DISABILITY AND DIGITAL SELF-DETERMINATION

DESIGN BY DESIGN BEKU

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CONTENTS

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INTRODUCTION AND OBJECTIVES

As our daily digital footprints grow, human society is grappling with new concepts, experiences and understandings of the relationships between our lives and the technologies that we use. Who are we as digital beings? Are we able to determine our 'selves' in a data-driven society?[11] How do we locate ourselves as empowered data subjects in the digital age? How do we re-imagine human autonomy, agency and sovereignty in the age of datafication?

Digital Self-Determination (DSD) is a valuable concept to consider some of these critical questions. Self-determination itself has always been a foundational or root concept related to human existence, with distinct yet overlapping cultural, social, psychological, philosophical understandings built over time. In a similar vein, DSD is a complex notion to be viewed from different perspectives, re-shaping what we understand as self-determination itself.

DSD fundamentally affirms that a person's data is an extension of themselves in cyberspace, and we need to consider how to provide a certain level of autonomy and agency to individuals or communities over our digital selves. The concept of Digital Self-Determination implies much more than just protecting personal data and privacy. Here, we are talking about determining the self in new digital life spaces. As such, DSD is a novel, evolving and multifaceted concept that enables us to navigate the complex dynamics of digital transformation.

In 2023, Point of View, Design Beku, Swissnex in India, and the Embassy of Switzerland in India convened a series of four studios on Disability and Digital Self-Determination. The day-long studios were held in Delhi in February, in Mumbai in March, and in Bengaluru in April and May, bringing together persons with disabilities (PWDs); technologists, designers and developers; disability rights activists; researchers; academics and civil society members. These studios were part of a larger effort of the **International Network on Digital Self-Determination** and the Directorate of International Law of the Swiss Federal Department of Foreign Affairs to operationalise DSD. It was one of several studios carried out in various countries looking at DSD in the context of open finance, mobile money, migration, education and tourism. We had a total of ***92 participants*** across the four studios: 82 in-person and 10 online. The studios explored DSD through the lens of diverse disabilities: visual, hearing, locomotor and psychosocial. We unpacked DSD through an intersectional feminist lens that recognised diverse yet interconnected cultural and social contexts

[11] *https://cyber.harvard.edu/projects/international-digital-self-determination-network#:~:text=Data%20is%20changing%20how%20we,in%20our%20data%2Ddriven%20spaces%3F*

In each studio, participants populated the evolving theory of DSD via concrete examples, illustrating its meaning and value in everyday life. Each studio functioned like a collective learning lab to build and further our shared understanding of Digital Self-Determination through the lens of disability.

The objectives of the four DSD Studios were to:

- Understand the root concept of self-determination and its key components
- Explore the concept of Digital Self-Determination through the lens of disability
- Co-create DSD through theory, practice, lived experience and concrete examples
- Operationalise DSD via a set of core principles and policy recommendations

4

DESIGN AND PROCESS

Importance of using design as a lens for DSD

Considerations of Digital Self-Determination are dominated by the role played by technology in shaping these parameters, but there is still very limited discussion of how the design of digital products and interfaces shape the experiences of users and profoundly influence their own capacity for agency to ensure self-determination in the digital world. Accessibility is often seen as a suitable response to these issues, but the paradigm of accessibility is severely inadequate to address the range of disabilities experienced. Despite the role it plays in making technology easier to use for persons with disabilities, guidelines focus more on user experience and play little to no role in making technology use safer and more privacy forward for PWDs. Their dependence on others to navigate a world meant for non disabled people means that they must "consistently engage in privacy management in their daily lives as they encounter professionals, friends, and strangers who press up against the privacy barriers that able-bodied people take for granted." (Mcrae et al, 2020)

Technology when being built for the contexts of disability can often include “the risk of exploitation and invasion of privacy” as they might be very data intensive in order to provide a personalised experience – “service providers who wish to adopt technology are faced with the challenge of determining how to use it in a way that respects individuals’ personal privacy while also maintaining safe and secure living conditions.” (Brand et al, 2020).

Standards such as those put forward by the W3G consortium for accessibility have profound limitations. Even adjustments made for the visually disabled are not sufficient to facilitate ease of use - screen readers “are a retrofit technology developed to patch up the accessibility gap left by the exclusionary design of web pages through a visual user interface alone” (Oswal, 2019).

Standards, regulations, policy frameworks

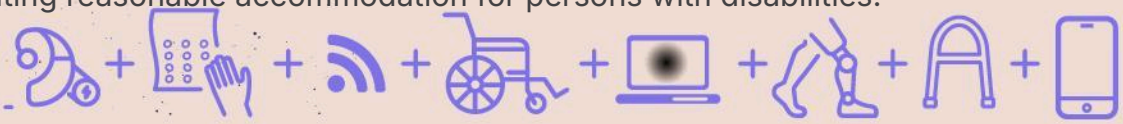
Right of Persons with Disability Act, 2016: The Right of Persons with Disability Act 2016 is the primary document for the protection of the rights of persons with disabilities to ensure their full participation. The Act provides several direct and indirect provisions (such as Section 2(y) “Reasonable Accommodation”, Section 40 on “Accessibility”, and Section 42 on “Access to Information and Communication Technology”) to ensure that technology products and services are accessible to a person with disabilities.

Rights of Persons with Disabilities Rules 2017: The 2017 rules under Rule 15 (2) task the respective Ministries and Departments to ensure compliance with accessibility standards.

Guidelines for Indian Government Websites (GIGW): The GIGW provide a framework for websites to be designed in accordance with Web Content Accessibility Guidelines (WCAG) 2.0 standards. The GIGW enables websites to obtain certification by the Standardisation Testing and Quality Certification Directorate, after audit.

National Policy on Universal Electronic Accessibility, 2013: The National Policy ("Policy") on Electronic Accessibility recognizes the need to eliminate discrimination on the basis of disabilities and to facilitate equal access to Electronics & ICTs. The National Policy also recognizes the diversity of differently-abled persons and provides for their specific needs. The Policy covers accessibility requirements in the area of Electronics & ICT by different stakeholders. It recognizes the need to ensure that accessibility standards, guidelines and universal design concepts are adopted and adhered to.

Web Content Accessibility Guidelines (WCAG): The WCAG defines how to make web content more accessible to persons with disabilities. While adhering to these guidelines is optional, various versions of the WCAG have been issued. It operates on four principles; perceivable, operable, understandable and robust. It provides a path to ensuring compliance and demonstrating reasonable accommodation for persons with disabilities.



Point of View's review of curricula available online to help train developers and designers to use these accessibility guidelines found that they most required a certain level of literacy to comprehend fully, and all rooted in a Global North context. Most of the resources are in English, and require a high level of English proficiency to understand.

Designers and developers are not trained adequately to address the challenges of PWD users as they are only exposed to designing for disability as an add-on, rather than a feature which expands the scope of use, and can in fact contribute to innovative customisation for people who do not have disabilities as well! The range of features and affordances on average are quite narrow, forcing users to conform to what the product requires rather than the other way around. While there have been cases in the US threatening legal action against organisations that do not sufficiently provide for accessibility in their digital products, such regulatory frameworks in India are insufficient and rarely enforceable.

Product teams are rarely trained sufficiently to imagine alternatives from the outset for digital products. An accessibility layer that allows users to customise their own use, exists but has very low adoption. Products have a very low bar of checking tickboxes of compliance, rather than ensuring effective use in action by PWDs, leading to "checklists, automated tools and analytics act[ing] as proxies for disabled experience, and can inhibit rather than encourage collaborations between developers and disabled users." Continuous and sustained efforts have to be in place to ensure that developers and designers are always up to date with solutions and knowledge about how to build accessibility.

"...disability itself is so socially and culturally contingent (Shakespeare and Watson, 2001) [...] accessibility is an interaction rather than the discrete property of a particular product or service." (qtd. in Lewthwaite et al, 2019)

Designing technology is never a neutral endeavour: values are baked into user experience design, and the imagination of any product should ideally always incorporate the possibility of how it might be used by PWDs, without exception. There is a tendency to segregate products meant for PWDs, and this can lead to exclusion, especially as citizenship, services, personal relationships and participation in the political economy is increasingly rapidly mediated by digital technology. Consistent training in up to date methods to ensure optimisation of technology for disabled users would ideally be part of training for designers and developers, to ensure that it is present from the outset rather than an add-on.

When we examine accessibility through the lens of user experience, we see that accessibility is:

- A core value, not an item on a checklist.
- A shared concern, not a delegated task.
- A creative challenge, not a challenge to creativity.
- An intrinsic quality, not a bolted-on fix.
- About people, not technology.

(From *A web for all: A manifesto for critical disability studies in accessibility and user experience design,* Lewthwaite et al, 2018)

ENVISIONING THE STUDIOS

"Listen, don't assume"

At the outset of planning these studios, we realised that the key to facilitating a useful dialogue about designing for PWDs would only be possible if designers and technologists were in conversation with them in order to truly understand their needs – "nothing about us without us" as disability justice demands. The major areas which this conversation covered were:

1. Standards and policy regulations
2. Designing for a range of disabilities
3. Recommendations from PWDs
4. The constraints felt by designers, either due to their organisational context or lack of
5. awareness of how PWDs navigate technology

Despite a raft of standards and regulations in India, the lack of enforcement of these policies often mean that these intentions fall at the first hurdle, and do not contribute meaningfully to creating a more equitable world for PWDs. Merely using or implementing accessibility guidelines does not contribute to a nuanced understanding of how PWDs use technology, or their felt needs. Everyday, often essential activities such as banking, are exclusionary. For Deaf and hearing impaired customers are not contacted in the mode they prefer; relatives and friends are not permitted to be “trusted intermediaries”. Ensuring colleagues have basic knowledge of sign language, ensuring workplaces have accessibility help desks, implementing pre-meeting homework by colleagues without disabilities to reduce information overload during meetings were just a few changes PWDs would like to see in the workplace.

PWDs made a number of suggestions that they would like to see in technology design. PWDs pointed out that designers should take pride in the fact they are making a difference in the quality of life of users, and that to do so is not to compromise on quality nor the promise of profitability (such as Apple, which has been relatively PWD friendly from the outset).

- PWDs advised that when upgrading an app from one version to the next, continuity must be ensured; allow users to toggle to previous versions in case the new added features don’t work sufficiently for them.
- Rather than merely think empathetically, designers should think about what it is like to be disabled. Disability can affect people's lives to any degree and at any point in their lives, which demonstrates why such an approach is essential – to imagine designing for oneself in a different situation.
- A variety of input and output configurations should be kept in mind when designing technology, such as keyboard, mouse, adaptive devices etc. Technology should be able to cater not only to the user but also to the different environments that PWDs might find themselves in, such as a Deaf person who is using a caption application to navigate an environment with many different accents, languages around them, such as an airport.
- The over reliance on technology when it is not essential can also overburden PWDs, such as QR codes in restaurants and physical spaces.
- The learning curve experienced by users should also be taken into account, and have settings for different user levels, such as basic, advanced, so that beginners/first time users can easily access the interface through a default beginner option.
- A “snakes and ladders” approach was suggested when designing for visually impaired users: a way of working with screen reader software should ensure that elements must be arranged in a linear manner. Snakes represent inaccessible components that upset flow, and ladders represent useful shortcuts (like skip etc.).

- For those who have motor or physical difficulties “handedness” can create an obstacle, so designers need to ensure that applications can be designed to work without a mouse or keyboard shortcuts.
- Multi-sensory and multi-modal options should be provided for learning or using tools,allowing multiple ways to attempt a task in apps (such as voice, text, visual aids etc.).
- PWDs need to know what features are available in order to use them, but websites don’t use easily navigable layouts. Inaccessibility at an early stage of use, can create deep frustration for the PWD user, creating a waste of time and effort, especially if there is a lack of options. PWDs don’t want to ask unfamiliar people for help in public spaces, as it brings with it a risk of vulnerability – they would much rather be self-reliant enabled by technology which works efficiently for them.

'I wish I knew...': designers' constraints and wishes

Once designers and developers had a more informed and robust sense of what PWDs need from the technologies they use, we facilitated a discussion to explore what might be obstacles for them to implement these shifts in their own organisations.

Significantly, many designers wished that there were platforms and spaces to understand more fully the lived experience and issues faced by PWDs, as most of the time designers are simply not aware about the challenges faced by their disabled users. The global nature of the tech industry means that it is challenging to focus on issues that are shaped by local contexts which affect PWDs. There are assumptions made about PWDs that prevent companies from engaging with meaningful accessibility: such as that they do not need access to certain spaces (eg: art, leisure) or that they do not have the financial capacity to pay for services. Rather than an afterthought, app blueprints should have checkpoints at the outset.

Android, the most popularly used mobile technology in India, is not adequately optimised for all disabilities. Features that disadvantage non-disabled users can be even more frustrating for users who are PWDs: for example, the infinite scroll on a newsfeed on social networks such as Facebook, X, LinkedIn places what the algorithm deems significant on top of the stack/scroll, not the newest or freshest posts (which users assume). A visually impaired user is likely to be misled by this feature because a screen reader might fail to pick up the dark patterns which force the user to encounter the "top" or most popular posts, rather than the most timely. Designers also need to understand how PWDs find communities online and interact in those spaces.

Internal pressures and obstacles

Designers and developers shared what they perceived as challenges in their processes, workflows and company cultures.

Incorporating accessibility into digital products can potentially take up more time, and thus might push up production costs, especially since one solution can't work for all. Especially in smaller start-up ecosystems, there is a need to prioritise due to lack of sufficient bandwidth, and accessibility is often not considered a priority. The lack of directly perceived business value means that it is difficult to persuade the executive and/or product manager layer that it is worth investing in accessibility-first design, and the culture of building technology which has to work at scale means that there is little consideration of how PWDs might benefit from accessible technology.

There is very little awareness of how meaningful accessibility looks like for a wide range of disabilities, as design schools and training programmes rarely go beyond the very basics. There are no widely available best practices with regards to developing for disabled users, especially specialised and relevant knowledge, such as for data visualisation and maps, nor is there sufficient research available on how to provide design support for different kinds of disabilities.

This lack is also very palpable in considering how to design for Indian PWD users, which would entail considerations of multilingual as well as contextual variety. Many organisations do not undertake basic accessibility checks, unless it is imagined directly relevant to the product. Baseline documents to evaluate and score usability across a wide spectrum of disabilities would be helpful, similar to developer tool **Google Lighthouse.**

CONCLUSION

"We can't loiter in digital spaces, but just uncomfortably exist." [22]

We were a mixed bag of different genders and sexualities: disability activists, technologists, researchers, digital entrepreneurs. We broke down the big concept of DSD by focusing on its core component: the self. How can I be my self in digital spaces – from dating apps to digital payment systems? What gives me more of a sense of self in these spaces? How can design, technology and policy contribute to helping me determine myself in digital spaces? What does it mean to loiter and wander through digital spaces as ourselves, who we are, including spaces of desire, romance, sex and pleasure? Of determining ourselves online?

We looked at Accessibility. Platform designs that account for disability. Safety. A sense of belonging. Community. All of these are vital aspects of self-determination in digital spaces. Many disabled persons at our meeting talked of digital communities helping them survive in many different ways. But the aim is not just survival – the idea is to flourish online. To do that, it's not enough to have accessibility as an after-thought; what's needed is Accessibility By Design, front and centre.

[22] *https://www.tarshi.net/inplainspeak/loitering-towards-desire/*

General [33]

- Building awareness on making digital environments accessible so that they are easy to use, to interact with, to maintain privacy and security.
- Applying co-designing methods with people with disabilities where designing the technology using data that aligns with the expectations and needs of people with disabilities.
- Applying data intelligence using mechanisms and technologies like analytics, and artificial intelligence to predict better and intuitively.

Recognition & external measures

- A comprehensive accessibility curriculum that takes into account all significant categories of disabilities, with valid certification.
- Creation of an accessibility maturity checklist, with different parameters to measure compliance.
- A watchdog agency to ensure digital products meet a certain standard of accessibility, with some form of penalty if requirements are not met, and to reward organisations with certification and/or scores as well as tax breaks and subsidies to encourage continuing access optimisation.
- An ombudsman to receive complaints regarding the lack of compliance by digital products with accessibility standards.
- Awards for best practices in accessibility and inclusive design.

Internal systems

- Mandatory in-house accessibility audits.
- Involving PWDs in user testing, focus groups, testing prototypes.
- Incorporate relevant frameworks, processes and practices to ensure accountability, have specific horizontal and vertical incorporation responsible for implementation.
- System wide shifts: funneling resources and money towards shaping strategy and organisational practices to make accessibility a central priority.
- Demonstrate the business case of accessible products.
- Organise training sessions for industry professionals by PWDs.
- Proactively hire PWDs to ensure more diverse perspectives are represented on teams.
- Create open source internal documentation, guidelines, methods and tools.
- Recruit inclusive design experts.

[33] *C20 Policy Recommendations for Digital Inclusion by Point of View*

Innovation

- Explore different approaches with regards to where in the design process accessibility might be implemented – should each software application have accessibility “built in”? Or should there be an accessibility layer (context aware, adaptive) that would handshake with the app that would enable it to fit the requirements of the user? Can we use AI to build in that flexibility in the OS, and/or hardware devices?
- How can we use research from AI to inform accessibility features that are suited specifically to the Indian context, socially and linguistically?

Social

- Having inclusive digital kiosks that facilitate people with disabilities to participate in voting. For instance, they do not have to depend on someone to guide them while they vote, rather being able to do it independently.
- It is essential that all government websites and apps are accessible to avail of various facilities and services. For instance, it was brought to our attention that the UDID website is not accessible and hence, it’s difficult for people to apply for the identity card.

Education

- Digitising significant exams with the inculcation of ‘choice’ while opting for accessibility accommodations so that it caters to the diverse needs of every disability. For instance, the SAT exam has multiple options whether the examinee with a disability would like to use tactile or image descriptions or have someone with them to describe the images and many more options.
- Skill building of the ecosystem in accessible digital norms and principles within the curriculums of design schools, web development courses, management courses, entrepreneurship etc.

Employment

- Creating portals, corporate websites, and apps that apply wholistic accessibility measures rather than ‘half-baked accessibility’ that are extremely dangerous as they facilitate a certain extent of access to potential employees to apply for opportunities but end up getting stuck at a juncture where access is not available, making them start all over again with a guide.
- A consistent accessible model for tools, payment gateways, and accounting softwares that facilitates leaders and entrepreneurs, employees with disabilities to run their businesses independently or manage their finances independently.

Health

- Creating mechanisms that enable consumers with disabilities to identify the various pharmaceutical products through accessible digital tools. For instance, a tool that facilitates a person with disability to identify the name of a medicine strip or check its manufacturing and expiry date.
- Digital innovations enable a patient with disability to communicate crucial details such as insurance data, medical background particulars, or other information.
- Healthcare apps, websites, and tools are compliant with the digital accessibility principles so that every patient with disability can maintain their physical, mental and reproductive health independently.

Products

- Digitising significant exams with the inculcation of 'choice' while opting for accessibility accommodations so that it caters to the diverse needs of every disability. For instance, the SAT exam has multiple options whether the examinee with a disability would like to use tactile or image descriptions or have someone with them to describe the images and many more options.
- Skill building of the ecosystem in accessible digital norms and principles within the curriculums of design schools, web development courses, management courses, entrepreneurship etc.

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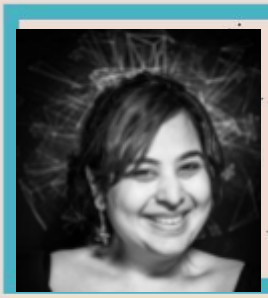

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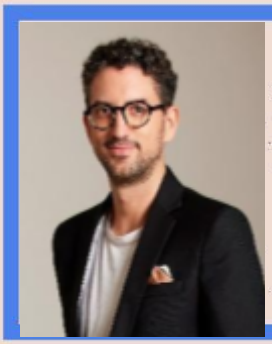

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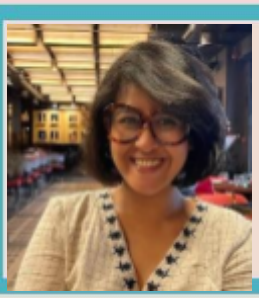

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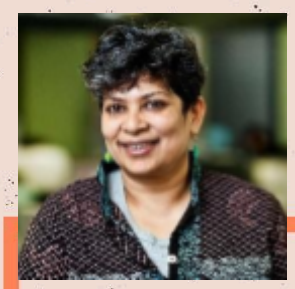

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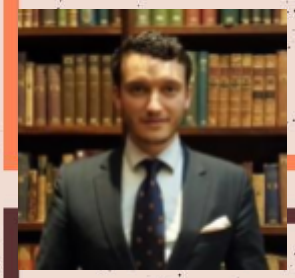

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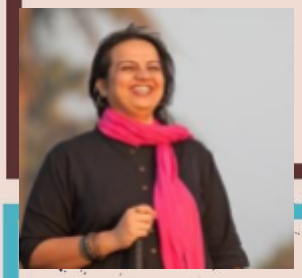

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21

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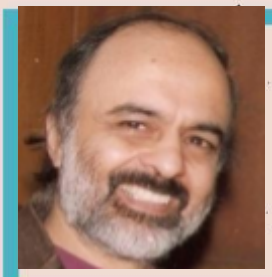

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22

point of view

Point of View, founded in 1996, is a non-profit working with women, girls, and gender and sexual minorities to build their digital skills, capacities, understandings, and knowledge to shape and inhabit digital spaces.

DESIGNಬೇಕು ಡಿಸೈನ್BEKU

Design Beku, founded in 2018, strives to dismantle expectations created by market-driven notions of design by following design justice principles, that advocate designing with communities, and not for.

swissnex

Swissnex in India, Consulate General of Switzerland strives to accelerate positive transformations at the frontiers of knowledge. Working across disciplines, they foster the exchange of ideas, knowledge and talent between Switzerland and India.

Schweizerische Eidgenossenschaft
Confédération suisse
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The Embassy of Switzerland in India is the official representation of Switzerland, and covers all matters concerning diplomatic relations between the two countries.

23