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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?' 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.

<sup>1</sup> 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



## STUDIOS

## STUDIO 1: DELH

At the first-of-its-kind DSD Studio held in Delhi in February, we had 25 participants including persons with disabilities, technologists, researchers, disability rights advocates, lawyers, digital entrepreneurs, and queer and trans activists. At this exploratory studio, we thought about the big question of digital accessibility and beyond: ways in which technology enables as well as limits individuals with disabilities from having a digital life — being present, seen, counted, be themselves or not.



We began with stories!

Lused to paint when I was young – but the functionality of taking out a paintbrush and drawing paper was inaccessible. Canva takes into account my access needs more; it's a blank canvas, a creative space for my disabled rage and dissent. — a queer disabled woman.

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In a conversational session facilitated by Nidhi Goyal (Rising Flame) and Bishakha Datta (Point of View), participants shared a spectrum of experiences — stories and anecdotes of self-determination in digital spaces: Things they did that made them feel they were self-determining or becoming more who they are in digital spaces; experiences that made them feel they were less who they are in digital spaces, the taking away of self-determination.

Participants spoke about occupying, inhabiting, hanging out and loitering online: from Facebook, Twitter and LinkedIn to Canva and Google Docs. They spoke about feelings of safety, un-safety, vulnerability, freedom, mental health, and community across online spaces. There were stories of accessibility, inclusivity, and the ability to express. Stories of digital spaces offering opportunity, employment, financial autonomy, and often, a 'level-playing ground'. Some found a sense of belonging on the internet – a space where they could assert themselves and talk about inequalities they navigate. Some talked about privacy and anonymity: While anonymity can cloak one's identity vis-a-vis other humans online, every action is still invisibly being recorded as data by the machine, which means we are not anonymous to digital infrastructures. How much power and control do we have in shifting tech designs and narratives?

What came through were a range of accessibility 'pain-points' that people with disabilities experience in digital spaces, and the interconnectedness of our digital and physical experiences: ableism, gender norms, stigma and shame that extend to digital spaces. Platforms are largely binarised in their design, where people of marginalised genders and abilities are expected to *bury their identity and exist in a non-disabled way*. It's not just technology or digital features but also social norms and parameters that impact our right to self-determine.









## An informal panel talked about digital accessibility and more

Sunil Abraham (Meta), software developer Arun Mehta, George Abraham (Score Foundation) and Brindaalakshmi K (Point of View) drew from the stories and lived experiences, and shared a range of ways in which individuals and communities have been using technology to self-determine themselves; beyond just an understanding of digital accessibility.

We looked at imaginations of universal access, and explored ideas such as having an infrastructure where accessibility is a part of the drawing board when the tech design is conceptualised: where it would be difficult to create inaccessibility, as opposed to accessibility being an afterthought. A panelist spoke about how big tech companies don't consider people with disabilities a part of the digital ecosystem and their user base. Accessibility isn't meaningful when people with disabilities are not part of development teams or involved in design processes, which shows in tech features like screen readers that often read out unnecessary information and make online experiences difficult for people with visual disabilities.

We talked about bigger questions of people of marginalised identities being historically distanced from tech and design landscapes – and how we can promote an enabling environment where they can create tech that impacts change in their lives. We thought about how we understand Digital Self-Determination in the context of intersectional identities: caste, class, religion, disability, gender, sexuality. How do digital identification documents read people of marginalised identities? Digital experiences of people with disabilities are not homogenous, but are closely interconnected with their intersecting identities.



We recommended changes we'd like to see in tech, design, and policy



In facilitated group discussions, participants thought about how technology, policy and design can enable Digital Self-Determination for people with disabilities. The discussions led up to a Twitter Spaces event "Disability and Digital Self-Determination: What's the Missing Link?" that brought voices of persons with disabilities to the center in thinking about self-expression, self-determination, agency, consent, safety (and more!) in digital spaces. Participants shared their recommendations around accessible design: not an afterthought, mobile phone-friendly, easy interfaces. We spoke about onus: a multi-stakeholder approach to digital accessibility where the onus is not just on people with disabilities to fix the problems. There were ideas around designing accessibility and design curriculums that could help integrate digital accessibility in education. We thought about how accessible and affordable technology is for people with disabilities across caste and class locations. Who builds tech? Who is it built for? There were recommendations for robust redressal mechanisms on platforms to address issues that limit one's access to the platform or its features. And there were imaginations of what an inclusive policy framework can look like: ideas of inclusiveness that aren't homogenised but are representative of a spectrum of disabled experiences.

Through the day-long studio, we thought of challenges, opportunities, and solutions, and looked at Digital Self-Determination as not just a tech response, but as part of being considered a full human being. These ideas helped shape the next studio in Mumbai.

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## **STUDIO 2: MUMBA**

The second studio held in Mumbai in March built on ideas that emerged from discussions around accessibility 'pain-points' at Studio 1 in Delhi. The studio was co-designed with Design Beku. This was a 'hybrid' studio with 15 participants in-person and 4 online. Among the participants were persons with disabilities, technologists, researchers, disability rights advocates, and people working in the intersections of gender and tech. Here, we furthered our imaginations of what DSD could mean to persons with disabilities, identified accessibility challenges that they experience in digital spaces, and brainstormed ideas for building technologies, tools and platforms that bridge accessibility gaps and work for all.

## We unpacked digital accessibility through the lens of disability and self-determination

In a conversational session facilitated by Padmini Ray Murray of Design Beku, participants shared their lived experiences and anecdotes around some of the accessibility 'pain-points' they experience in using apps, platforms and digital spaces; what works well in terms of accessibility; and experiences navigating these technologies in the contexts of specific disabilities. They spoke about pain-points that are experiential, such as multilinguality, interface experiences, and usability; as well as concerns and anxieties around data collection, content moderation, and governance apps that need personal identification, and so on. Participants shared about accessibility challenges on banking apps and platforms, such as, complex speech-to-text features, inaccessible OTP processes because of the short window of time allowed to enter these passwords, and inaccessible interfaces for people with visual impairments. There's a range of accessibility concerns on social media as well. Blind individuals navigate social media using screen readers which often read out unnecessary information like emojis, likes, comments etc. that aren't relevant, but what the person is actually looking to read is difficult to navigate to.

## What you'll read in a second, I'll probably read in an hour

There were conversations around mental health impact as well. All these apps assume that you are monotasking, whereas they are cluttered spaces, overwhelming for many! While everyone's communicating, I don't think anyone's being seen and heard. We need to think about psychological safety and fatigue while talking about accessibility. How are we **defining functionality in the design of apps? What kind of harm is task-switching doing?** Task-switching on apps can be a major cause of anxiety. There's a high mental health cost

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Participants spoke about dating apps, which do not recognise persons with disabilities as part of their user-base, and hence remain largely inaccessible. There's also a pressure to give out personal . identifiable information on dating apps, which raises privacy concerns for persons with disabilities and gender and sexual minorities. There were conversations about accessibility on gaming apps as well, and feelings of isolation that persons with disabilities experience on some games.

On a gaming app meant for blind people, you have the option to create a private game with a password on it. But you can't play it with friends who aren't blind – because the screen is blank and it works only on screen readers. The assumption is that if you're blind, you'll play only with other blind persons.

Through the day-long studio, we thought of challenges, opportunities, and solutions, and looked at Digital Self-Determination as not just a tech response, but as part of being considered a full human being. These ideas helped shape the next studio in Mumbai.



#### We brainstormed 'dream machines'!

In a speculative design exercise in curated small groups, participants thought about what the ideal accessible tool, app, platform or digital space looks like to them. They thought about technologies for public, private, classroom or work use, and more! They reflected on the kind of features, accessibility tools, design aspects, affordances, etc. the 'dream machine' might have.

A range of features emerged as desirable. Technologies where users have full and complete control of their data. Tech that is based on feminist principles: open source, affordable, accessible. Apps and platforms that enable local data storage, are versatile & adaptive, and switch to suit user needs. Technologies that recognise informed consent with easily understood data storage principles, are simple, conversational, comforting, joyful, safe, and multilingual.

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## Ideas that emerged from the exercise:

### 1. A software and hardware layer framework

A lot of the problems are fixable. The reason why they continue to exist is because the whole onus of fixing those is on developers who are often not capable of doing this because of lack of knowledge, time, or budget. What if we take the onus away from developers? This group imagined three layers in digital technologies.

- **Software layer**: Imagining a framework that is placed above the OS and before the apps layer, that works on any device: laptop, phone, tablet, computer! Within this framework are all the possible ways of ensuring accessibility: speech-to-text, text-to-speech, keyboard, and so on. There will be a range of choices within a single framework.
- Hardware layer: Devices have their own limitations in terms of weight, haptics, the touch and feel of the device, and so on. Imagining devices that provide an accessible experience to users
- where the output could be anything: the screen of the phone/desktop/projected screen etc., that will work on the basis of inputs like eye movements, gestures, speech, and so on. This will help solve inaccessibilities around devices and hardware.
- **Privacy:** Imagining technologies where the user has full and complete control of their data. This is based on feminist principles: open source, affordable, accessible.

## 2. CheckMate: #ItsAMatch!

## We considered what it is that would make us feel joyful and safe in digital spaces This group created a checklist that can be used by developers, designers, product owners and technologists. They also envisioned a rating system for digital products based on how much they match the accessibility criteria in the checklist.

The group imagined four categories in the checklist:

**a) Physical:** Is the device grippable? Are the buttons prominent? Users should be able to handle a device easily.

**b)** Visual: People with different abilities are able to navigate through easily – thinking of alignments, color combinations, text and fonts, images. Applications need to have accessibility filters for people to customise their website/app experience as per their own needs.

**c)** Experience: The device, app or platform should have more prompts for an accessible experience. It should also have a space for users to share their experience of the product, and feedback that can help improve accessibility – a community space to share ideas and concerns that are heard and recognised.

**d) Privacy:** It will demystify privacy concepts in simple, conversational language and be built around informed consent. The user will have complete information on what they're giving consent to: what their data is being used for, what cookies are for, and so on.

### 3. Forever Learners

A learning ecosystem focused on accessible experiences. The features are:

a) Accessible-by-design: It is less like a phone and more like a Kindle, with multi-sensory features.

**b)** Something that would get children excited about learning, and also cater to people in school, out of school, in open school. It will also integrate entitlements that students of different socio-economic backgrounds have.

c) Open access and continuous learning: While it is focused on schools, it is relevant to life-long learners, and is open for all to access and use.

## 4. LevelUp!

A device that gives equal opportunity to persons with disabilities to participate in events, conferences, community spaces, etc., connect with each other, and more.

The input that one feeds into the device would give them the preferred information. The device works across the following in providing an accessible experience for persons with disabilities.

- a) Visual impairment
- b) Scanning for non-verbal cues
- c) Lip reading
- d) Cross- disability inclusion
- e) Identifying emotions



### We reviewed accessibility curriculums and identified gaps

In a small group activity, participants reviewed various existing accessibility curriculums to examine if these would help them build their proposed products, and if they meet the criteria and accessibility checks they proposed. They identified gaps and made recommendations. Participants talked about how the curriculums can be more exploratory towards evolving technologies and also look at hardware, design aesthetics and so on. There were discussions around accessibility education as a core idea and not an 'add-on' – about integrating accessibility courses in mainstream education programs such as architecture, engineering, design, technology, etc. Participants observed that most of the accessibility curriculums they reviewed had a Western, US-centric approach, which doesn't apply to a fully international context. They also observed the need for accessibility curriculums to make the leap from being simply functional to being fulfilling and joyful to use. Overall, they observed that most of the accessibility curriculums fall short in terms of practicality and implementation.

The day ended with a Twitter Spaces event where we shared our experiences from the day-long studio, talked about our imaginations of dream machines, and made recommendations to address the gaps that currently exist on platforms, apps and devices.

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## **STUDIO 3: BENGALURU**

At the third studio held in Bangalore in April we explored DSD primarily through the lens of accessibility-by-design for persons living with disabilities. The studio co-designed with Design Beku built on ideas that emerged from discussions at Studio 2 held in Mumbai, around 'dream machines' and building inclusive and accessible technologies that work for all. Among the 26 participants at Studio 3 were persons with disabilities, technologists, designers and developers, researchers, disability rights advocates, policy experts, and people working in the space of assistive and accessible technologies. Here, we thought about how the ideas of 'dream machines' can be transformed into reality, with focus on accessibility-by-design.



#### We deepened our exploration of DSD and what it looks like for persons with disabilities

In a conversational session facilitated by Padmini Ray Murray of Design Beku, we invited persons with disabilities, organisations working with the community, and technologists to share what DSD means to them and their community. Participants shared their perspectives on DSD as achieving full independence over digital tech that a person uses, having accessibility-by-design as a core idea right from the drawing board in designing technologies and having more customisable options in digital technologies for meaningful accessibility.

Participants also talked about the rural-urban divide in accessing technologies and digital media. "Websites that take 10 seconds to load in Bengaluru take 20 minutes to load in some rural areas. Even 'accessible' infrastructures are not functional in rural areas – we don't have lightweight versions of these that would run locally on a device to be able to provide a basic experience if not the whole; or versions that can run on 2G. From government websites to platforms for pleasure – like just scrolling on Instagram – many platforms that are 'accessible' are heavy on bandwidth and don't work in rural areas." Participants questioned the power that platforms hold in defining people's experiences online and reflected on the expectations to reveal one's marginalised identity on platforms and the unequal experience that these requirements can create. "Being spotted, isolated or discriminated against based on your identity as a person with a disability is a major concern. I feel more and more vulnerable as we are living increasingly in a world of digital twins." There were experiences of DSD at the intersections of gender and disability, where women with disabilities are disproportionately affected by inaccess to digital devices and social network.

Participants shared enabling resources as crucial tools for DSD, such as Enable India's Vaani which is a multilingual platform where people with disabilities share information and extend community support in rural areas. They reflected on contradictions they observed with the term 'accessibility' itself, and thought of digital accessibility not as a matter of checking boxes but about being just and fostering an equally enabling environment for persons with disabilities. *"A lot of accessibility approaches are one-size fits all..."* "The RBI came up with an app called the money app which is supposed to tell you what currency you're holding. But in using it in a marketplace, a blind person will have a cane in one hand, shopping bags etc...it's inconvenient." There were conversations about barriers to DSD for persons with disabilities in accessing government welfare schemes, benefits and provisions that are often buried under multiple layers of digital portals that are inaccessible.

Participants reflected on the challenges with unimodal design as a major limitation to achieving DSD for persons with disabilities, and the problems with design inclusion as an afterthought or just an imagination or a 'special case' without any consideration of the fullness of individuals for whom the digital product is designed.

PWD stakeholders and technologists, designers and developers speed-dated!



Persons with disabilities and those working in the disability rights sector were paired with people from the tech, design and developers' community. In a speed dating activity, PWD stakeholders discussed what they wished people in the tech sector understood about their relationship with technology with their conversation partner; similarly designers and developers discussed what they wished they knew about how persons with disabilities navigate technology. Participants then shared their learnings on post-it notes, and the activity then moved to an affinity mapping exercise conducted by Padmini Ray Murray of Design Beku to map the intersections, interactions and relationships between the learnings gathered from the conversations.

Participants spoke about challenges and barriers related to standards, thought about how standards can be simplified and made more accessible, reflected on protocols around accessibility at workplaces, and identified ways in which banking and tax paying processes can be made more accessible for persons with disabilities, especially for Deaf and hearing impaired consumers.

There were conversations on pan-disability design – **Design for disabled people as people**, and not as a space for 'inclusion' Participants reflected on the importance of providing choices through customisation, which is crucial to designing with an intersectional lens: for persons with disabilities across rural and urban demographics.

There were a range of ideas around guidelines for building accessible and inclusive tech, while recognising diverse disabilities as opposed to a 'one-size-fit-all' approach, centering the lived experiences of persons with disabilities and involving them in design and decision-making processes in building technologies.

Technologists, designers and developers shared challenges they have to navigate in terms of awareness gaps related to the diverse needs of persons with disabilities and the problems with assumptions that persons with disabilities do not need access to certain digital spaces that exclude them from the target user base, and reflected on ways in which these gaps can be addressed.

We furthered our imaginations of 'dream machines' in a speculative design exercise

In a small group activity, participants reflected on how best we can work together to make digital products that work for everyone. This was a speculative design exercise that drew on outputs from Studio 2: participants discussed the feasibility of and steps required to create inclusive and accessible digital spaces and technologies.

1) LevelUp: Participants built on the idea of a device that enables equal opportunity for persons with disabilities to participate in events. They reflected on what communication looks like in these spaces. The conversation started with the assumption that the device would be for persons with disabilities, but then evolved into an idea for persons without disabilities, that will help them be aware of the people present, the kind of disability they have, how they can approach or engage with a person with a disability, and understand different kinds of expressions without having biases, with the help of visual indicators. The idea included components such as lip reading, and participants thought of how this can be localised, recognising how lip reading is multilingual and can be translated. This idea would also include something like a first aid box where people can share resources, materials, devices, etc. This would also include a tool to help people make sense of an environment and enable them to navigate it in a more accessible way.

2) A software and hardware layer framework: This would be an open source and modular tool catering to the 21 disabilities recognised officially. This is a product that also learns with persons with disabilities over time. It is self-expansive and efficient in the backend – one line of code is enough for developers to build it, as opposed to complex tech building processes. There is a range of hardware options to plugin to make it accessible to anyone. This would be built by tweaking the code of already existing similar tech ideas, where developers learn from people who have already been solving these issues, and from lead users who are persons with disabilities.

**3)** Forever Learners: Participants built on the idea of an OS where users can build multiple apps constituting a learning ecosystem. The learning ecosystem is built on the core idea of making learning accessible for any student at any stage in their life. Content specifications would include removing language barriers – including sign languages in the interface, and easy descriptions and interpretation of content for Deaf persons and people with intellectual disabilities. The system would also enable building communities and forums so students can be connected with each other. The platform is a mix of a physical and digital ecosystem: it connects students to the right people – across financial spaces, anganwadis, English medium schools, etc. It also connects teachers, students, AI assisted learning models, resources, and so on. It would also include a device like a Kindle dedicated to learning, with a mic, camera, sign language-to-speech and speech-to-sign language customisations, and tactile displays for students with visual impairments. Learning can also be gamified with immediate rewards making students' goals tangible so they feel motivated.

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4) #CheckMate: It's a match: Participants elaborated on the idea of a checklist that can be used by technologists, policy experts, and developers to meet accessibility requirements for digital products. This will have five primary components:

- 1) Physical: Standardising physical components such as buttons, addressing fragility, making the device modular, and having customisable haptics.
- 2) Visual: It should not differentiate between disabled and non-disabled users in terms of
- how it looks for both. There should be settings for people for accessibility, eg. filters.
- 3) Experience: It covers the life cycle of the product: pre-purchase, purchase, use, and after-use experiences. Both the designer and the user should be more aware of the options that can be put in place or used for a more accessible experience; eg. simplifying navigation.
- 4) Privacy: Users have autonomy about what information to divulge, what not to, about their disability or other identities. Developers will think about how to make privacy policy language simpler.
- **5) Policy**: There will be a committee that gives a score to the digital product based on the requirements on the checklist.

These conversations informed the fourth and final studio in Bengaluru, where participants thought about how policy can help transform these ideas into reality.





## **STUDIO 4: BENGALURU**

At the fourth and final studio held in Bengaluru in May, we explored DSD primarily through the lens of policy, implementation, practice and innovation. We furthered our imaginations of how policy and innovation can help transform the ideas around inclusive and accessible technologies, into reality. This was a hybrid event with 16 participants in-person and 6 online. Among the participants were persons with disabilities, policy experts, technologists, designers and developers, researchers, disability rights advocates, and people working in the space of assistive and accessible technologies.



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We learned more about how digital accessibility is addressed in policy, implementation, practice and innovation in India

In a panel discussion moderated by Bishakha Datta (Point of View), Nirmita Narasimhan (accessibility policy researcher and consultant), Shilpi Kapoor (Barrier Break), Sagar Sodah (Engineering Lead, EdTech), and Pramit Bhargava (Founder, Louie Voice Control) shared their perspectives around policies on digital accessibility, policy implementation, creating social impact through accessible tech, and ideas for accessibility-by-design.

Nirmita Narasimhan traced policy milestones around digital accessibility, including the Convention on the Rights of Persons with Disabilities, Indian government guidelines on web accessibility, the Rights of Persons with Disabilities Act 2016, and accessible ICT standards for products and services. She shared reflections on challenges around awareness and implementing these policies and standards. Shilpi Kapoor spoke about a range of factors that are essential to achieving holistic accessibility in digital spaces. Shilpi talked about the need for awareness measures and conversations on the breadth of things that digital accessibility includes, which is much more than just web accessibility, and includes diverse ways in which accessibility can be ensured in terms of touch, feel, holistic experience, and different disabilities *It's about the web, mobile apps,* services, kiosks at the metro session, check-in counters at airports, banking solutions, e-books, everything! Shilpi also spoke about the need to teach accessibility to designers, technologists, and product owners as a skill set in formal education. Sagar Sodah spoke about how accessibility, self-determination and a culture of inclusion need to work in tandem. Disability is more about the environment than about the person. Sagar also talked about using one's skill set to create social impact through accessible technologies. Pramit Bhargava shared more about assistive and accessible technologies, such as Louie, which provides end-to-end assistance to the user, thus enabling a holistic accessible experience, unlike popular assistive technologies which are able to do only snippets of certain tasks, and do not provide end-to-end support. Pramit emphasised the need for building global tech products which cater to regional and local linguistic diversities and can use combinations of languages.

## We examined gaps in policy implementation

In a parallel session facilitated by Padmini Ray Murray, persons with disabilities and representatives of the disability rights and justice sector discussed the gaps they have experienced in the implementation of policies, including lack of communication with regards to policies that affect them, and how to avail of what these policies offer. They spoke about gaps in terms of language inaccessibility, availing the PWD ID card, misrepresentation of persons with disabilities in policy conversations, static assessment guidelines, low access to information among persons with disabilities, issues around data privacy, surveillance and biometrics, lack of adequate funds for policy and standard implementation, and the need for holistic accessibility instead of a one-size-fit-all approach.

### We discussed how to create delightful products for people with disabilities

In a parallel session facilitated by Padmini Ray Murray, persons with disabilities and representatives of the disability rights and justice sector discussed the gaps they have experienced in the implementation of policies, including lack of communication with regards to policies that affect them, and how to avail of what these policies offer. They spoke about gaps in terms of language inaccessibility, availing the PWD ID card, misrepresentation of persons with disabilities in policy conversations, static assessment guidelines, low access to information among persons with disabilities, issues around data privacy, surveillance and biometrics, lack of adequate funds for policy and standard implementation, and the need for holistic accessibility instead of a one-size-fit-all approach.

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#### ...and then we joined the dots

In a guided discussion facilitated by Padmini Ray Murray, participants reflected on how policy can work together with digital product organisations to create an ecosystem which promises Digital Self-Determination for people with disabilities. In this session, the group that had discussed creating inclusive products for PWDs in the parallel session, shared more about challenges and barriers around resources within their organisations and thought about how these can be overcome. The group that had discussed digital accessibility through the policy lens in the parallel session, shared more about the impact of gaps in policy implementation, and challenges.

## There's an idea of return on investment and the cost that goes into building/changing a product for accessibility – people with disabilities are not thought about as the user base

There were discussions about rethinking who the consumer is, in designing digital products. Participants discussed possibilities for consumer research with PWD consumers in order to establish that they constitute a 'sizeable market'. They shared experiences around how steps taken for accessibility in some cases, end up compromising other aspects of digital products, and the lack of adequate frameworks to refer to in order to address these gaps. There were also conversations about thinking of persons with disabilities as experts of their own lived experiences, needs and realities, and the need to include them in building digital products, in a reciprocal way, along with technologists, designers and product owners.

We ended with a grand finale!



We concluded the studio with a Closing Event – a panel discussion with Nidhi Goyal (Rising Flame), Pranav Savla (High School Student, Techie), Prateek Madhav (AssisTech Foundation) and Stefaan Verhulst (New York University GovLab), moderated by Padmini Ray Murray. The panel dived into the repository of knowledge and insights we gathered in our quest to understand and explore DSD for persons with disabilities, across the four studios. Panelists shared reflections on the necessity to bring DSD to the forefront as a research topic, how DSD resonates with disability rights and justice, personal and collective experiences that have been shaped by DSD, how accessible and inclusive tech building can be encouraged and nurtured, and recommendations for creating spaces where DSD seems possible. The closing event had an audience of 60 people from various stakeholder groups including persons with disabilities, civil society members, technologists, researchers, activists, and media professionals.



## CONCLUSION

## We can't loiter in digital spaces, but just uncomfortably exist

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.

We made a range of *recommendations* for unconditional access to the digital, or infrastructure that recognises people with disabilities as full human beings.

## **General**<sup>3</sup>

- 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.

<sup>2</sup> Loitering Towards Desire, published in In Plainspeak by TARSHI <sup>3</sup> C20 Policy Recommendations for Digital Inclusion by Point of View

### **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.

#### 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.

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• 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**

- Introducing strict laws that make it mandatory for digital products, technology and services to be accessible. For instance, a product cannot be sold until it meets the accessibility requirements.
- Having a consistent digital accessibility model or checklist that can be applied universally to avoid any discrepancies amidst products.

## **STUDIO 1: DELHI**

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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.



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 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.

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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.