

Beyond Identification: UDID and Disability Entitlements Among Families of Children with Autism in Lucknow, India

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ABSTRACT

The UDID card is a crucial way to identify people with disabilities, and help them get access to the benefits they're eligible for in India. However, having a UDID card doesn't mean you will be able to get what you need from the government, or even have enough money to take care of your family if your child has Autism Spectrum Disorder (ASD). This study looked at whether families of children with ASD in Lucknow, Uttar Pradesh had UDID cards; what kind of help they thought they received from the government; and whether they were able to find health insurance that would pay for their child's ASD-related care. We used a quantitative cross-sectional research design to collect primary data using a structured questionnaire with parents/caregivers. We used descriptive statistics (frequencies and percentages) to analyze the responses. Of the 167 families who answered the questions, 59.3% said their child had a UDID card, and 40.7% said their child did not have one. Also, 61.7% of the families said the government schemes did not help lower their costs, and 6.0% didn't know about the schemes. Lastly, 59.9% of the families said their health insurance didn't cover ASD-related care, and 37.1% said their health insurance covered some of the costs. Based on these results, we can see that there may be problems in connecting people with disabilities with the services they deserve, as well as providing adequate financial protection for families of children with ASD. We believe that we need to increase awareness about UDID cards; simplify getting the services you deserve; provide better information about health insurance; and provide better support systems for families trying to navigate disability services. In addition, we believe that we need to do more than just identify people with disabilities if we want to create inclusive environments where everyone receives the benefits they deserve.

Keywords: Autism Spectrum Disorder (ASD), Unique Disability ID (UDID), certification of disability, welfare programs/schemes, health care coverage (insurance), rights and benefits of people with disabilities (disability entitlements), India.

1. Introduction

The identification of people who have disabilities is a critical element of an inclusive social-protection system. This process officially recognizes individuals as having a disability; therefore, it can provide individuals with the ability to receive the public services, welfare programs, educational support, and/or financial assistance for which they are eligible. For families of children with Autism Spectrum Disorder

(ASD), having official documentation of their child's disability may be especially important. Children on the autism spectrum require developmental, educational, rehabilitative, and supportive services throughout many phases of their childhood. While there are a number of benefits associated with receiving official documentation of a child's disability, the existence of these benefits alone will not guarantee that families can take advantage of them. To evaluate how effectively a social-protection program is functioning, researchers must consider the degree to which eligible beneficiaries are aware of the benefits available to them, whether or not eligible beneficiaries find it easy to navigate the application processes, whether or not eligible beneficiaries have the proper documentation to prove eligibility, and whether or not institutions providing services to eligible beneficiaries are capable of connecting those beneficiaries to those services.

The extent of disability in India underscores the need for improving existing systems. A survey of persons with disabilities in India conducted by the National Statistical Office from July-December 2018 indicated that the rate of disability was 2.2 percent of the total population; with 2.3 percent of the rural population being disabled and 2 percent of the urban population. The survey interviewed 118,152 households and identified 576,569 people as having some form of disability. The survey examined disability prevalence, availability of services/facilities, provision of caregiving, disability certification processes, and expenditures associated with disabilities. While the results do not specifically identify autism, they illustrate the significance of providing accessible disability assessment tools and service-delivery models on a national level (National Statistical Office [NSO], 2019). [1]

In regard to the identifying of children with Autism Spectrum Disorder (ASD), it is essential to focus on the connection between being recognized as disabled formally and the ability to obtain assistance. Estimates regarding the prevalence of Autism should be assessed based on where they came from; the age group that was used; and the methods that were employed when gathering the data, not on the assumption that they are representative of the general population's disabilities. On a larger scale, the inability to identify and categorize disabilities can impact how administrative records are analyzed and what types of services are planned for individuals. Therefore, improving the accuracy of documentation about disabilities, as well as developing better data collection systems for disabilities, will benefit both individuals who need access to benefits, as well as policy makers who wish to implement policies supported by research.

2. The Unique Disability ID (UDID): purpose and institutional significance

The Unique Disability ID (UDID) program was initiated by the Indian government through the Department of Empowerment of Persons with Disabilities (DEPwD), part of the Ministry of Social Justice and Empowerment, with the objective of developing a national database of disability certification and identification. As stated in the department's guidelines, the UDID program will establish a standard format for issuing disability identification documents, allow applicants to apply for cards online and track their application progress, maintain updated applicant data and track changes to that data, and enhance transparency and efficiency in providing services to individuals who qualify for benefits based on their disabilities. Ultimately, the UDID card will enable all individuals with disabilities across India to be recognized as such, which will enable them to access various government programs and services that are available to people with disabilities (Department of Empowerment of Persons with Disabilities [DEPwD], n.d.).

The UDID system is very important as it provides a way for people with disabilities to apply for support

by linking their disability identification to the administrative processes they must go through to receive support. The official website allows people to apply online, check the status of their application, and view information regarding certification and authorized authorities. People who cannot apply independently may have their application completed by a parent or legal guardian in accordance with the rules established for each group. This is important since going through the disability certification process can require a person to undergo a medical evaluation, provide documents to the government, and coordinate with family members and public agencies.

The Rights of Persons with Disabilities Act of 2016 creates the legal basis for identifying people who have a disability. It includes autism as an officially recognized type of disability that can be covered under the Act. In addition, the Act establishes a general framework for protecting the rights of people with disabilities, and includes provisions related to equality and non-discrimination, education, access, social protection and other aspects of participation and support. The UDID initiative exists within the context of this wider framework of disability governance and helps to create standard processes for identifying and certifying individuals as having a disability (Government of India, 2016). [3]

However, the importance of UDID should be clearly defined. The UDID card provides a way to identify individuals with disabilities and possibly provide access to eligible benefits; however, having a UDID card does not automatically grant you access to all government benefits. Each scheme has its own rules about who can apply, what kind of disability assessments are needed, how much money someone can earn, how old they can be, where they can live, whether they need to go to school, how to submit an application, etc. Therefore, there is a clear distinction between having a UDID card and being aware of available schemes, applying for schemes, getting approved for a scheme, and receiving aid.

3. Facilities and entitlements that UDID can help individuals access

UDID can help individuals access available disability-related benefits by providing a consistent way to document their disability. When we look at how UDID can be used to document a person's disability, we see that it is especially useful for programs that specifically require proof of disability through either a certificate of disability or through UDID documentation, as part of the process of applying and qualifying for those programs.

An example is the Assistance to Persons with Disabilities for Purchase/Fitting of Aids and Appliances (ADIP) scheme run by DEPwD. This scheme provides support to qualifying individuals with disabilities in obtaining assistive devices that will allow them to achieve rehabilitation, independence and participation. DEPwD's published guidance outlines the UDID-related documentation required to obtain assistance through this scheme, which is based on the type of disability, income level and other eligibility criteria. It is important to note that ADIP is not a cash transfer scheme, nor does it provide coverage for autism related therapies. Rather, whether or not ADIP would be beneficial to an individual depends upon their assessed needs and what types of assistive devices can be obtained through the ADIP scheme (DEPwD, n.d.). [4]

Disability identification can be helpful when applying for educational support. DEPwD offers scholarships for students who meet the definition of "benchmark disability" and the requirements of the individual scholarship program. Many of these programs will ask for both disability documentation and evidence of income, education level, etc., along with other eligibility requirements. Whether or not these programs apply to a child with Autism Spectrum Disorder (ASD) will depend upon the child's situation

and the specific guidelines that are currently being followed. A child having a UDID card does not automatically mean he/she qualifies for a scholarship.

The National Trust has developed disability-specific programs for eligible individuals with autism as well as other designated disabilities; these include early intervention, day-care, respite-care, residential support, and health insurance initiatives. Specifically, Niramaya is a health insurance program specifically designed to meet the needs of those who qualify for services through the National Trust. Each program will have its own eligibility criteria and application processes. Documentation regarding your disability (i.e., UDID) could potentially aid in determining whether you are eligible to receive benefits from a particular program; however, it is important to remember that each program has its own set of rules and guidelines that need to be reviewed individually.

More generally, the documentation of disabilities may be used as evidence when applying for various government benefits, concessions, educational supports, rehabilitation services, and social security programs. However, as noted above, the specific benefits available to an applicant will depend on the relevant laws, schemes and authorities that implement those laws and schemes. Therefore, the real benefit of the UDID system is not only having the card but also its ability to assist with the identification of and access to entitlements for which an applicant may qualify.

The distinction between obtaining a UDID card and understanding what services a child with ASD can receive is particularly significant for families. Even though a family has successfully obtained a UDID card, they may still be confused about the specific schemes that apply to their child; the location of the office where they should submit their application; the extra documentation needed; and/or the process of following up on a pending request. Therefore, when assessing the success of implementing UDID, it is necessary to examine the complete path of identifying the disability through to raising awareness, submitting an application, enrolling, and receiving benefits.

4. From disability identification to effective access: the research problem

While the existence of a national disability-identification system provides an important administrative base, the actual usefulness of such a system is dependent upon whether families are able to use their formal recognition as a means of accessing meaningful support. Thus, it is necessary to maintain a clear separation among the availability of an entitlement, the possession of the documentation necessary to apply for that entitlement, and the receipt of a benefit. While these three elements are related, they represent three different aspects of disability inclusion.

The problem of how to best provide services to families of children with ASD is especially important because of the diverse types of services these families might need. Although obtaining a disability certificate could be an essential part of some service programs, it alone does not answer all of the questions about what services are available, who is eligible, how to apply for them and whether there is enough help. A family that does not have a UDID card may be having trouble getting certified, may be waiting on an application, or may already have some other type of documentation as proof of disability. On the other hand, a family with a UDID card may not have applied for a service program, or may not meet the eligibility requirements for the program. Rather than making assumptions, we should use research to determine which scenario applies.

The present research is focused on parents' or caregivers' possession of UDID cards for their children with Autism Spectrum Disorder (ASD), in Lucknow, Uttar Pradesh. Based upon the questionnaire data provided by the authors, out of the total 167 respondents, 99 (59.3%) stated that their child had a UDID

card, whereas 68 (40.7%) said that their child did not have a UDID card. Therefore, about 40 percent of the surveyed families indicated that their child did not own a UDID card. This suggests a significant lack of documentation within the study sample and provides a starting point for exploring the extent to which disability-identification systems are able to reach individuals.

The research found that 103 individuals (61.7 percent) stated that there had been no benefit from government programs in reducing their expenses; 10 individuals (6.0 percent) indicated that they did not know about any such programs. Additionally, 100 individuals (59.9 percent) stated that they did not have health insurance coverage for care associated with Autism Spectrum Disorder (ASD). This information provides context to explain why it is important for families to identify disabilities. However, this does not show that the absence of a UDID led to the reported lack of program support or insurance coverage. This study does not provide information about why some respondents lacked a card. Therefore, these results should be viewed as descriptive evidence of reported documentation and support experiences and not as evidence of a cause-and-effect relationship.

The research looks at the relationship between UDID possession and respondents' reports of public scheme support; therefore, the research examines the issue of disability identification within a larger context of accessing social protection. The purpose of this study is not to imply that having a card automatically grants benefits, but rather to determine the degree to which formal disability identification is present in conjunction with self-reported access to support. In doing so, this study will lay a groundwork for exploring ways in which information, administrative assistance, inter-agency cooperation, and disability-focused social work can assist families in accessing their entitled rights.

Aim and contribution of the study

This study is designed to explore the extent of use of the UDID card by families of children with ASD in Lucknow, Uttar Pradesh, and to determine how important this card is for accessing appropriate public welfare and support services related to disability.

The study is guided by the following questions:

1. In the survey of families, how many have said that their child has a UDID card?
2. What can we conclude from these results regarding how we might improve access to disability identification for families of children who have been diagnosed with Autism Spectrum Disorder (ASD)?
3. How do you think the process of identifying and accessing government schemes for eligible families through UDID related information and entitlement-navigation support can be enhanced?

The main value added by this paper is that it brings together the results from the local survey and the Indian Disability Identification System. In doing so, the authors make a distinction between having a UDID card and knowing about it, being eligible for it and receiving benefits. They show how important it is to consider disability identification as an integral part of accessing entitlements. The authors' results could help shape practice in social work, disability-support organizations and future research into barriers to certification and the practical accessibility of government support for families of children with ASD.

Review of Literature

The way disability is identified in India determines who has access to entitlements. However, identifying someone as having a disability is not easy because of the limited number of people that can be certified. There are two levels of certification: People who have a disability level from 0-39% will, according to

the law, be considered "disabled but not eligible for any benefits under disability category as of present law," and only people who reach the 40% benchmark will receive most of the benefits available (Subramanyam et al., 2022). Autism adds further complexity to this system due to the disagreement over how autism should be assessed. The Gazette Guidelines provide both a single percentage for one Vineland Social Maturity Scale Band on one page, and a range on another page, as well as providing no guidelines regarding whether or not to map moderate autism (ISAA 107-153) into 60-79% disability, with no decision rule provided (Chatterjee & Sahay, 2024).

The scheme's architecture is documented; the RPwD Act of 2016 expanded recognized categories from 7 to 21, and explicitly added autism (Gowda et al., 2019)(Ravi, 2026), and certification provides access to scholarships, reservations, travel discounts, assistive technology, and healthcare coverage (Subramanyam et al., 2022). Niramaya – designed specifically for people with disabilities, without age restrictions, and covering out-patient expenses — enrolled just 96,716 individuals through the end of fiscal year 2018–19 compared to the Census 2011 count of 1.5 million people with intellectual disabilities, and Madhya Pradesh accounted for more than two thirds of those enrolled (Angothu & Muliya, 2020)(Angothu et al., 2022). Thus, having entitlement on paper does not equate to receiving benefits in reality.

Among 316 parents, 44.8% obtained a disability certificate; however, 82.2% were unaware of any national health insurance programs (Chauhan et al., 2021). The lack of professional awareness is also high: only 15.6% of 231 healthcare professionals were aware of the UDID program (Kumar et al., 2024). Stigma prevents the use of the UDID — 85% of parents in an autism program did not know about the benefits of the card or how to obtain it, and 40% feared being labeled negatively; however, the number of people who have the UDID increased to 48% as of April 2022 after a destigmatization campaign (Brien et al., 2023). Most of the existing evidence regarding awareness of the UDID is based upon 560 patients with locomotor disabilities (Badhal et al., 2025) and cannot provide information about autism families.

The consequences are financial. Diagnostic delay (mean age 4.67 years at diagnosis; 42.4% misdiagnosed) (Malhi et al., 2023) always comes before certification. Additionally, 71.25% of families had catastrophic out-of-pocket expenses (Sakhardande et al., 2026), and the median monthly expense was ₹20,000 (Islam et al., 2024). There is no studies that have measured the possession of a UDID against the awareness of, certification for, and verification of receiving a UDID by families of children with ASD. This is especially true for families in Uttar Pradesh where accessibility audits have shown poor implementation of the program and socio-economic marginalization of individuals with disabilities (Shrivastwa & Dubey, 2025). This study will address this gap in knowledge in Lucknow.

Research Methodology

The study utilized a quantitative and cross-sectional research methodology to investigate UDID Card Possession and Access to Government Welfare Schemes and Health Insurance among Parents of Children with Autism Spectrum Disorder (ASD) in Lucknow, Uttar Pradesh. Primary data was gathered via a structured Google Forms questionnaire that was completed by parents/caregivers of children with ASD who had been recruited from applicable schools, centres, and organizations.

The study is focused on the status of a respondent's UDID card, how well they believe that they receive support from government welfare programs, and if their health insurance will cover costs associated with caring for someone with autism spectrum disorder (ASD). Frequency and percentage analyses were

used to describe the respondents' experiences and determine where there may be barriers in accessing disability-related benefits. The results of the research are descriptive in nature and apply only to the participants of the study.

Findings and Discussion

The results of this study suggest that there may be a disconnection between identifying a child as having a disability and providing access to welfare services to their family. This is true for families of children who have been diagnosed with Autism Spectrum Disorder (ASD) in Lucknow.

A significant number of families are still not included within the formal disability-identification system: Of the respondents to the survey, 59.3 percent stated that their children had UDID cards, while 40.7 percent did not. This demonstrates that there is a large percentage of families involved in this research project that have yet to obtain a UDID card for their child.

Low perceived benefit from government programs: A total of 61.7 percent stated that they did not receive any help in reducing their household expenses through government programs; 31.7 percent said they received some level of help from these programs; and 6 percent indicated that they did not know whether or not they were receiving help from the government. The above results suggest that there may be issues with public awareness of available government programs, access to those programs, eligibility criteria, and the ability of currently existing welfare programs to meet the needs of the people.

Gaps in health insurance coverage: Roughly 59.9% stated that they did not have any health insurance coverage for ASD-related treatment, whereas 37.1% had some level of insurance coverage. These percentages suggest that families will still incur significant financial burdens when seeking medical assistance for their children with ASD even after receiving some type of disability-related support services.

Identification does not equal entitlement: The study highlights the difference between having an identification card for your disability and successfully obtaining relevant benefits. This disparity can be caused by administrative procedures, lack of knowledge about available programs, eligibility requirements and challenges in finding out about different program options. However, as noted above, the barriers to access must be studied directly and not inferred based on the descriptive data.

The overall results of the study indicate that disability inclusion cannot simply be about identifying those with disabilities but rather providing those individuals with the ability to obtain the benefits they are entitled to, financial security through insurance or other means, and long-term support from an institution.

Suggestions and Policy Implications

Build on knowledge of UDID and outreach: Provide clearly stated information regarding what a UDID is (Disability Certification), how to apply for one, and required documents. This can be done by schools, autism centers, healthcare organizations, and social workers.

Set up entitlement facilitation services: help desks in hospitals, rehab centers, and special schools can help families apply for their UDID cards, check if they qualify for schemes, and apply for benefits.

Increase accessibility to health insurance coverage: Relevant policymakers and relevant insurance providers must provide clear information regarding what types of autism-related assessments, therapies, rehabilitations, and other related services will be covered by the policy, as well as any limitations on coverage (i.e. exclusions), and the reimbursement process.

Integrate Disability Identification with Welfare Delivery: To reduce the administrative burden of families having to search out and access separate services when they may qualify for several programs, all UDID-related service delivery should be integrated with information and referral services for relevant welfare schemes.

Enhance the function of social workers: Social workers are able to provide support to families by providing entitlement counseling, assisting with documentation, making referrals, and following up with the family as well as identify why some families who qualify for assistance may be unable to receive it.

Improve accountability and tracking of process steps: In addition to tracking UDID issuance authorities must track awareness of the program, completion of applications, enrollment into the program, and ultimately receipt of eligible benefits, specifically targeting those families who may be unserved or under-served by other programs.

To promote additional empirical research: Empirical research on a larger scale within Uttar Pradesh will determine if there is a relationship between holding a UDID card and increased awareness, participation in schemes and benefits received, utilizing respondent-level data and suitable statistical methods.

Concluding Argument

This study emphasizes the need for families to view the UDID card, in addition to being a form of identification, as a possible way for them to receive disability-related benefits. The ability for families to utilize the UDID card to access these types of benefits is dependent upon whether or not they are able to meet eligibility criteria, and ultimately receive meaningful assistance. To make the process of accessing benefits more inclusive for families, coordinated awareness campaigns, accessible administrative support, more defined insurance options, and systematic tracking of how benefits are being provided will be necessary. It should be noted that the results reported in this paper describe the characteristics of the study sample and may not represent other populations. Therefore, additional studies will be required to identify those variables that contribute to individuals accessing benefits.

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