Counting persons with disabilities, a prerequisite to "making them count"

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How many of us have known a person with disability at school, or college or at our workplace? Despite a large number of the population suffering from some form of disability, there is a certain invisibility around persons with disability (PwD). They suffer multiple challenges – physical, social and economic. Families and communities often consider them a 'burden', and physical access barriers confront them on an everyday basis. With these barriers, most of them do not undergo schooling or any formal education and are unable to join gainful employment, being forced to lead a life of economic dependence. Most of them suffer poor health as their health conditions often need specific attention and access to specialised medical help and affordability are both barriers, which leaves their specific conditions untreated.

As per the World Report on Disability published in 2011, more than 1 billion persons in the world have some form of disability. This corresponds to about 15% of the world's population. 110-190 million people have very significant difficulties in functioning.

Persons with Disabilities refers to persons suffering from not less than 40% of any disability as certified by Medical board. In India, approximately 26.8 million people are disabled, nearly 2.22% of the total population. Of these, around 18.7 million people (69%) reside in rural areas and 8.1 million people (31%) in urban areas. Persons with locomotive disability (20.3%) form the largest category of the total disabled population, followed by hearing impaired (18.9%), visually impaired (18.8%), speech impaired (7.5%), mentally challenged (5.6%), mentally ill (2.7%) and persons with multiple disabilities (7.9%). 45% of persons with disability are illiterate, compared to 26% of all Indians.
Source: Census of India, 2011

Persons with disability – an unverified count
With the enactment of Rights of Persons with Disabilities Act, 2016 in India, the types of disabilities have been increased from existing 7 to 21 disabilities. *There has been no enumeration of PwDs, after the extension in the list of disabilities, and the numbers of PwDs will be much more than the census estimate. It is estimated that the present count of Persons with Disabilities in India could be anywhere between 50 to 80 million.*

"In India, the disability sector in general estimates that 4-5% of the population is disabled. The Planning Commission recognizes this figure as 5%. A report by the World Bank states that while estimates vary, there is growing evidence that persons with disability… constitute between 4-8% of India's population," *Source: Persons With Disability and the Indian Labour Market: Challenges and Opportunities, Meera Shenoy, International Labour Organisation, December 2011.*

A 2007 World Bank report says that while India has one of the most progressive disability policy frameworks in the developing world, implementation is poor. The report's key recommendation is to "get the basics right", especially identifying people with disabilities as soon as possible after onset. More than a decade later, nothing seems to have changed.

Different states follow different methods to identify people with disabilities and extend benefits to them. *The absence of a comprehensive database of persons with disabilities and an effective tracking mechanism leaves out many persons, and limits sustained follow-up of those who have been reached.*

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The Rights of Persons with Disabilities Act 2016, enshrined upon the Central and State governments to provide services, create facilities and give support to people with disabilities in order to enable them to have equal opportunities.

Addressing persons with disabilities – some key issues

The CRPD Alternate Report for India, submitted to the Committee on the Rights of Persons with Disabilities in response to the initial report submitted by the Government of India (11 February, 2019 by: National CRPD Coalition-India, towards Parallel report, 2019) notes the following:

Lack of proper identification and education: Early intervention for children with disabilities, especially deafblind, and multiple disabilities is non-existent. Only 93 out of 640 districts have District Early Intervention Centres (DEIC). There is no disaggregated data on number of children with disabilities registered. Inspite of policies for inclusive education, enrolment and retention of children with disabilities remains dismal. While enrolment is claimed to be 40%, at elementary level, the enrolment rate is merely 1.26-1.16% against total. Similarly, below 1% are enrolled at secondary level which drops to 0.25-0.27% at high school level. There is a long-standing demand to bring Special Schools under MHRD.

Lack of rehabilitation and employment: Merely 251 out of 640 districts in India have DDRCs (District Disability Rehabilitation Centres). Many of them are non-functional. Reservation in jobs for PwDs has now increased from 3% to 4%. The average employment rate of people with disabilities is 0.28 percent in the private sector and 0.54 percent in the public sector. Additionally, 87 percent of persons with disabilities in India worked in the informal sector. The International Labour Organization (ILO)'s 2011 report 'Persons with Disability and The India Labour Market: Challenges and Opportunities' states that 73.6% of the disabled in India are still outside the labor force. Of these, those with the mental disability, disabled women and those in rural areas are the worst neglected.

Lack of efficiency in spending : The central governments contribution towards the specific expenditure for persons with disabilities as a percentage to total expenditure has remained constant at merely 0.02% in the last three years. Unfortunately, while on one hand the total allocation towards disability is inadequate; on the other hand, there is high underutilization of even these funds each year. Moreover, all functioning schemes are based on the erstwhile PWDA without amendments. New mainstream programs do not address disability specific requirements.

Lack of disability disaggregated data and poor monitoring : Absence of disaggregated data is a failure across all levels of governance in all sectors that makes it difficult in designing, implementing and monitoring programmes. Though RPDA talks about social audit of all schemes and programs concerned with persons with disabilities, this is not reflected in policy design.

Non-uniform coverage of entitlements : Disability certification is the key to access entitlements and social protection programs across the states, however, till August 2017, only 57.98% of the disabled population have been issued disability certificates[1]. Moreover, there is a non-uniform coverage of entitlements with a stark variation across regions in fund allocation for per-capita spending in different States and union territories. Persons with disabilities living in rural areas are ignored in coverage.

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[1]Annual Report, Department of Empowerment of Persons with disabilities 2017-18. Accessed on 17.12.18 at http://disabilityaffairs.gov.in/upload/uploadfiles/files/Annual%20Report%202017-18%20(E)(1).pdf

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Lack of participatory process : There is a lack of involvement of persons with disabilities in policymaking and planning by all ministries[2].

The issue of Disability Certificates
On the basis of the assessment of degree of disability as certified by a medical authority, a Disability Certificate (DC) is given to the disabled person and this is the basis for availing benefits under various government schemes. In interactions with disabled persons and organisations working with Persons with Disabilities, several issues emerged:

- It is alleged that among those who have Disability Certificates, some have duplicates from various states, as the Disability Certificate in one state is not recognised in another, while some have outdated/invalid certificates.

- Corruption is said to be rampant, and several persons without disabilities obtain Disability Certificates. There is also the case of 'Temporary' and 'Permanent' disability, which is often mis-used. Benefits meant for PwDs are therefore often denied to those deserving them.

- Lack of awareness of the benefits of a Disability Certificate, limited information of government programmes and schemes for persons with disabilities and cumbersome processes in obtaining a Disability Certificate have been cited are major reasons for low coverage of Disability Certificates.

- One of the key hurdles is the process of certification by a Medical Board, comprised of specialists, located at designated medical institutions. These medical institutions are located in the state capital or District Headquarters. A benchmark disability of 40% is a pre-requisite for availing most of the benefits and schemes of the Central and State Government.

UDID - creating a credible information system of persons with disabilities
The national project to convert disability certificates into Unique Disability Identity cards (UDIDs) was launched in 2016 with the objective to ensure persons with disabilities (PwDs) avail all government benefits irrespective of their domicile status. The UDID card with an 18-digit number is designed to ensure that benefits reach the deserving beneficiaries, eliminate possibility of duplication, and allow tracking of benefits directed at individual based on the nature of disability.

Inspite of its versatility, there are no government notifications making the UDID card universal in application. Hence persons with disability must continue to make separate applications to avail of Rail and Air concessions as well as Bus cards.

The principal aims of UDID are (Source: https://www.unescap.org/sites/default/files/India_15.pdf.):
- To create a National Database for Persons with Disabilities (PwDs) by identifying and issuing a Unique Disability ID Card to every Person with Disability through a web-portal
- Issue Disability Certificate not only to those who are still uncovered but also to persons with new types of disabilities under enactment of RPwD Act 2016
- Encourage transparency, efficiency and ease of delivering government benefits to PwDs pertaining to Scholarship, Skill training, Inclusive Education, Rehabilitation, Pension, Railway concessions to PwDs across the country

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- Tracking of physical and financial progress of benefit delivery at all levels of hierarchy of implementation – from Village level, Block level, District level, State level and National level

To build a UDID database, it is imperative to consider the following types of applicants for defining the future state of processes:
- PwDs who don't have any Disability certificate
- PwDs who already have a Disability Certificate
- PwDs who have applied for Disability Certificates and their certificates are under process
- PwDs whose application was rejected / want to re-apply for Disability Certificate

The UDID database includes the following information for each person with disability:
1. Personal details
2. Disability details
3. Employment details
4. Identity details (including Aadhar)
5. Bank details (as per the Jan Dhan Yojana)
6. Education details
7. Disability certificate (manually issued in past) details
8. UDID number
9. UDID dispatch details
10. Scheme related details

The process to cover all persons with disabilities under UDID was launched across the sates in a phased manner in 2016. The intention was to cover the nearly 30 million Persons with Disability under UDID by the end of 2018.

In the two years since the roll out of the UDID process, 463 districts of 27 States/UTs have generated 1.12 million UDID Cards. This accounts for less than 4% of persons with disabilities. (Source: PIB: Achievements of Department of Empowerment of Persons with Disabilities (DEPwD) during 2018, December 17, 2018).

As of March 17, 2019, as per the official UDID website of the Department of Empowerment of Persons with Disability (http://www.swavlambancard.gov.in/), 5,429,072 applications were received online for UDID Card of which 1,374,111 UDID cards are issued.

The state wise status is as follows: Madhya Pradesh(3,05,161), Rajasthan(2,94,835), Odisha(1,99,063), Uttar Pradesh(1,56,780), Gujarat(1,16,394), Chhattisgarh(1,11,975), Maharashtra(71,007), Tamil Nadu(37,131), Haryana(29,386), Punjab(22,206), Jharkhand(9,813), Kerala(3,940), Meghalaya(3,624), Jammu And Kashmir(3,262), Himachal Pradesh(2,250), Chandigarh(1,768), Andaman And Nicobar Islands(1,501), Bihar(1,346), Tripura(1,162), Mizoram(937), Daman And Diu(321), Sikkim(121), Arunachal Pradesh(91), Dadra And Nagar Haveli(17), Delhi(13), West Bengal(4), Karnataka(2), Telangana(1)

Mechanism for implementation of UDID project

The State Commissioner for PwDs is a vital position to ensure effective implementation of UDID as well as provisions of the RPWD2016. However, many states do not have a State Commissioner for PwDs.

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Training is provided to all states by the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment on the UDID project and application. Further, financial support is provided from the MoSJ&E for the appointment of a State Coordinator for UDID project implementation. This position is also not filled in many states.

Additionally, resources are allocated for procurement of appropriate IT infrastructure as well as support for publicity and awareness at the district level.

The institutional framework for UDID implementation is as follows (Source: Department for Empowerment of People with Disabilities, Ministry of Social Justice and Empowerment):

Institutional Framework For Udid Implementation
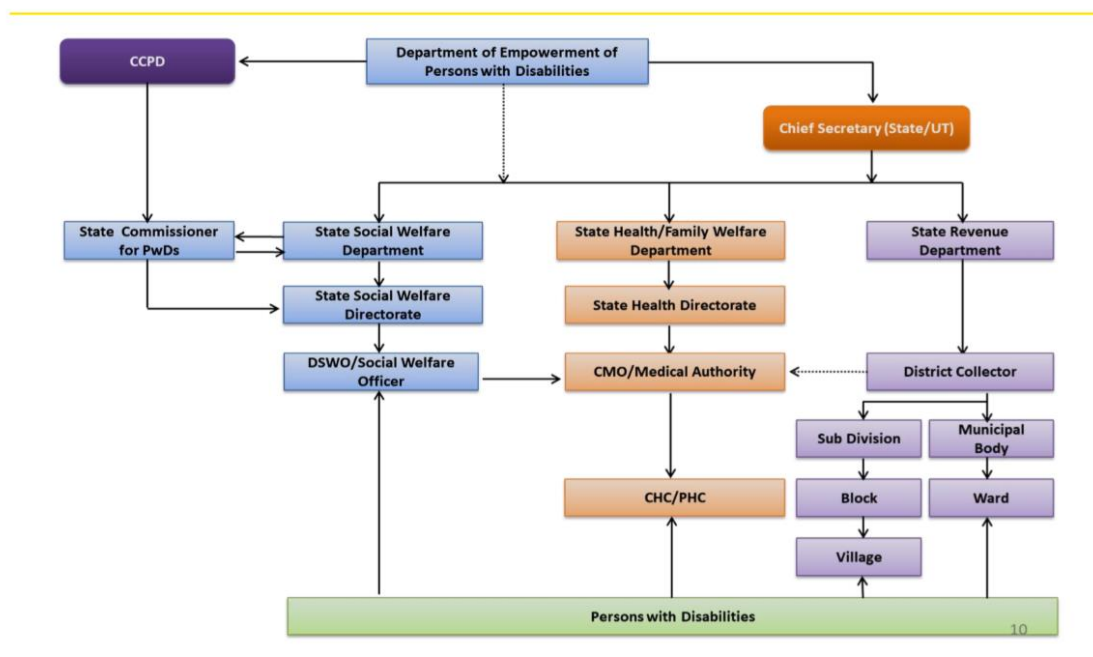
The current mechanism for generating a UDID allows persons with disabilities to register online on the UDID website - http://www.swavlambancard.gov.in/ - if s/he has the relevant documents at hand. These include a valid ID card, a bank account, proof of residence, and Disability Certificate (if available)

The registration can be done through camps organised by the government, CMO office, office of the District Social Welfare Officer, Common Service Centre, personal computer, etc.

Once the person is registered and a registration ID is generated, it is transmitted to the appointed Chief Medical Officer, at designated District Hospitals, who has to make the assessment of the disability, together with a medical board which is constituted for the purpose. A date is scheduled for verification of the disability and appropriate specialists are identified depending on nature of disability. The degree of disability is assessed and verified by the medical board, and uploaded on the individual's profile on the UDID portal. Once the assessment and verification is completed the specified medical authorities issue the UDID Card electronically. This part of the process is under the Ministry of Health.

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Once this is step is completed, the Department of Empowerment of Persons with Disabilities, under Ministry of Social Justice and Empowerment has responsibility to deliver the UDID card by post to the beneficiaries at the address mentioned by them during online registration.

Challenges in widespread coverage of Persons with Disability under UDID

The coverage of persons with disability under UDID remains abysmally small in the two years that it has been in operation. Less than 5% of persons with disabilities have so far received UDID. While less than 60% of the persons with disability have Disability Certificates, converting these into UDID has not been straightforward. The issue of slowness in coverage of UDID has been flagged repeatedly by the Standing Committee On Social Justice And Empowerment (2018-19) (Sixteenth Lok Sabha), Ministry Of Social Justice And Empowerment (Department of Empowerment of PwD)

The key challenges that appear to be affecting widespread application of UDID are as follows:

1. Identification and counting of persons with disabilities

With the enactment of the Rights of Persons with Disabilities Act, 2016, the number of categories of disability went up from 7 to 21. While some of these were a refinement of existing categories, new categories were also added. However, there is no reliable count of actual number of persons with disabilities, after expansion of the categories. By and large it remains incumbent on the PwD and their families to enrol themselves for the Disability Certificate and/ or UDID. Lack of awareness of UDID, digital illiteracy and lack of access to technology are all factors which limit registration for UDID by PwD. Further, given the social stigma around disabilities, many people remain un-identified.

Innovative means are adopted in a few places. Examples of gathering local level data include:

- In Tiruchi district of Tamil Nadu, the process of UDID registration involves anganwadi workers. A pilot project is in progress for spot registration with tablets provided to anganwadi workers.
- In Odisha, under the Bhima Bhoi Bhunnakhsyama Samrthya Abhiyan, camps are organised at the block level to spread awareness and also to do spot registration of persons with disabilities.

Recommendation:

The notion of disability is complex and understood differently by individuals, cultures, specialists and academics all over the world. The understanding of different types of disabilities needs to be standardised and communicated to Persons with Disability, their families, data collectors and local government authorities.

The UN's Washington Group (https://www.cdc.gov/nchs/washington_group/) questions on disability status provide a solution to this with a standard global definition and method to measure disability. Rather than use yes/no answers, The Washington Group's questions ask respondents to position themselves on a four-point scale according to their level of difficulty and focus on six functional areas. Data collectors can ask the Washington Group's questions without any medical knowledge, following short training on understanding stigma and discrimination.

A cadre of local people, linked with the Gram Panchayat, needs to be trained to identify persons with disabilities and also for spreading awareness on provisions of Rights of Persons with Disabilities 2016, and various programmes and schemes of the Government for PwDs, with appropriate IEC material.

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Early identification of disabilities is important to plan relevant support. There should also be relevant capacities the ICDS/ Primary School as well as the local PHC/ CHC. The functionaries should be aware of the various support available to PwDs.

Requisite capacity building needs to be done at the Gram Panchayat in enumeration and maintaining database of persons with disabilities. The database of persons with disability must be disaggregated at the Gram Panchayat, Block and District level by type of disability, so that appropriate actions at local and individual level can be planned and monitored.

2. *Simplifying procedures for application of UDID: Digital barriers*

The procedure for application of UDID simplifies to a great extent the steps that a disabled person would have had to go through to receive a certification of the disability and avail benefits. After the initial registration, the persons with disabilities are able to apply online for a UDID card. They will also be able to track the status of their application. Both people with a pre-existing Disability Certificate and those not having a Disability Certificate can apply for the UDID.

As it is a web-based application it is purported to minimise the transaction cost that a person with disability must go through, and the time and effort spent. The process presumes a level of literacy as well as digital access. Given that a bulk of disabled persons live in rural areas, their access as well as awareness of digital applications is limited. Different states follow different norms in having support centres which can help persons with disability to fill in the form and upload all the relevant information. Further, there are technical problems in the UDID portal. For eg. if an error is made in the entry, there is no way to undo or rectify it. This often leads to rejection of the application, and a fresh application has to be then made. This process often takes several months to complete.

Further, the accepted ID proof for registration under UDID are Aadhaar, PAN Card, Driver's License. Given the prevailing uncertainties around Aadhaar enforcement of the same is an issue. At the same time, most persons with disability are not likely to have either a PAN Card or a Drivers License. This is especially an impediment for persons with disabilities in rural areas, who may have none of these ID proof. Similarly, it is expected that persons with disability applying for UDID will have their own bank accounts. This may not be the case for many, and the barriers in process for opening an account need to be factored as well. There are also inconsistencies with regard to RBI guidelines for opening bank accounts for persons with mental disabilities/ challenges, and this limits their ability to apply for UDID.

Unlike the Revenue Department which is linked to Common Service Centres, Department of Social Justice has no such link and this makes it a challenge for PwDs to access the digital portal.

Recommendation:

The local cadre identified should be able to provide support to Persons with Disabilities to make the UDID application. Their services may be linked with Common Service Centres at Gram Panchayats.

Relevant guidelines need to be formulated for Gram Panchayats to facilitate PwDs with relevant documents/ proofs which are necessary for the UDID application.

3. *Coordination with Health Department: Constitution and availability of Medical Board for verification/ certification of disability*

One of the crucial steps is verification of the nature and extent of disability by a medical board. The Chief Medical Authority at the district level is the node for such certification. The constitution of the

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Medical Board and availability of the concerned persons (including specialists depending on the nature of disability) on the designated date is a crucial step in completing the process. Often district level medical institutions lack specialists who can undertake assessments, this further delays the process, or forces the person with disability to go to specialised institutions which are further away.

While the responsibility of issuing UDID vests with the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice and Empowerment, they are dependent on the Ministry of Health for a crucial step in application of the UDID.

While the UDID purports to reduce the time and effort caused by multiple trips and related expenses, it still places the onus entirely on the person with disability and their family. While simplified in comparison to the pre-existing process of obtaining a Disability Certificate, it still remains out of the reach of a majority of persons with disability.

Recommendation: The process of verification of disabilities by the Medical Board of the Ministry of Health needs to be simplified, to minimise hardships of PwDs and their families. Localised options need to be developed. Targeted transport support and subsistence allowance will be of great value to PwD, especially with limited literacy and economic means, for visiting the District Hospital for UDID verification. There needs to be close coordination between the Department for Social Security (Empowerment of PwD) and Department of Health to ensure that verification processes are conducted in a scheduled and timely manner with minimal delays.

Case Study 1: Reaching benefits to Persons with Disability in Odisha

The Social Security and Empowerment of Persons with Disability (SSEPD) Department was created as a separate entity during 2015-16, being bifurcated from Women and Child Development Department to deal with government schemes for the Senior Citizens, PWD and Transgenders. SSEPD Department has been working for the overall development of Persons with Disability, provide social security pension, provide pension to destitute and PWD through a host of specially designed schemes and programmes.

SSEPD has an elaborate field formation with the District Social Security Officer (DSSO) to assist the Collector in each District and a Sub-divisional Social Security Officer (SSSO) in every sub-division. Besides this, there are Block Social Security Officer (BSSO) at the Block level who assist the Block Administration in implementing the social security programmes. There are 421 cadre posts, 521 clerical staff and 30 peons, spread across field offices in 314 blocks and 112 ULBs. The number of PwD staffing is not known.

The Department has a statutory body known as State Commissioner for Persons with Disability (SCPD), State Institute for Disability Rehabilitation (SIDR) at Bhubaneswar and District Disability Rehabilitation Centres (DDRC) in eight out of the 30 districts to undertake disability rehabilitation activities. The SSEPD implements the Odisha Rights of Persons with Disabilities Rules, 2018 which came into force on June 26, 2018. With effect from 1st April 2018, the SSEPD Department, Government of Odisha, initiated the Bhima Bhoi Bhinnakshyama Samarthya Abhiyan (BBSA) to be operated in a mission mode with manifold objectives. SSEPD seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. The BBSA scheme focuses on the following broad objectives:

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- To create an enabling environment to ensure equal opportunities, equity, social justice & empowerment of persons with disabilities with focus on grass root PwD population.
- To encourage voluntary action and participation of all stake holders for ensuring effective implementation of the Rights of Persons with Disabilities Act, 2016.
- To expand outreach activities for rehabilitation of PwDs and create facilities for providing high-tech rehabilitation services.
- To promote individual and group initiatives by PwDs for employment, self-employment and other socio-educational services.
- To strengthen the existing implementation machinery and create facilities for coverage of all uncovered areas of the state for ensuring complete coverage of PwDs.

The BBSA is geared to make available the whole range of services necessary for rehabilitation of PwDs with a view to include persons with disabilities in the mainstream of society and actualizing their potential. Its key focus is on:

- Provision of certificates under UDID, smart cards and assistive devices to all Persons with Disabilities through organization of Samarthya Sibirs.
- Supply and fitting of aids & appliances to all Persons with Disabilities in the state and assistance to Persons with Disabilities for minor surgeries, complicated surgeries & smart appliances.
- Strengthening aids & appliances fabrication workshops for enhancing production capacity & repair of aids & appliances.
- Provision for equipped mobile van service for providing services to PwDs at door step.
- Socio-economic rehabilitation including promotion of group initiatives, supply of self-employment kits to PwDs & Community based Rehabilitation programmes.
- Skill upgradation and entrepreneurship development training, organization of job fairs, pre-recruitment coaching, strengthening SHGs under Mission Khyamata.
- Scholarship to children of persons with disabilities pursuing Higher Education.
- Sensitization of Government employees & community through awareness generation and IEC activities.

The organization of "Samarthya Sibirs" is intended as a single window approach for providing multi-sectoral services to PwDs, on a campaign mode within a given time frame throughout the State. Samarthya Sibirs are to be held in each block area by dividing the block into suitable numbers of clusters of gram panchayats as many times during the year as required.

The camps are planned to be organized in two phases in each location. In the first camp the process of identification, registration for Disability Certificate/ UDID is made and in the second camp the assistive devices are then provided as per the assessment made for each beneficiary in the first camp. The main elements are - Pre-assessment of disability; Issue of disability certificate/ ID Cards/ Pass books; Income, residence, caste certificates/transport concession; Support for Corrective Surgeries; Empanelment of PwDs for Special Education/ Scholarships; Selection of PwDs for skill training/ bank linkage; Empanelment for Disability Pension & other Social Security Schemes 8. Supply & fitting of aids and appliances (mobility & educational); Assistance for Self Employment Kits; Formation of SHGs of PwDs. All PwD irrespective of age and category of disability are entitled to avail all or any of services as envisaged provided he/she has not availed the same previously.

Implementation of the UDID project in Odisha

The intent of UDID, launched by Government of India in 2016, is to streamline the support extended through State and Central level programmes and schemes, and necessary support towards eligible

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PwD. As per Census 2011, there are over 12 lakhs Persons with Disability in Odisha. As of 2012, about 48% of the PWD had received Disability Certificates. Odisha was among the states where the UDID process was launched in the First Phase. Coverage of all eligible PwDs under UDID was to be completed by December 2018. However, the rollout of UDID has been mired in several challenges. 196,000 UDID cards have been issued against over 4 lakh registrations by PwD across the State. Over 20,000 applications were rejected on technical grounds (*Source: personal communication with SSEPD office on 15th March 2019. Note: The SSEPD website which shares data for 2017-18, reports 62,609 UDID Cards have been issued across districts*)

Key persons met during the study:

- Mr.K.V.S.Rao, Director, Department of Empowerment of Persons with Disability, Ministry of Social Justice and Empowerment

- Mr. Susanta Mahapatra, Director, Social Security and Empowerment of Persons with Disability, Government of Odisha

- Mr.Sannyasi Behera, District Social Service Officer, Social Security and Empowerment of Persons with Disability, Government of Odisha

- Ms.Sruti Mohapatra, Director - Swabhiman – Odisha State Information and Resource Centre for Persons with Disability

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