mantras while worshipping, participate in puja, sing Bhajans, and attend parties." A third reported, "I participate in religious places, pray to god and goddess and also visit temples and churches."

Their varying engagement in rituals, parties, family events, and picnics indicates degrees of inclusion or exclusion (Source: Case Study of Person with Autism, 2020). Parents' lives change drastically after an autism diagnosis. They focus entirely on caregiving; some quit jobs, and most mothers devote all their time to their child, reducing social interactions. One parent said, "I don't have any personal life. I give 100% of my time to my child; other than that, there is nothing, just focused on how to take care of my child. As I am from out of the valley, my work and family are in my hometown. Many parents live in rentals and leave everything for their children. I'm not renting in Kathmandu, but I have to be here, leaving my husband and family behind for my baby." Another described conflict with neighbors: "I live in a rented house. The house owner complains that my child is naughty, hyper-active, sensitive, and temperamental. They lack awareness of autism and judge my child's behavior superficially" (Source: FGD of Parents of Children with Autism, 2020). Political leaders agree that PWA receive minimal societal support. One stated, "There is no good support from society for PWA. I think they should be prioritized and supported accordingly. Though PWA may receive certain government support, I think there are no priority programs from the government side. The situation of PWA is not good. All the burden is on the family.

The status of PWA is very poor in society. They need lifelong care; family members are badly affected" (Source: Semi-Structured Interview of Political Leaders, 2020).

Religious leaders call for specialized care centers but reveal persistent segregation. One urged, "Society should have separate caring centers for PWA. Government should set up separate caring, playing, teaching, and even working environments for these people. They need more love and special care." Another added, "First, parents need to give opportunities to these children. If they don't get any opportunities from their parents, then society can't do anything. PWA who have some abilities should get opportunities and acceptance by society. Parents and their children's roles matter. Society should love, care, and give affection. They need special schools, educational and recreational centers, places where they can have positive vibes. Awareness regarding autism is required. Parents should know methods, and special programs should be developed" (Source: Semi-Structured Interview of Religious Leaders, 2020).

Recognition

In a case study, a young adult with autism shared heartfelt expectations: "I just wish they could give me a normal life and then just teach me how to handle different life situations but not in a very difficult manner. I just wish I could understand how to cope with life. I feel it is very difficult to become self-sufficient. I wish that people would be more accepting of our kind; many autistic people are being oppressed right now, they are teased, mocked, and bullied in school and society. People often make autism memes, and I don't find them tasteful because they take advantage of something I cannot help. Society should be more serious about autism; they should not take it as a joke, and they should be more considerate towards us. I want the government to adapt the education system so it fits better with autistic people, to create special plans and things for autistic people because I cannot study like regular people. I also want the education system to be reformed in general, not just for autistic people but all people, because many view the education system as flawed and problematic, it doesn't allow for people to sleep properly. There should also be stronger policies against bullying; people should be more aware of bullying and its consequences. Modern society doesn't care enough about bullying; they need to be more observant."

When asked what he wanted to tell non-autistic people, he added: "I just want to tell them that I deserve love; I don't deserve to be cast out from society. I need affection like regular human beings. I shouldn't face discrimination; society keeps making jokes about us, but it's not fair. Regular people should accept autistic people; they should not throw us aside, they should try to help us" (Source: Case Study of Person with Autism, 2020). In a FGD, parents described expectations for social inclusion. One parent said, "There should be social awareness programs in society. Information about autism should reach every household. Every individual should know about this condition so our

children will be adopted easily in society. There needs to be a topic on autism in the school curriculum so teachers are also aware of this condition." Another urged: "I think there should be a proper planning system at schools so that children with autism can also be enrolled in school. There needs to be a proper curriculum. Children with autism should be eligible to enroll in mainstream schools; this concept needs to change. Every child should be enrolled in school. For this, teachers need to be trained, but they should be enrolled in school. The Nepal government should take necessary action through national planning."

A parent with heavier concern asked: "What happens when our children become adults and, in old age, who will look after them? My biggest concern is what next when I are no more. I'm concerned about long-term support mechanisms, whether our community can support them in these situations. These are my expectations from society. I am mainly concerned about long-term rehabilitation" (Source: FGD of Parents of Children with Autism, 2020).

Religious leaders offered candid observations: "Usually people may make fun of them, use them for personal benefit, and not allow them to be in esteemed posts." A Buddhist monk said, "Most of these people are in a pitiful situation in society. Society makes it more difficult for them to have a good status. They totally depend on their parents. I know one adult person who may be just like autism; still he is looked after only by his father and mother." Brahma Kumari remarked, "No, I don't have much idea. I think society might humiliate them, but they should be treated equally." A pastor said, "Society hasn't identified such conditions yet. Society perceives this as a natural phenomenon and thinks it will be healed slowly" (Source: Semi-Structured Interview of Religious Leaders, 2020). Political leaders knew of disability policies but lacked autism-specific awareness. One Maoist leader admitted, "Yes, I know about disability policy but not for autism." A UML leader said, "Yes, I have an idea about the policy and acts for PWA in Nepal, but I haven't done a deep study." When asked about needed policies, they proposed: "Policy should be made in all tiers of government. Rehabilitation centers should be developed at the local level with budget allocation. The government should be specific and focused on the needs of PWA in Nepal, focusing on education and health as priorities, with proper mobilization of Female Community Health Volunteers (FCHV) for early identification.

Policies on education and health, protection of human rights, provision of special centers for education, and focus on socialization and inclusion policy are needed. Policies on vocational training and job orientation to make them independent with a support system, a better platform for independence, allowances and support, all these should be provided. According to the level of disability, their needs may differ. They should be given opportunities as per their capabilities. I think the government should provide full support to severe cases" (Source: Semi-Structured Interview of Political Leaders, 2020).

Belief System

Disability in Nepal has historically been viewed in mythological or religious terms: people believed those with disabilities were possessed by spirits or punished for past wrongs. Although urban areas like Kathmandu now identify and diagnose more conditions, barriers remain unaddressed. According to WHO and the UN Convention on the Rights of Persons with Disabilities (UNCRPD), disability entails functional limitations and participation restrictions. ASD is newly recognized in Nepal; its invisibility complicates identification and acceptance. One parent in a 2020 FGD described how relatives viewed her child: "Though my family members are educated, as you know in Hindu culture, there is some belief in religious norms and values. They asked me to perform several 'Puja' worship to gods and goddesses, fast, and call Dhami and Jhakris to get rid of the problems. Different temples were visited; 'Bhakaal' was fulfilled; 'Kulpuja' was performed. However, they are also convinced that there needs to be medical intervention too" (Source: FGD of Parents of Children with Autism, 2020). Religious leaders recognized stigma and traditional beliefs but were unfamiliar with ASD. One said, "I have heard this terminology for the first time. However, I think this may be a mental disease. I have some students who don't concentrate at all and just stare or be in their own world." Another remarked, "No, I haven't heard. I thought it might be a disease due to sin of past life."

A third admitted, "I have heard this for the first time. I have no idea at all" (Source: Semi-Structured Interview, 2020). Political leaders were more informed about disability in general but not ASD specifically. A Maoist leader said, "Yes, I think autism and intellectual disability are the same." A UML leader added, "Yes, I have heard. It is a disease caused due to a genetic problem. They have physical and mental difficulties. They can be changed as time goes on." Though these leaders have moved beyond purely traditional beliefs, they require targeted education about ASD (Source: Semi- Structured Interview, 2020).

Discussion

The findings of this study confirm that perceptions of ASD in Nepal remain fragmented reflecting limited societal integration. While parents and caregivers demonstrate nuanced, lived- experience awareness and strong familial acceptance, broader religious figures, and political leaders, frequently exhibit superficial understanding and welfare-oriented attitudes, undermining genuine inclusion.

Awareness

Recent years have seen significant global progress in public awareness and health responses for autism, particularly in early identification, which partly explains rising prevalence. Nonetheless, researchers still struggle to fully understand autism, employing varied methodologies to address this gap. Botha and Cage (2022) used a mixed-method design to examine how autism researchers portray autistic people and research itself, exploring whether greater inclusion

of autistic individuals reduces ableist narratives. They applied content analysis to identify ableist cues, dehumanization, objectification, and stigmatization, and used binary logistic regression to determine predictors of fewer ableist cues, exemplifying methodological rigor aimed at challenging stereotypes. In South Africa, a study at Autism Western Cape Organization found that unawareness, poverty, and traditional beliefs significantly hinder understanding of autism (Laitila [2]). Although some families and professionals gained awareness, broader societal perceptions remained unchanged. Similarly, Nepal faces barriers, religious beliefs, social stigma, economic challenges, and political obstacles, that severely limit awareness, underscoring an urgent need for community education to dispel misconceptions and contest harmful cultural narratives. Euro-American studies on caregivers of children with autism spectrum disorder (CASD) highlight high stress, anxiety, and depression levels (Al Farsi, et al. [3]).

Nepalese caregivers, primarily parents, encounter comparable burdens compounded by inadequate understanding, struggling to obtain accurate diagnoses and correctly assess severity, which leads to misclassification in disability identity cards. These systemic issues emphasize the critical importance of enhancing awareness at both community and policy levels.

Acceptance

Although some progress has been made, acceptance of individuals with autism remains limited in many societies. Laitila (2018) noted that, despite a few South African families and professionals advocating for autistic people, widespread societal acceptance was lacking. In Nepal, deeply rooted cultural and religious beliefs similarly constrain acceptance. Parents frequently act as the sole advocates for their autistic children, with minimal self-advocacy by autistic individuals themselves. Siblings and extended family members play crucial roles in socializing autistic children, as highlighted by Bhandari (2019). A qualitative field study in Jhapa and Sunsari districts, which included perspectives from autistic children, their families, and scholars, revealed significant gaps in autism education and awareness. Family members often rely on limited knowledge to support autistic relatives, underscoring the need to shift societal attitudes from sympathy to a rights-based approach that recognizes autistic individuals as deserving of full participation. Nepal's Disability Act 2074 classifies disabilities by severity to issue identity cards, but ambiguous criteria lead to misclassification, denying many individuals access to essential services. Only those with "profound" or "severe" disability cards qualify for government benefits, leaving many autistic people without necessary support.

Appreciation

Recognizing the inherent value and contributions of individuals with autism is essential for true appreciation. Although professionals have made some progress, broader community appreciation remains limited. Parents and caregivers frequently act as advocates for their

autistic children's needs and rights (Doda et al., 2024), and societal acknowledgment of these efforts is critical to creating environments where autistic individuals can flourish. Field research in Nepal highlights the pivotal influence of religious and political leaders in promoting appreciation; sensitizing these leaders could spur wider acceptance and advocacy. Local communities, including neighbors and extended families, must also adopt supportive roles. Evidence-based recommendations indicate that community education about autism can dispel harmful myths and foster inclusive practices (Heys et al., 2016). Although Nepal's Disability Act officially recognizes autism as a distinct category, implementation remains weak; guidelines for disability card distribution are unclear, resulting in inconsistent benefit allocation. My findings reveal that only half of eligible individuals receive appropriate support. Addressing these shortfalls requires coordinated action from the Ministry of Women, Children, and Senior Citizens (MOWCSC), the Ministry of Health and Population (MOHP), and the Ministry of Education, Science, and Technology (MOEST) to ensure equitable policy enforcement and genuine appreciation.

Recognition

Despite legislative recognition of ASD in the Disability Act 2074, implementation suffers from ambiguous classification criteria. Parents of PWA receiving "Moderate" cards struggled to access free health, education, and transportation benefits reserved for "Severe" or "Profound" disability classifications. The lack of clear functionality-based measures for ASD severity undermines rights-based support. These findings resonate with Ability Manch's (2022) critique of Nepal's disability ID card guidelines. Moreover, the absence of ASD-specific training for health workers and FCHVs traps families in delayed diagnoses and inadequate service access, issues mirrored in global policy analyses (Doda et al., 2024). Long-term support anxieties, "Who will care for my child when I am gone?", underscore systemic neglect of PWA livelihoods.

Cross-Group Comparisons

Comparing stakeholder groups reveals marked divergences. Parents and PWA hold intimate, experiential knowledge of ASD, shaping authentic narratives across 3AR stages. Religious leaders, while intellectually versed in doctrine and social values, lack concrete understanding of ASD, defaulting to pity or spiritual remedies. Political leaders acknowledge policy frameworks but lack actionable insights, underscoring the need for targeted capacity building. This divergence emphasizes that genuine inclusion demands multi-tiered interventions across micro (family), meso (community), and macro (policy) levels.

Limitations and Future Research

Several limitations must be considered. First, the purposive sample was confined to Kathmandu Valley, limiting transferability to rural or ethnoculturally distinct regions. Perceptions in far-western provinces may diverge due to varying traditional norms and service

availability. Second, while triangulation across case studies, FGDs, and interviews enhanced credibility, a larger sample of self-advocates (PWA) could have provided deeper insights into adult experiences across functionality levels. Third, translation from Nepali to English, despite rigorous cross-checks, may have resulted in subtle meaning shifts. Fourth, male representation among parents was lower (3 fathers vs. 6 mothers), potentially underrepresenting paternal perspectives. Future research should expand to multiple provinces, incorporating quantitative surveys to quantify 3AR stage prevalence and measure intervention impacts over time. Longitudinal studies are needed to assess how awareness campaigns or policy changes influence PWA quality of life and community attitudes. Additionally, exploring digital platforms for ASD self-advocacy could illuminate novel pathways for strengthening PWA voices in Nepal.

Conclusion

This study demonstrates that perceptions of ASD in Nepal remain fragmented across awareness, acceptance, appreciation, and recognition. Parents and caregivers often exhibit a commendable understanding of autism but are overburdened and in need of substantial support from extended family and community networks. Interactions with verbal individuals with autism, particularly those with mild to moderate functioning levels, reveal deeply moving experiences. These individuals frequently express feelings of neglect, discrimination, and social isolation, citing challenges in forming friendships and sharing their emotions. Their heartfelt aspirations for recognition, respect, and opportunities underscore an urgent need for societal transformation. In Nepal, where religious norms and political ideologies profoundly influence social dynamics, the understanding and involvement of religious and political leaders become critical. This study highlights the limited awareness among these leaders about autism, demonstrating the importance of fostering their consciousness to build a more inclusive society. By implementing the detailed recommendations outlined, ranging from vocational training to sibling support networks, Nepal can transition from pity-driven responses to genuine inclusion, ensuring that Persons with Autism achieve their full potential and receive the recognition they deserve.

Recommendation

To transition from fragmented perceptions to cohesive inclusion, coordinated action across family, community, and policy spheres is essential. This requires a multifaceted approach that includes: community-wide awareness campaigns through partnerships with ministries and leveraging local media; sensitization workshops for religious leaders to bridge cultural and rights-based perspectives; reforms in inclusive education to equip teachers with ASD-focused training and pilot supportive classroom models; development of comprehensive ASD assessment guidelines to ensure fair service eligibility; and the establishment of regional ASD resource centers staffed with interdisciplinary teams. Additionally, structured parent-to-parent support

networks and sibling engagement programs foster a sense of shared responsibility and learning within families. Vocational training tailored to individual strengths and incentivizing inclusive workplaces pave pathways for economic participation. Anti-bullying initiatives and inclusive social policies promote empathy and community integration, while long-term social security mechanisms address the economic needs of caregivers and individuals with autism. These recommendations aim to address identified gaps, aligning with evidence-based practices to transition Nepal towards a rights-based and inclusive society.

References

- Botha M, Cage E (2022) "Autism research is in crisis": A mixed-method study of researchers' constructions of autistic people and autism research. Frontiers in Psychology 13.
- Laitila N (2018) Awareness, acceptance & appreciation: A road to changing views on autism in South Africa. Laurea University of Applied Sciences pp. 60.
- Al Farsi O A, Al Farsi Y M, Al Sharbati M M, Al Adawi S (2016) Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: A case- control study. Neuropsychiatric Disease and Treatment 12: 1943-1951.
- Bhandari S (2019) Socialization of children with autism. AutismCare Nepal Society pp. 90.
- (2022) An innovative model for disability screening and issuing disability identity card. Ability Manch Pvt. Ltd pp. Kathmandu, Nepal 14-15.
- Ritchie J, Spencer L (1994) Qualitative data analysis for applied policy research. In A Bryman, R G Burgess (Eds.,). Analyzing qualitative data pp. 173-194.
- (2015) Health, Neurodevelopmental disorders (3rd edn.,). updated October 2015). U.S. Environmental Protection Agency. America's Children and the Environment
- (2023) Annual report: A national center for autism. AutismCare Nepal Society p. 13.
- Barbotte E, Guillemin F, Chau N, Lorhandicap Group (2001) Prevalence of impairments, disabilities, handicaps and quality of life in the general population: A review of recent literature. Bulletin of the World Health Organization 79(11): 1047-1055.
- Baskota M (2016) Nepal disability policy review. Disability Research Center, School of Arts, Kathmandu University pp. 1-20.
- 11. Beart S, Hawkins D, Stenfert K B, Smithson P, Tolosa I (2001) Barriers to accessing leisure opportunities for people with learning disabilities. British Journal of Learning Disabilities 29: 133-138.
- Bhattarai S (2007) Research methodology p. 26. Wichita State University, Department of Anthropology.
- 13. United Nations Economic and Social Commission for Asia and the Pacific (2003) Biwako Millennium Framework for action towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific, Asia and Pacific Decade of Disabled Persons 2003-2012.
- Bogossian A, Rothwell D, Lach L, Nicholas D, Bailey S, et al. (2014) Financial stress among parents of children with neurodisabilities in Canada: The role of 'complexity'. International Journal of Developmental Neuroscience 47(A): 130.

- Boyle C A, Boulet S, Schieve L A, Cohen R A, Blumberg S J, et al. (2011)
 Trends in the prevalence of developmental disabilities in US children, 1997–2008. Pediatrics 127(6): 1034-1042.
- Creshwell J W (2014) The selection of research approach. In V. Knight (Ed.,). Research design: Quantitative, qualitative and mixed methods approaches (4th ed.,). Pp. 14-15. Sage Publications, Inc.
- 17. (2018) Data and statistics on autism spectrum disorder. Centers for Disease Control and Prevention.
- 18. Doda V, Kennedy C, Kaur M (2024) Policies for individuals with autism: Gaps, research, and recommendations. Cureus 16(1): e51875.
- 19. Edelson S M, Nicholas D B, Stoddart K P, Bauman M B, Mawlam L, et al. (2021) Strategies for research, practice, and policy for autism in later life: A report from a think tank on aging and autism. Journal of Autism and Developmental Disorders 51(1): 382-390.
- Ervin D A, Merrick J (2014) Intellectual and developmental disability: Healthcare financing. Frontiers in Public Health 2: 160.
- 21. Heys M, Alexander A, Medeiros E, Tumbahangphe K M, Gibbons F, et al. (2017) Understanding parents' and professionals' knowledge and awareness of autism in Nepal. Autism: The International Journal of Research and Practice 21(4): 436-449.
- 22. Maenner M J, Warren Z, Williams A R, Esther Amoakohene, Amanda V Bakian, et al. (2023) Prevalence and characteristics of autism spectrum disorder among children aged 8 years, Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. MMWR Surveillance Summaries 72(2): 1-14.
- Msall M E (2005) Measuring functional skills in preschool children at risk for neurodevelopmental disabilities. Mental Retardation and Developmental Disabilities Research Reviews 11(3): 263-273.
- 24. Pastor P N, Reuben C A (2008) Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004–2006. Vital and Health Statistics. Series 10, Data from the National Health Survey 237: 1-14.
- Petrou S, Johnson S, Wolke D, Marlow N (2013) The association between neurodevelopmental disability and economic outcomes during mid-childhood. Child: Care, Health and Development 39(3): 345-357.
- 26. (2007) International classification of functioning, disability and health (ICF). Rehab Scales.org. World Health Organizatrion.
- Shrestha M, Santangelo S L (2014) Autism: Challenge in Nepal. In V Patel, V Preedy, C Martin (Eds.,). Comprehensive guide to autism. Springer.
- Shrestha M, Shrestha R (2014) Symptom recognition to diagnosis of autism in Nepal. Journal of Autism and Developmental Disorders 44(6): 1483-1485.
- 29. Shrestha R, Dissanayake C, Barbaro J (2019) Age of diagnosis of autism spectrum disorder in Nepal. Journal of Autism and Developmental Disorders 49(6): 2258-2267.
- 30. Simpson R (2003) Policy-related research issues and perspectives. Focus on Autism and Other Developmental Disabilities 18(3): 192-196.
- 31. (2001) A situation analysis of disability in Nepal: Report of disability sample survey conducted by New Era for National Planning Commission. UNICEF; National Planning Commission, Nepal.
- 32. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin M S, et al. (2022) Global prevalence of autism: A systematic review update. Autism Research 15(5): 778-790.

ISSN: 2574-1241

DOI: 10.26717/BJSTR.2025.63.009947

Surendra Bajracharya. Biomed J Sci & Tech Res



This work is licensed under Creative Commons Attribution 4.0 License

Submission Link: https://biomedres.us/submit-manuscript.php



Assets of Publishing with us

- Global archiving of articles
- Immediate, unrestricted online access
- Rigorous Peer Review Process
- Authors Retain Copyrights
- Unique DOI for all articles

https://biomedres.us/