

Implications of the Digital Personal Data Protection Act, 2023 on Persons with Disabilities



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Executive Summary

India's new Digital Personal Data Protection (DPDP) Act, 2023, intends to protect persons with disabilities by bringing in the consent of a lawful guardian, wherever applicable (Section 9(1), DPDP Act). However, after the law was passed, disability groups raised concerns about the law. In this paper we present findings from a research study to understand:

- a. perspectives, lived experiences and perceptions of persons with disabilities in the digital context and
- b. responses to the provisions pertaining to persons with disabilities in the DPDP Act.

Persons with disabilities view privacy as an important construct and are concerned that data pertaining to their disability status may be used to their detriment or further exclude persons with disabilities from access to digital services. Current data collection practices are viewed and invasive and not choice based. Specific challenges we have identified in the implementation of the DPDP Act vis-à-vis persons with disabilities are:

- a. Existing digital inaccessibility is likely to make data privacy notices and consent forms inaccessible for persons with disabilities.
- b. Long, complicated and jargon filled privacy notices and consent statements create barriers to persons with disabilities in providing informed consent.
- c. Data pertaining to a person's disability may be collected without necessity, merely to comply with the law, and then be used to their detriment causing further exclusion.
- d. The DPDP Act presents an incomplete understanding of guardianship for persons with disabilities and the role of the legal guardian.
- e. Combining the provision on data protection pertaining to persons with disabilities with the provisions pertaining to children, disregards and infantilizes persons with disabilities.
- f. DPDP Act is incompatible with the Rights of Persons with Disabilities Act, 2016 (RPwD Act) and United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), as it compels persons with disabilities who have a guardian to provide consent through the guardian only. Thus, the DPDP Act is feared to create a denial of autonomy and personhood of persons with disabilities.
- g. Varied perceptions and interpretations of the term "Legal Capacity" for persons with disabilities creates practical impediments to the exercise of full decision-making capacity of persons with disabilities.

We recommend that the DPDP Act be amended by deleting the mandate under Section 9(1) of obtaining consent of persons with disabilities through their legal guardian where appointed. Instead, the DPDP may mandate that necessary accommodations/ support to elicit informed consent of persons with reduced decision-making capacity is made available. Hence the ministry of information technology may in the interim, refrain from publishing rules pertaining to the implementation of Section 9(1) for persons with disability. Additionally, the DPDP Rules may reference mandatory accessibility standards notified under IS 17802, in respect of privacy notices, consent forms and dispute resolution mechanisms.

Problem Statement

Consent is a conscious, informed, and freely given agreement, often forming the foundation of contractual relationships. In the world of artificial intelligence and big data, where personal information is continuously collected, processed, and shared between and across numerous platforms, consent has become a very important facet: it ensures that individuals maintain control over their personal data, thus safeguarding their privacy and autonomy.

Consent for data collection in the digital medium is taken through a privacy/consent notice issued by the provider of the digital service. A consent notice typically contains details of what personal data would be collected, the purpose of processing such data, the way the user may exercise their rights and the procedure for a user to make a complaint. Such consent notice may precede or accompany the request for consent by the user.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognizes that persons with disabilities are entitled to the full and equal enjoyment of all human rights and freedoms, including accessible digital environments.¹ Ensuring that all digital citizens, including persons with disabilities, have agency, autonomy and control over their personal data without any discrimination is crucial. Inclusive data protection practices are essential in furthering this. They ensure that every individual can access and use digital services without fear of breach. By safeguarding personal information, especially sensitive information such as one's disability status, inclusive data protection practices enable equitable participation in the digital sphere.

Despite laws to the contrary, the digital landscape is fraught with several challenges for persons with disabilities. Inaccessible digital infrastructure complicates the ability to engage with digital platforms, while compatibility problems with assistive technologies can hinder pathways to obtain and provide informed consent. Frameworks and processes for consent must also uphold the autonomy and decision-making capacity of persons with disabilities. Laws on consent in the context of persons with disabilities must take holistic, informed and inclusive approach.

¹ Clause v, Preamble to the United Nations Convention on the Rights of Persons with Disabilities

Provisions in the Digital Personal Data Protection Act 2023 on Persons with Disabilities

The enactment of the Digital Personal Data Protection Act, 2023 (DPDP Act) in India marked a significant step towards safeguarding individual data privacy in India. The Act has the following provisions pertaining to the mode of data collection, processing and protection of persons with disabilities.

Section 2(j) – Definition of Data Principal	<p>“Data Principal” means the individual to whom the personal data relates and where such individual is—</p> <p>(i) a child, includes the parents or lawful guardian of such a child;</p> <p>(ii) <i>a person with disability, includes her lawful guardian, acting on her behalf</i></p>
Section 9 – Processing of Personal Data of Children	<p>(1) <i>The Data Fiduciary shall, before processing any personal data of a child or a person with disability who has a lawful guardian, obtain verifiable consent of the parent of such child or the lawful guardian, as the case may be, in such manner as may be prescribed.</i></p> <p>Explanation—For the purpose of this subsection, the expression “consent of the parent” includes the consent of lawful guardian, wherever applicable.</p>

India’s DPDP Act, recognizes the special needs of persons with disabilities. We appreciate the intent of the lawmakers in making special considerations for persons with disabilities.

Upon the publication of the DPDP Act, concerns emerged from persons with disabilities about its provisions, interpretation and implementation. We felt that it was necessary to conduct a research study to understand the perspectives, lived experiences and perceptions of persons with disabilities about access to the internet, data and privacy in the digital context and their responses to the DPDP Act.

This paper presents insights from our study on:

- (a) the impact of the DPDP provisions on persons with disabilities
- (b) the challenges that are foreseen in the implementation of the DPDP Act vis-a vis persons with disabilities and
- (c) recommendations to ensure that the spirit of equal protection of data to persons with disabilities envisaged under the UNCRPD is achieved.

Considering that the DPDP Act is expected to have immediate and far-reaching impact on digital processes and services affecting the way persons with disabilities access digital services, the government's rule-making power (under Section 9 of the DPDP) as it pertains to persons with disabilities must be exercised only after a full understanding of how people with disabilities are likely to be affected by the DPDP Act – both from a legal and practical point of view.

We hope that these insights and recommendations will inform the rule making process, which should give full effect to the rights of persons with disabilities to exercise their ability to provide informed consent, autonomy, choice and freedom.

Methodology for the Study

To conduct the study, we used secondary and primary research methodologies.

a. Secondary desk review included scoping of different laws and policies around data privacy and digital consent across various jurisdictions. This was published as a legal primer.² The literature review also entailed the review of guardianship laws and decision-making capacity for persons with disabilities focused on India.

b. Primary research involved 3 primary components namely, a survey, in-depth interviews with different stakeholders, and observations of challenges in signing up for services and accessing consent protocols on websites for persons with disabilities.

Survey

A survey was conducted to understand the internet use patterns of persons with and without disabilities. A total of **105 persons without disabilities** and **94 persons with disabilities** took the survey.³ In addition, one parent responded on behalf of a person with disability. See Annexure 1 for details on survey participants such as age, gender, education levels, types of disabilities, and severity of disabilities. Almost half of the sample had people with blindness and a more evenly distributed sample among those with low-vision and locomotor disabilities. The high representation of people with blindness is due to convenience sampling. More details on the participant profiles are found in Annexure 1.

In-depth Interviews and Focus Group Discussions

A total of 30 stake holders (including persons with disability, disability rights activists, data privacy experts, digital platform representatives) were interviewed for the purpose of the study. We conducted **nine** in-depth interviews with different stakeholders including legal experts, persons with disabilities, activists, policymakers, and representatives from civil society organizations. In addition, **three focus group discussions/consultations** were conducted with different stakeholders including representatives from civil society initiatives, corporations, activists, parents, Foundations, NGO representatives, corporations, and public policy specialists. More details are provided in Annexure 1.

² <https://www.pacta.in/digital-data-protection-consent-protocols-for-disability.pdf>

³ 94 PwDs responded to the survey – 92 accepted to take the survey; 91 self-reported and 1 taken by a parent on behalf of the person with disabilities.

Experiential Observations

An observation was conducted with **four persons with disabilities** on their challenges in usage of the digital services, signing up for services, and reading privacy policies. Details of the observation and the participants are provided in Annexure 1.

Access to the Internet - Access and Usage Patterns of the Internet by Persons with Disabilities

The penetration of the internet has increased over the last decades in India.⁴ Despite such progress, only 56% of the country has access to the internet.^{5,6} Digital penetration is higher in rural areas compared to urban areas, and more men have access to them.⁷ Overall mobile penetration in India has gone up over the last two decades (83 users per 100 people) but we still lag behind other developing countries.⁸ Furthermore, there exists literature on internet access and usage patterns among the general population where most users were found to access entertainment, communications, and social media apps.⁹ For persons with disabilities, however, there is no empirical literature on the extent of their digital access and usage patterns of the internet compared to those without disabilities.

a. Types of Digital Services Used by Persons with Disabilities

Through the survey, we found a relatively lower internet use among persons with disabilities compared to persons without disabilities. E-commerce and banking/financial apps were the most used apps among persons without disabilities. In contrast, the more popular websites/apps among the disabled population were found to be messaging/communications (89%), social media (85%), banking/financial (79%), e-commerce (68%), and entertainment (66%). Persons with disabilities were found to use Education Technology (Ed Tech) apps more (46%) than persons without disabilities (35%). The lesser use of the internet by persons with disabilities compared to the group without disabilities can be attributed to the inaccessibility of the websites, skew in access to devices and assistive technology, and skew in access to education for persons with disabilities.¹⁰

⁴ <https://www.statista.com/statistics/792074/india-internet-penetration-rate/>

⁵ <https://www.weforum.org/agenda/2020/08/internet-users-usage-countries-change-demographics/>

⁶ <https://www.pewresearch.org/short-reads/2024/02/05/8-charts-on-technology-use-around-the-world/>

⁷ https://www.iamai.in/sites/default/files/research/Internet%20in%20India%202022_Print%20version.pdf

⁸ <https://www.dataforindia.com/living-conditions-access-to-comm-tech/>

⁹ https://www.iamai.in/sites/default/files/research/Internet%20in%20India%202022_Print%20version.pdf

¹⁰ <https://cis-india.org/telecom/knowledge-repository-on-internet-access/accessibility>

Figure 1 shows the patterns of access for the two groups.

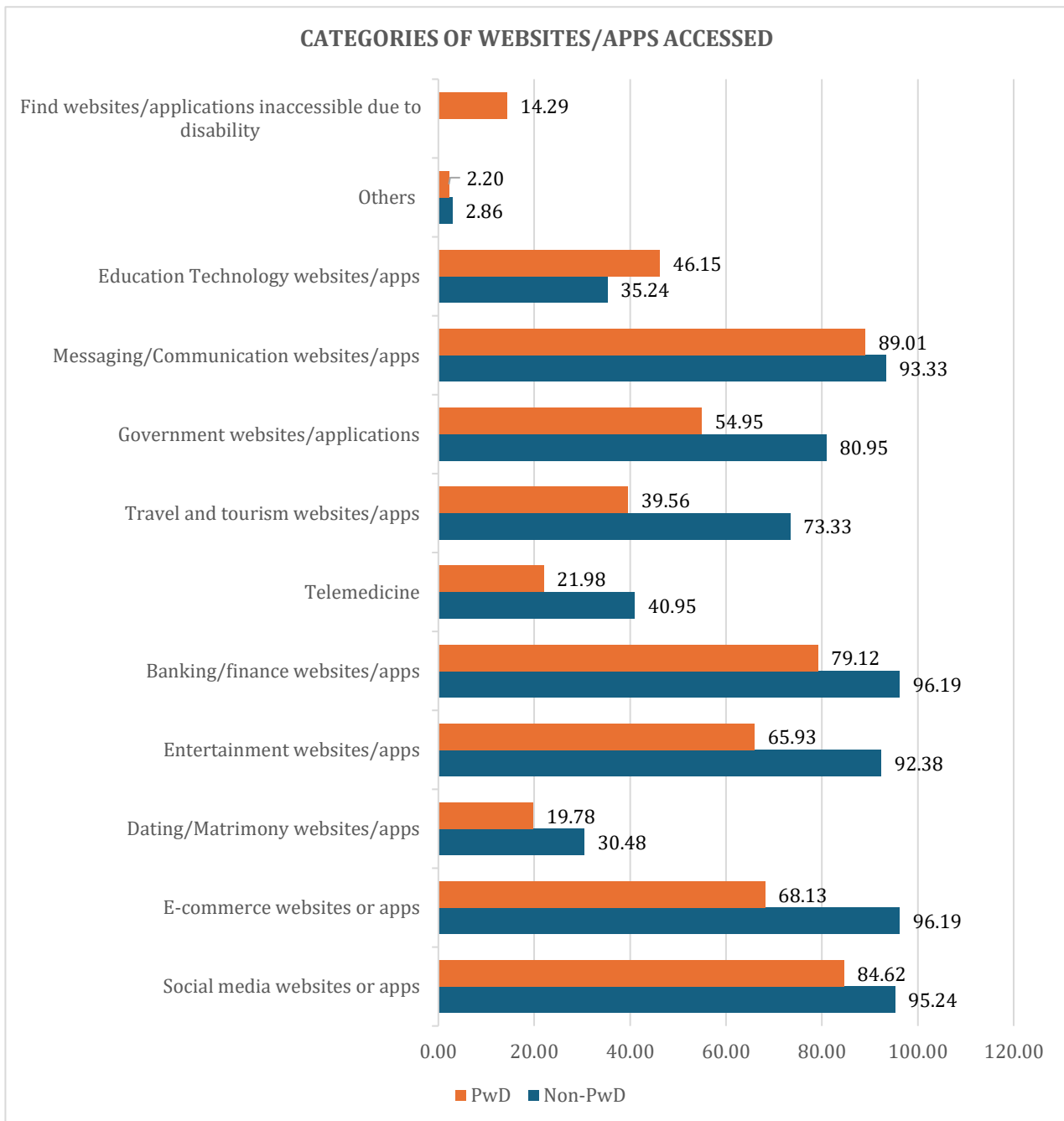


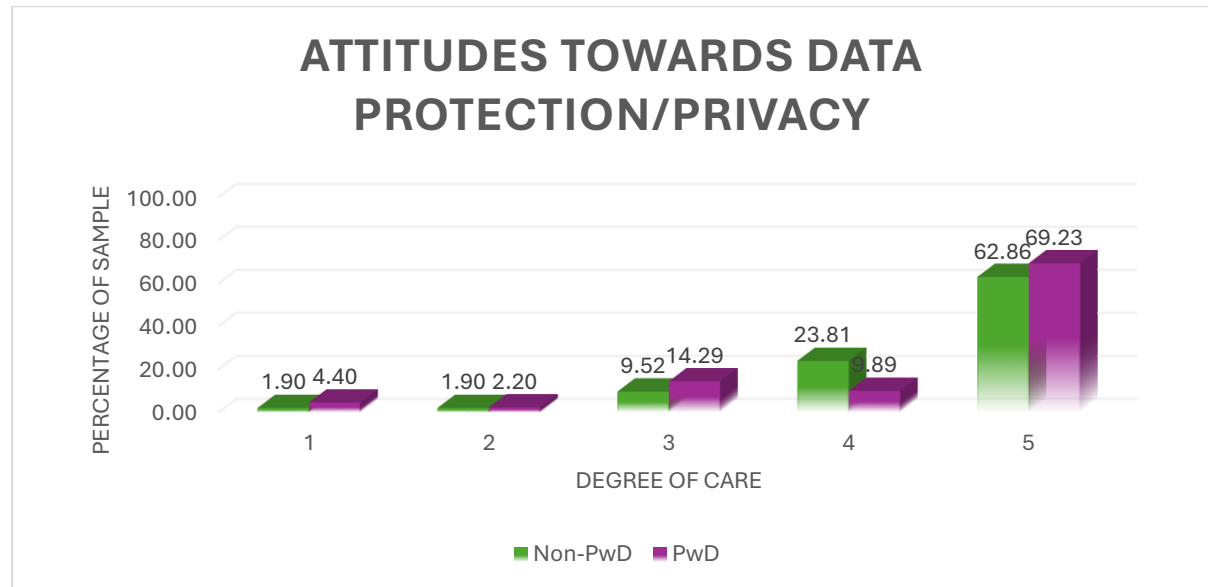
Figure 1: *Web access patterns of the two groups in the sample*

b. Perceptions & Concerns Pertaining to Digital Personal Data Protection for persons with disabilities

Persons with and without disabilities share similar perceptions of data privacy and fears of their privacy being compromised. Both persons with and without disabilities strongly care for their

privacy and the protection of personal data. Here it is seen that only marginally more PwDs (69%) feel strongly about protecting their data than persons without disabilities (63%). Figure 2 shows the overall attitudes of the two groups towards data protection.

Figure 2: *Attitudes towards data protection*



Scale: 1 – I do not Care; 2 – Somewhat Care; 3 – Neutral (Neither Care nor Not Care); 4 – Care; 5 –Strongly Care

Survey participants also expressed varying degrees of concern (somewhat worried, worried, and extremely worried) about:

- their data being misused (~55% persons with disabilities and ~60% persons without disabilities).
- their data being leaked (~57% persons with disabilities and ~63% persons without disabilities)
- not being allowed to opt out of data sharing (~64% persons with disabilities and ~65% persons without disabilities)
- sharing their data at sign-up (~62% persons with disabilities and ~73% persons without disabilities)

During the consultations, concerns about intrusive data practices were brought up repeatedly by participants:

“...a lot of times, say, it's an app that you don't need to provide location access to, like, say Twitter, right? But it often prompts you over and over again, that we should provide location access, right, so it and then it says that the functioning will not be accurate if it does not have location access. Right. So, in these kinds of messages, definitely, the messaging comes in English, which is, of course a barrier for many people with disabilities who use their phones in other languages. But also, that, it's meant to intimidate in the way that it is phrased. So you often say yes, and provide consent thinking that otherwise I won't get the full experience of the application.”

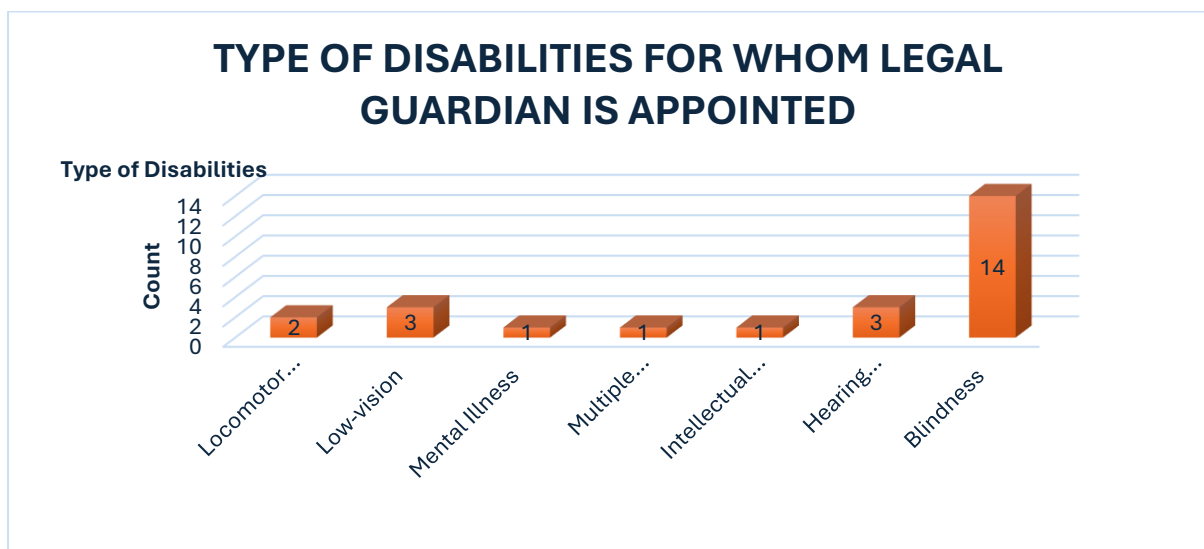
“...To be very honest, we have literally signed off our lives when it comes to using Google services. Right?”

“I do not want to share my data with anyone. While using applications I do not want to share information like location, but I have to share” - Reeshma

c. Role of Guardian in Accessing the Internet for Persons with Disabilities

66/91 persons with disabilities who took the survey did not have a legal guardian or were unsure of it. Only 25/91 persons with disabilities had legal guardians. More people with blindness had a legal guardian compared to any other disability. The distribution of types of disabilities who have a legal guardian is given in Figure 3.

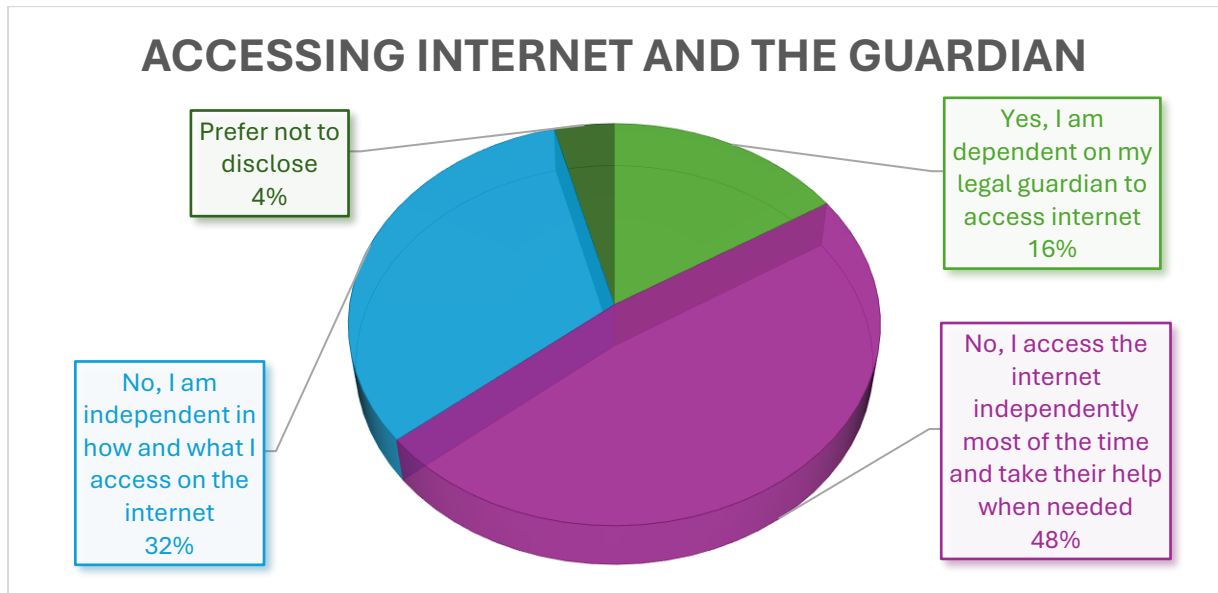
Figure 3: Distribution of type of disabilities and presence of legal guardians



More than half of them (56%) said that they had someone managing their everyday affairs but 71% said that the person supporting them did not assist them in accessing the internet. Almost

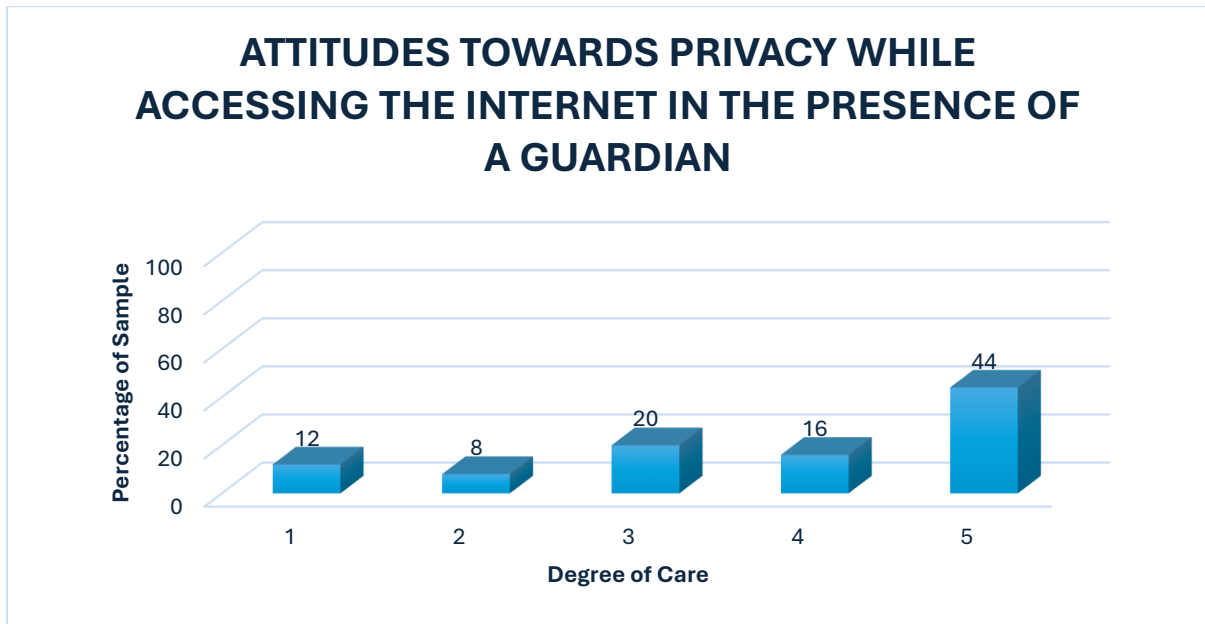
half of the sample said that they access the internet independently but take the help of a guardian when required. Only 16% said that they were dependent on their guardian to access the internet (Figure 4).

Figure 4: Assistance of the guardian in accessing the internet



When asked about their opinions on privacy in accessing the internet in the presence of a guardian, 60% of persons with disabilities said they cared about their privacy while only 12% said that they did not care (Figure 5) as against 67% of people without a legal guardian who cared about their privacy (Figure 6). The findings indicate a strong sense of need for privacy and thus, ascertaining individuality and autonomy among those with disabilities even in the presence of a lawful guardian.

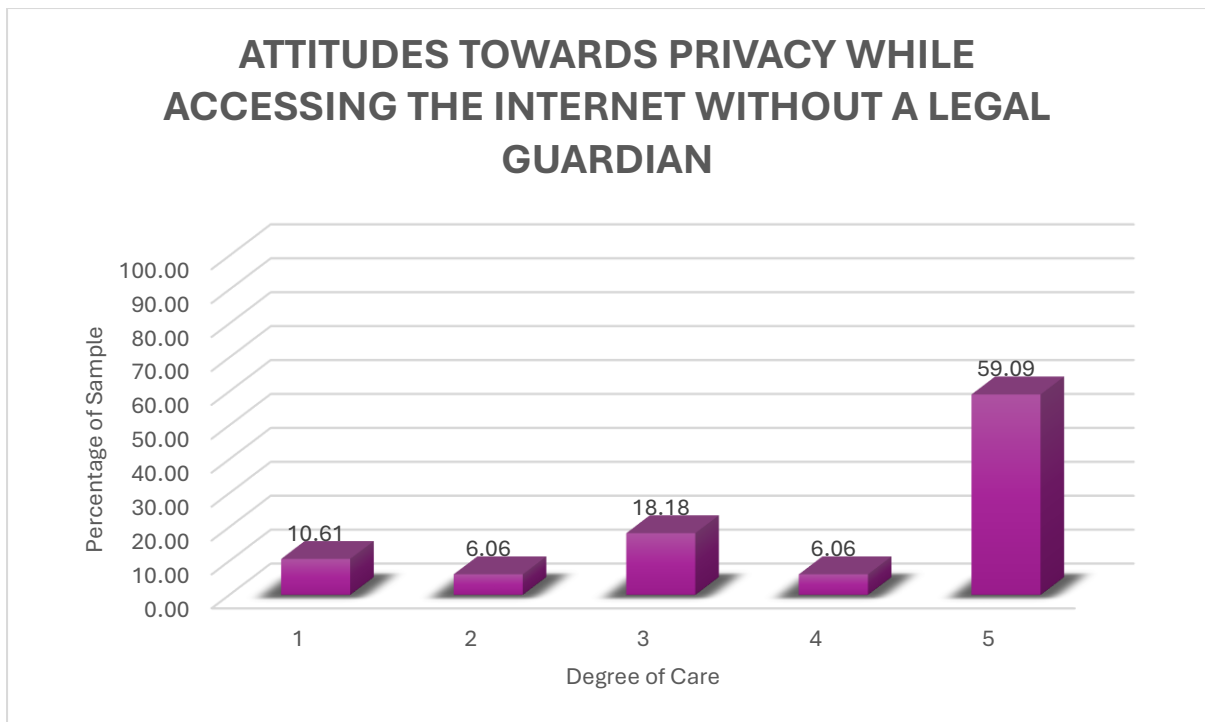
Figure 5: Attitudes toward privacy in the presence of a legal guardian



Scale: 1 – I do not Care; 2 – Somewhat Care; 3 – Neutral (Neither Care nor Not Care); 4 – Care; 5 – Care Strongly

Furthermore, more while using the Internet compared to those with a legal guardian.

Figure 6: Attitudes toward privacy when there is no legal guardian



Implications of DPDP vis-a vis Persons with Disabilities When Implemented in Letter & Spirit

Provision	Section number	Explanation	Implications on Persons with Disabilities
Grounds for processing personal data	Section 4	The data fiduciary may only process the personal data of an individual in accordance with the provisions of the Act, and for which purposes the data principal has given consent.	This means that a data principal's data (including the data of a person with disability) can be collected and processed only with their consent.
Notice	Section 5	<p>Every request for consent from the data principal must be accompanied by a notice informing them of:</p> <ul style="list-style-type: none"> (a) the personal data and the purpose for which it is being processed; (b) the manner in which the data principal may exercise their rights under the Act; (c) the manner in which the data principal may make a complaint to the Data Protection Board. <p><i>Note: the manner for (c) will be notified under the Rules.</i></p>	This will limit data processing to specific purposes for which consent was given. It reduces the risk of persons with disabilities' personal data being used for unintended or harmful purposes, ensuring that their data is only used as they have intended.

Provision	Section number	Explanation	Implications on Persons with Disabilities
		<p>(d) the contact details of the Data Protection Officer.</p> <p>The data principal should have the option to access the notice in English or any language specified in the Eighth Schedule to the Constitution. (Section 5(3))</p>	
Consent	Section 6	<p>The consent taken from the data principal must be free, specific, informed, unconditional and unambiguous. It should involve a clear affirmative action, indicating agreement to process personal data for a specified purpose, and be limited to only the necessary personal data for that purpose.</p>	<p>The provision of a notice with every consent request ensures that all data principals, including persons with disabilities are fully informed of what they are consenting to.</p> <p>Unnecessary (to the purpose) personal data will not be collected from the data principal.</p>
Processing personal data of children/ persons with disabilities	Section 9	<p>(i) The Data Fiduciary shall, before processing any personal data of a child or a person with disability who has a lawful guardian obtain verifiable consent of the parent of such child or the lawful guardian. (Section 9(1))</p>	<p>This section safeguards the personal data of persons with disabilities, particularly those who may not be able to fully understand or consent</p>

Provision	Section number	Explanation	Implications on Persons with Disabilities
		<p><i>Note: the manner for obtaining the consent shall be prescribed by the Rules.</i></p> <p>(ii) The Data Fiduciary shall not undertake such processing of personal data that is likely to cause any detrimental effect on the well-being of a child. (Section 9(2))</p> <p>(iii) The Data Fiduciary shall not undertake tracking or behavioural monitoring of children or targeted advertising directed at children. (Section 9(3))</p>	<p>to data processing themselves, such as persons with cognitive impairments etc, by requiring the involvement of a legal guardian, where such legal guardian has been appointed.</p>
<p>General Obligations of the Data Fiduciary</p>	<p>Section 8</p>	<p>(i) Where personal data processed by the Fiduciary is likely to be used to make a decision that affects the Data Principal or is disclosed to another Data Fiduciary, the Data Fiduciary processing such personal data shall ensure its completeness, accuracy and consistency (Section 8(3)).</p> <p>(ii) The Data Fiduciary shall implement appropriate technical and organisational measures to ensure effective observance of the provisions of the DPDP (Section 8(4)).</p>	<p>Personal data related to disabilities can be particularly sensitive and is classified as sensitive personal information in some jurisdictions.</p> <p>Provisions under Sections 8(4) and 8(5) are crucial for persons with disabilities who may be at higher risk in case of a data breach. Secure data safeguards reduce the likelihood</p>

Provision	Section number	Explanation	Implications on Persons with Disabilities
		<p>(iii) The Data Fiduciary shall take reasonable security safeguards to prevent breach of personal data collected and processed by it. (<i>The Act does not define reasonable security safeguards</i>) (Section 8(5)).</p> <p>(iv) In case of a personal data breach, the Data Fiduciary shall intimate the Data Protection Board and each affected Data Principal. (<i>The manner of intimation shall be prescribed by the Rules</i>) (Section 8(6))</p> <p>(vi) Upon the Data Principal withdrawing the consent, or as soon as its reasonable to assume that the specified purpose for which the data was collected is no longer being served, the Data Fiduciary shall erase or cause other processors processing the data to erase such data. (Section 8(7))</p>	<p>of misuse of their personal information.</p> <p>Section 8(7) helps persons with disabilities exercise greater control over their personal information. Once the data is erased after the withdrawal of consent or when it is no longer needed, the risk of misuse or unauthorized access, especially of sensitive information, is minimized.</p>
Obligation to Establish Grievance Redressal Mechanism:	Section 8(9) and 8(10)	(i) The Data Fiduciary shall publish the business contact information of a person who is able to answer questions raised by the Data Principal about the processing of their personal data.	This enables the data principals to raise questions and address their grievances effectively. The recognition of guardians as

Provision	Section number	Explanation	Implications on Persons with Disabilities
		<p>(ii) The Data Fiduciary shall establish an effective grievance redressal mechanism.</p> <p><i>Note: the time period within which the grievance has to be redressed shall be prescribed by the Rules</i></p>	<p>substituted decision makers for persons with disabilities could imply that individuals who might require the support of guardians may also file grievances through their guardians.</p>

The DPDP Act is expected to create healthy data practices. However, several participants in the research vocalized concerns that the implementation of the spirit of law may not be possible for several reasons.

Challenges with the implementation of DPDP vis-a-vis Persons with Disabilities

a) Inaccessibility of web pages and apps may compromise data privacy in the digital context thus impeding DPDP implementation:

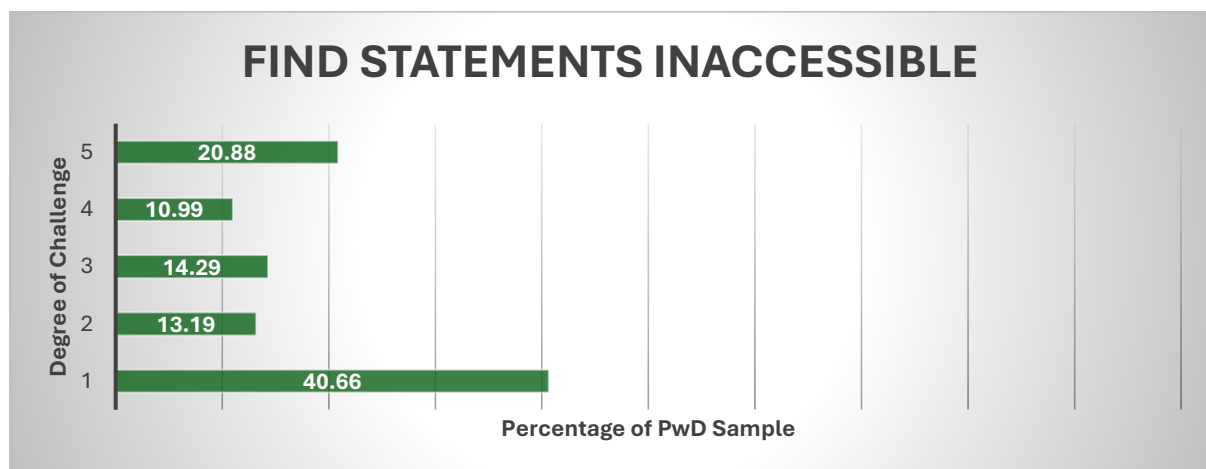
Implication on sections: Sections 4, 5 and 6

A prior study assessed the accessibility of 10 commonly used service-providing websites/apps including Paytm, Phone Pe, Ola, Uber, Flipkart, Amazon.in, Swiggy, Zomato, WhatsApp, and Telegram, it was found that WhatsApp had the highest accessibility rating and Paytm, Swiggy, Zomato, and Flipkart had low accessibility scores. The other apps had a medium accessibility rating.¹¹ This was raised as a concern by participants during our stakeholder discussions in the context of banking apps:

“The HDFC app remains inaccessible to me ... I could not navigate the app.” – A disability advocate with blindness

Inaccessible websites or apps imply that consent mechanisms too are inaccessible. Survey participants resonated with this concern, with nearly 45% of respondents finding the privacy policy/statement inaccessible across various degrees (somewhat challenging, challenging, and highly challenging)

Figure 7: Accessibility of Privacy Statements



¹¹ <https://vidhilegalpolicy.in/research/making-the-digital-eco-system-disabled-friendly/>

Scale: 1 – Not a Challenge; 2 – Somewhat Challenging; 3 – Neutral (Neither Challenging nor Non-Challenging); 4 – Challenging; 5 – Highly Challenging

One person with disability pointed out that the digital consent process is inaccessible.

“When we download an app there is obviously a consent on whether our data will be shared for a specific geography with the relevant companies or something for relevant tasks to be given, etc. And those kinds of consents are required to be given. Due to the inaccessibility of touch screens, only thing what I could do was to just to accept, we couldn't even go back, there was nothing (no option) for not accepting, there was nothing for continuing without such a provision in whatever way the app could continue. And there was no nothing to go backwards. The only way how you could get out of it was either to close the app completely and just forget about it. Or, you know, just accept” – A Founder of a Disability Initiative with Visual Impairment

Inaccessible apps and website architectures means that not only privacy in the digital context, but privacy itself is compromised. One participant shared as follows:

“If I have to use somebody's help for my money transfer, which is quite a basic need, it's very uncomfortable for me because my bank balance is now known to that third person...including my account and sometimes even password because she has to open the website. Now you can always say aapke password change karo [change your password] but Arrey! [expression of anguish] But why would I even want to do it? So, data sharing is uncomfortable. That's why I told you that the right to privacy for a blind person in India today is nothing but an illusion. It's not at all a fundamental right given to me. And I know the judges will not empathize because they can't imagine it, they, themselves have never had this kind of an experience.” – A Founder of a Disability Initiative with low vision

Case Studies on Challenges Persons with Disabilities Face in Navigating Privacy Policies of Websites

Case Study 1: Lack of Accessible Design – Labelling, Font Size for a Person with Blindness

Shyam¹² a person with blindness and 100% disability accessed the Swiggy and Ola privacy policies through his screen reader NonVisual Desktop Access (NVDA).¹³ For the Swiggy App, he found that the Sign-Up tab was not labeled and the privacy policy lacked a tab focus for the screen reader to pick up. When entering the privacy policy page, he found the heading of the section in the privacy policy was not marked as a header with only the font size and type differing to mark the distinction. He used the search tab to look for the text that the researcher wanted him to read. A similar issue was noticed for the Ola application on the web, where the

¹² Shyam is a web accessibility expert at a leading disability NGO in Bangalore.

¹³ <https://www.nvaccess.org/>

privacy policy was nested in the terms and conditions and not placed up front. The webpage was inaccessible to the screen reader and Shyam needed the assistance of a sighted person to guide him to the terms and conditions tab. Shyam inspected the HTML code to navigate to the privacy policy as the privacy policy was not marked as a link, which the screen reader could not pick up. The privacy policy had no headers to distinguish text from headings for navigation. Additionally, the headings were too lengthy. On the phone Ola App, Shyam found the check box against terms and conditions inaccessible.

Case Study 2: Lack of Accessible Design & Font Size for a Person with Low Vision

Reeshma, is a person with low vision and the presence of only central vision in the left eye. Reeshma uses the magnifier feature to assist in navigating the screen and finds computers more accessible than phones for her usage. This is because when she magnifies text, she needs to scroll (to the left and right) to complete reading the sentence, making it difficult to keep continuity in reading and comprehension.

Reeshma found the Amazon.in website more accessible due to the color contrast but found that the sign-up tab was not easily visible. On the phone too, she felt that the figure was not intuitive to detect the sign-up tab. Reeshma found the text in the privacy policy on the Amazon.in webpage more accessible than the Paytm page where she encountered problems with font type and size, word design, and spacing. Furthermore, when Reeshma used her magnifier, the text became pixelated making reading hard for her.

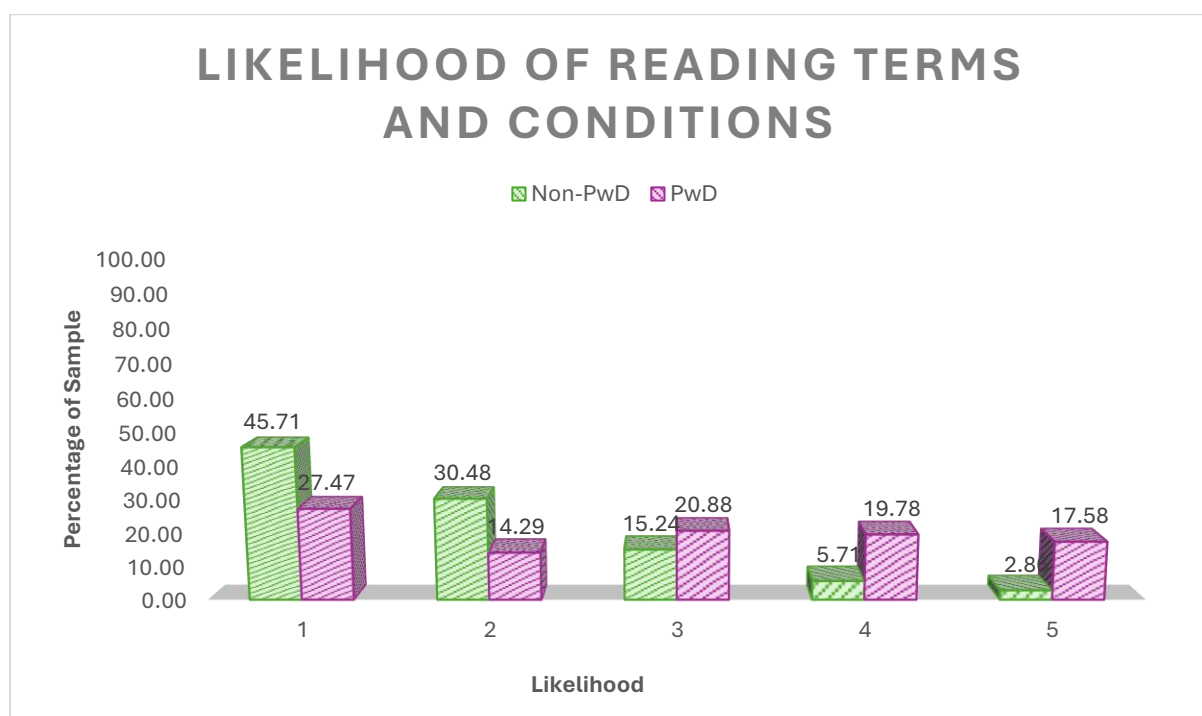
b) There are challenges in reading and comprehending consent statements due to length, language thus impeding the implementation of DPDP

Implication on sections: Sections 4, 5 and 6

Digital platforms often employ consent mechanisms that assume a uniform level of capacity among users. This overlooks the diverse support needs of persons with disabilities, resulting in consent processes that may be inaccessible or difficult to navigate for some individuals. Consent protocols in the digital sphere lack customization options to accommodate the specific needs and preferences of users with disabilities. This lack of flexibility prevents individuals from exercising meaningful consent, thereby compromising their rights and privacy.

Persons with disabilities displayed relatively more willingness to read the privacy policy and terms of use than their non-disabled counterparts, as can be seen from Fig 8.

Figure 8: *Reading of Terms and Conditions and Privacy Policies*

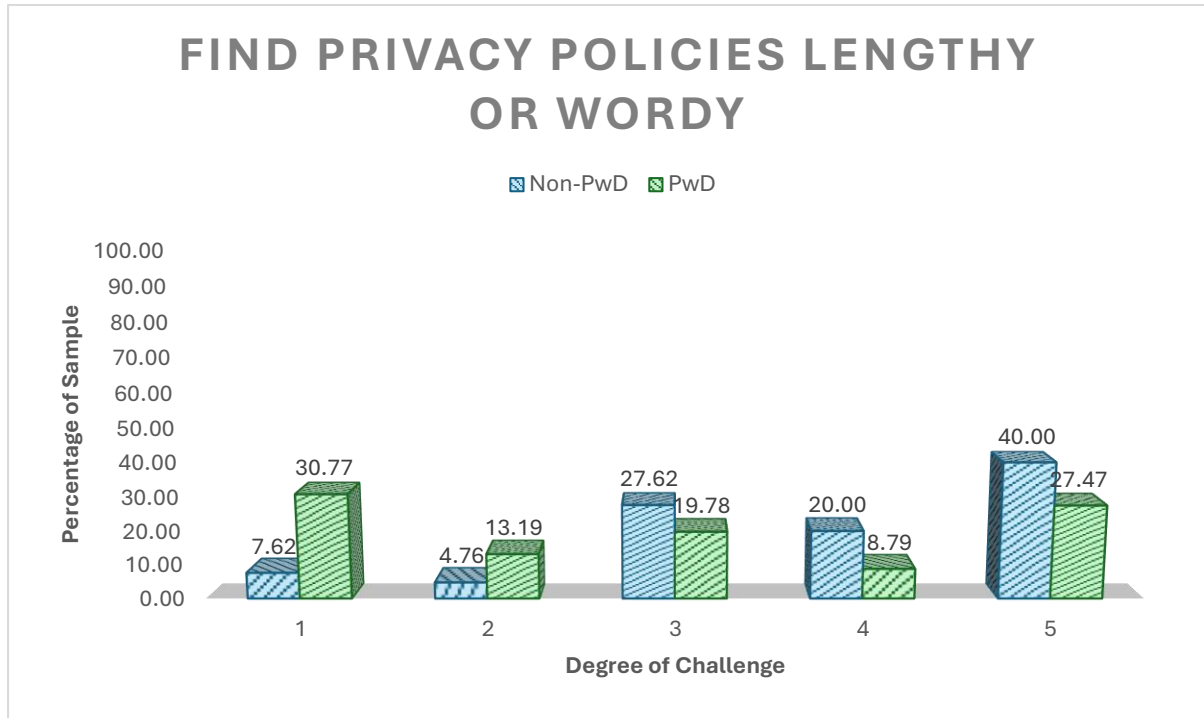


Scale: 1 – Not at All Likely; 2 – Somewhat Likely; 3 – Neutral (Neither Likely nor Unlikely); 4 – Likely; 5 – Always Read/Highly Likely

However, significant percentage of persons with disabilities (~40%) did allude to finding privacy policies and terms of use challenging because they were long and wordy (See Figure 9). A similar challenge was pointed out by persons without disabilities with ~60% of

respondents finding privacy policies and terms of use challenging because they were long and wordy.

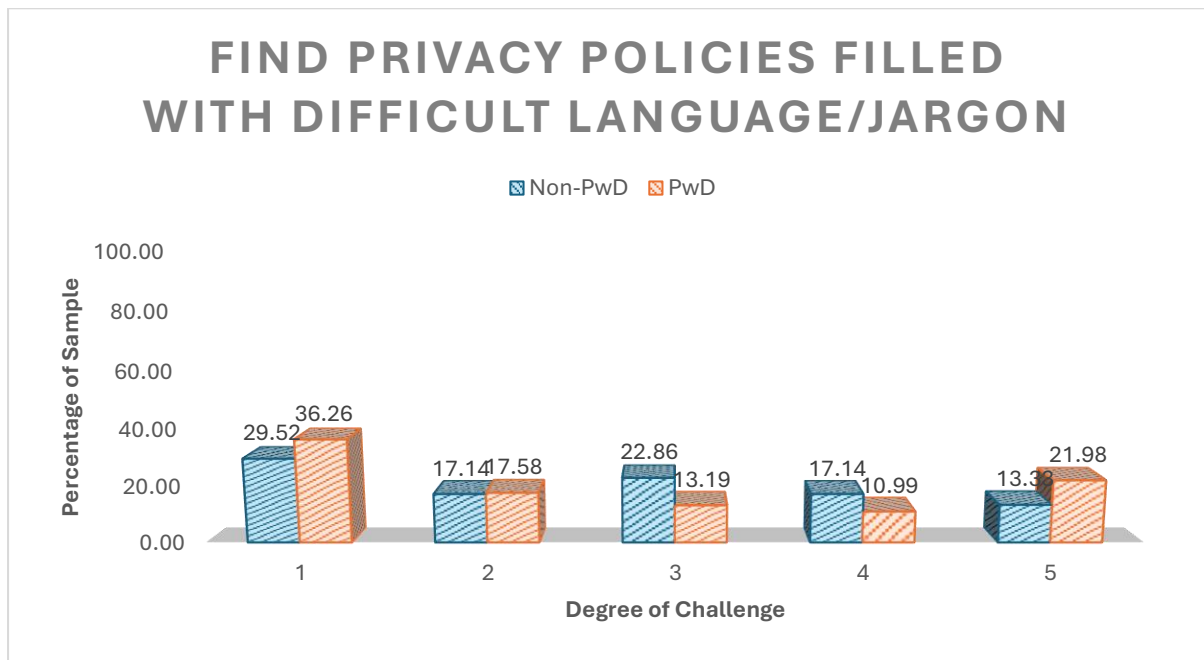
Figure 9: Attitudes towards the length of consent statements



Scale: 1 – Not a Challenge; 2 – Somewhat Challenging; 3 – Neutral (Neither Challenging nor Non-Challenging); 4 – Challenging; 5 – Highly Challenging

Another reason for the difficulty in comprehending privacy policies was the use of difficult language ridden with jargon. Nearly 50% of respondents with disabilities identified jargon as a barrier to understanding privacy policies across varying degrees (somewhat challenging, Challenging, and Very Challenging). 37% of respondents without disabilities took a similar view. (See Figure 10). This is especially to be noted for persons with intellectual disability, with barriers and inability to comprehend.

Figure 10: Attitudes towards the language used in privacy statements



Scale: 1 – Not a Challenge; 2 – Somewhat Challenging; 3 – Neutral (Neither Challenging nor Non-Challenging); 4 – Challenging; 5 – Highly Challenging

Difficult to comprehend language was brought up during the stake-holder discussions as well:

“There is definitely no easy-to-read version of those privacy notices, ...most people are just reading it, or just moving to the next step because it doesn't feel like you have much of a choice in the process....”

“Most of the time, all of us sign agreements on websites with privacy and terms of use policies that most of us don't know the language of. So the question is, where is this (DPDP) going to come?”

“Generic statements are used in privacy statements – there is no visibility on which data will be used for what purpose. Data is misused by a lot of service providers.”

Case Study 3: Challenges in Comprehending Privacy Policies for a Person with Intellectual Disability

Nikhil is a person with intellectual disability with a percentage of 65-85% (unsure). When Nikhil navigated to the privacy policies on the Amazon.in and Zomato webpages and apps, he found challenges in terms of text comprehension. Nikhil preferred contrasts (by highlighting the text) to provide breaks in the long wordy texts for easy comprehension and increasing focus. Nikhil also took time to comprehend the text and needed support to interpret the language in the privacy policy.

- c) **It is feared that data pertaining to disability status will be collected, against the will and comfort of persons with disabilities, and in dis-service to persons with disabilities.**

Implication on Sections 4, 5 and 6

In India, there is no standard mechanism to secure consent from the data principal. A few platforms take implicit consent wherein by signing up for services, one agrees to the privacy policy/notice. In other cases, platforms provide a tick box to explicitly give consent to the privacy notice. A standard mechanism to secure consent is required to ensure protection of persons with disability as the law sets out to do. For the implementation of the DPDP Act, 2023, it is expected that the obligation under Section 9 would require platforms to ask questions at two levels as provided below:

Are you a person with a disability?

Yes

No

Do you have a legal guardian under the NT Act/RPwD Act?

Yes

No

If the answer to both questions is ‘Yes’, the platform will proceed with taking consent of the lawful guardian. If the answer to the second question is ‘No’, the platform will be left with information about the disability of an individual with no processing purpose for such data. The manner in which consent may be secured from individuals requires users to disclose information about their disability. Therefore, even though routing consent through legal guardian may not be a mandate for persons with disabilities with no legal guardian, disclosure of disability data may become inevitable, unless consciously avoided.

Participants also questioned the operational feasibility of such a question. Even when posed with the question on disability (or even age) one may tick the option that is less onerous, that is to state that ‘I am not a person with disability’.

“which child is going to go out there or which adult, so to speak, is going to go out there and volunteer information, ji mujhe dyslexia hai (that I have dyslexia), if not specifically asked. And even if it is asked, even if it is asked, because they can tick whatever they want.”

Such disclosure or collection of data by platforms without any connection with services provided by the platform was raised as a privacy concern and as intrusive by a number of interview participants.

“...And if I'm gonna go shopping on Amazon, why do I need to tell Amazon that you don't want a person with a disability or not? I mean, that's violating our privacy...”

“let's say I put out a learning portal tomorrow, right? And this learning portal says, if you are a person over 18, identify yourself. In that case, here, I'm not going to ask the next question. Are you a person with disability? Because I'm not even going to ask the question? Are you male, female?”

When posed with the question of comfort with sharing disability related data with platforms, a number of interview participants stressed on the **purpose** of such disclosure. If such disclosure of disability data is required to provide services for the benefit of persons with disability, the participants were relatively comfortable with sharing data. For instance, Namma Yatri collects information on disability to extend support to the rider based on their disability. An interview participant, a disability advocate and a person with cerebral palsy, connecting the comfort in disclosure with benefits stated,

“When I share my disability status on Namma Yatri, I benefit since I would need some accommodations. But on a social media site, what would I benefit by sharing my disability status. It is quite random and an infringement of my privacy. What will they do? Its none of their business....”

Ideally, platforms should choose to collect disability data only if it is associated with specific services aimed at persons with disabilities or if any accommodations are required to access services. Otherwise, the thumb rule should be that all platforms and services should be accessible as per Indian standard mandated under the RPD rules, hence for general services, there should not be any requirement to gather disability data and any inaccessibility or exclusion on the part of platforms and services would be a violation of the law. One platform participant in the stakeholder discussion shared resonance with this view:

*“At (omitted for confidentiality purposes), we do not collect this (disability) data for customers as of now. We do collect this for our delivery partners, as well as our merchants and restaurant partners.... We haven't witnessed a lot of resistance when asking for this data.... There is no mandate to share.....But what we do ensure is that if we are collecting this data, it is anonymized, there are no repercussions that particular stakeholder faces. And actually, on the contrary, **we are able to benefit them in some manner. And that is also the reason why we have not started collecting this data for customers, because we do not know how we can directly benefit them (emphasis supplied) ...”***

Some participants also highlighted that disability data may also be used against the interests of persons with disabilities. One of the interview participants raised a concern that in the

event of disclosure of disability for loans, the person may get higher interest rates even though disability is not necessarily a marker of creditworthiness.

Implications of Non-Disclosure of Disability-Related Data on Persons with Disabilities and their Guardian

Data Principal under the DPDP Act, in addition to providing consent for data, exercises the right to manage, review or withdraw the consent, get any information on data processing and file a complaint with the Board. In addition to such rights, the Data Principal has the obligation to provide authentic information, not file false complaints and other obligations. Breach of obligations by the Data Principal may lead to the imposition of a penalty on the Data Principal.

Section 2(j), DPDP Act, defines Data Principal to include a legal guardian in case of a person with disabilities, thereby shifting the onus on the legal guardian to exercise rights and fulfill obligations on behalf of a person with disabilities.

As seen above, a person with disabilities may choose to not disclose their disability status for various reasons. This leads to the question, what are the implications of inaccurate information on disabilities? Will such non-disclosure vitiate the transaction or nullify the actions of the person with disabilities on the platform?

Case Study 4

Aryan is a person with autism who has a legal guardian appointed under the RPwD Act to provide assistance with making financial transactions (bank transactions above the value of INR 50,000). In accordance with the DPDP Act, Shikha, the legal guardian, also provides financial data sharing consent on digital platforms on behalf of Aryan.

In August 2024, to avail services on 'Z' platform, Aryan was required to provide information about his disability. Shikha signed up on the platform and provided information that Aryan is a person with Autism with 40% severity on behalf of Aryan. In July 2025, Aryan underwent a disability certification test and found that the severity of his disability had changed from 40% to 60%. Shikha did not update this information on 'Z' platform.

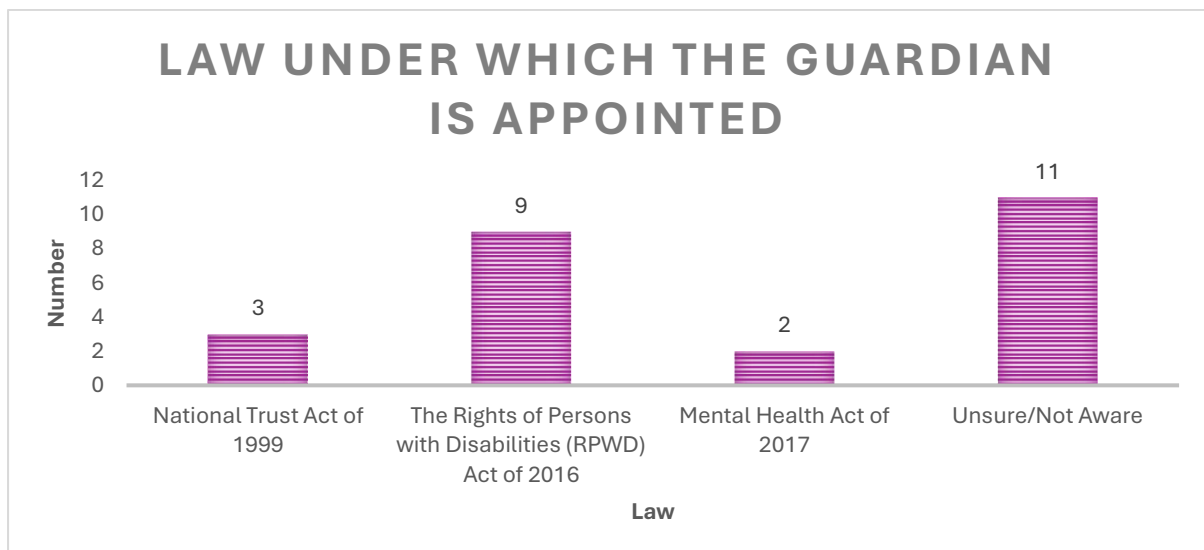
Section 15(e) imposes an obligation on the Data Principal to provide authentic information while exercising the right to correction. In the event of breach, penalty may be imposed under Section 33, DPDP Act. A failure to correct/update information may lead to imposition of penalty on Shikha.

- d) **The DPDP presents an incomplete understanding of practical realities surrounding guardianship for persons with disabilities and the role of the guardian.**

Implication on: Section 9

Legal guardianship is not mandatory in India and is governed under two laws the NT Act and RPwD Act for adult persons with disabilities. In our survey, a majority of the persons with disabilities had a guardian appointed under the RPWD Act, 2016 (Figure 11).

Figure 11: Guardianship Laws



The role of the guardian under each law is different. The role of the guardian is limited under the RPwD Act as opposed to full guardianship under the NT Act. The RPwD Act provides for the appointment of a legal guardian for limited purposes and to provide support to the individual in making decisions. (See Table 2 Under Annexure 2 for a detailed comparison, though the question of which guardian is preferred to be covered by the DPDP is not in the scope of our recommendations). In practice, the role of the guardian may not correlate with the type of disability or the law under which they are appointed, creating tensions between the actual role of the guardian and the role intended under the statute under which they are appointed.

Case Study 5

Arvind is a person with cerebral palsy that impacts his ability to make financial decisions. Therefore, the court has appointed a limited guardian, Soham, who provides support to

Arvind in making financial decisions. Arvind wants to sign up on a gaming platform wherein he needs to share his non-financial but personal information. Can Arvind give consent for sharing such data? Or by virtue of Soham being the legal guardian, even though appointed only for taking financial decisions, he will be required to give consent on behalf of Arvind?

Box 1

Questions pertaining to guardianship that arise under the DPDP and remain unanswered

1. If the guardian is appointed under the RPWD Act (limited guardian providing assisted decision-making support to the person with disability on specific matters envisaged under the guardianship order), it is not clear how the mandate of the guardian would extend to providing consent on behalf of the person with disability, because the role of the guardian is one of limited guardianship and the role is described under the specific order of appointment as a guardian. Prospectively, would it mean that guardianship orders under the RPWD should contain guidance on consent for sharing the personal data of the person with disability in the digital medium. But it is not clear how it would apply retrospectively. For the guardianship certificate issued prior to the enforcement of the DPDP Act, will new certificates be issued, or such mandate will be construed as implied? Additionally, guardians would need to be sensitized on how to share data of persons with disability in a manner that is in close consonance with the privacy preferences of the person with disability.
2. If the guardian is appointed under the NT Act, this would be in direct conflict with autonomy as a human right recognized for persons with disabilities under the UNCRPD, thus positioning the RPWD act to be in conflict with the UNCRPD.
3. Can a lawful (legal) guardian choose to not act as a lawful guardian for the purposes of DPDP Act? Or by virtue of being a legal guardian under guardianship laws, the rights and obligations would accrue upon such a legal guardian under the DPDP Act?"

Box 2

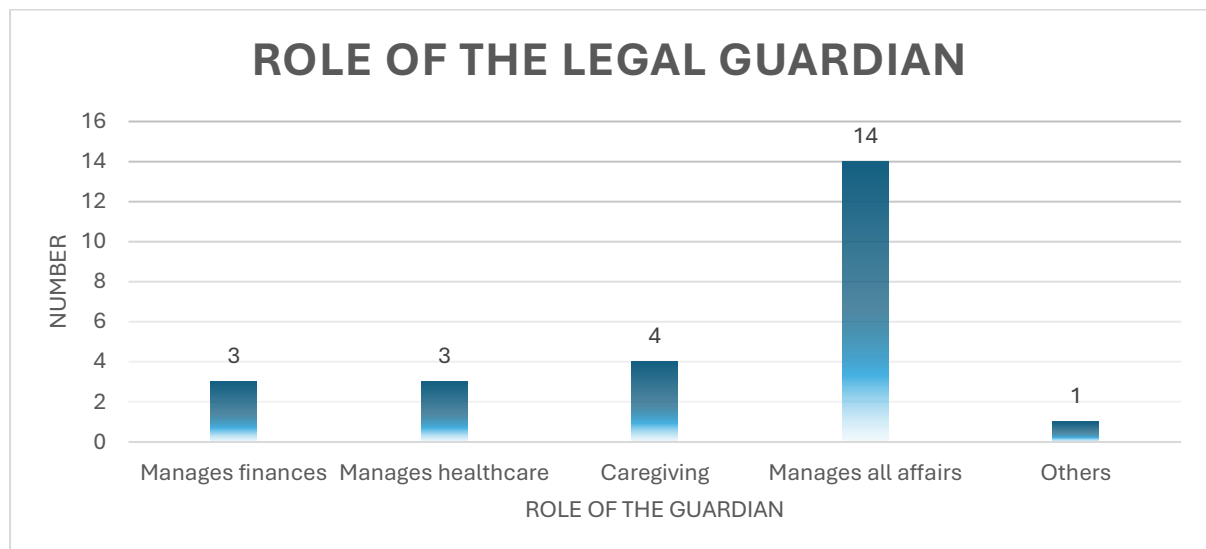
Dissonance between the intended and actual role of the guardian

Let us consider the legal guardian under the RPwD Act. (Since the legal guardian under the RPwD act is in consonance with the UNCRPD and the legal guardian under the NT Act is not compatible with the UNCRPD, let us disregard the NT Act, for the moment). The guardian under the RPwD is envisaged as follows (as per Sec 14 of the RPwD Act, 2016):

- that a person with disability be given adequate support to facilitate decision-making.
- If the person is not able to make a decision after receiving such support, a limited guardian is appointed to provide further support and make case-specific legally binding decisions.
- Such decisions must be taken by the guardian in consultation with the person with disability

However, in reality, the role of the guardian does not manifest as such. Insights from the survey also point in this direction, as legal guardians manage all affairs for more than half of the persons with disabilities (in our survey) as shown in Figure 12.

Figure 12: Role of the guardian



“A person with disability becomes like a credit or debit card without activation, because they will always need their guardian to consent on their behalf.”

Legal obligations and penal consequences on the data principal may further result in the legal guardian acting in their own interest rather than acting in the interest of the person with disability. One of the interview participants highlighted that by adding the legal guardian within the definition of Data Principal, the law has effectively endowed the guardian with such rights and responsibilities that they may not want or wish to shoulder.

“a data principal in case of person with disability is their legal guardian. And data principal have certain rights and responsibilities. So, for example, the data principal has the right to call for summaries of activity and summary of the data that's stored with various fiduciaries which you may or may not want and even for that matter the guardian may not want to have.”

Penalties as provided under the DPDP Act for breach of observance of duties by the Data Principal (in this instance by the guardian) may act as barrier for the legal guardian to prioritise the interest of the person with disability.

“Guardianship is not a success in India. Several persons with disabilities feel that guardians do not act in their favour. Guardians are not obliged to take a decision in consultation with the person with disability whose guardian they are...”

Interview participants, questioned the requirement to collect such information

“.... Guardianship has become like an Aadhaar Card – even though it is not compulsory, people ask for it. This provision seems to take away the personhood of persons with disabilities...”

Box 3: Nominated Representative under the Mental Healthcare Act

The Mental Healthcare Act provides for appointment of a nominated representative for persons with mental illness. The MH Act, prima facie, presumes that the person has the capacity to make decisions regarding their mental healthcare or treatment. Therefore, the nominated representative does not take all the decisions for the person with mental illness. The nominated representative acts for or on behalf of a person with mental illness only in accordance with conditions laid out under the MH Act. For instance, in case of admission or treatment of a person with mental illness with high support needs in a mental health establishment, the consent of the nominated representative is required for such admission and treatment.

The role of nominated representative under no circumstances penetrates sectors other than mental healthcare or treatment, therefore, this report for the purpose of application of Section 9 does not interpret nominated representative as the lawful guardian. Furthermore, such a nominated representative may be covered under Section 14, DPDP

Act wherein the Data Principal may nominate any individual to exercise rights in the event of incapacity (inability due to unsoundness of mind or infirmity of body) of Data Principal.

- e) **DPDP Act is incompatible with the RPwD Act and UNCRPD, as it compels persons with disabilities who have a legal guardian to act through the legal guardian only. Thus, the DPDP is feared as denying autonomy and personhood of persons with disabilities.**

Implication on sections: Section 9(1)

The DPDP (Section 9(1)) reads as follows:

(1) The Data Fiduciary shall, before processing any personal data of a child or a person with disability who has a lawful guardian, obtain verifiable consent of the parent of such child or the lawful guardian, as the case may be, in such manner as may be prescribed.

Explanation—For the purpose of this sub-section, the expression “consent of the parent” includes the consent of lawful guardian, wherever applicable.

A plain reading of Sec 9(1) appears to presume that the appointment of a legal (lawful) guardian (whether under RPwD Act or NT Act) is an indication of inability of the person with disability to make legal decisions in the digital sphere, because it substitutes the consent of the person with disability, with the consent of their legal guardian, *wherever such legal guardian is appointed*. This position is grossly incompatible with the recognition of decision-making capacity under the RPwD Act, which is based on the UNCRPD, and is ratified by India (See Box 4 for Capacity under the UNCRPD).

On being asked about the need for Section 9, a group of interview participants stated that the requirement to route consent through a legal guardian will take away the autonomy of a person with disability to access the internet and make decisions.

“The law should not result in diminished autonomy of a person if they are able to take a call. One should use the power of consent from the legal guardian only when needed.”

One of the interview participants highlighted that *“there is no discussion in the DPDP Act on whether the person has capacity now, does not have capacity, may have capacity tomorrow”*, thereby avoiding any discussion on the evolving nature of capacity. Based on the nature of decisions, a person may have the capacity and with requisite support may acquire the capacity to make decisions.

A disability may be physical, intellectual, mental or sensory. Accounting for the spectrum of disabilities, there cannot be a blanket presumption to imply that a person with disability

does/does not have decision making abilities. Additionally, a person with cerebral palsy with 30% severity may have a different capacity than a person with 80% severity. Therefore, capacity may also vary with the severity of disability. The DPDP Act does not take a capacity driven approach in the way that the Australian law takes, and instead relegates the consent of persons with disabilities who have legal guardians to be substituted with their guardian's consent. In a theoretical interpretation of the law, this approach is sound if the guardian referred to is restricted to the legal guardian under the RPwD Act,(and not the NT Act) but the practical dissonance in the manifestation of the role of the legal guardian (see Box 2), means that a guardian is likely to deprive the autonomy and personhood of the individual.

Another participant, an activist and person with disability pointed out intersections that may further dis-enfranchise persons with disabilities:

"I might be a woman who may not be able to buy a sanitary napkin (on an online platform), because I my guardian would need to give consent for me to access the website."

On the other hand, a few participants, while recognizing the legal capacity of persons with disabilities, stressed on the need of such a provision to protect individuals who require the guardian to either provide support or make decisions on their behalf. One of the interview participants representing a group of parents of children with intellectual disabilities stated,

"Increasingly whether we like it or not, all children are exposed to screen and online resources that obviously includes persons with intellectual and developmental disabilities, I definitely recognize that all of them have legal capacity. But when it comes to the complications, by way of wrong implications of the acts, being done by them, we need to take that into account....there can be or there may be a need to provide for such small number of cases, as mentioned earlier, who may have already taken up guardianship, and who may still need that sort of protection as safeguards against the financial and other legal implications arising out of the presence of this person on them."

A few interview participants strongly objected to housing of provision on persons with disabilities along with the provision on 'processing of personal data of children' on account of infantilization of persons with disabilities and holding them at the same level as children.

"Persons with disabilities and Children cannot be clubbed together. This infantilises persons with disabilities. Persons with disabilities have legal capacity as recognised under the UNCRPD."

Considering that the guardianship provisions under the RPwD is not implemented as envisaged in letter, and the existence of another legal guardianship system under the NT Act, the current framing of Sec 9 of the DPDP Act puts the data protection law in conflict with the UNCRPD. This view is endorsed by the Centre for Law and Policy Research in their comments to Section 9 of the DPDP Act (attached at Annexure 3) to this report.

Box 4

Capacity under the UNCRPD

- a. Capacity is unique for each individual

Capacity varies from one person to another and may be different for each individual subject to environment and social factors.¹⁴ Unique social circumstances, emotional and intellectual abilities and access to support or resources also determine the capacity of an individual.

- b. Capacity is a dynamic construct

A person's ability to make decisions may change over time and with change in social and environmental factors.

- c. Capacity varies with the nature of decision

A person may have the capacity to make decisions about certain aspects of their lives, but not for others. Therefore, with the variation in nature of decisions, the capacity may vary.

¹⁴ General comment on Article 12: Equal recognition before the law, UNCRPD.

f) Interpretation of the term “Legal Capacity” impedes the exercise of full decision-making capacity of persons with disabilities.

In the digital context, providing consent to share data on the internet in return for access to digital services (such as email, ticket booking, online bank transfers etc.) amounts to a legal contract. Under the Indian Contract Act, there are three conditions for the validity of a contract – (a) the contract must be made by the free will of a person with capacity to contract (b) for consideration and (c) for a lawful object.¹⁵

Consent notices serve as vital contracts in data protection, establishing a clear, legally binding agreement between the user and the data fiduciary. Data fiduciaries are held accountable through these consent notices. If they fail to adhere to the terms of the agreement, they can face significant legal consequences. For instance, under the Digital Personal Data Protection Act (DPDP), a data privacy breach can result in fines of up to INR 50 crore for the data fiduciary.¹⁶ This legal accountability underscores the seriousness of these contracts (i.e consent notice and consent) and thus, it is important for a consent notice to fulfil aspects of a valid contract, as per the Indian Contract Act. Stressing on the significance of consent notices as contracts, Pranesh Prakash a technology law and policy expert stated,

“As long as you consider data as part of your rights and so data protection as part of your rights, the answer is yes (the framing of section 9 of DPDP is appropriate as regards persons with disabilities). So, if data protection is important, this contract that you've entered into, with an app provider, is also important. Now, it may not seem like a big deal when you're doing it, because it takes all of 10 seconds rather than two months that the land transaction, etc. takes. And in fact, it may not be a big deal to you. But it is a legally binding decision that affects rights.”

To be able to contract, the legal capacity of the persons entering into the contract is of great importance. Legal capacity is the ability of a person to enter into a legally binding contract. Legal capacity determines whether a person can vote, get married, enter into all contractual relationships etc.¹⁷ Disabilities encompass a wide range of conditions, each with its unique impact on an individual's cognitive, physical, sensory, and mental

¹⁵ Section 10, Indian Contract Act, 1872

¹⁶ The Schedule, DPDP Act

¹⁷ European Union Agency for Fundamental Rights. Legal capacity of persons with intellectual disabilities and persons with mental health problems. available at https://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems-factsheet-en_0.pdf

abilities. Some disabilities may affect certain aspects of decision-making while leaving others unaffected. For example, a person with a cognitive disability may have difficulty understanding complex legal documents related to a real estate transaction but may be fully capable of making decisions regarding a simple online purchase. Legal capacity may be externally facilitated/ augmented by providing requisite support to an individual with limited decision-making capacity. This position has been recognised under the UNCRPD¹⁸ and the RPwD Act¹⁹ wherein the law while recognising legal capacity of persons with disabilities requires that requisite support must be provided to enable the person to make decisions.

However, in practice, this approach is not always adopted, as the perception of capacity to contract remains obfuscated. Consequently, persons with disabilities are denied services such as banking, insurance, financial transactions in their own name, as service providers take a disability-first approach.²⁰ Despite legal provisions to the contrary members of systems do not recognise varying levels of capacity and a person with reduced decision-making capacity is thus deprived of their decision making capacity under the law.

While consent notices are essential for establishing clear, legally binding agreements and ensuring data fiduciaries' accountability, the current approach to legal capacity and practical aspects of consent mechanisms fails to accommodate the non-binary nature of capacity for persons with disabilities.

¹⁸ Article 12, United Nations Convention on the Rights of Persons with Disabilities

¹⁹ Section 13, RPwD Act.

²⁰ Delivering Justice Solutions to Persons with Disabilities through Online Dispute Resolution Platforms, available at https://pacta.in/Delivering_Justice_Solutions_to_Persons_with_Disabilities_through_Online_Dispute_Resolution.pdf

Box 5

Legal Capacity under Indian Contract Law

Legal capacity is a vehicle that drives meaningful participation in the society.²¹ Denial of legal capacity means depriving an individual/ group of their personhood and their capacity to act.²² For a contract to be valid, all parties involved must have the capacity to understand its terms and obligations. Several factors affect a person's legal capacity:

- i. **Age:** Minors, usually under the age of 18, generally do not have the capacity to enter into contracts, except for necessities or contracts that benefit them.
- ii. **Unsoundness of mind:** Individuals must have the mental ability to understand the nature and consequences of the contract.
- iii. **Intoxication:** A person under the influence of drugs or alcohol at the time of entering into a contract may lack the capacity to contract if they cannot understand the contract's nature.
- iv. **Legal Status:** Certain individuals, such as bankrupts or felons, may have limited capacity to contract.

Under the Indian Contract Law, (i) and (ii) are considered to be factors that determine capacity to contract.

The Indian Contract Act states that a “person is said to be of sound mind for the purpose of making a contract, if, at the time when he makes it, he is capable of understanding it and of forming a rational judgment as to its effect upon his interests.”²³ Therefore, persons with disabilities can enter into contracts unless their specific condition affects their cognitive ability to such an extent that they cannot understand the nature and consequences of the contract.

²¹ Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal Recognition before the Law, para. 13.

²² Article <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf>

²³ Section 12, Indian Contract Act

Recommendations

Recommendation 1 – Remove mandate for guardian consent in Sec 9

Challenge

The DPDP presents an incomplete understanding of guardianship for persons with disabilities and the role of the guardian.

DPDP Act is incompatible with the RPwD Act and UNCRPD, as it presumes that persons with disabilities who have a guardian do not have capacity and would need to act through the guardian only. Thus, the DPDP is feared as denying autonomy and personhood of persons with disabilities.

Legal Capacity as a binary concept under contract law is an impediment to the exercise of full decision-making capacity of persons with disabilities

Specific Provision to be Changed

Amendment to sec 9 DPDP - delete mandate of obtaining consent of persons with disabilities through legal guardian where appointed.

Recommendations for DPDP Rules/ amendment to Act

- The Act may be amended to remove the mandate for guardian consent for persons with disabilities in Sec. 9.
- Government may consider constituting a committee comprising persons with disabilities, their parents/guardians, service providers etc. to determine the process for obtaining informed consent of persons with reduced decision-making capacity.
- Until such time, Government may refrain from drafting any rules pertaining to the implementation of Section 9(1) for persons with disabilities.

Recommendation 2 - Accessibility compliance

Challenge

Inaccessibility of webpages and apps, difficulty in reading and comprehending lengthy or complex statements in consent notices would impede the implementation of DPDP Act.

Specific Provision to be Changed

Exercise rulemaking powers under Sec 5(1) and 13 (1).

Recommendations for DPDP Rules/ amendment to Act

- Compliance with Rule 15 of RPWD Rules, which specifies IS 17802 as the standard to be followed for all public and private digital infrastructure, to be made mandatory. This will ensure that consent for digital personal data collection and processing practices and grievance redressal mechanisms are accessible and inclusive.

Recommendation 3 – Minimize data collection

Challenge

Data pertaining to disability status may be collected unnecessarily.

Specific Provision to be Changed

Exercise rulemaking powers under Sec 5(1)

Recommendations for DPDP Rules/ amendment to Act

Provide obligations for data fiduciaries to minimize collection of data pertaining to disability status as well as personal data of persons with disabilities.

Recommendation 4 – Consequences for incorrect disclosure

Challenge

Data principals may disclose inaccurate data and get penalized therefore.

Specific Provision to be Changed

Exercise rulemaking powers under Sec 5(1) pertaining to the form of notice.

Recommendations for DPDP Rules/ amendment to Act

The Rules may mandate that the user should be made aware of the consequences (risks) of providing wrong/ inaccurate data on disability status and the specific benefits of disclosure if any. If in any case such information has been mistakenly provided by the data principal, no penalties should apply.

Annexures

Annexure 1 - Methodology

A mixed methods design was used to uncover attitudes and perceptions towards the new DPDP Act, 2023 concerning persons with disabilities. While the study was envisaged as a qualitative study with experts and persons with disabilities holding positions of influence, the findings from the consultations revealed general inaccessibility of websites and consent processes. This led to the quantitative piece of work.

Qualitative Approach

The qualitative approach involved focus group discussions in the form of stakeholder consultations and in-depth individual interviews. We conducted 3 FGDs/consultations – 1. With nine participants who were a mix of representatives from civil society initiatives, corporations, and activists, 2. Had six participants with parents, Foundations, and NGO representatives, 3. With six participants from corporations and public policy specialists. In addition, nine individual interviews were conducted with legal experts, persons with disabilities, activists, policymakers, and representatives from civil society organizations. All consultations and interviews took place online and lasted between 45-60 mins each. Interviews were

Quantitative Approach

Survey

A survey containing questions on internet usage patterns, challenges in consent protocols, and concerns with data sharing were explored with persons with disabilities and those without. In addition, for persons with disabilities, questions around legal guardianship and their role in internet access were examined. A total of 105 persons without disabilities and 94 persons with disabilities responded. Of the 94 persons with disabilities, 2 declined to take the survey and 1 parent responded. Hence, a total of 91 self-reported answers were selected for analysis.

The survey was distributed among Pacta's networks and civil society organizations for persons with disabilities and those without. For persons without disabilities, social media posts were created to amplify the survey.

Survey Sample

People without Disabilities

General demographic details of the participants were collected such as age, gender, and highest level of education. Below is the description of the profiles of the participants.

Figure 1: Age distribution of the Non-PwD Sample

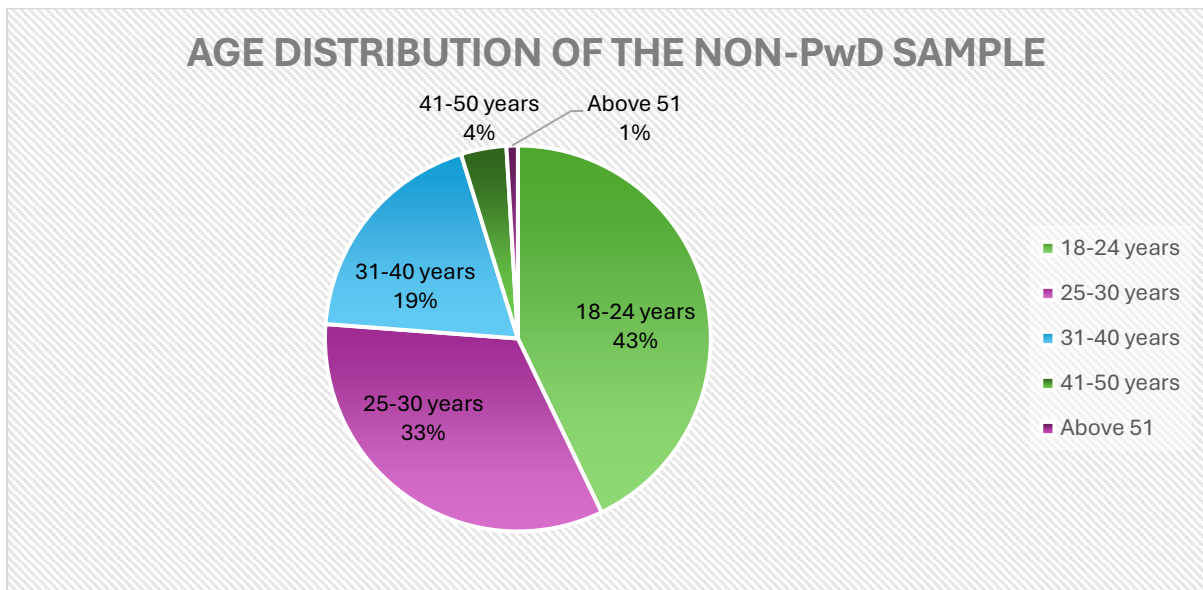
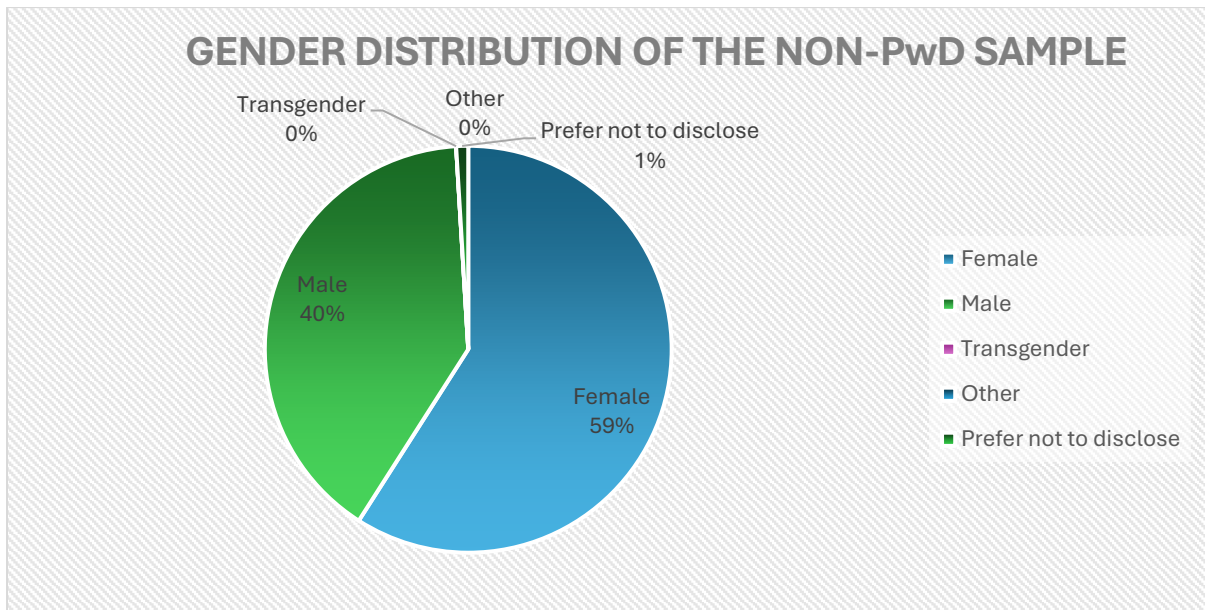


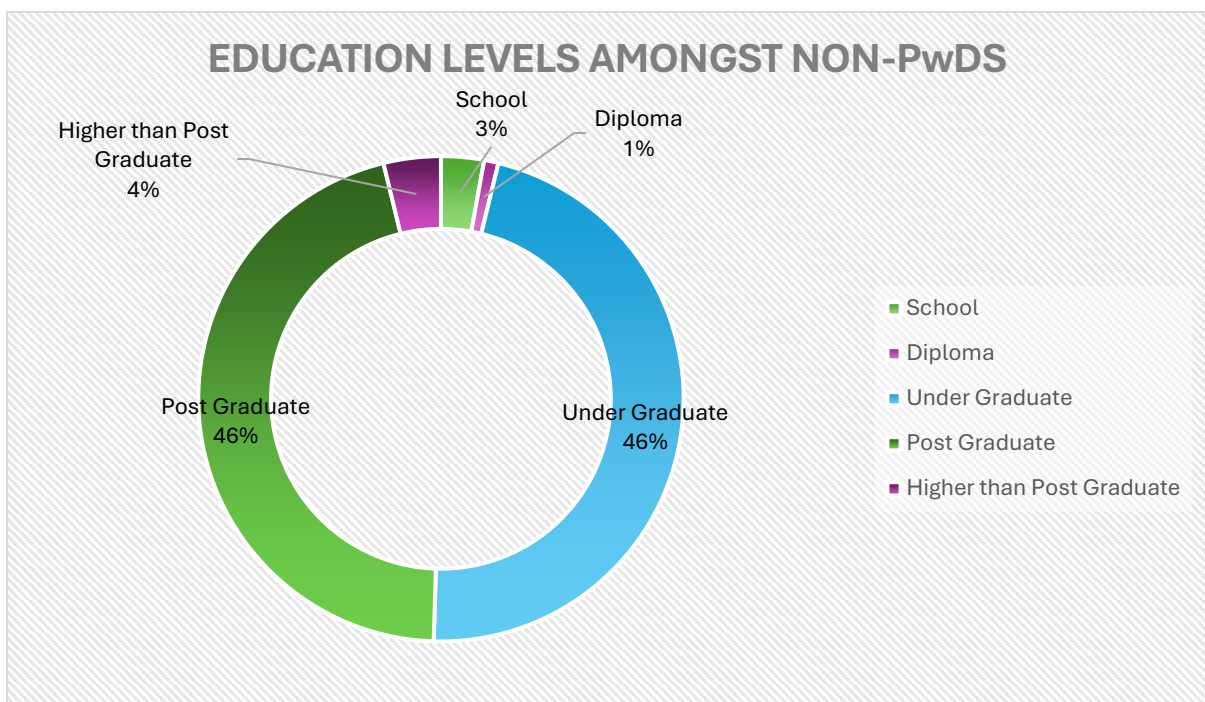
Figure 1 shows the age distribution of the non-PwD sample. The figure shows that about 76% of the sample were in the age groups of 18-30 years with greater representation of those between 18-24 years. Furthermore, there were more females/women in the sample accounting for 59% followed by males/men (40%) as shown in **Figure 2**. The higher sample of women could be due to the nature of the sampling done (i.e., convenience), which was based on Pacta's networks.

Figure 2: Gender distribution of the Non-PwD sample



There was an equal distribution of undergraduates and post-graduates in the sample accounting for 92% of the sample. Those with higher than post-graduate and having completed schooling were minimal.

Figure 3: *Education qualifications among Non-PwDs*



People with Disabilities

For the persons with disabilities sample, the distribution of age, gender, and educational qualifications was more varied. Figure 4 shows the age distribution in the sample of PwDs who

took the survey. Most of the PwDs were within the age group of 18-40 years, representing 81% of the sample with larger numbers in the age group of 18-24 (similar to the non-PwD population). Additionally, 12% belonged to the age group of 41-50 years. However, the sample had more males/men (74%) than females/women (24%), as depicted in Figure 5. Literature shows that women with disabilities in lower and middle-income countries had higher rates of digital exclusion had lower access to mobile devices and had a lower likelihood to use them compared to their male counterparts.²⁴ Other factors such as stigma, lack of education, and violence create greater social exclusion for women with disabilities.²⁵ This could be one of the reasons for the lower representation of women/other gender minorities with disabilities in the sample.

Figure 4: Age distribution of the PwD Sample

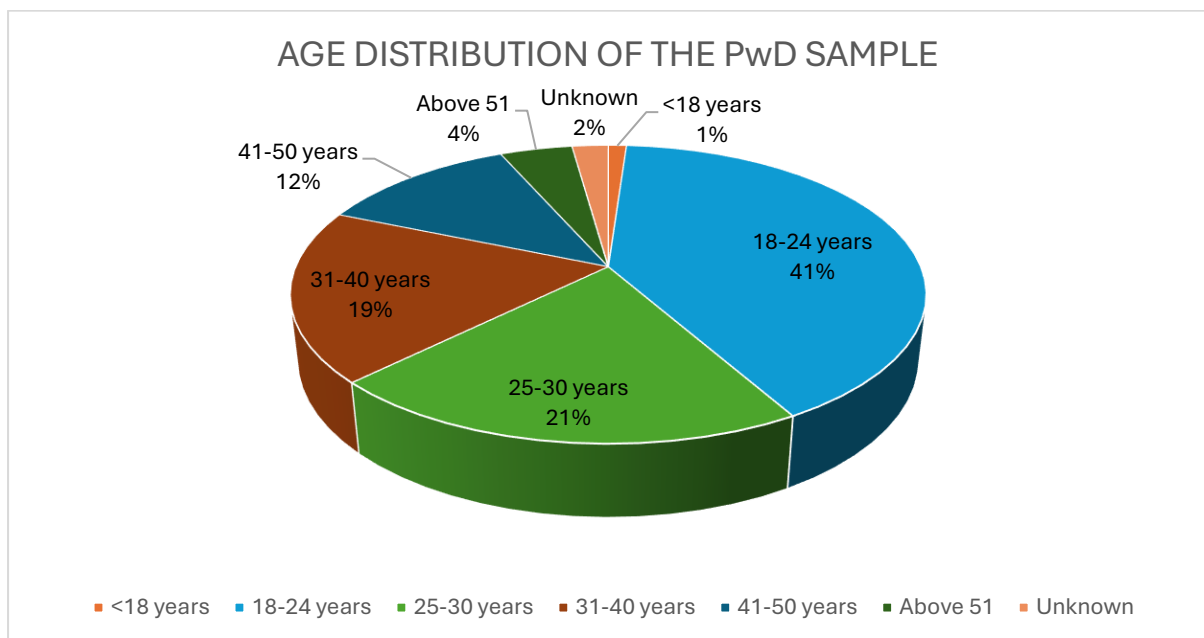
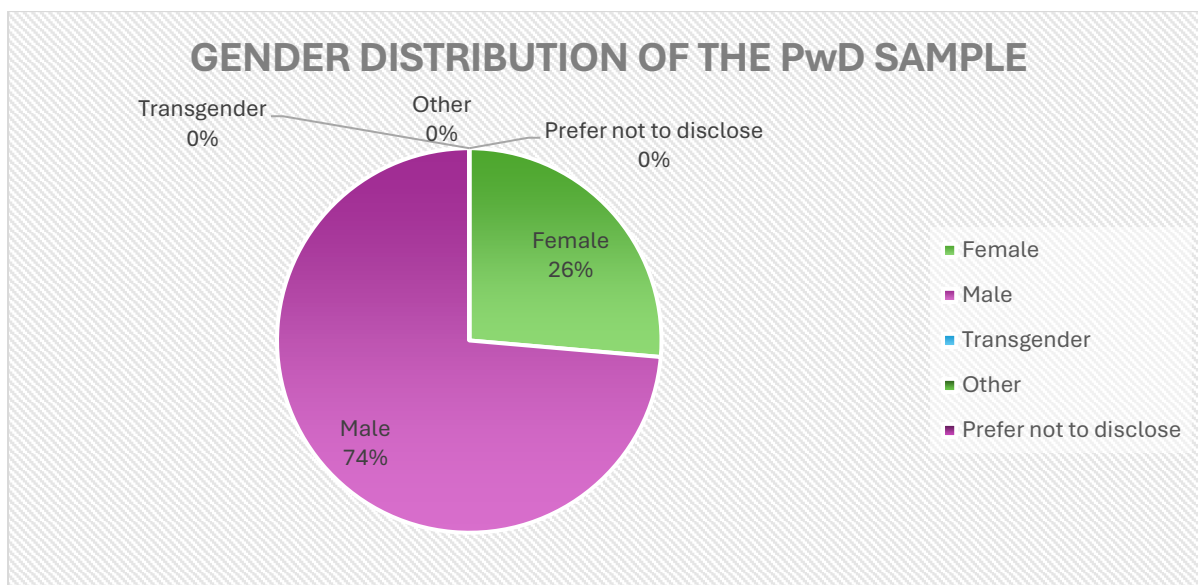


Figure 5: Gender distribution of the PwD sample

²⁴ https://www.gsma.com/solutions-and-impact/connectivity-for-good/mobile-for-development/wp-content/uploads/2020/07/GSMA_Digital-Exclusion-of-Women-with-Disabilities_44pp_ACCESSIBLE.pdf

²⁵ <https://www.unicef.org/media/131316/file/Accessible%20and%20inclusive%20digital%20solutions%20for%20girls%20with%20disabilities.pdf>

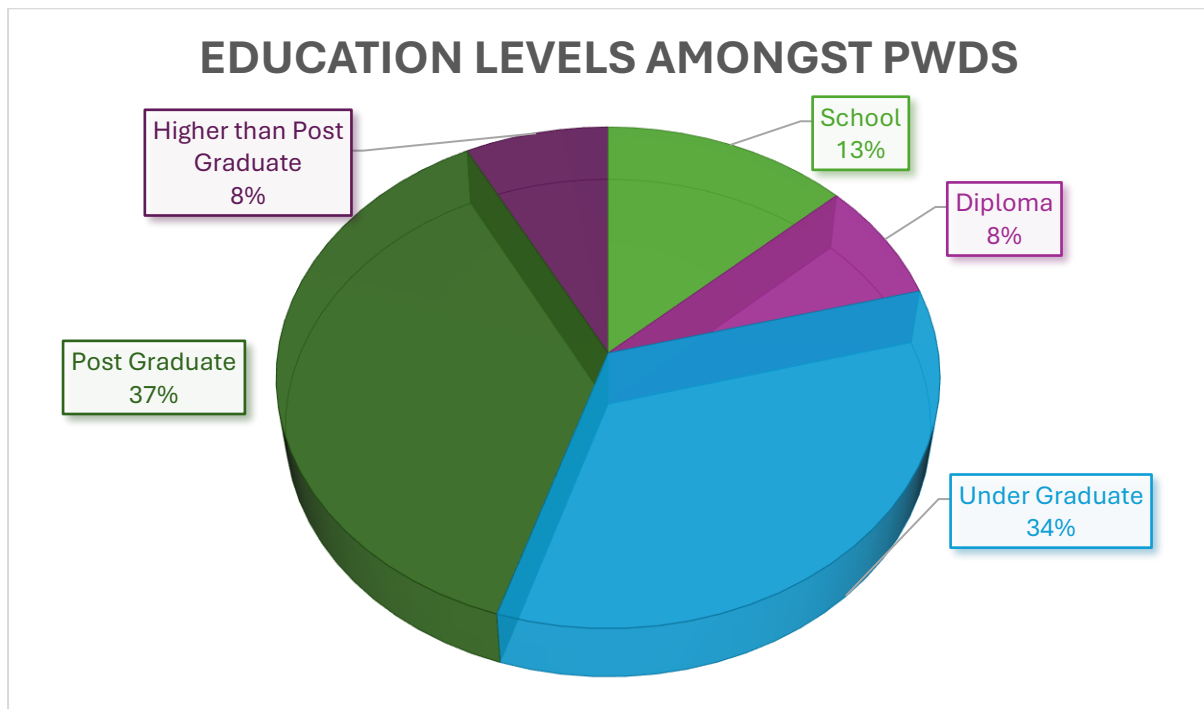


Levels of education varied among PwDs with the highest representations (71%) of those with undergraduate and post-graduate degrees. While there were fewer numbers of those with completion of school and higher than post-graduate compared to those with undergraduate and post-graduate degrees in the group, the numbers were greater than the non-PwD groups. 8% had diploma degrees compared to 1% in the non-PwD group. Access to education for those with disabilities is a challenge in India and the increasing severity of disabilities leads to greater challenges in accessing education and work opportunities.^{26,27} Therefore, the proportion of PwDs holding school certificates and diplomas is higher than the non-PwD population.

²⁶ <https://www.unicef.org/rosa/media/16996/file/Country%20Profile%20-%20India.pdf>

²⁷ <https://www.epw.in/journal/2022/44-45/special-articles/challenges-persons-severity-disabilities.html>

Figure 6: Education qualifications among PwDs



11 of the 21 disabilities (as per the Rights of Persons with Disabilities (RPwD, 2016) were represented in the sample. Almost half of the sample had people with blindness and a more evenly distributed sample among those with low-vision and locomotor disabilities. The distribution chart is shown in Figure 7. The high representation of people with blindness is due to convenience sampling as well as from inputs from our stakeholder consultations that revealed certain types of disabilities (such as blindness, low-vision, intellectual and developmental disabilities, and those with limb disabilities) facing greater challenges on the internet. Additionally, Figure 8 shows the severity of disability with a majority of those with greater than benchmark disability. 61/91 individuals had >81% disability. Since a majority of those with disabilities in the sample have blindness, there is a higher proportion of those with >81% disabilities.

Figure 7: Types of disabilities in the sample

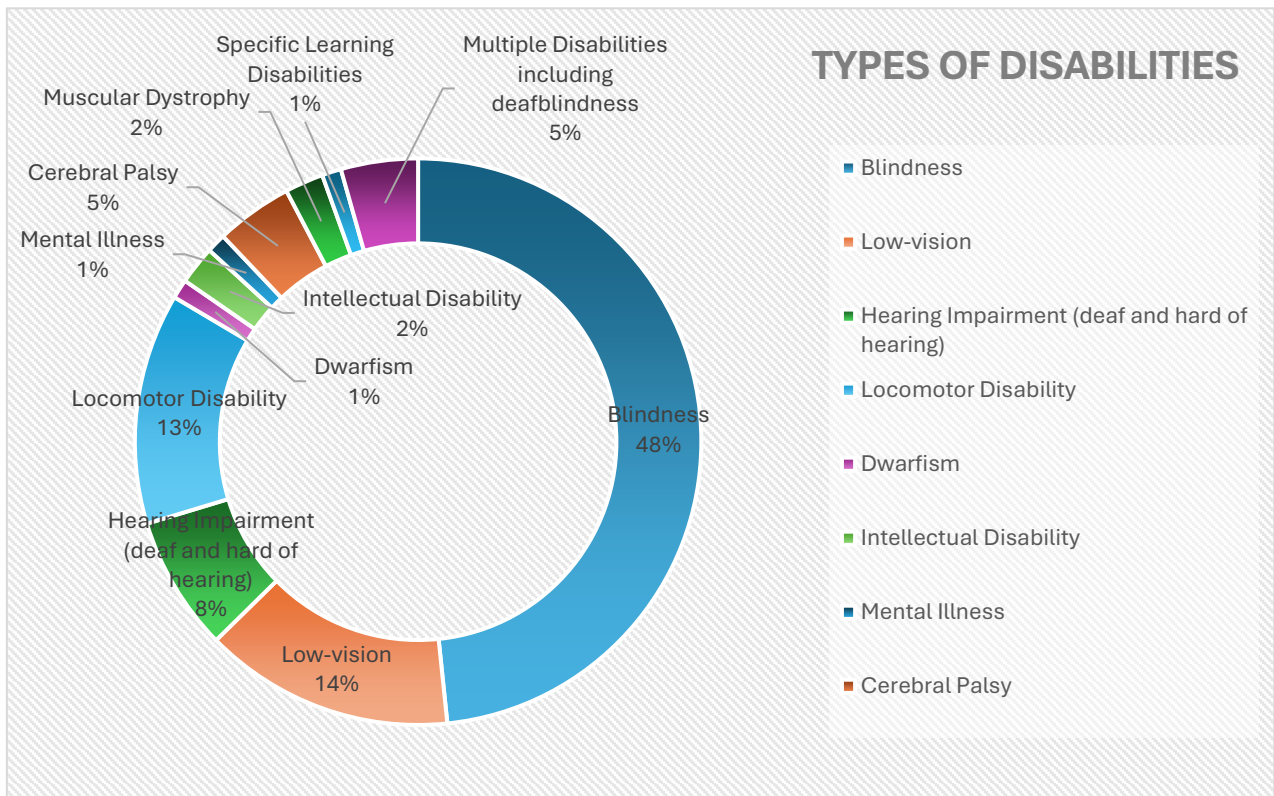
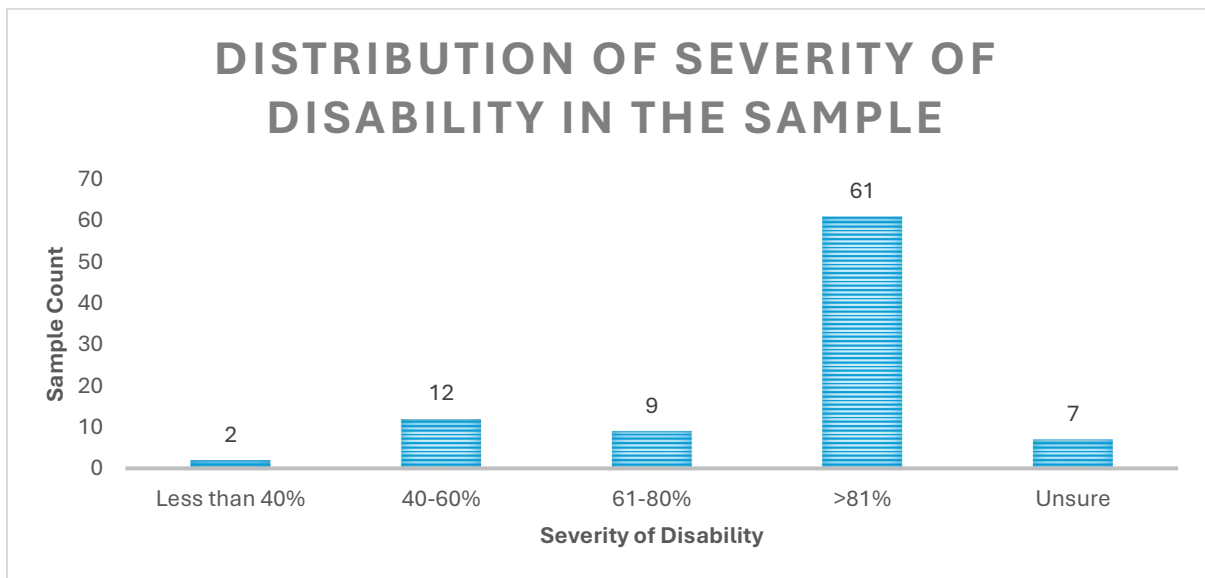


Figure 8: Severity of the representative disabilities in the sample



Observational Experience

An observation was conducted to understand and report how persons with disabilities practically navigate and interact with the consent framework on the service websites. The observation was done on seven websites.²⁸ The service applications/websites are listed below.

- a. Paytm
- b. Ola
- c. Swiggy
- d. Zomato
- e. Amazon.in
- f. Flipkart
- g. WhatsApp

Participants

- **4 persons with disabilities** were recruited for the study.

The study included those who fulfilled the following criteria

- Individuals with disabilities who are between 18-50 years of age
- Individuals with disabilities who use the Internet every day
- Individuals who are mostly independent in the use of the internet (i.e., who do not entirely depend on a legal guardian or family member/friend for accessing the internet)
- Individuals who can read and understand English.

Table 1: Participant Profile

#	Name (pseudonyms are used)	Age	Type of Disability	Severity of Disability	Type of Accessibility Feature Used
1	Shyam	25	Blindness	100%	Screen Reader (NVDA)
2	Nikhil	40	Intellectual Disability	65-85%	None (highlights or needs contrast)

²⁸ Jauher et al. (2023). Making the digital ecosystem disabled friendly - An evaluation of the accessibility of ten widely used apps in India. Vidhi Center for Legal Policy. <https://vidhilegalpolicy.in/research/making-the-digital-eco-system-disabled-friendly/>

					to help breakdown text for better comprehension)
3	Reeshma	22	Low Vision with Central Vision in the Left Eye	15-20%	Magnifier
4	Shekhar	40	Mental Illness (Bipolar Disorder Type II)	50%	None

Recruitment

Participants will be recruited from a leading disability organization in Bengaluru. Staff were requested to participate in the study. Participation was completely voluntary.

Participants were assigned 2 websites to navigate on a laptop and phone. The order of randomization for each participant is below.

Order for randomization per participant

Pattern #	Sites/Apps (Round 1)	Sites/Apps (Round 2)
1	Zomato	Amazon.in
2	Swiggy	Ola
3	Amazon.in	Paytm
4	Flipkart	WhatsApp

Procedure

Researchers explained the purpose of the experiment to the participants.

To

Are you aware of the terms and conditions and privacy policy on websites? We are keen to understand how you navigate and access these privacy policies so that you gain the information needed on how these websites use and share your data. We will give you two service providers

*websites where you need to navigate to the privacy policy and read through some highlighted parts. This you will do on both on the computer and phones. If you get fatigued or find it difficult, we can stop at any time. The whole process will take between **45-60 mins**.*

After you have completed the experiment, we will spend some time talking about your challenges. Your participation is completely voluntary and extremely valuable to us.

When you are ready, we will start the experiment. We will start by taking your consent."

Once explained consent was taken.

This experiment is conducted as a part of the research study by Pacta and Saksham Disability to assess access to digital platforms and data sharing on such platforms. As a part of this experiment, we will observe and assess the way you navigate and understand data-sharing privacy clauses. We will retain information from the experiment only for the duration of the research study. We will not disclose or share your personal information with any other entity. We will follow security standards to maintain the confidentiality of your personal information.

I consent

I do not consent

4. Once consent was taken, researchers started the experiment.

For computer

- a. The participant went to the Chrome browser and opened the website that was given to them.
- b. In case the person with a disability preferred help, help was provided.
- c. Navigation at each step was observed.
- d. Participants were asked to find the privacy policy and to navigate to the privacy policy page.
- e. Under the privacy policy page, researchers had prepared highlighted sections for the participants to read out and explain what they had understood. The participants read a few lines under each section. Participants were asked to stop if
 - i. Exhausted or
 - ii. had understood
- f. Observations were noted on a sheet.

For phone

- a. Once the participant had completed navigating the assigned website on the computer, they were asked to go to the corresponding app on the phone.
- b. Participants were asked to identify the terms and conditions and privacy policy page.
- c. Participants were asked to go to the privacy policy page and asked if they had difficulties in reading the text or navigating the page.
- d. Observations were noted on a sheet.

In addition to the observations, participants were asked about their experiences in participating in the experiment and the challenges they had. Additionally, participants were asked about what privacy meant to them particularly in the digital space and as a person with a disability.

Annexure 2 – Guardianship under the National Trusts Act and RPwD Act

Table 2: Comparison of the NT Act and RPWD Act on various aspects of legal capacity and legal guardianship

Features	National Trust Act 1999	Right of Persons with Disability Act 2016
Application	This Act applies to individuals with disabilities who are diagnosed with conditions related to autism, cerebral palsy, intellectual disability (previously known as mental retardation), or any combined occurrence of two or more of these conditions. Additionally, the Act encompasses individuals experiencing severe multiple disabilities.	The Act applies to individuals with disabilities, defined as "persons experiencing long-term physical, mental, intellectual, or sensory impairments which, when interacting with various barriers, hinder their full and effective participation in society on an equal basis with others."
Objective	The Act's primary goal is to establish the National Trust, a national body dedicated to furthering the welfare of individuals with disabilities. This encompasses comprehensive oversight of matters concerning guardianship and decision-making , alongside promoting their socio-economic well-being.	This Act serves as India's implementation of the UNCRPD. It aims to advance the rights of individuals with disabilities, including autonomy and equality, through various provisions. These include: <ul style="list-style-type: none"> • Non-discrimination: Prohibiting discrimination against individuals with disabilities in various spheres of life. • Equal legal capacity: Recognizing the equal legal capacity of individuals with

Features	National Trust Act 1999	Right of Persons with Disability Act 2016
		<p>disabilities, dismantling discriminatory practices that previously denied them agency in decision-making and participation.</p> <ul style="list-style-type: none"> • Access improvement measures: Implementing measures to ensure accessibility and remove barriers that hinder their full participation in society.
Decision-Making Capacity	<p>While the Act itself does not explicitly define "decision-making capacity" for individuals with disabilities, it does offer guidance through the process of appointing a guardian. The Local Level Committee, responsible for such appointments, must consider whether the individual with a disability genuinely requires a guardian to assist with decision-making. This implies an implicit understanding of decision-making capacity as the ability to make informed choices and manage one's affairs without undue influence.</p>	<p>Aligning with the UNCRPD principles, the Act acknowledges the equal legal capacity of all individuals with disabilities. Consequently, it discards the concept of "decision-making capacity" as a basis for disenfranchisement. However, recognizing that some individuals may require support in exercising their legal rights, the Act introduces the concept of a limited guardian. This mechanism allows for support in making specific legal decisions when the individual's capacity is deemed insufficient.</p>

Features	National Trust Act 1999	Right of Persons with Disability Act 2016
Process of appointment of Guardian	<p>The Act draws on the traditional guardianship model but takes the consent of the PwDs for the appointment of a guardian. This guardian assumes responsibility for the person's care, maintenance, and property. While the Act avoids directly referencing decision-making, it implies the guardian acts as a surrogate decision-maker once appointed. However, crucially, the Act lacks clear principles or standards guiding the guardian's actions, raising concerns about the potential for undue influence and compromised autonomy.</p>	<p>While the Act doesn't explicitly outline a formally supported decision-making approach like the UNCRPD, it echoes its principles through the emphasis on supporting individuals with disabilities in exercising their legal capacity. This support is implicit in various provisions. Additionally, the Act recognizes that even with support, some individuals might still struggle to make specific legal decisions. In such cases, upon application to the District Court (or other authority as may be notified by the respective state), a limited guardian can be appointed to assist with those specific decisions, ensuring legal capacity is upheld while acknowledging individual needs.</p>
Safeguards and Limitations	<p>The Act establishes safeguards for individuals under guardianship by mandating appointed guardians to disclose details of the person's property after appointment and submit annual reports. These measures promote transparency and accountability. Furthermore, guardianship can be revoked if the guardian abuses, neglects the person, or misuses their property, ensuring the person's</p>	<p>The Act acknowledges the importance of supported decision-making and introduces safeguards to prevent abuse and conflicts of interest. It prohibits support persons from assisting where conflicts arise, protects the validity of past transactions even if the support person changes, and forbids undue influence. However, the crucial aspects of detailed procedures and clear guidelines for addressing actual abuse or conflict situations are absent. This lack</p>

Features	National Trust Act 1999	Right of Persons with Disability Act 2016
	well-being and protecting their rights. However, the complaint can be only made by parents, relatives or friends, not by the PwDs themselves.	of clarity could leave individuals vulnerable in such situations.

Annexure 3 – Comments by the Centre for Law and Policy Research on Section 9, DPDP

CLPR Comments on Section 9 of the Digital Personal Data Protection Act, 2023 in the context of the rights of persons with disabilities

1. Section 2(j) of the Digital Personal Data Protection Act, 2023 (“DPDP Act”) states that in the case of persons with disability, their legal guardian shall also be included in the definition of "Data Principal".

2. The wording of the section suggests that all persons with disability have or require a legal guardian. This is squarely against the scheme of the Rights of Persons with Disabilities Act, 2016 (“RPD Act”), which recognizes in Section 3, the inherent dignity, right to personal liberty and legal capacity of persons with disabilities. There are various categories of disability, most of which do not compromise mental acuity and capacity of individuals. Further, even in cases of intellectual disabilities, the capacity to consent is dynamic and such individuals may only have the need to appoint a legal guardian in certain circumstances or at specific times or in a certain manner. Consequently, Section 14 of the RPD Act only provides for the appointment of guardians only for a limited time and purpose. The presumption in 2(j) of the DPDP Act that a legal guardian shall be included along with PWDs is a clear violation of their rights to non-discrimination and autonomy.

3. Response to Section 9 of the DPDP Act:

(i) As noted by various stakeholders, the inclusion of Persons with Disabilities in a provision which pertains to the Data Fiduciaries' responsibilities towards children is per se arbitrary and without application of mind. The margin note for the section reads "Processing of personal data of children", which makes it clear that the section is designed only to apply to children and minors. In fact, persons with disabilities are only specifically covered under sub-section (1) but not in sub-sections (2)-(5) even though sub-sections (4) and (5) pertain to exemptions to the application of sub-section (1).

This raises the question of whether persons with disabilities are meant to be clubbed with children and minors in the latter sections or whether the DPDP Act contemplates no situation where a Data Fiduciary may process the personal data of a person with disability having a guardian unless consent from the guardian is obtained.

(ii) S.9 refers to "persons with disabilities with a lawful guardian" and requires consent of such guardian to process their personal data. However, it is vague on the nature of the guardianship. Under the RPD Act, guardianship must be limited to a specific period of time for a specific decision and situation and shall be in accordance with the will of the person with disability. It is only in certain cases where total support to take legal decisions is granted based on the nature and circumstances in question. Alternatively, for persons with autism, mental retardation and cerebral palsy or severe multiple disability, the National Trust Act 1999 prescribes that a guardian may be appointed based on whether it is necessary to support the person and for which specific purposes. Consequently, in cases of persons having a lawful guardian, such guardians will not be empowered to provide consent for processing of data under the DPDP Act unless specifically appointed for the purpose.

(iii) Notwithstanding the textual vagueness of the section, the requirement of a guardian's consent for the processing of data of PWDs is contrary to law. Under Section 13(2) of the RPD Act, persons with disabilities have legal capacity on an equal basis with others in all aspects of life. It is for this reason that guardians may be appointed only in specific cases and for a specific purpose. Further, Article 12 of the UN Convention on the Rights of Persons with Disabilities, 2006 (“UNCRPD”) states:

“(1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

(2) State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”²⁹

The DPDP Act applies the legal presumption of children's incapacity to consent to PWDs which runs counter to the rights of persons with disabilities enshrined under the UNCRPD and the RPD Act. The presumption of a lack of legal capacity and the reference to a legal guardian for all persons with disabilities thereby amounts to discrimination on the basis of disability and a lack of recognition of their legal capacity.

These sections under the DPDP Act are thus in complete violation of the RPD Act and need to be amended to delete references to persons with disabilities. They are a setback to the rights-based approach to disability established by the Rights of Persons with Disabilities Act, 2016 and the Mental Healthcare Act 2017 in line with India's obligations under the UNCRPD.

²⁹ Art. 12, UN General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Annex I, 13 December 2006.