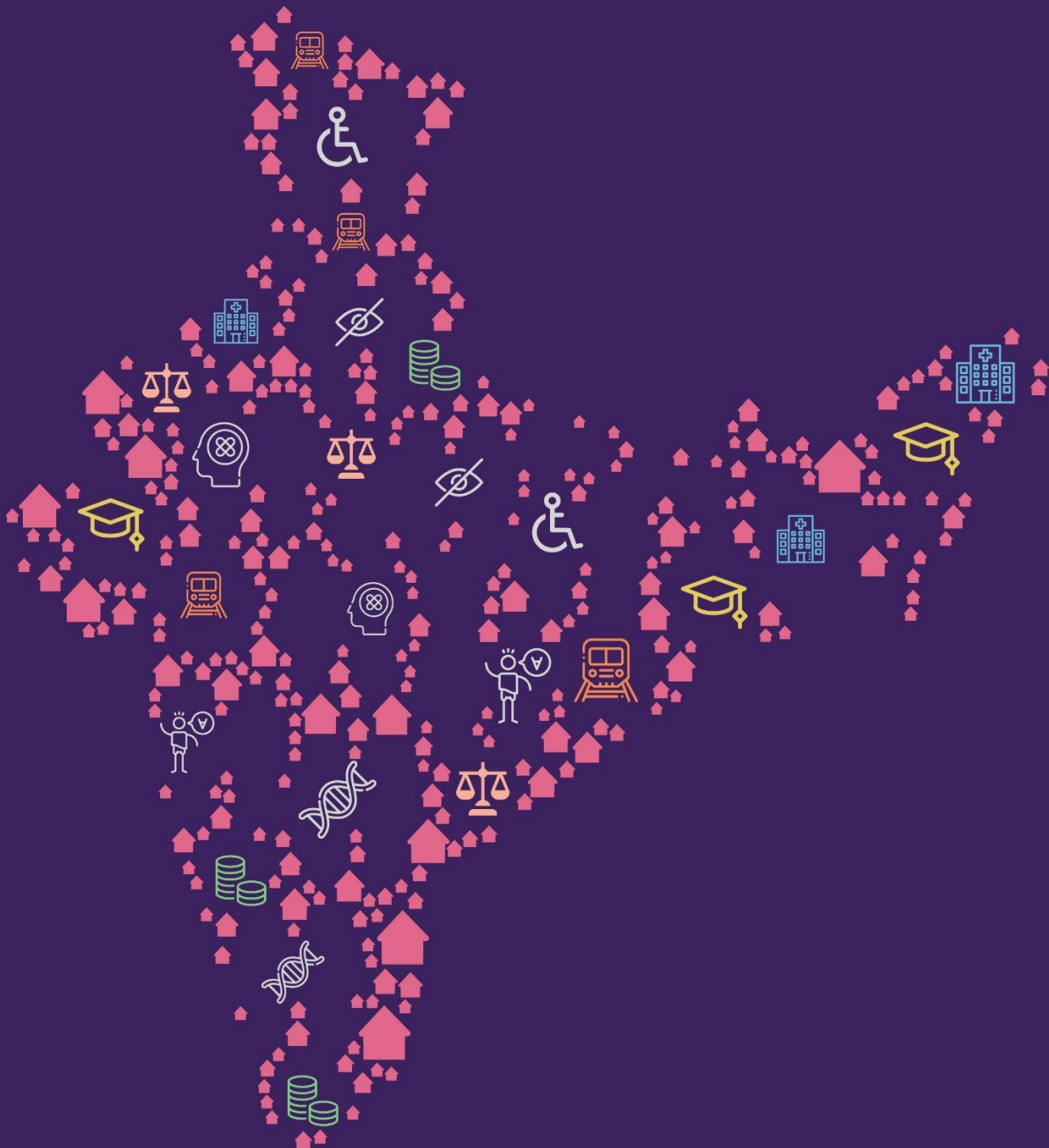


Understanding the Data Gaps

in National-Level Databases in the Disability Sector in India



About Pacta

Pacta is a Bengaluru (India) based boutique law and policy think tank dedicated to supporting civil society organizations, universities, and non-profit initiatives. It has an unflinching commitment to provide legal and policy consulting support for public service delivery. Acknowledging the crucial role of research and scholarship for social development, Pacta engages in law and policy research through self-driven and collaborative projects. Focus areas are – Philanthropy, Disability, Education, Gender, and Information Technology.

Acknowledgments

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Preface

Governance and policy making cannot be successful without data. For marginalized groups that often rely on the state for basic survival, lack of accurate, adequate, and robust data on the beneficiaries leads to uneven availability and distribution of the support. Data on persons with disabilities in India is poor across different sectors despite national and international commitments to strengthen data around disability. India suffers from outdated, inaccurate, inadequate disability data due to lack of disaggregation, inconsistent definitions, non-robust data collection methodologies, and lack of inclusive indicators in data capturing exercises.

The report provides the reader a breakdown of disability data at the central level in India. We establish the history of disability data in India and the legal policy pushes towards collecting such data. We highlight some of the major central population-level data sources and analyze the disaggregation by disability in these data sets. Furthermore, we compare and contrast prevalence rates of disability based on the identified major population-level data in India. Lastly, we highlight the disability data defined under the Sustainable Development Goals (SDGs), and bring forth issues in data capturing under some select SDGs. Finally, we conclude with some recommendations to strengthen data around disability based on our analysis for different stakeholders to fulfill their responsibility of “no one left behind.”

This is the first of our working paper series on data gaps in the disability sector. Future papers will highlight sectoral gaps and provide sector-focused, actionable research that will help close the gap in the disability space.

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1. Introduction

Data is crucial for effective administration and governance to include and reach all sections of society. Marginalized groups, typically the groups that require government aid, get left out in the counting due to inaccessibility, improper measures, lack of enumerator training, and stigma. Persons with disabilities, who form the highest percentage of marginalized groups globally and on the increase in terms of prevalence rates¹, often get left behind in such exercises. The lack of adequate, accurate data, particularly in lower and middle income countries such as India, lead to persons with disabilities being more prone to adverse socioeconomic outcomes, poor health, lower educational attainment, higher unemployment, increased poverty, increased physiological stress, and decreased access to services compared to those without². Thus, perpetuating a cycle of multi-dimensional poverty and exclusion.

To enable a positive transition and promote greater inclusion for persons with disabilities in India, adequate, robust, updated, and convergent data is required to accurately identify issues the community faces across different facets. The central and state governments are making adequate efforts to include persons with disabilities in the mainstream with forward-thinking policies and schemes. However, inadequate data often leaves persons with disabilities yearning for their rights. Therefore, timely, high-quality and accessible data on persons with disabilities, is important for designing and implementing meaningful and effective policies and schemes.

1.1. Positioning the Study

We position the study from the lens of understanding the data ecosystem of persons with disabilities and subsequently, establish the existing practices around data enumeration in India.

The study is important for the following reasons:

- There exists data on persons with disabilities, however, little is known on the extent of data being collected and the sources.
- Lack of knowledge on the gaps in the data sources, their availability and accessibility.
- Lack of understanding on the level of convergence of data (i.e., is the data consistent across different sources?).
- Assessing viable means to strengthen data through understanding the various sources of data collection.

¹ <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

² <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-10826-5#ref-CR12>

The Story So Far...

2. Disability in India through Numbers

Disability prevalence in India, according to the Census 2011, is 26.8 million. This translates into 2.2 percent of India's population. This figure, however, is often contested on grounds of undercounting.³ In one of its reports on disability in India, the World Bank (2009) estimated that 5 and 8 percent of the Indian population were people with disabilities.⁴ Further, other indigenous data sources point to different counts of persons with disabilities (as discussed in the report), leaving a large gap in tracking the population of persons with disabilities in India.

The variability in prevalence numbers apart, currently available evidence points to the fact that persons with disabilities in India continue to face multiple deprivations due to lack of effective implementation of policies and benefits.⁵ Enrollment in education is low and falls with a rise in the level of schooling⁶, and employment numbers are low with only 36 percent identified as working⁷. Further, interventions to support persons with disabilities have seen limited success. 76.4 percent of persons with disabilities did not receive any aid/help from the government.⁸ Only 4 percent of persons with disabilities received disability pensions in the year 2021-22.⁹

While these numbers are indicative of the status of persons with disabilities in India, they do not allow for a comprehensive and updated picture. Datasets (when present) are in silos and therefore, create inconsistent and non-interoperable databases on persons with disabilities in India. This raises questions on **what central-level datasets exist on persons with disabilities** and **what does India's data ecosystem lack when it comes to the representation of persons with disabilities?**

In the following sections, we look at the evolution of disability policy, and its translation to data collection methods and disability data sources in India. Subsequently, we analyze the findings to report on discrepancies and gaps in disability data from the perspective of disability prevalence

³ <https://timesofindia.indiatimes.com/india/rural-disabled-undercounted-in-2011-census/articleshow/28025244.cms>

⁴

<https://documents1.worldbank.org/curated/en/577801468259486686/pdf/502090WPOPeopl1Box0342042Bo1PUBLIC1.pdf>

⁵ <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-1125>

⁶ <https://unesdoc.unesco.org/ark:/48223/pf0000368780>

⁷ https://www.nhfdc.nic.in/upload/nhfdc/Persons_Disabilities_31mar21.pdf

⁸ https://mospi.gov.in/sites/default/files/publication_reports/Report_583_Final_0.pdf

⁹ <https://idronline.org/article/advocacy-government/no-budget-for-persons-with-disabilities-in-india/>

rates. We further analyze indicators under the Sustainable Development Goals (SDGs) from the perspective of capturing data on persons with disabilities. In the final section, we provide recommendations to provide and facilitate the development of comprehensive and updated data on persons with disabilities.

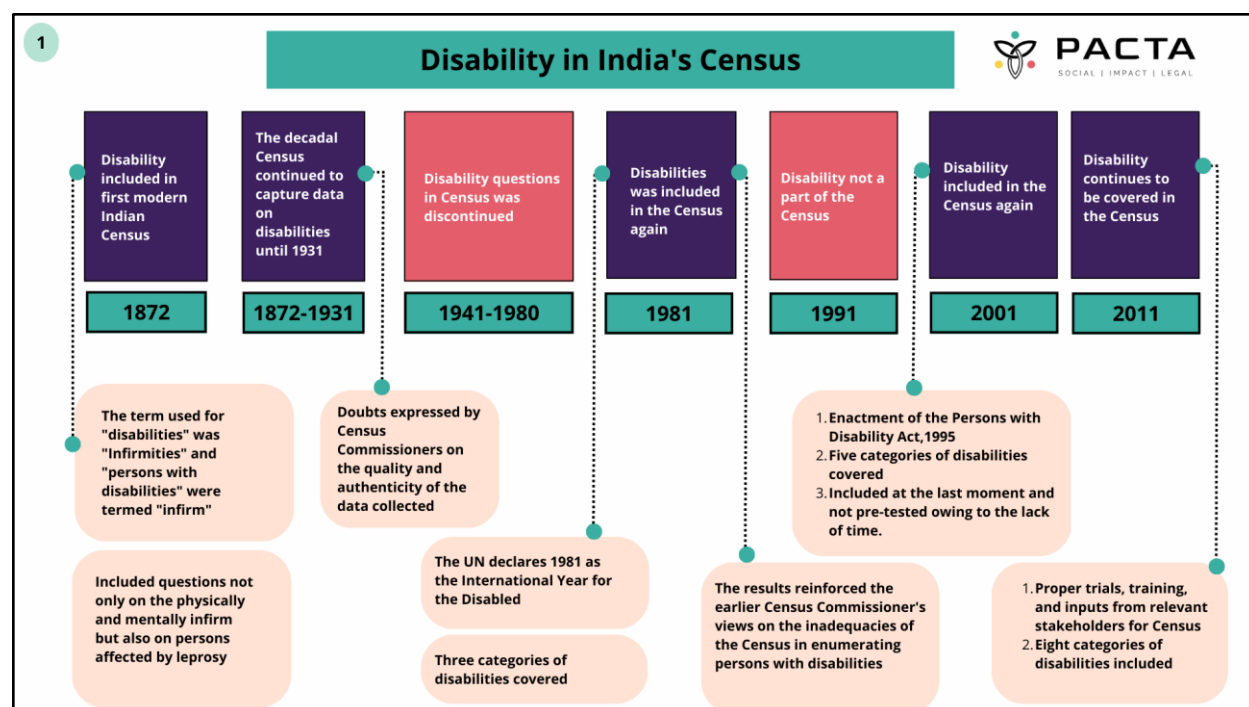
3. Disability Data in India

The collection of disability data in India has a long history. Over the decades, the concept of disabilities, the international conventions on disabilities, as well as the means of capturing disability data have evolved. These changing narratives have shaped disability data collection in India. Thus, an understanding of India's current disability data landscape requires both a historical and a contemporary perspective. In the following section, we explore different sources of disability data in India, and discuss some of the broader challenges emerging with respect to the availability of disability data.

3.1. Disability and the Census

In India, the Census has been the oldest source of data on persons with disabilities. However, there have been several discontinuities between 1872, when disability was first included in the census exercise, and 2011, the most recent census. **Figure 1** captures the history of disability data as a part of India's decennial census. The data from Census 2011, collected before Rights of Persons with Disabilities (RPWD) came into force, continues to be the only population-level data on disability today, given the delay in the latest Census, which was to take place in 2021. The delay leaves a lacuna in reliable data on persons with disabilities due to the time elapsed and the limited types of disabilities covered in Census 2011.

Figure 1. Disability in India's Census over the Decades

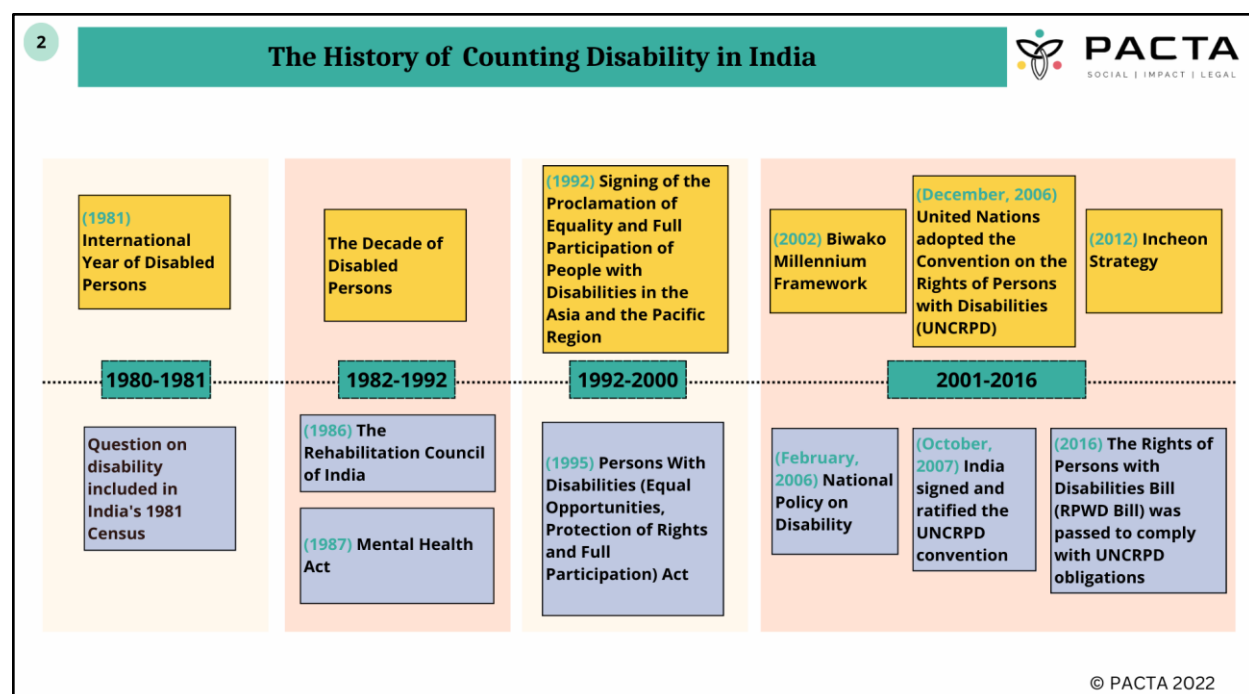


3.2. The Evolution of Disability Policies in India

India's approach to disability policy in general and disability data collection, in particular, are largely informed by the efforts of multilateral organizations over the years.¹⁰ The first UN instrument that specifically focused on persons with disabilities was the Declaration on the Rights of Disabled Persons (1975). However, the first time international initiatives translated into effective change in India was in 1981 when the year was declared "the International Year of the Disabled", and the period between 1982-1992 was declared "the Decade of Disabled Persons". The decadal Census, which was due the same year included questions on disability for the first time after the 1931 Census. This was followed by several other developments, including signing of other international instruments, enactment of laws and establishing institutions addressed to persons with disabilities. The most recent development (i.e., the enactment of the Rights of Persons with Disabilities (RPWD) Act, 2016) is also a consequence of India's ratification of the United Nations Convention on Persons with Disabilities. **Figure 2** captures the evolution of international efforts and the parallel shifts in India's disability legal and policy paradigm.

¹⁰ <https://www.jstor.org/stable/25664414>

Figure 2. International Conventions on Disability and India's Disability Policy Initiatives



3.3. Provisions on Disability Data in International and National Frameworks

While achievement of the desired outputs and outcomes under the disability policies and strategies are contingent upon several factors such as political will, resources and implementation capacity, the measurement of progress by harnessing periodic high-quality disability-related data is one of the most critical factors. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) under Article 31 calls for data collection and disaggregation to ensure the rights of persons with disabilities.¹¹ In a paper by Mont et al. (2022) on the need for harmonizing disability data¹², the authors provide four distinct purposes that disability data serves as described in **Box 1**.

¹¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>

¹² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10072006/pdf/nihms-1878683.pdf>

Box 1. Functions of disability data

- a) To describe the functional status of the population by sex, age, type and degree of disability, date of onset and cause of disability.
- b) To disaggregate outcome indicators and identify gaps in participation between persons with disabilities and other people.
- c) To identify factors that result in participation gaps between people without and persons with disabilities.
- d) To evaluate the outcomes of interventions designed to address the participation gaps between persons with and without disabilities.

The importance of data in disability has been established in the literature. Furthermore, the UNCRPD, and the other international conventions on disabilities also include clauses on data collection and dissemination. **Figure 3** captures some such clauses. In India, legislations and policies on disabilities highlight the need for data and statistics as presented in **Figure 4** - some as a fall out of the international conventions.

Figure 3. Disability Data-Related Clauses in International Frameworks and Conventions

3

India's International Commitments on Disability and Data

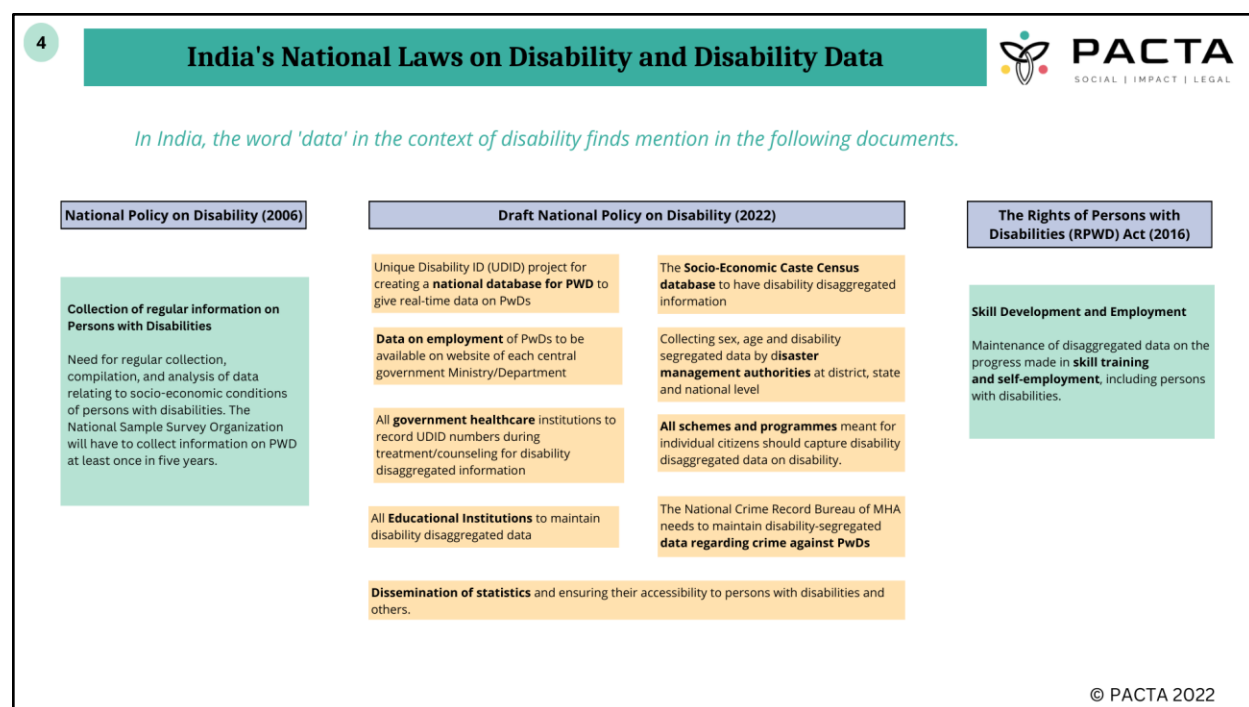


India has been a part of several international conventions and commitments on disability that emphasize the collection of quality data.

<div style="background-color: #FFD700; padding: 5px; border: 1px solid black; margin-bottom: 5px;">Bivako Millennium Framework (2002)</div> <div style="background-color: #FFF9C4; padding: 5px; border: 1px solid black; margin-bottom: 5px;">Governments to develop, by 2005, their system for disability-related data collection and analysis and to produce relevant statistics disaggregated by disability to support policy-making and programme planning.</div> <div style="background-color: #FFF9C4; padding: 5px; border: 1px solid black;">Governments to adopt, by 2005, definitions of disability based on the Guidelines and Principles for the Development of Disability Statistics, which will allow intercountry comparison in the region.</div>	<div style="background-color: #FFD700; padding: 5px; border: 1px solid black; margin-bottom: 5px;">United Nations adopted the Convention on the Rights of Persons with Disabilities (2006)</div> <div style="background-color: #E0F2F1; padding: 5px; border: 1px solid black; margin-bottom: 5px;">States Parties to collect appropriate information, including statistical and research data</div> <div style="background-color: #E0F2F1; padding: 5px; border: 1px solid black; margin-bottom: 5px;">The information is to be disaggregated and used to assess the implementation of the Convention and to identify and address the barriers faced by PWD in exercising their rights.</div> <div style="background-color: #E0F2F1; padding: 5px; border: 1px solid black;">Dissemination of statistics and ensuring their accessibility to persons with disabilities and others.</div>	<div style="background-color: #FFD700; padding: 5px; border: 1px solid black; margin-bottom: 5px;">Incheon Strategy (2012)</div> <div style="background-color: #FFF9C4; padding: 5px; border: 1px solid black; margin-bottom: 5px;">(Goal 8) Improve the reliability and comparability of disability data</div> <div style="background-color: #FFF9C4; padding: 5px; border: 1px solid black; margin-bottom: 5px;">(Target 8.A.) Produce and disseminate reliable and internationally comparable disability statistics in formats that are accessible by persons with disabilities</div> <div style="background-color: #FFF9C4; padding: 5px; border: 1px solid black;">(Target 8.B.) Establish reliable disability statistics by the midpoint of the Decade, 2017, as the source for tracking progress towards the achievement of the goals and targets in the Incheon Strategy</div>	<div style="background-color: #FFD700; padding: 5px; border: 1px solid black; margin-bottom: 5px;">Sustainable Development Goals (2015)</div> <div style="background-color: #E0F2F1; padding: 5px; border: 1px solid black;">(17.18) By 2020, enhance capacity-building support to developing countries, including least developed countries and small island developing States, to increase significantly the availability of high quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts</div>
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Figure 4. Data-Related Provisions in India's Disability Policies



3.4. Disability Data in India: An Analysis of Disaggregation in Sample Surveys

Currently, India captures information on its population through several sources including the Census, sample surveys, and administrative data from different sectors. Sample surveys, one of the methods used in capturing population-level information, are crucial to the regular monitoring of socioeconomic and other development-related indicators, as well as to evaluate policy outcomes. Since the sample surveys offer a rich source of information, disaggregation based on disability can help capture valuable statistics on the group to inform programmatic and policy reforms.

Furthermore, we undertook a brief exercise to assess if disability disaggregation was a practice in sample surveys conducted in India. This involved studying and classifying national surveys based on the scale/type of data collection exercise and the extent of disability disaggregation. If a particular survey questionnaire asked whether the respondent or their family members had any disabilities, or if they had access to certain benefits or facilities as someone with disabilities, then the tag “*present*” was used. In surveys where disabilities appeared only as an optional response to a general question, the disability disaggregation status was termed to be “*partial*.” For instance, in the **Employment and Unemployment Survey Questionnaire**, Section 5.1. has a question on status of usual principal activity. The response code for it included the option of “*not*

able to work due to disability.” Finally, the tag “absent” was used for surveys that had no mention of disabilities on their questionnaires.

The tables in **Figure 5(a)** and **Figure 5(b)** present the datasets that were analyzed, their status of disability disaggregation, and the details on whether the respective databases of the surveys are currently available online.

Figure 5(a). *Disability Disaggregation in Sample Surveys*

Survey	What it captures	Data Collection	Disability Disaggregation	Online Data Availability
Ease of Living Survey	Quality of Life	Household Survey	Present	Unavailable
Household Social Consumption: Education	Education	Household Survey	Present	Available
National Family Health Survey	Demographic and Health	Household Survey	Present	Available
Persons with Disabilities in India	Socio-Economic	Household Survey with Focus on Disabilities	Present	Available
Persons aged 60 Plus survey	Demographic	Household Survey	Present	Available
Drinking Water, Sanitation, Hygiene and Housing Condition in India	WASH	Household Survey	Partially	Available
Employment and Unemployment Situation in India	Labour and Employment	Household Survey	Partially	Available
Employment, Unemployment and Migration Survey	Migration	Household Survey	Partially	Available
India Human Development Survey (IHDS)*	Human Development	Household Survey	Partially	Available
Situation Assessment Survey of Agricultural Households	Agriculture	Household Survey	Partially	Unavailable

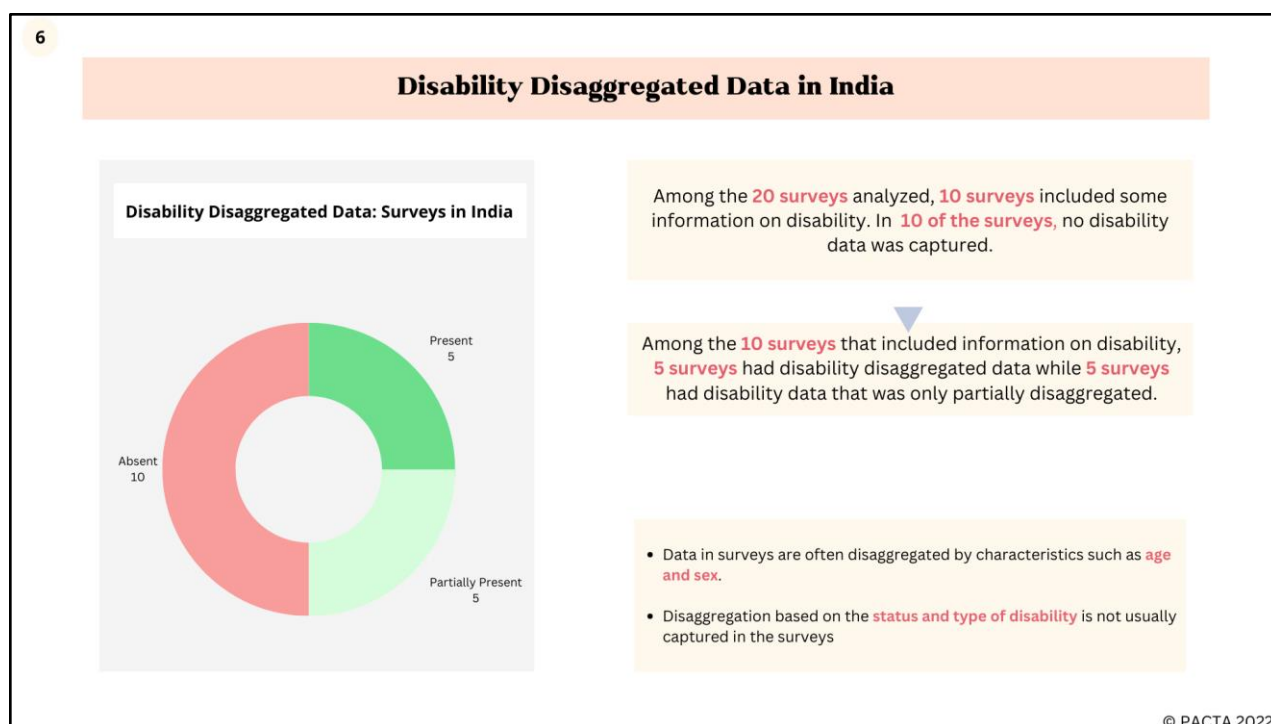
*IHDS is not a government data source. It is conducted by National Council of Applied Economic Research (NCAER) and University of Maryland

Figure 5(b). *Disability Disaggregation in Sample Surveys (contd.)*

Survey	What it captures	Data Collection	Disability Disaggregation	Online Data Availability
Household Expenditure on Services Durable Goods	Durable Goods	Household Survey	Absent	Available
Global Adult Tobacco Survey	Health	Household Survey	Absent	Available
Social Consumption: Health	Health	Household Survey	Absent	Available
Land and Livestock Holdings	Land and Livestock Holdings	Household Survey	Absent	Available
All India Rural Financial Inclusion Survey	Financial Inclusion	Household Survey	Absent	Unavailable
National Survey on Extent and Pattern of Substance Use in India	Health	Household Survey	Absent	Unavailable
Periodic Labour Force Survey	Labour and Employment	Household Survey	Absent	Unavailable
Rapid Survey on Children	Health	Household Survey	Absent	Unavailable
Sample Registration Survey	Demographics	Household Survey	Absent	Unavailable
Comprehensive National Nutrition Survey (CNNS)	Health	Household Survey	Absent	Unavailable

Figure 6 provides a summary of the disability disaggregation among sample surveys. Through the exercise, we found that out of the 20 surveys, only 5 surveys had disability disaggregation in total and another 5 had partial disaggregation. Among all the surveys, only one specifically addressed disability (i.e., the **Survey of Persons with Disabilities in India, 2018**). Out of the 5 surveys that provide for disability disaggregation, only the **Ease of Living Survey** does not include the type of disabilities. In cases where there is disaggregation, the data captured aspects include the age and sex of persons with disabilities among other indicators such as ‘access to insurance scheme’ or ‘inability to work due to disability’. Despite having basic demographic data on persons with disabilities that often allow to measure prevalence rates, crucial indicators such as type or severity of disabilities cannot be wholly tracked, limiting the utility of the data when it comes to studying critical intersections.

Figure 6. Summary of Disability Disaggregation in Sample Surveys



In analyzing the sample surveys further to understand the scale, purpose, and level of granularity of the data being collected, we used the UNICEF framework¹³ to classify the datasets as shown in **Figure 7(a)** below.

¹³ <https://data.unicef.org/resources/producing-disability-inclusive-data-why-it-matters-and-what-it-takes/>

Figure 7(a). Framework of Analysis of Sample Surveys

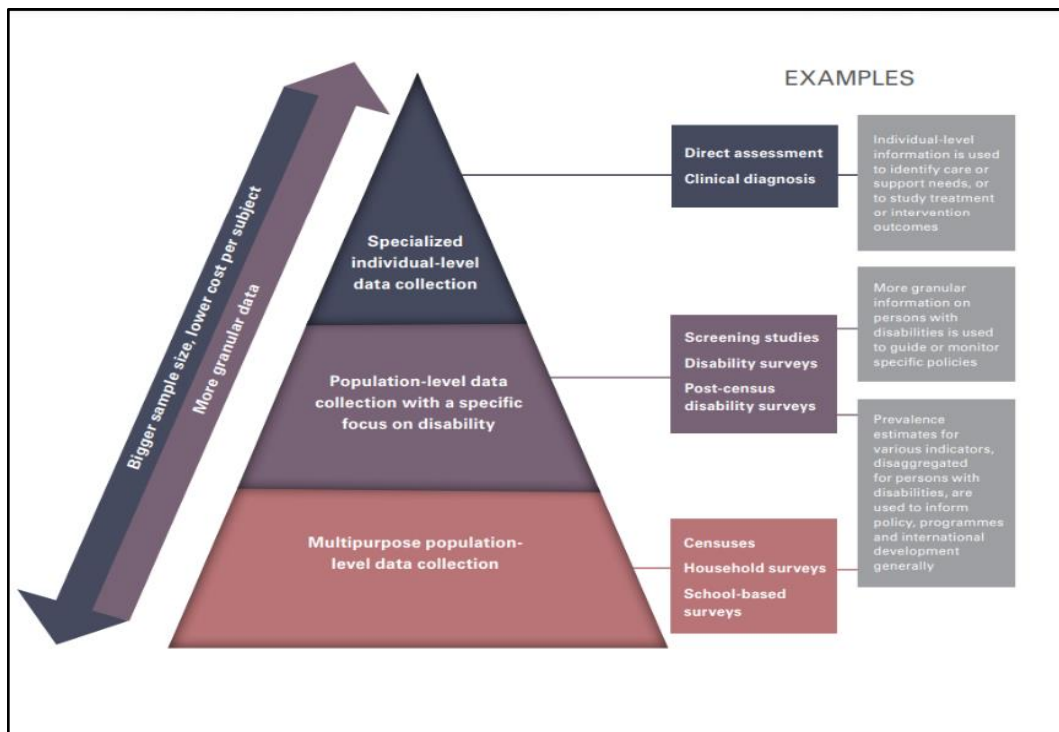
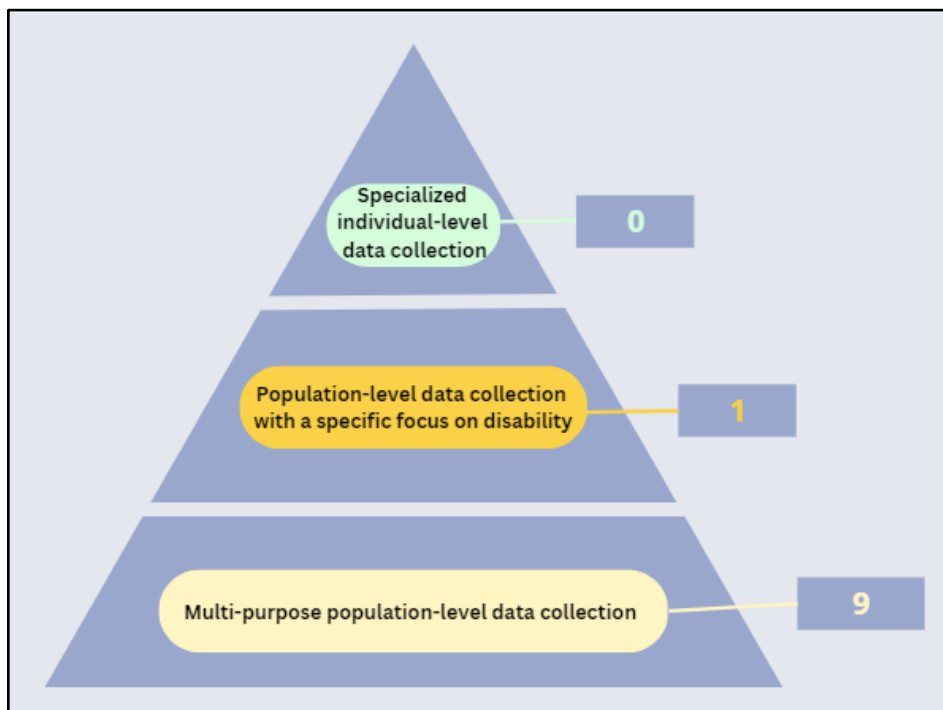


Figure 7(b). Classification of Sample Surveys based on Framework



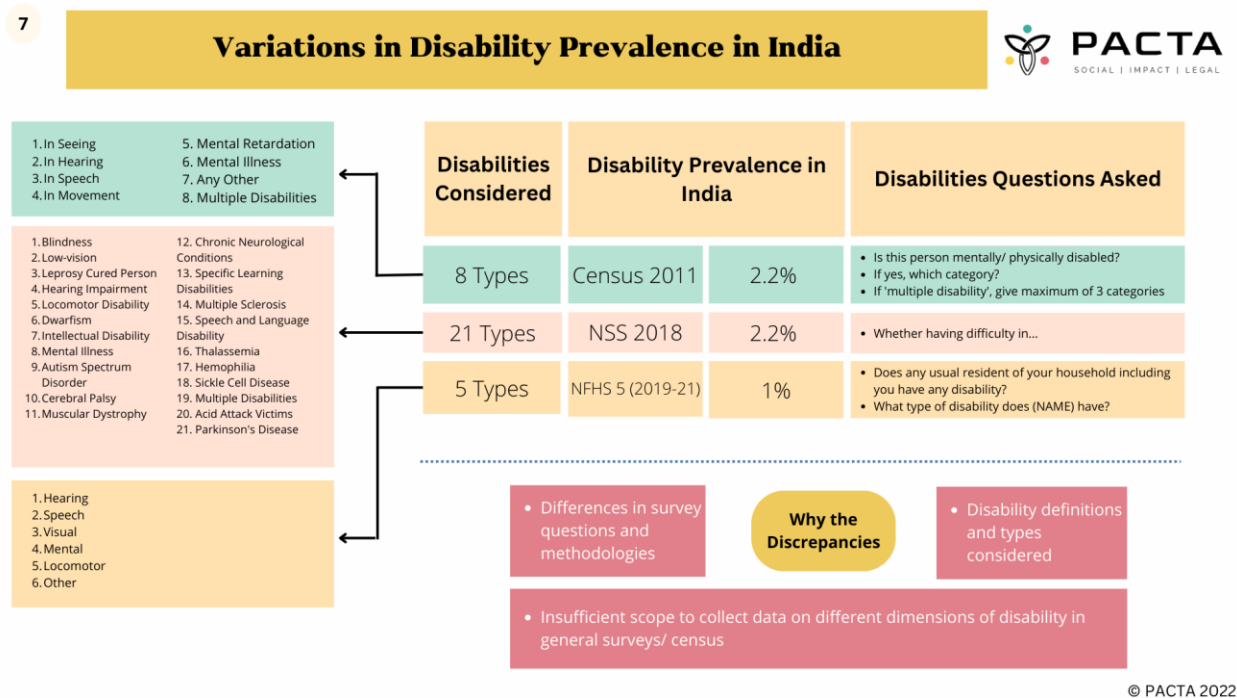
When the framework was applied to our datasets, we found that 9 out of the 10 surveys that disaggregate data by disability lie at the bottom of the pyramid (**Figure 7(b)**). Thus, the surveys have large sample sizes, but are less granular that can be used for programmatic and policy decision-making processes. However, currently, there is no open-source individual-level data available in India. We may have access to more micro-level data through the Unique Disability Identity (UDID) project as the database gets populated and functional. A convergence of all data can help create a broader understanding on the needs of persons with disabilities and help towards better program implementation in the country.

4. Disability Data in India: Challenges and Gaps

The limited disability disaggregated reporting in sample surveys is one of the barriers to the availability of data on persons with disabilities. However, even in cases where there is some degree of disaggregation, there are pertinent challenges. For instance, there are variations in the disability numbers reported by different surveys. **Figure 8** summarizes three major, periodic sources of disability data in India - Census, National Sample Survey (NSS) Survey of Persons with Disabilities, and National Family Household Survey (NFHS). However, it may be noted that the Census for this decade has been delayed and the upcoming NFHS 6 has dropped disability from its questionnaires citing technical reasons, and hence will no longer contribute to disability data in India.¹⁴

¹⁴ <https://scroll.in/article/1051272/india-has-axed-queries-on-disability-from-key-survey-and-theres-no-easy-way-to-fill-the-data-gap>

Figure 8. Variations in Disability Prevalence Numbers and Definitions under Different Data Sources in India



The discrepancies identified in Figure 8 are at a macro level revealing prevalence rates of disabilities in the country based on the inclusion or exclusion of certain types of disabilities. A deeper understanding of gaps and discrepancies in the determinants of a person's life such as health, education, and livelihood statuses is possible through further research on specific thematic areas. For each of these sectors, there can be multiple sources of data being collected at the national level. For instance, data on education of persons with disabilities is collected through the Census, various surveys and through administrative databases such as Unified District Information System for Education Plus (UDISE+). Therefore, to better understand the data gaps in any specific sector, detailed analysis of each relevant dataset is a critical next step.

Some questions that arise based on the initial research are described in Box 2.

Box 2. Questions that Arise from Our Initial Research

- a) Do these different sources of data complement each other to provide a comprehensive picture of education on persons with disabilities - in other words, **are datasets interoperable?**
- b) Are these datasets missing out on certain data points that could be critical - **is the data complete, meaningful, reflective, and robust?**
- c) Are these sources of data getting periodically updated - **is the data updated?**

Addressing questions posed in Box 2 can help shed light on finer details of gaps in disability data in India.

5. Disability Data and Sustainable Development Goals Tracking

The Global Indicator Framework for Sustainable Development Goals contains disability-specific indicators under different goals.¹⁵ India, however, has not included most of these indicators in the National Indicator Framework.¹⁶ Thus, tracking the progress of persons with disabilities under various SDGs is not optimum and reflective in India. SDGs provide a measurable, quantifiable opportunity for development, however, non-inclusion of certain groups such as persons with disabilities project an inaccurate picture of development in the country.

The following **Figures 9-14** map out the disability-specific indicators in the Global Indicators Framework¹⁷ for certain SDGs, and check the existence of corresponding indicators in the National Indicator Framework¹⁸. In addition, we look at whether India is currently collecting data that would allow disability-specific indicators from the global list to be tracked despite not having corresponding National Indicators. We found that in some cases, incorporating disability-specific indicators would not have yielded any results as relevant disability data is not currently being collected. For instance, there is no source of existing data that would allow for tracking of indicators under SDG 16. On the other hand, some disability-specific indicators under SDGs 1, 4, 8, 10 and 11 are currently not being tracked, despite having the required data. To further elaborate,

¹⁵ <https://www.un.org/disabilities/documents/2016/SDG-disability-indicators-march-2016.pdf>

¹⁶ <https://mospi.gov.in/sites/default/files/NIF.pdf>

¹⁷

https://unstats.un.org/sdgs/indicators/Global%20Indicator%20Framework%20after%202023%20refinement_Eng.pdf

¹⁸ <https://mospi.gov.in/sites/default/files/NIF.pdf>

for instance, indicators related to coverage of social protection for persons with disabilities could be tracked using the data of beneficiaries under schemes such as Indira Gandhi National Disability Pension Scheme (IGNDPS) to allow tracking of disability indicators under SDG 1.

Figure 9. Disability Indicators under SDG 1 (No Poverty)

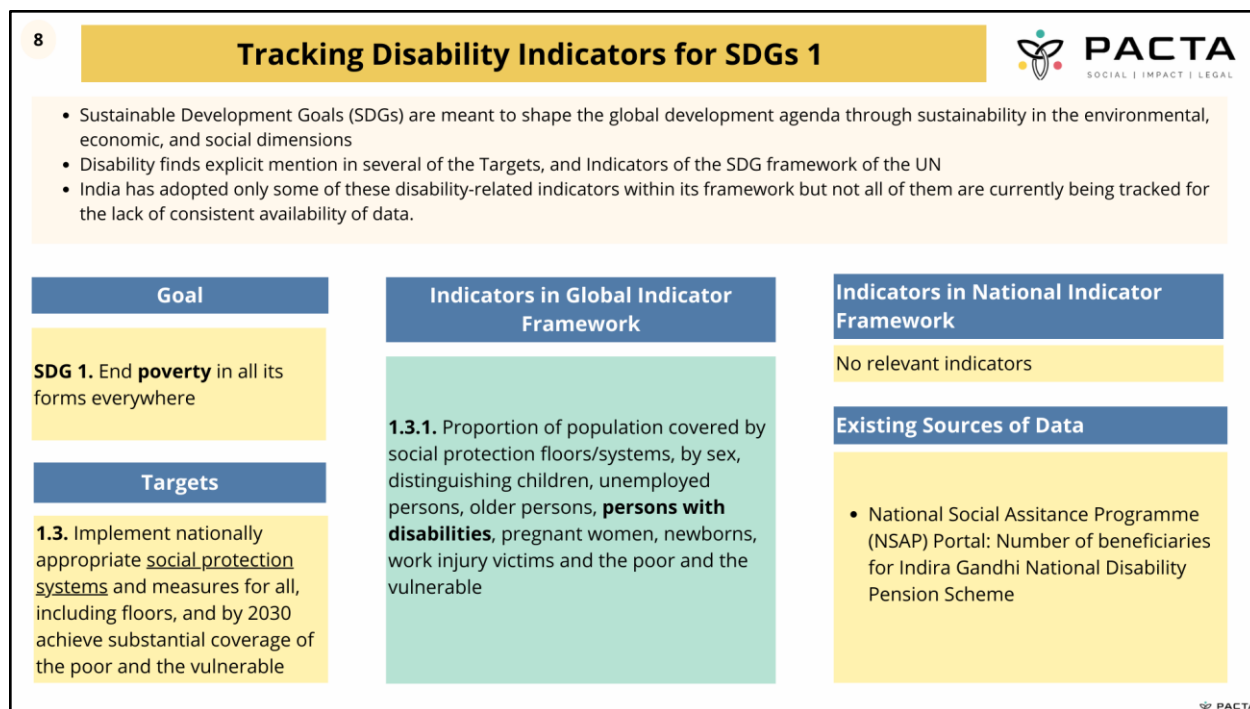


Figure 10. Disability Indicators under SDG 4 (Quality Education)

9 Tracking Disability Indicators for SDG 4 in India		
Goal	Indicators in Global Indicator Framework	Indicators in National Indicator Framework
<p>SDG 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all</p>	<p>4.5.1. Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict affected, as data become available) for all education indicators on this list that can be disaggregated</p>	<p>Proportion of schools with access to: (c) adapted infrastructure and materials for students with disabilities/ disabled friendly ramp and toilets</p>
Targets	<p>4.a.1. Proportion of schools with access to: (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions)</p>	<p>Enrolment ratio of children with disabilities</p>
<p>4.5. By 2030, <u>eliminate gender disparities</u> in education and <u>ensure equal access</u> to all levels of education and <u>vocational training for the vulnerable</u>, including persons with disabilities, indigenous peoples and children in vulnerable situations</p>		Data Available
<p>4.a. <u>Build and upgrade education facilities</u> that are child, disability, and gender sensitive and <u>provide safe, non-violent, inclusive and effective learning environments</u> for all</p>		<ul style="list-style-type: none"> NSS Persons with Disability Survey 2018: Enrolment UDISE+: Access to inclusive infrastructure Census: Highest level of education

Figure 11. Disability Indicators under SDG 8 (Decent Work and Economic Growth)

10 Tracking Disability Indicators for SDGs 8 in India		
Goals	Indicators in Global Indicator Framework	Indicators in National Indicator Framework
<p>SDG 8: Promote sustained, inclusive, and sustainable economic growth, full and productive employment, and decent work for all</p>	<p>8.5.1 <u>Average hourly earnings</u> of female and male employees, by occupation, age and persons with disabilities</p>	<p>No relevant indicators</p>
Targets	<p>8.5.2 <u>Unemployment rate</u>, by sex, age and persons with disabilities</p>	Data Available
<p>8.5 By 2030, achieve full and <u>productive employment and decent work</u> for all women and men, including for young people and persons with disabilities, and <u>equal pay</u> for work of equal value</p>		<ul style="list-style-type: none"> Census: Work status NSS Persons with Disability Survey 2018: Type of work (activity status) NFHS 5: Work status and type of work

Figure 12. Disability Indicators under SDG 10 (Reduced Inequalities)

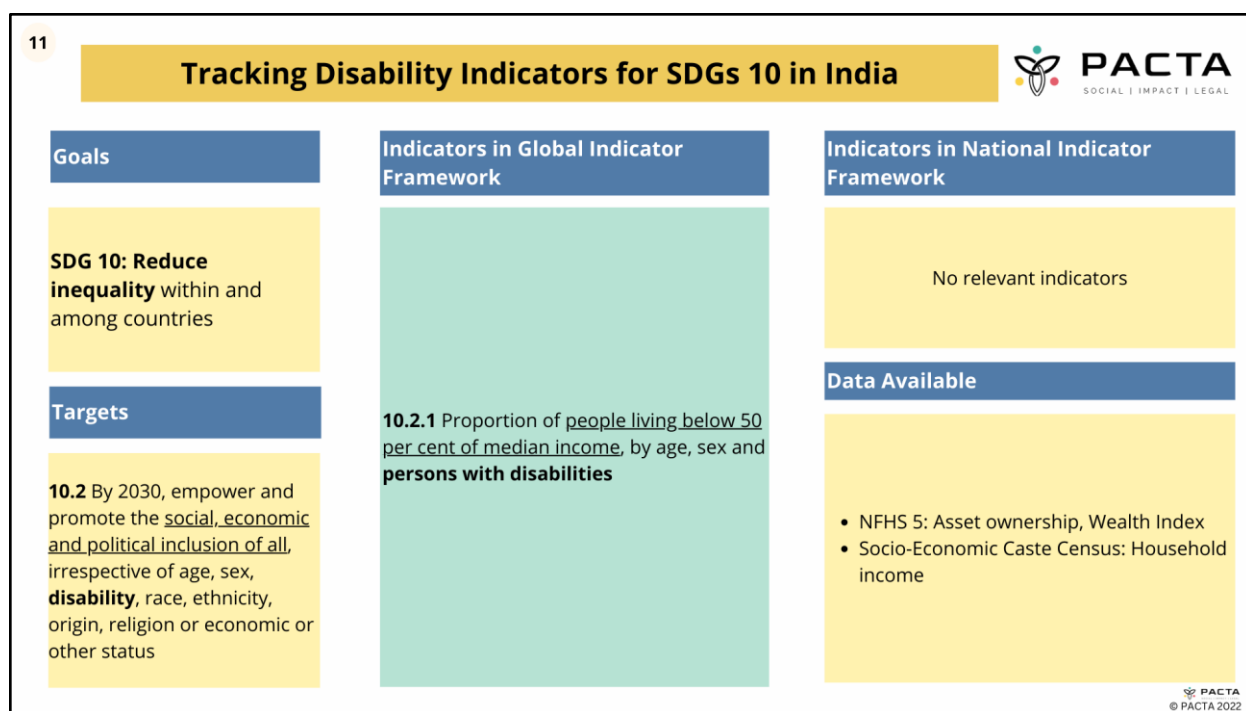


Figure 13. Disability Indicators under SDG 11 (Sustainable Cities and Communities)

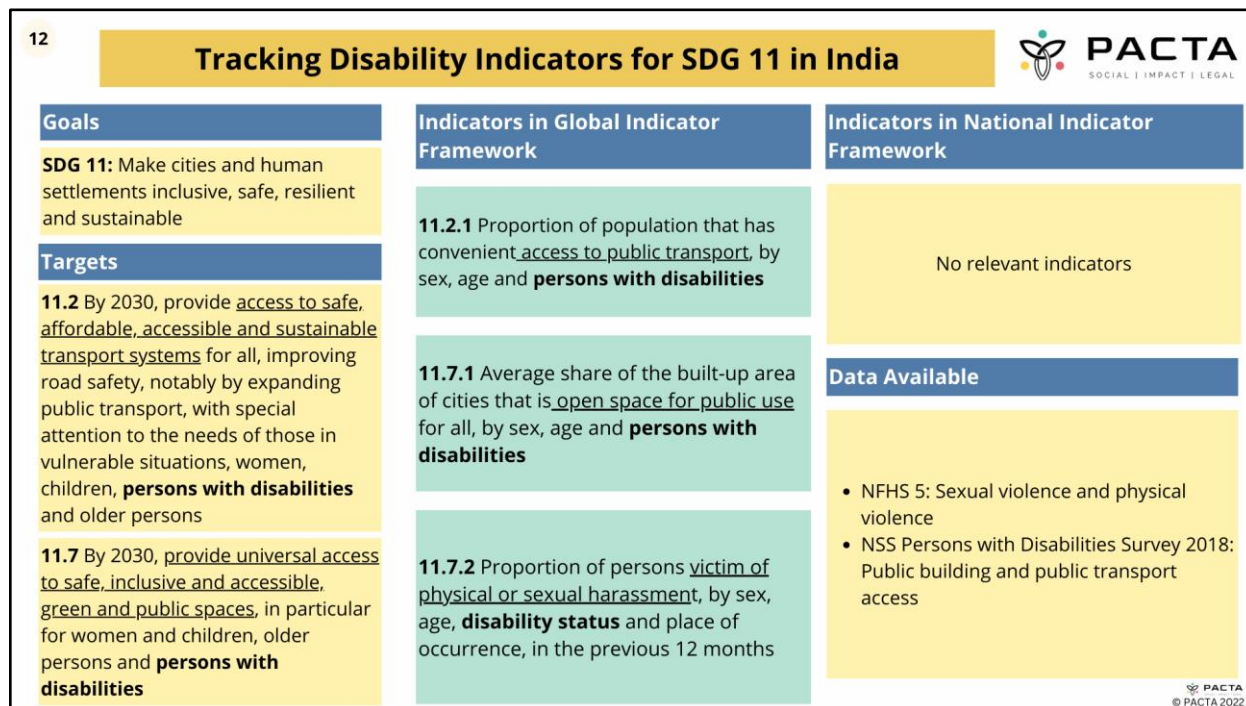


Figure 14. Disability Indicators under SDG 16 (Peace, Justice and Strong Institutions)

13 Tracking Disability Indicators for SDG 16 in India		
<p>Goals</p> <p>SDG 16: Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels</p>	<p>Indicators in Global Indicator Framework</p> <p>16.7.1 Proportions of positions (by sex, age, persons with disabilities and population groups) <u>in public institutions (national and local legislatures, public service, and judiciary)</u> compared to national distributions</p>	<p>Indicators in National Indicator Framework</p> <p>No relevant indicators</p>
<p>Targets</p> <p>16.7 Ensure responsive, inclusive, participatory, and representative decision-making at all levels</p>	<p>16.7.2 Proportion of population who believe <u>decisionmaking is inclusive and responsive</u>, by sex, age, disability and population group</p>	<p>Data Available</p> <ul style="list-style-type: none"> No datasets

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6. Conclusion and Recommendations

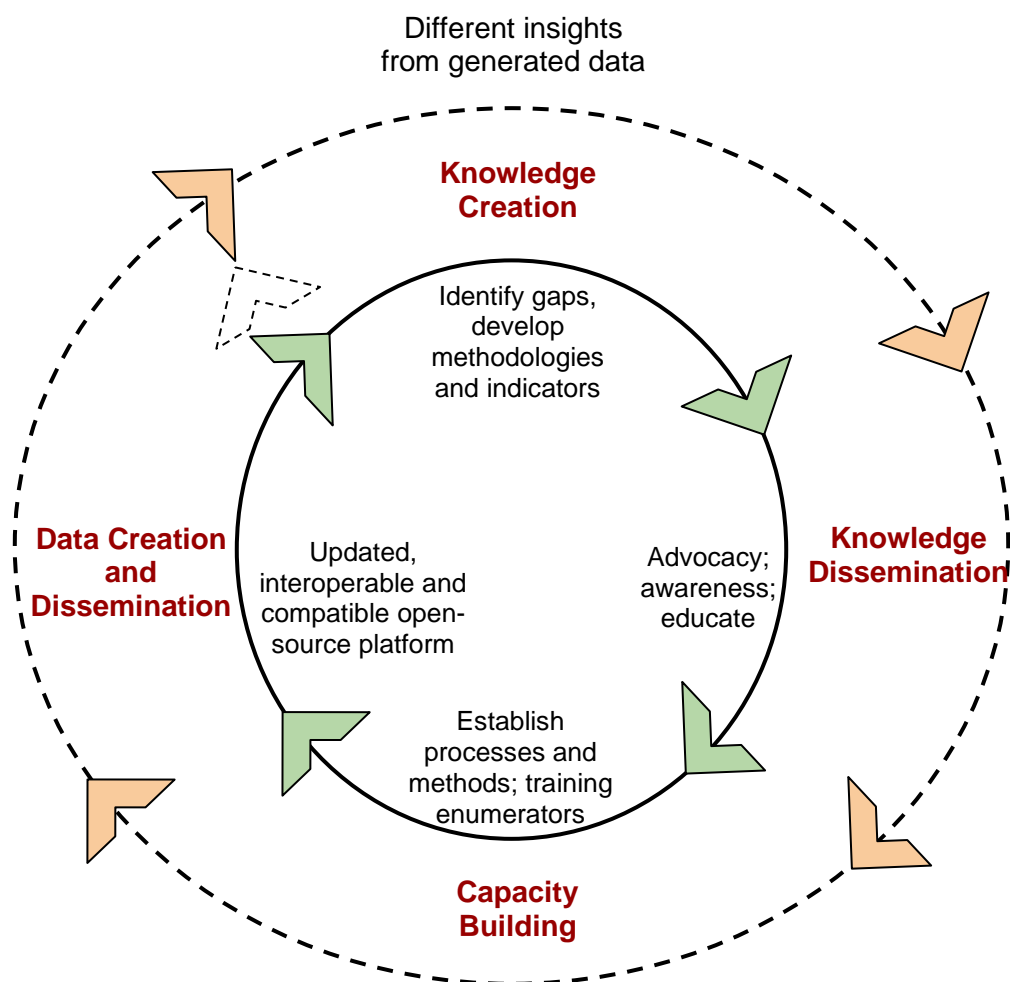
The disability data ecosystem has evolved in India since its beginning in 1872, but there remains much to be improved. The insights garnered from this report highlight the need for:

- **updating** of disability data at better frequency,
- **bringing consistency** in definitions to bring in completeness, relevance, accurate and reflective data,
- **disaggregating** data across sectors based on disability, and
- **enhancing compatibility and interoperability** between different existings datasets that capture disability, **creating** more datasets, and **making** data openly available.
- **developing relevant indicators** across sectors to capture individual-level data that is meaningful and reflective of the challenges faced by persons with disabilities.

To achieve these goals, taking various stakeholders into confidence and solving for systemic challenges becomes key. Therefore, going forward, there is a need to undertake specific thematic analysis to create knowledge on sector specific gaps in disability data and find ways to address these gaps.

To enhance the disability data ecosystem in India, the following recommendations could be a starting point defined within the circle as shown in **Figure 15**.

Figure 15. *Proposed Process of Strengthening Disability Data*



The figure above describes a cyclical process to strengthen data in the disability space. The inner circle represents recommendations based on the current state of disability data in the country to help increase the quantity and quality of data. The outer circle represents the next level of engagement by different stakeholders once there is more data gathered and made available (i.e., when some level of robustness and transparency is achieved in the data). Data dissemination will lead to new knowledge creation or continue to serve to improve data around disability under the existing buckets of gap identification/creating robust methodologies/developing relevant indicators. In the short- and long-term recommendations, the loop will never cease and will continue to serve in creating and maintaining data on persons with disabilities. At every stage,

disability data needs to go through a process of **knowledge creation, knowledge dissemination, capacity building** and ultimately **data creation and dissemination**.

6.1. Knowledge Creation

- **Identify Gaps:** Further research to clearly establish the limitations of the current methodologies through which disability data is collected including the use of disability definitions.
- **Develop Methods:** Develop methodologies that best capture disability and related vulnerabilities in the Indian context. For example, though the Washington Group Short Set (WGSS) questionnaire is considered to better capture disabilities than the questionnaires based on medical definitions of disabilities, research has shown that the former might not accurately capture all cases of disabilities in India¹⁹. Further, methodologies must be found to disaggregate by disability in the different existing surveys and data capturing tools.
- **Develop Indicators:** There is a need to meticulously plan and determine optimal indicators and metrics that reflect the disability ecosystem accurately. It is important that these indicators are intersectoral, meaning that disability is tracked across education, health, employment, gender, justice and other development goals. Consultations with relevant stakeholders and international approaches can drive the development of such indicators in India.

6.2. Knowledge Dissemination

- **Advocate:** Advocating to make disability disaggregation obligatory in all surveys.
- **Awareness:** Awareness programs in different fora on the importance of capturing disability data to improve development outcomes across different sectors.
- **Educate:** Educational programs for different relevant stakeholders such as Civil Society Organizations (CSOs) to help drive initiatives on data collection from the ground level.

6.3. Capacity Building

- **Establish Processes and Methodologies:** Collaborating with stakeholders and agencies responsible for conducting national surveys to train and establish processes and adopt methodologies that can improve the quality, reliability and frequency of disability data.

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https://www.researchgate.net/publication/328311289_Measuring_Disability_in_an_Urban_Slum_Community_in_India_Using_the_Washington_Group_Questionnaire

- **Train on Additional Indicators:** Train and co-opt relevant stakeholders on incorporating disability-related indicators into the National Indicator Framework, especially in cases where the data required for tracking progress is already being collected.
- **Train Enumerators:** Train enumerators on the various disability indicators to capture data accurately.

6.4. Data Creation and Dissemination

- **Open-Source Platform for Disability Data:** Creating a platform as a single point of access for all types of disability data that is updated, interoperable, and compatible. This platform can serve as an open-source database for easy access to quality disability data by different industry stakeholders including academicians, think tanks, independent researchers, policymakers, CSOs, and the community members themselves. Under the Draft National Policy on Official Statistics (NPOS)²⁰, there is a plan to develop an Integrated Data System (IDS) as a data warehouse which would allow for data exchange, collaboration, compatibility, integration and interoperability across national and state, and various disaggregation levels. Making disability data a part of this ecosystem can optimize access and utility of the data.
- **Integrate with Open Government Data Platform (OGD) India:** The open data platform²¹ currently provides access to several critical datasets that are collected by the government. Developing ‘disabilities’ as a category/sector and bringing all available sources of disability data under it can improve access to existing data. Currently, discovering disability data on the OGD platform is difficult.
- **Creating Data Trusts:** Collaborative efforts between private organizations and companies to set up disability data repositories or trusts can enable the release of valuable data from data monopolies and siloed data ecosystems. Such data collaboratives can facilitate innovations and policy solutions, resulting in societal impact at individual and community levels.

Owing to factors such as costly infrastructure, the need for trained resources, and concerns about privacy, establishing and maintaining data ecosystems gets complicated. However, a challenging task must not prevent us from addressing the barriers in the collection of disability data. Small and collective steps toward data collection can help overcome the data gaps. Leveraging the

²⁰ https://www.mospi.gov.in/sites/default/files/announcements/Draft_Revised_NPOS.pdf

²¹ <https://data.gov.in/>

improvements in technology and advancing research in the field of disabilities will allow us to overcome blind spots in the disability data ecosystem.

Table 1 provides the recommendations mapped to relevant stakeholders. The mapping allows us to envision roles and responsibilities by different players in the ecosystem and recognize that disability data is a collective effort.

Table 1: *Recommendations Mapped by Stakeholder*

Recommendation	Activity	Stakeholders
Knowledge Creation	Identify Gaps	<ul style="list-style-type: none"> - Parent/caregiver and persons with disabilities networks <ul style="list-style-type: none"> - NGOs and CSOs - Think Tanks - Academic Institutions and Academicians - National Statistical Commission (NSC) - Central Statistical Commission (CSC)
	Develop Methods	<ul style="list-style-type: none"> - Statisticians and Disability experts - Government statistical bodies (NSC, CSC, and others) <ul style="list-style-type: none"> - Survey institutions (NSSO) <ul style="list-style-type: none"> - Think Tanks (?)
	Develop Indicators	<ul style="list-style-type: none"> - Statisticians and Disability experts - Government statistical bodies (NSC, CSC, and others) <ul style="list-style-type: none"> - Survey institutions (NSSO)
Knowledge Dissemination	Advocacy	<ul style="list-style-type: none"> - Parent/caregiver and persons with disabilities networks <ul style="list-style-type: none"> - CSOs and NGOs - Think Tanks
	Awareness	<ul style="list-style-type: none"> - Parent/caregiver and persons with disabilities networks <ul style="list-style-type: none"> - CSOs and NGOs - Think Tanks - Relevant Government Departments

	Educate	<ul style="list-style-type: none"> - Think Tanks - Relevant Government Departments
Capacity Building	Establish Process and Methodologies	<ul style="list-style-type: none"> - Statisticians and Disability experts - Government statistical bodies (NSC, CSC, and others) <ul style="list-style-type: none"> - Survey institutions (NSSO)
	Train on Additional Indicators	<ul style="list-style-type: none"> - Statisticians and Disability experts - Government statistical bodies (NSC, CSC, and others) <ul style="list-style-type: none"> - Survey institutions (NSSO)
	Train Enumerators	<ul style="list-style-type: none"> - NGOs and CSOs <ul style="list-style-type: none"> - Think tanks - Government stakeholders
Data Creation and Dissemination	Open Source Platform for Disability Data	<ul style="list-style-type: none"> - Government stakeholders <ul style="list-style-type: none"> - Think Tanks - CSO/NGOs - Academicians
	Integrate with Open Government Data Platform (OGD)	<ul style="list-style-type: none"> - Government stakeholders <ul style="list-style-type: none"> - Think Tanks - CSOs/NGOs - Academicians
	Creating Data Trusts	<ul style="list-style-type: none"> - Think Tanks - CSOs/NGOs - Academicians - Corporates