State of Unique Disability Identity (UDID) Implementation in Telangana

Insights from a Survey Study









Preface

The Unique Disability Identity (UDID), an identity card for persons with disabilities in India, allows them to avail of services provided by the Center. The UDID project creates a central-level database of persons with disabilities in the country, allowing the central government to streamline benefits and increase the efficiency of service delivery to beneficiaries.

While the UDID project is well-intended, the process of obtaining the card is tedious. The current study was inspired by early survey results of Nayi Disha showing the challenges faced by parents/caregivers in obtaining the UDID in Telangana. Acknowledging the hardships, Pacta and Nayi Disha conducted a large-scale survey across five states in 2023: Karnataka, Madhya Pradesh, Maharashtra, Telangana, and Uttar Pradesh to obtain a deeper understanding of the challenges to ease the process of obtaining a UDID through informing policy changes.

The survey study shows a large variation in the implementation of the UDID across states.

This report highlights the findings from the State of Telangana.

Message

The UDID (Unique Disability ID) was introduced as a national database to standardize and streamline the registration of individuals with disabilities, ensuring access to government services and benefits. However, its implementation has varied across states, creating challenges for persons with disabilities and their families in availing the certificate. This inconsistency limits access to government schemes and benefits linked to the UDID, and the national database remains incomplete when individuals are unable to apply.

In Telangana, for instance, the requirement of a Saderam card for UDID registration complicates the process, and the lack of standardized medical assessments further restricts access to services for families.

We are grateful to Pacta for conducting research in partnership with Nayi Disha to highlight these issues. This research sheds light on the challenges faced by persons with disabilities and their families in obtaining the UDID certificate and emphasizes the need for a uniform, simplified process to ensure equitable access for all.

- Prachi Deo

Founder-Executive Director, Nayi Disha

Acknowledgments

This report carries the effort of several people and friends of Pacta. This report is compiled by Krithika Sambasivan under the guidance of Nivedita Krishna (Founder-Director, Pacta) with contributions of the Pacta research team comprising - Riddhi Lakhiani and Gokul Nath (data analysis), Greeshma (qualitative research), Sudeshna Bose and Susan Job (report design and content editing) and many interns and volunteers.

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We thank our respondents who willingly participated in the survey.

We acknowledge the Azim Premji Foundation, the Nayi Disha team, and parent associations in Telangana supported us in distributing the survey tool among their networks.

We extend our gratitude to the Nayi Disha social work team for their valuable insights on the challenges in implementing the UDID project in Telangana and other States of India.

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Background

The UDID (Unique Disability Identity) project, introduced by the Department of Empowerment of Persons with Disabilities in 2016, Ministry of Social Justice and Empowerment, aims to build a national database for persons with disabilities in India.

The UDID enables easier access to government benefits and services for persons with disabilities across the country.

Benefits of the UDID

Loan at concessional rates from the National Divyangjan Finance and Development Corporation (NDFDC)

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Free special educational courses offered by the Rehabilitation Council of India (RCI)

Free assistive devices under the Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP) Scheme

Free special education, vocational training courses, and rehabilitation services provided by National Institutes and Composite Regional Centres

National Overseas Scholarship Scheme for Persons with Disabilities



Free skill training from empanelled training institutions

Free rehabilitation education under the Deendayal Disabled Rehabilitation (DDRS) Scheme

GST concession by the Ministry of Industries for the purchase of vehicles for locomotor disabilities

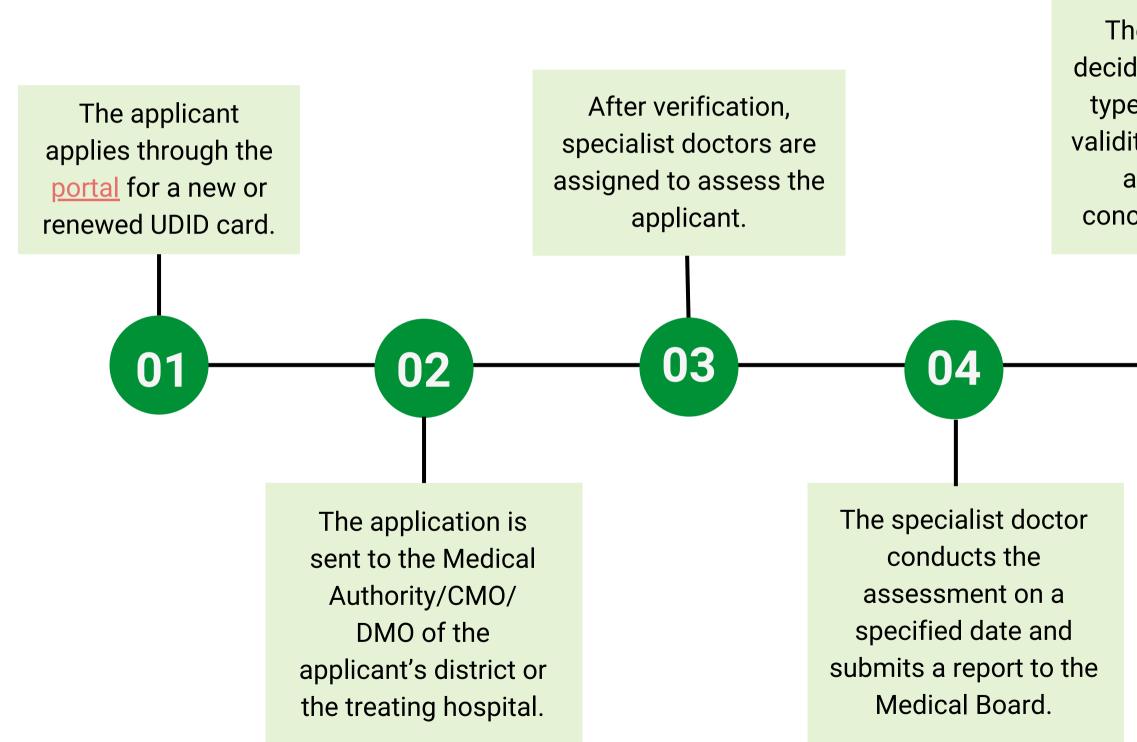
Disability Pension, transport facilities, and other benefits offered by the State/Union Territories based on their respective arrangements

Benefits of the UDID: The reality? Benefits should accomodate all irrespective of the severity

The government should clarify that a UDID (Unique Disability ID) will not be issued for disabilities below the 40% threshold. However, this information is not consistently communicated. Additionally, various schemes require a disability percentage of 40% or higher for eligibility. I have not seen a UDID issued for those below this threshold. It is essential that individuals with a 40% disability can access benefits, and the criteria for these schemes should be reconsidered to accommodate those with lower percentages.

- A social worker

Card Issuance Process



The Medical Board decides on the disability type, percentage, and validity of the certificate, and informs the concerned CMO/DMO.

05

Based on the assessment by the CMO/DMO, a UDID card is generated and dispatched to the applicant via Speed Post.

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Types of UDID Cards Issued

White Card: For less than 40% disability

Yellow Card: For 40% to 79% disability

Blue Card: For 80% and above

Amendments to the UDID Process Amendments likely to increase the difficulty in obtaining the card

The Union government has notified the Rights of Persons with Disabilities (Amendment) Rules, 2024 (RPwD Rules) under the Rights of Persons with Disabilities Act, 2016, introducing changes to the process of applying for and obtaining disability certificates and UDID Cards.

The amended rules require all applications to be submitted through the UDID portal and the time frame for issuing certificates and UDID cards has been extended from one month to three months. Applications may now be deemed void if the relevant medical authority fails to take a decision within two years.

Challenges Multiple hurdles faced by the beneficiaries in obtaining the card

People face various challenges in obtaining UDID cards, including a lack of awareness, technical issues, and hurdles in the medical assessment process. In some cases, cards are officially dispatched but not delivered to the <u>recipients</u>.

Unlike the state disability certificate, the UDID card does not provide direct benefits like pensions (unless linked to the State benefits), which may lead to limited awareness and motivation to obtain it. With only 17 central schemes mandating its use, the incentive to apply remains low.

The government has not provided sufficient benefits to motivate us to obtain the disability card. While there are concessions like loans, these primarily benefit the middle and upper-middle classes. For lower-income families, the process is cumbersome, leading us to question whether we should pursue it or accept our current situation.

The online application process, predominantly in English, further restricts accessibility for many.

- Parent of a child with disability

Research Objectives

01

To understand the state of implementation of the UDID in Telangana through a survey of persons with disabilities and their families.



To examine some of the challenges faced with regard to the implementation of the project from the lens of the beneficiaries.

Number of Beneficiaries Discrepant numbers do not reveal actual state of implementation

- - % of the population of persons with disabilities in Andhra **Pradesh** to India's Total (Census 2011):
 - 8.45% (approx. 22,64,600 persons with disabilities)
 - Since Telangana was formed in 2014, Census 2011 doesn't provide specific data for the state.
 - Population of people with disabilities in Telangana (Telangana Social Development <u>Report 2017</u>):
 - **3%** higher than the national average of 2.21%

- 15,34,000

The lack of updated population-level data on persons with disabilities makes it hard to assess the state of implementation in Telengana.

• Total number of UDID Cards issued in India (As of <u>Dec 23, 2024)</u>: 1.53 Crores • Number of UDID Cards issued in Telengana:

Methodology for Current Study

Karnataka

Participants:

- Persons with Disabilities
- Parents/Care givers

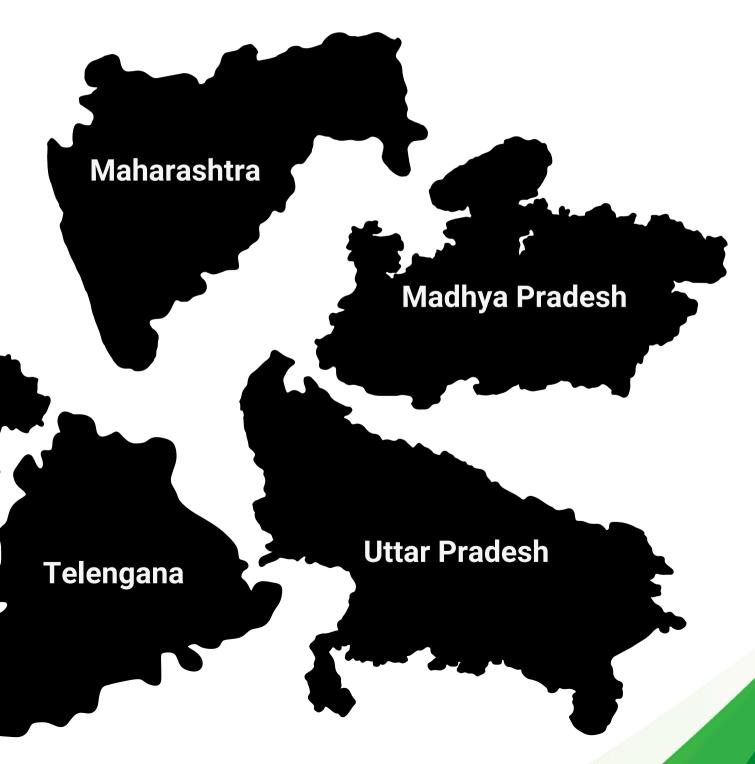
Survey Medium: Google Forms

- Translated into **four regional languages**
- **Distribution Method:** Circulated through parent groups and NGO networks
- A representative from **local NGOs assisted** participants with disabilities or no digital access.
- Anonymous participation

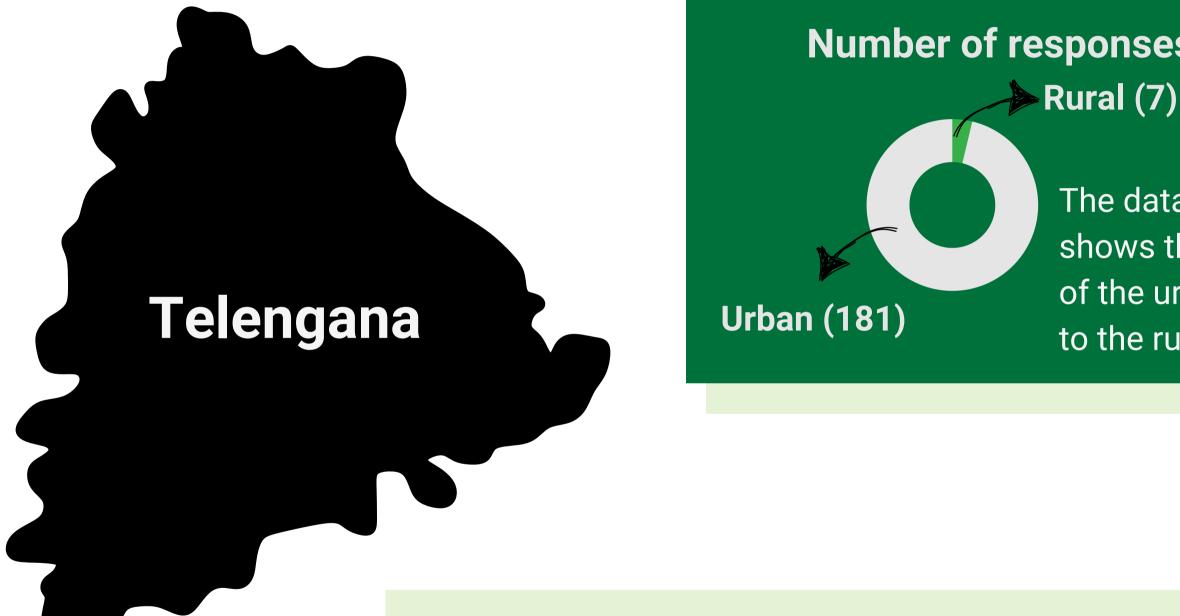
Data Analysis: Cleaning and analysis done in Python



States Covered



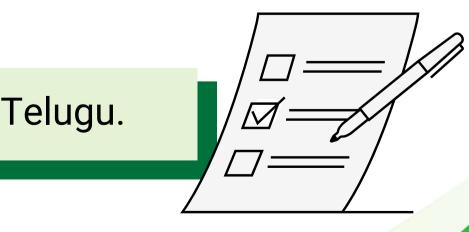
State-Specific Methodology: Telengana



The Google form was available in Hindi and Telugu.

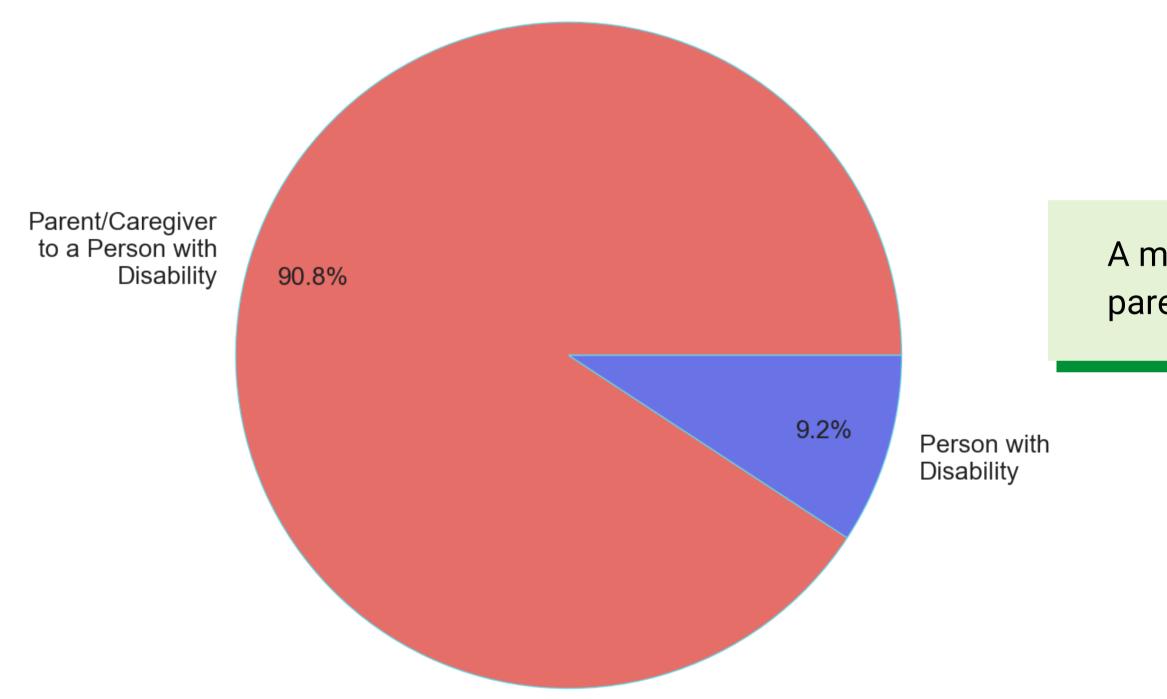
Number of responses from Telangana : 195 Rural (7)

> The data (for the available data points) shows that there is a high representation of the urban population (181) compared to the rural population (7).



Respondent Demographics

Survey Respondent Profile



A majority of respondents were parents/caregivers.



Age of Respondents

• Parents/Caregivers

22 years	42 years	70 years
(Youngest)	(Average)	(Oldest)

 Persons with disabilities (reported by parents/caregivers) 1 year 13 years 62 years (Youngest) (Average) (Oldest)

• Persons with disabilities (self-reported)

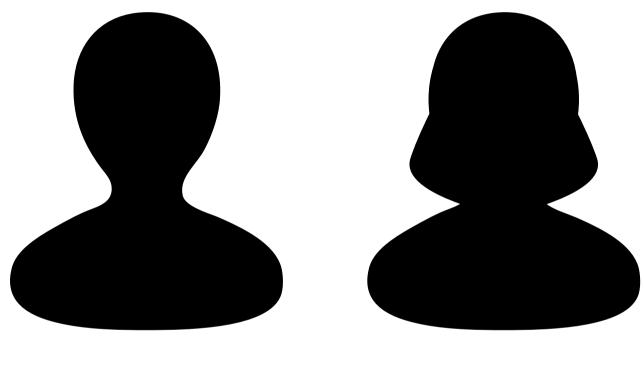
22 years	39 years	64 year
(Youngest)	(Average)	(Oldest

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Gender Distribution of Persons with Disabilities



Higher distribution of males in the sample

In the group reported by parents/caregivers, there were 72.3% male compared to 27.7% female persons with disabilities.

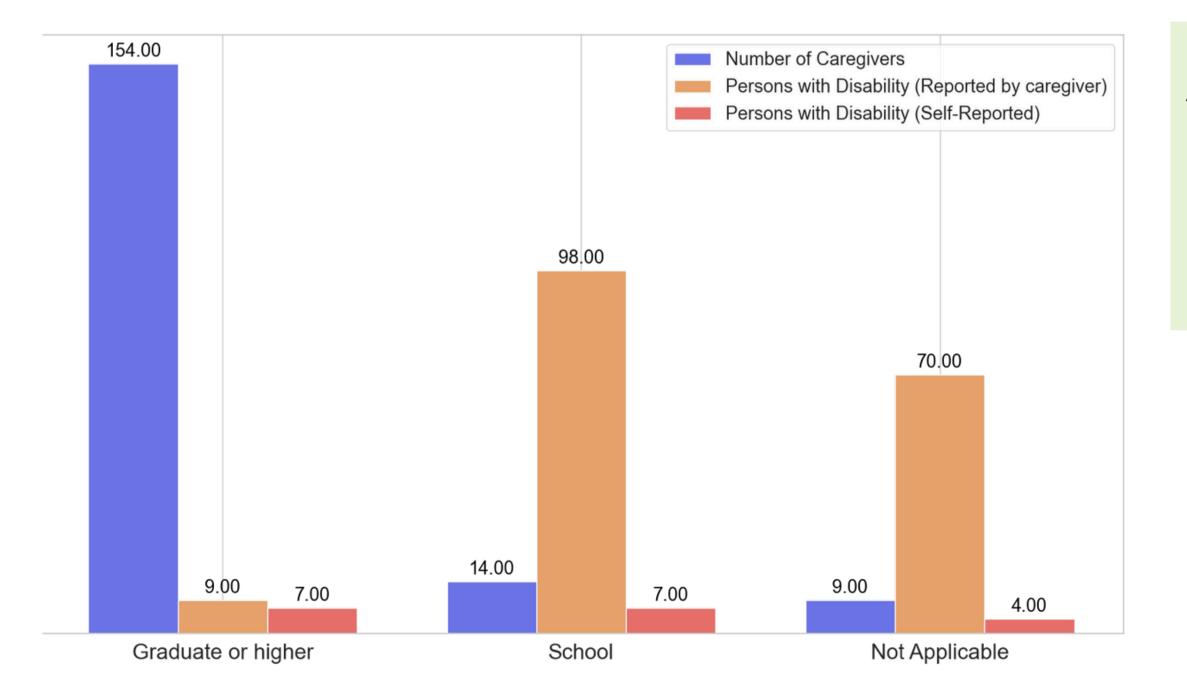
In the self-reported persons with disabilities group, there were 66.7% male compared to 33.3% female.

71.8%

28.2%

Overall Gender Distribution

Educational Levels of Respondents

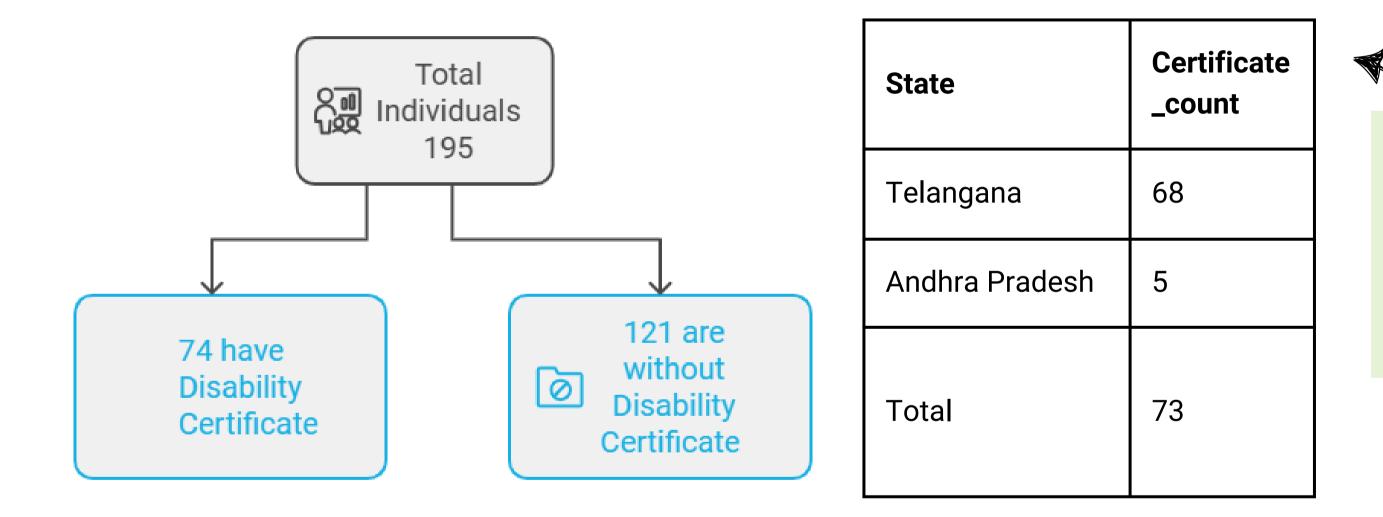


A majority of the parents had a graduate or higher level of education

Out of the 177 parents/caregivers surveyed, 87% have a graduate or higher level of education.

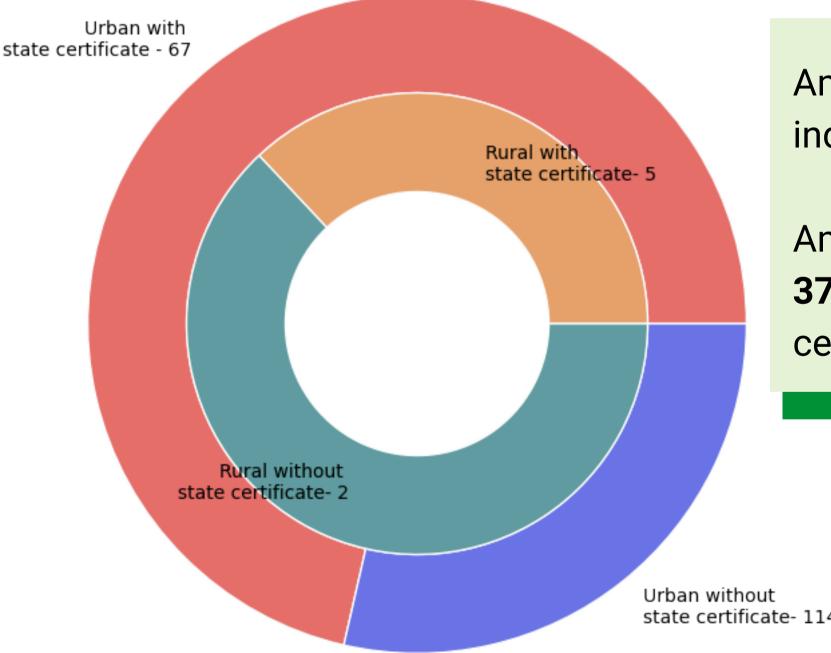
State Disability Certificate Status

38% of the sample had state-issued disability certificates; 91.8% had Telangana-issued certificates



The table shows the States that have issued certificates indicating that only five respondents have migrated to Telangana.

A majority of persons with disabilities do not have state-issued disability certificates

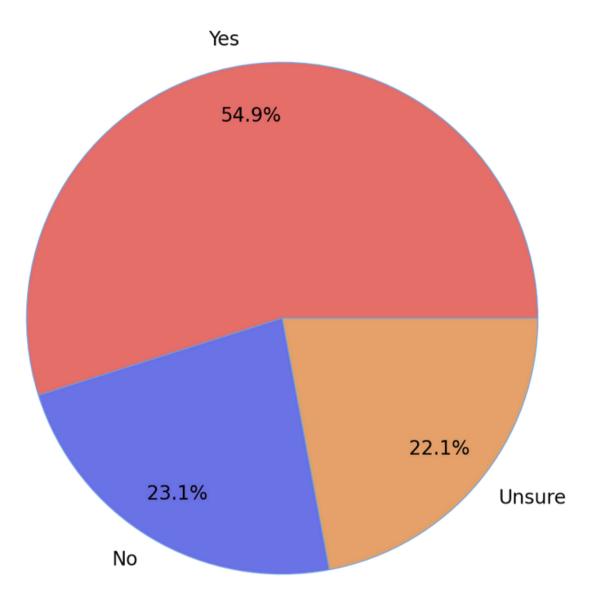


Among the respondents, 28% of rural and 63% of urban individuals do not possess state-issued disability certificates.

Among the respondents, 5 out of the 7 rural individuals and **37%** of urban individuals possess state-issued disability certificates.

state certificate- 114

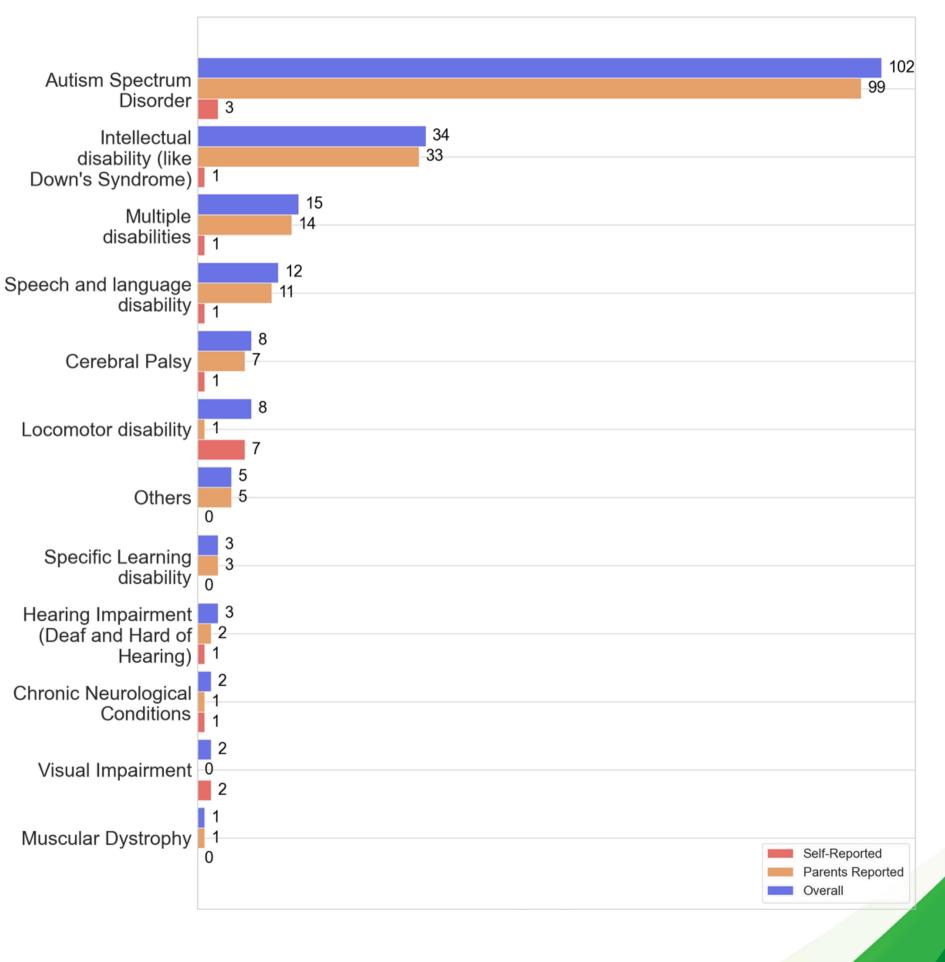
Diagnosis of Permanent Disability in the Sample



Based on the disability certificate, more than half of the respondents reported having been diagnosed with a permanent disability.

Disability Types in the Sample

- Responses from parents/caregivers showed representation of persons with Autism Spectrum Disorder, Intellectual Disability, Multiple Disabilities, and Speech and Language Impairment.
- Self-reported responses were from individuals with Locomotor Disabilities.

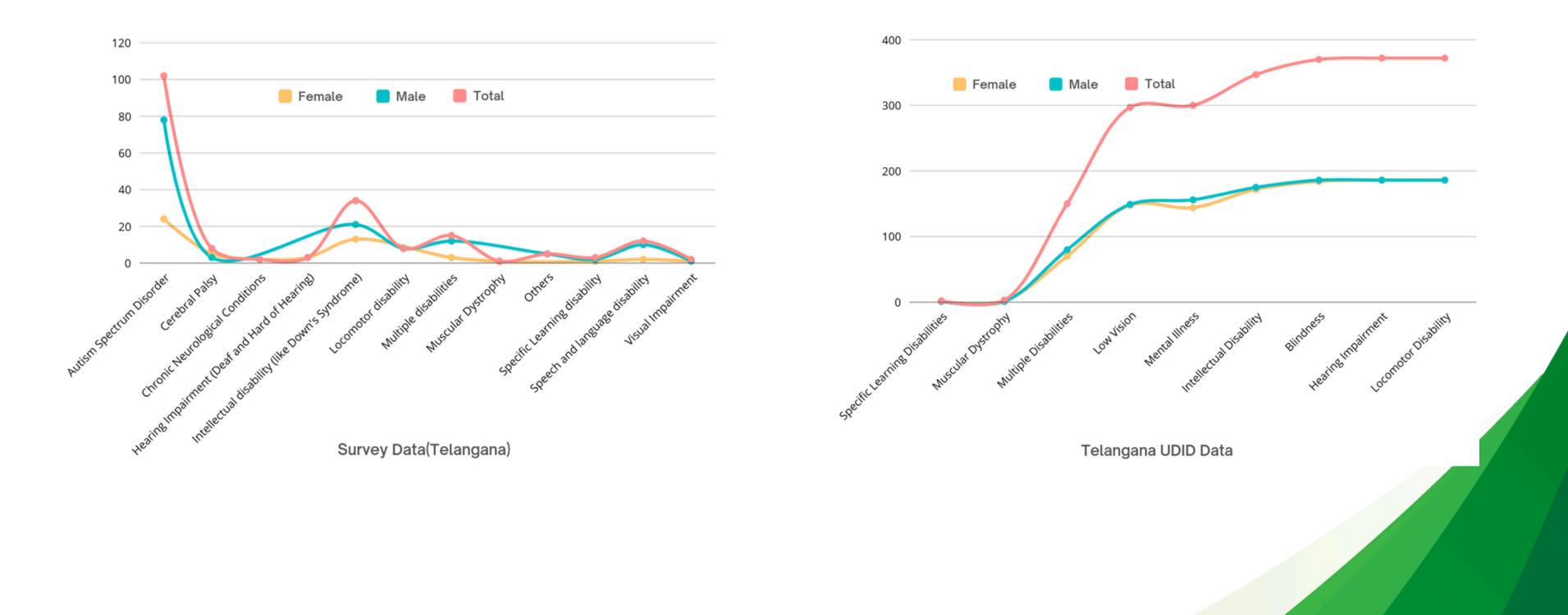


Access to the UDID Card is based on the disability type

We receive queries on our helpline mostly from individuals with disabilities, including low vision, intellectual disabilities, and cerebral palsy. We see fewer cases of Down's syndrome and other locomotor disabilities. However, in the field, I have observed that locomotor disability cards or certificates are issued more easily and frequently than those for individuals with intellectual disabilities. About 70-80% of the inquiries come from caregivers, while around 20% are from individuals with disabilities, primarily adults who can care for themselves.

- A Social worker from Nayi Disha

Significant variations in National Reports and Survey data on UDID issuance based on disability type

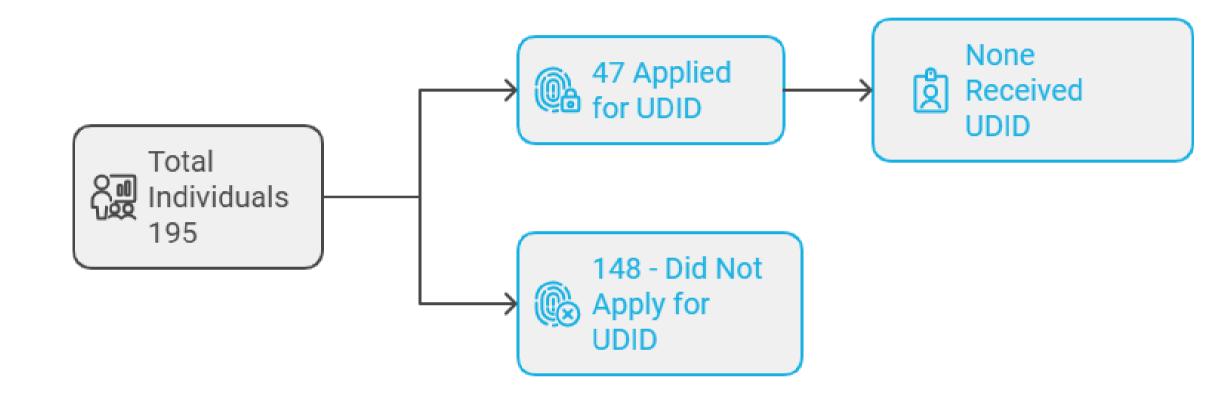


Analysis of the Data Trends

- Given the low number of UDID registrations in the state for only a few types of disabilities, it is evident that very few people have received a UDID card.
- Among this population, individuals with Locomotor Disabilities, Blindness, and Hearing Impairments are the most represented, whereas developmental disabilities are the most represented in our data. This is due to the sampling methodology used.

State of UDID Implementation in Telangana

UDID Application Status



- 24% of the sample applied for the UDID card and none (who applied) received their card at the time of the survey.
- 76% of the sample had not applied for the UDID card at the time of the survey.



Reasons for not Applying

Overall Reasons

1) Inadequate knowledge of ID benefits

2) Technical Issues in accessing the website

3) Difficulty in gathering documents

4) Unavailability of medical officers

5) Lack of knowledge about

application process

Telangana Urban (141 total issues out of 181 responses)

• Telangana Rural (4 total issues out of 7 responses) • Inadequate UDID knowledge (4 cases)

Rural Vs. Urban

 Inadequate UDID knowledge (107 cases) • Issues around obtaining the Sadarem certificate and Aadhaar-related problems (10 cases) Unavailability of Medical authorities (7 cases) • Difficulties in gathering documents (11 cases)

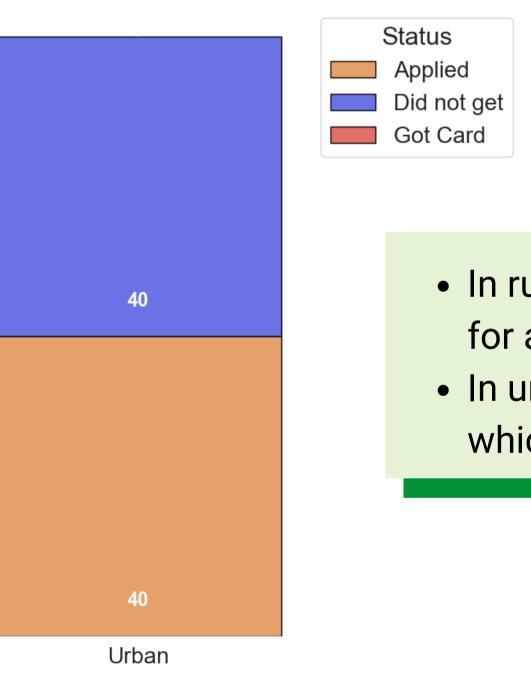
Accessibility Issues in Rural Areas

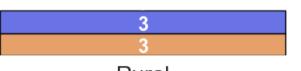
Many parents, particularly in rural areas, struggle to complete the online UDID application process. Mothers without access to smartphones often lack the resources to manage these applications independently. They will need support, from the nearest cyber café or an organization that can assist them. While offline options, such as visiting the CMO office, are available, the process is poorly outlined on the website, creating confusion about whether an online application is still required.

- A Social worker from Nayi Disha



UDID Application Status by Rural-Urban Divide



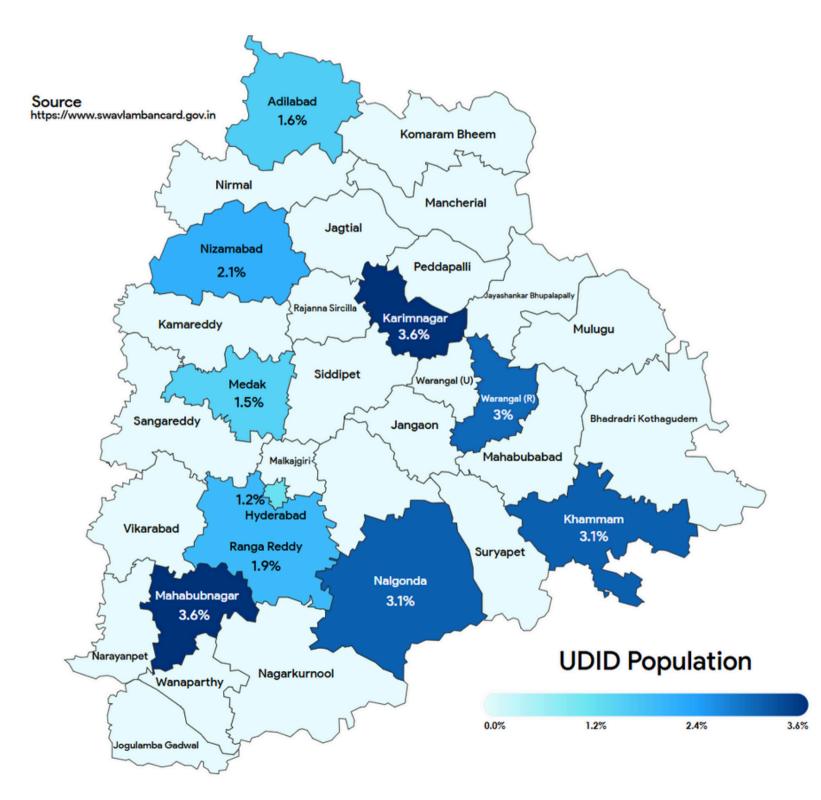


Rural



- In rural areas, 3 out of 7 respondents applied for a UDID card.
- In urban areas, 40 respondents applied, out of which 0 received the card.

Distribution of UDID cards in Telangana - proportion of UDID issued to the projected population of persons with disabilities per district (expressed as a percentage)

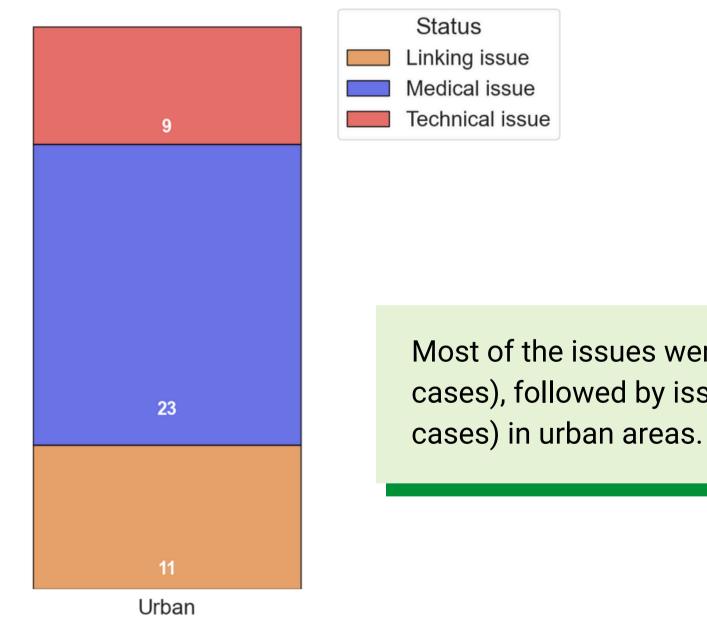


Based on the 2011 population data, we identified 10 common districts before and after partition of Andhra Pradesh. Here are the proportions corresponding to each district. Calculations show that the districts have a UDID coverage of between 1-3%. **Hyderabad shows the lowest coverage of 1.2%.**

Challenges faced in the **UDID Process**

Challenges in applying for the UDID

UDID Application Issues







Most of the issues were related to medical assessments (23 cases), followed by issues linking state certificates to UDID (11

Voices from the Ground



Technical Issues in Uploading Documents

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When individuals upload their documents, there are specific file types and size requirements that many parents are unaware of.



Lack of Clarity on Steps during the Online Application Process

A major challenge is that parents are often unclear about the next steps in the application process. There is a lack of notifications; even when parents provide their email addresses and phone numbers, they do not receive updates. After submitting an application, they should receive a notification indicating that their application has been submitted and that they need to visit an assessment center. Currently, many parents are unaware of these requirements and do not know where to print receipts or what to do next. As a result, about 80% of inquiries are from parents simply waiting for the UDID card to arrive, unaware that they need to undergo an assessment first. Clear communication about the process is essential.

Hospitals are not Equipped to Conduct UDID Assessments for all **Disability Types**

Even though hospitals are listed on the receipt, many deny performing assessments, causing parents to repeatedly visit different hospitals. There should be clarity on which hospitals are authorized to conduct specific assessments to prevent unnecessary visits. Not all hospitals are equipped for every type of assessment; for instance, hearing impairment assessments are only available at a few specialized hospitals, and the same applies to learning disabilities.

Lack of Proper Assessment Tools

Parents have expressed concerns that the government lacks a proper assessment tool. They believe the current assessment methods are inadequate, as they do not accurately reflect their children's intellectual disabilities. For instance, one parent mentioned that her child, who excels in math but struggles with certain calculations, was denied a disability card because the assessment indicated a disability of less than 40%. This benchmark seems unhelpful for parents and poses significant challenges.

Need for Standardized Procedures and Clear Definitions

Some implementing agencies, like district hospitals and medical boards, fail to recognize conditions such as specific learning disabilities, dyslexia, and dyspraxia as eligible disabilities for UDID card. For example, one parent struggled to obtain a UDID card despite reaching out to multiple contacts. There should be clearer definition of eligible disabilities and better recognition of smaller disabilities. While 21 disabilities have been recognized, there is potential for further categorization. A standardized process for UDID applications is necessary to improve the system

Limitations of the Study

- The study was done using Google Forms; hence, there was little representation from different regions of Telangana and socio-economic groups. This could be due to internet access issues and the methodology adopted for the survey tool's distribution (based on a convenience sampling method).
- The forms were distributed through NGO networks and parent groups, hence the sample may reflect only certain disability groups. Therefore, the results cannot be generalized to the population.

Concluding Remarks

The implementation of UDID in Telangana shows negative trends.

- Parents with higher levels of education show lesser difficulty in navigating the UDID process.
- A high representation of the male gender was seen in this survey.
- For the self-reported group, the representation of locomotor disability in this survey is due to a lack of difficulty in navigating digital technology compared to other disability groups.
- There is a low rate of possession of state disability certificates and a lack of possession of UDID cards among the respondents reflecting a systemic problem in the State.

In a few cases where there were issues obtaining the card, medical issues and issues linking state-disability certificates dominated the narrative. From our experience of understanding the landscape of UDID in the country, the challenges faced also tend to be individualized and unique. However, there are broader systemic issues to be addressed to ease the process for a majority of beneficiaries, particularly in Telangana.

Recommendations



Determination of reasons for not obtaining the State-disability certificate and the UDID in Telangana even after application is crucial to breaking barriers in applying and receiving disability benefits.



Efforts to increase awareness of the benefits of UDID must be made to ensure that the purpose of the project is fulfilled and rights of persons with disabilities are effectively granted.



Greater awareness among NGOs/parent groups regarding the challenges in linking the Sadarem certificate and the UDID is important. Further steps are to be taken to ensure that parents can navigate these challenges and issues smoothly to obtain the UDID.



Formal recognition of the role of institutions such as NGOs and CSOs to ease the process of obtaining the UDID.



Encourage and fund camps for UDID registrations, as well as for medical camps in both rural and urban settings.



06

• Clear guidelines to hospitals or medical professionals are to be provided to ease the medical certification process within hospitals.

Need standardized procedures and clear definitions. Some implementing agencies, like district hospitals and medical boards, fail to recognize conditions such as specific learning disabilities, dyslexia, and dyspraxia as eligible disabilities for UDID cards. For example, one parent struggled to obtain a UDID card despite reaching out to multiple contacts. There should be a clearer definition of eligible disabilities and better recognition of smaller disabilities. While 21 disabilities have been recognized, there is potential for further categorization. A standardized process for UDID applications is necessary to improve the system.



07

Streamline communications with those seeking the certification, particularly with medical assessments. Better systems such as Chatbots or helplines must be opened to enable access to information regarding the UDID.

A simple addition could be made to the application process. For example, it could state, "Please have the following documents ready: your correspondence address and an updated Aadhar card." This guidance could be presented before they start filling out the form.



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