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IP International Journal of Ocular Oncology and Oculoplasty

Journal homepage: <https://ijooo.org/>

## Original Research Article

# Assessment of visual disability, clinical and demographic profile from Unique Disability Identification Details (UDID) card applicants in Regional Institute of Ophthalmology (RIO) in South India

Ranjitha C Sadananda<sup>1,\*</sup>, Aswathi M Menon<sup>1</sup>, Sujatha Rathod<sup>1</sup>, Anuradha Appaji<sup>1</sup>, Harish B Hanumantharayappa<sup>1</sup>

<sup>1</sup>Dept. of Ophthalmology, RIO Minto Ophthalmic Hospital, Bengaluru, Karnataka, India



### ARTICLE INFO

#### Article history:

Received 19-01-2022

Accepted 29-01-2022

Available online 09-05-2022

#### Keywords:

UDID CARD

Visual disability

blindness

low vision

benefits

Retinitis pigmentosa.

### ABSTRACT

**Aims:** To ascertain the degree and causes of visual disability, clinical and demographic data of UDID card applicants at RIO MOH Karnataka South India.

**Materials and Methods:** It is a cross-sectional observation study, data collected from the UDID PORTAL where applicants applied between July 2019 to March 2020. Totally 551 applicants details were collected. Degree of visual disability and its causes, demographic details like age, gender, education, marital and employment status, annual income along with that other clinical details were ascertained.

**Results:** Among the 551 applications, 368 were men and 183 were women highlighting a significant gender bias. Almost 2/3<sup>rd</sup> of applications were in the age group 20 to 50. 60% of applicants were married. 95% of applicants were in the blind category while only 4.3% were certified as having low vision. 47% of applicants were BPL Card holders and were dependent on the family member for livelihood. 47% of the applicants had completed basic education (10<sup>th</sup> std/SSLC). Retinitis pigmentosa was the top cause of blindness.

**Conclusion:** Retinal pathologies constitute the leading cause among them majority had Retinitis pigmentosa. Genetic counseling plays a significant proactive role in the prevention of the disease. Creating awareness among employers to provide adequate protective equipment could help in reducing the disease burden of phthisis bulbi. Government and NGOs should prepare appropriate plans and implement them to rehabilitate individuals with visual disabilities. There is a need to create better awareness about the benefits of UDID CARDS in the community in general and among people with blindness and low vision in particular.

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## 1. Introduction

With an estimated prevalence of blindness of 0.45%, India is home to third of world's blind population (12million/35 million).<sup>1</sup>

The registration of blindness and low vision in India is voluntary and has to be certified by an ophthalmologist.<sup>2</sup> The rights of persons with disability act 2016 fixes the roles

and responsibility of safeguarding the rights of people with disabilities in the state.<sup>3</sup>

This act also defines visual benchmark disability as having at least 40% disability due to any cause or illness. Upon certification by a recognised medical board of a government hospital people with benchmark disability would be eligible for several benefits and welfare measures.<sup>4</sup> Blindness registers have been playing a vital role in assessing incidence and prevalence of visual

\* Corresponding author.

E-mail address: [ranjitha.2704@gmail.com](mailto:ranjitha.2704@gmail.com) (R. C. Sadananda).

disability.

The UDID project was instituted and organized by the Dept of Empowerment of people with disabilities Govt of India. It is a wholesome and integrated system for issuing universal ID cards and disability certificates to the differently abled individuals. These would not only include the person’s identification but also the information of the disability. Apart from ensuring uniformity at a national level, it also helps in making the whole process transparent and efficient, which helps the GOVT in delivering the benefits to the target population. It will also facilitate long term follow up of the beneficiaries at all the levels of implementation from the grassroots to national level.<sup>5</sup>

To the best of our knowledge since the inception of the UDID project no study has been conducted to analyse data available on its database hence we designed this cross-sectional observational study to analyse this. Even though this might not provide the prevalence of various causes of visual disabilities or blindness in the community it is going to provide important insights into the demographic features and a clinical profile of the applicants from the local population.

1.1. Purpose of study

1. To study the degree of visual disability.
2. To study the cause of visual disability in applicants.
3. To study the socio economic and clinical profile of applicants.
4. To study the demographic profile of applicants.

2. Materials and Methods

This is a cross sectional observational study conducted at RIO, MOH, a Tertiary eye care centre, Karnataka. Details of the applicants who had applied in UDID portal between July 2019-to march 2020 were assessed. Total of 551 applicants were received under Bangalore urban district which has 5 Taluks catering to about 1 crore population.

Recent guidelines issued by THE GAZETTE OF INDIA and the Dept. of Family Welfare were considered for the visual disability categorisation while assessing the applications applicants.

Demographic data, degree of visual disability, clinical data were collected from all the applicants from UDID Database Portal were compiled and assessed. Reassessment was done in few low vision patients to confirm the degree of disability. Table 1

3. Results

Nearly 2/3rd of the applicants were men. Chart 1

375 applicants (68%) belong to the working age group 20 – 50 years. Table 2

While 296 applicants were married, 216 were unmarried including children in the age group of 0-10 years .

Table 1: Visual disability categorisation.<sup>5</sup>

Better Eye best Corrected	Worse eye Best Corrected	Percent Impairment	Disability Category
6/6 to 6/18	6/6 to 6/18	0%	0
	6/24 to 6/60	10%	0
	Less than 6/60 to 3/60	20%	I
6/24 to 6/60 Or Visual Field less than 40 up to 20 degree around centre of fixation or hemianopia involving macula	Less than 3/60 No Light Perception	30%	II (One Eyed person)
	6/24 to 6/60	40%	III a (low Vision)
	Less than 6/60 to 3/60	50%	III b (low Vision)
	Less than 3/60 to No Light perception	60%	III c (low vision)
Less than 6/60 to 3/60 or Visual field less than 20 up to 10 degree around centre of fixation	Less than 6/60 to 3/60	70%	III d (low Vision)
Less than 3/60 to 1/60 Or Visual field less than 10 degree around centre of fixation	Less than 3/60 to No Light perception	80%	III e (Low Vision)
Only HMCf Only Light perception No light perception	Less than 3/60 to No Light perception	90%	IV a (Blindness)
	Only HMCf Only Light perception No light perception	100%	IV b (Blindness)

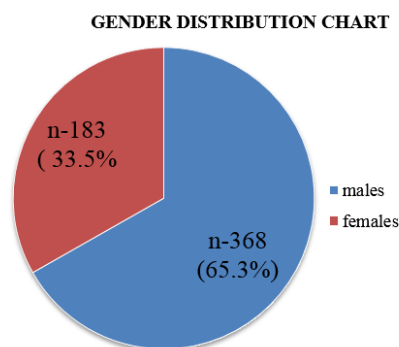


Chart 1: Distribution of applicants according to gender

Table 2: Distribution of applicants according to age.

Age in yrs.	Number	Percentage of disability
0 to 10	17	3.08 %
10 to 20	60	10.88%
20 to 30	109	19.7%
30 to 40	136	24.68%
40 to 50	130	23.59%
50 to 60	66	11.97%
60 to 70	23	4.17%
70 to 80	5	0.95%
80 to 90	5	.95%

36 applicants did not provide details of their marital status. Table 3

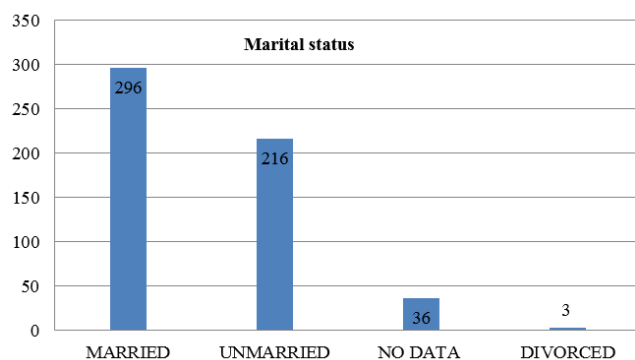


Chart 2: Distribution of applicants according to marital status

Table 3: Profile of patients based on low vision or blindness.

	Blindness 90%-100 %		Low Vision 40 % - 80%
Male	180(32.6%)	169 (30.9%)	19 (3.4%)
Female	115 (20.8%)	6 (11.0%)	7 (1.27%)

Almost all (95%) of the applicants were categorized as blind (visual disability of 90% and 100%).

Less than 5 % of applicants were under the low vision category (visual disability 40%-80%).

Visual disability criteria are taken from the (Table 1).

Visual Impairment Certification Criteria and Gradation.

Table 4: Distribution of applicants according to Education Qualification.

Education qualification	Number	Male	Female
Illiterate	41 (7.4%)	25	16
Primary	53 (9.6%)	28	25
Higher primary	107 (19.41%)	77	30
Sslc	96 (17.4%)	72	24
Senior secondary	63 (11.43%)	41	22
Diploma	9 (1.6%)	7	2
Graduate	82 (14.88%)	57	25
Post graduate	36 (6.5%)	22	14
No details available	64 (11.1%)	39	25

Nearly half of the applicants had completed basic education (10<sup>th</sup> std/SSLC). About 20% of the applicants were graduates.

Table 5: Employment of the applicants according to the gender

	Male	Female
Employed	112 (20.36%)	35 (6.35%)
Unemployed	176 (31.94%)	110 (19.96%)
No details available	80 (14.51%)	38 (6.89%)

Around 50% of applicants were unemployed and dependent on their family for their livelihood. Around 26% were employed, the majority of them being men. Only 6% females are employed in various private and govt sectors. No details about the employment were mentioned in 118 applications.

Table 6: Distribution of applicants according to the annual income

Annual income per annum	Male	Female	Total
<10k	171 (31.03%)	98 (17.78%)	269 (48.81%)
10k -1 lakh	89 (16.15%)	22 (3.99%)	111 (20.14%)
1 lakh -5 lakh	29 (5.261%)	13 (2.359%)	42 (7.61%)
>5 lakh	13 (2.3%)	6 (1.08%)	19 (3.38%)
No details available	66 (11.97%)	44 (7.98%)	110 (19.95%)

Nearly half of the applicants (48%) were from below poverty line and were economically dependent on the other family members. Where as 3 % of applicants had an annual income of >5 lakhs, no data was available for 30% of applicants.

**Table 7:** Distribution of applicants according to the diseases

Causes	Number	Percentage
Congenital	79	14.3%
Retina	189	34.3%
Glaucoma	13	2.3%
Anterior segment	55	9.9%
Neurological	64	11.6%
Pathological myopia	26	4.7%
Phthisis bulbi	115	20.8%
Miscellaneous	10	1.8%

Retinal disorders (34%) are the major cause of visual disability among the applicants followed by phthisis bulbi (20%) and congenital eye diseases(14.8%).

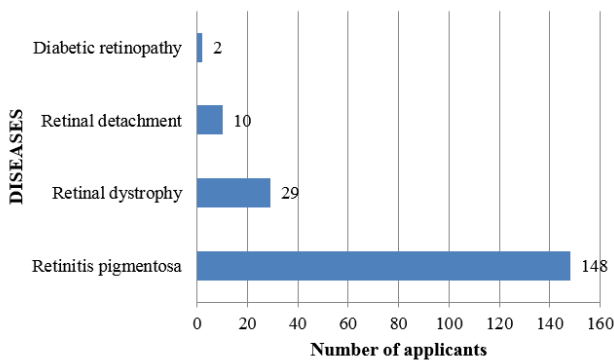


Chart 3: Distribution of applicants according to Retinal Pathology

Among the retinal disorders, retinitis pigmentosa was the leading cause of blindness which accounts for 77% of the retinal pathologies followed by retinal dystrophies.

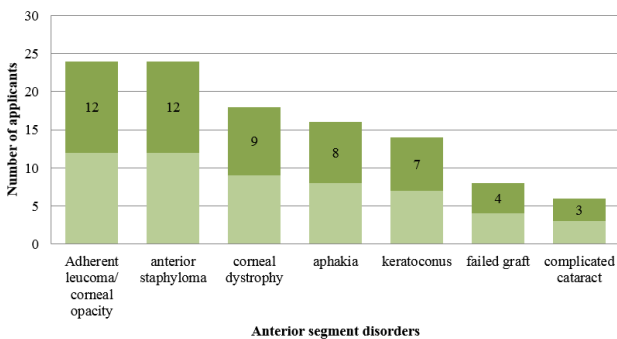


Chart 4: Distribution of applicants according to Anterior Segment Disorder

Anterior chamber pathologies accounted for about 10% of the disabilities.among the anterior segment disorders corneal grafts and anterior staphyloma together accounted for more than 45%of the cases.

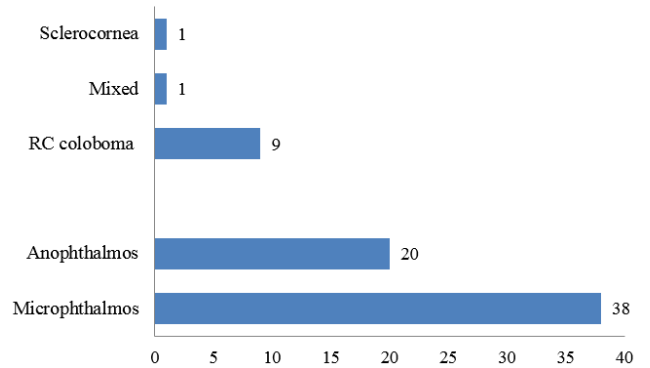


Chart 5: Distribution of congenital malformations

Out of 79 congenital ocular diseases, the visual disability among microphthalmos contributed to 48% of cases.

### 3.1. Neurological causes

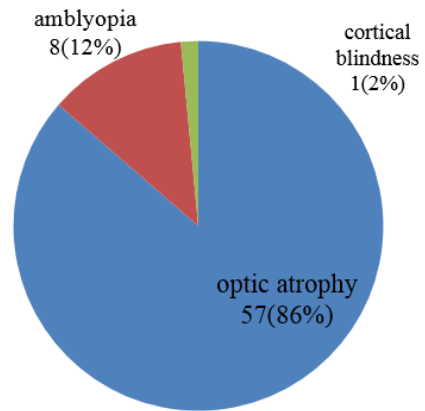


Chart 6: Distribution of diseases based on the neurological causes

9% applicants suffered from neurological diseases, optic atrophy being the most common cause

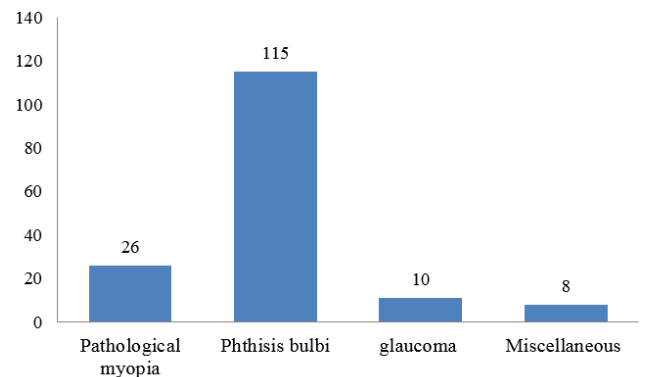


Chart 7: Distribution of diseases in others category

Out of 551 applicants, 115(20%) applicants had phthisis bulbi, the cause could not be ascertained due to lack of further clinical details.

#### 4. Discussion

Visual disability/blindness has major impacts on personal and socioeconomic aspects of one's life. The impact is more profound in developing countries due to the limited opportunities, financial support and awareness. The findings of our study were conforming to similar studies conducted previously in India, and will help to add to the pool of evidence based data in order to enhance awareness and to plan prevention, and rehabilitation strategies.

Our study found that almost 2/3<sup>rd</sup> (65.33%) of the UDID applicants were males. This gender bias was observed in other Indian studies such as that conducted by Abastha et al in Bihar,<sup>6</sup> Gosh et al in west Bengal<sup>7</sup> and Joshi et al in central India.<sup>8</sup> The preponderance could be attributed to the fact that males are more active outdoors and hence more in need of the available benefits than females. Another reason which might explain this gender bias would be low literacy levels among women, as well as social obstacles to accessing the certification system which is institution based.

When we analysed the age distribution of the applicants we found that nearly 70% of the applicants were in the age group of 20 to 50 years this is the most productive age group of the society there by explaining the greater need of certification be it for the purpose of education, employment, tax and conveyance benefits. This result agrees with the findings of the Ghosh et al study.<sup>7</sup> We noted in our study that very few applicants were there at both the extremes of age 'as the UD ID registration process is mainly web-based unfamiliarity with these processes along with reduced need for certification might also explain lower level of certification in the elderly age group The latter group might also be dependent on breadwinners of the family, and might have hindrance to the application process.

Half of the applicants were married, which can enhance the social and personal support to the disabled.

While About 50% of the applicants had completed basic education (10th standard or SSLC). 20% of the applicants had completed atleast graduation. At every educational level men outnumbered women.

Nearly Half of the applicants were unemployed, fell below the poverty line, and were economically dependent on other family members. These results were similar to the results of other Indian studies. 2002 survey conducted by the government of India found that a whopping 80% of the blind people in rural India did not have a source of income. These findings emphasize the need for enhancing the education and employment benefits as well as enhancing awareness among the blind population and their caregivers regarding the UD ID cards and their benefits as well as various social security measures undertaken by the government.

We found that people with 100% visual disabilities accounted for almost all the applicants. A similar outcome was noted by Kareemsab et al.,<sup>9</sup> Gosh et al.<sup>7</sup> Percentage of blindness were allotted in accordance with Visual disability criteria.<sup>7</sup>

Our study found that RP, a retinal disease was the single largest cause of disability followed by phthisis bulbi.

148 (26%) of applicants were blind due to Retinitis pigmentosa, emphasizing the need for genetic counselling, and awareness programs about the dangers of consanguineous marriage. Similar findings were noted in other studies such as those by Joshi et al.<sup>8</sup>

Phthisis bulbi accounted for 20% of cases. But details pertaining to the causes of phthisis were not documented in records. This was followed by congenital disorders is the next leading cause for blindness, microphthalmos accounting for half of the cases. Congenital malformations were found to be a major cause of blindness in other studies as well.<sup>7-10</sup> Siddegowda et al had suggested a correlation between prevalence of consanguineous marriage, and congenital rubella syndrome in India.<sup>11</sup>

10% of applicants had anterior segment pathologies causing blindness, with corneal opacity being the leading cause. Corneal dystrophies, keratoconus, and failed corneal graft were responsible for 9, 7 and 4 cases respectively. Aphakia and complicated contributed to disability in 11 cases. Garg et al in their review of literature had analysed the need, availability and survival of corneal grafts in various countries. They noted that, even though developing nations like India carry the major load of corneal blindness, eye donation rate and graft survival are poorer in these countries compared to developed nations.<sup>12</sup> In our study, the causes of opacities, graft failure or aphakia were not available from records. However these findings further emphasise the need for improving awareness about eye donation and increasing the availability of corneal transplantation services to the common man.

Other major causes of blindness noted were neurological, optic atrophy being the most common cause, pathological myopia, and glaucoma. This calls for improving screening services for glaucoma and also increasing the availability of low vision aids and other rehabilitation for the visually challenged population.

The limitation of our study is that data was collected from records, and hence missing details could not be collected or verified directly from subjects. Strength of our study was the large number of study population.

#### 5. Conclusion

Unique Disability Identification card (UDID) is a one stop for disability certificates, for those with a benchmark disability of 40% or more. The pre requisites and process to obtain the card as well as its benefits should be publicized using mass media to improve awareness among common

public about the same.

Despite being educated, most of the blind population suffers from due to lack of employment opportunities. Government policies to ensure job reservation, conveyance benefits, vocational training are required urgently to ensure better quality of life to this population.

The fact that retinitis pigmentosa and congenital disorders are responsible for lion's share of blindness.

Calls for urgent need of easy accessibility of genetic counselling in govt. hospitals, and preventing consanguinity by creating public awareness and if possible legal measures.

Strict implementation of work safety laws and improving awareness are required to reduce ocular trauma which further leads to corneal scarring or phthisis. Enhancing awareness and routine screening for treatable conditions such as glaucoma and diabetic retinopathy, improving eye banking services are of ever increasing requirement in these challenging times.

Govt can also consider a policy of opt out, instead of opt in for organ donation. So as to address the huge need availability gap in corneal transplantation. Addressing those without complete blindness with early rehabilitation including Low vision aids will improve the quality of life of visually challenged.

## 6. Conflict of Interest

The authors declare that there is no conflict of interest.

## 7. Source of Funding

None.

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## Author biography

**Ranjitha C Sadananda**, Assistant Professor

**Aswathi M Menon**, Senior Resident

**Sujatha Rathod**, Professor

**Anuradha Appaji**, Assistant Professor

**Harish B Hanumantharayappa**, Resident Medical Officer

**Cite this article:** Sadananda RC, Menon AM, Rathod S, Appaji A, Hanumantharayappa HB. Assessment of visual disability, clinical and demographic profile from Unique Disability Identification Details (UDID) card applicants in Regional Institute of Ophthalmology (RIO) in South India. *IP Int J Ocul Oncol Oculoplasty* 2022;8(1):46-51.