

SELF-ID RESOURCE GUIDE



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Foreword

In January 2023, the Valuable 500 released a white paper entitled ESG & Disability Data: [A Call for Inclusive Reporting at the World Economic Forum in Davos.](#)

In this body of work, we highlighted the fact that disability inclusion is strikingly absent from standardised key performance indicators, metrics or targets through which organisations measure their impact, performance, and the value they bring to society.

We also noted significant gaps in the global business community's knowledge of employees with disabilities, and that these gaps have consequences for companies and for workers ranging from minor frustration to serious impediments in performing their roles and exclusion from safety-critical systems and processes.

The 5 KPIs we included in the white paper represent a call to action on behalf of our 500 companies and any willing organisation within the global business community to address the disability data void.



The Valuable 500 Disability Inclusion KPIs are:

Workforce Representation

What percentage of the company's workforce identifies as disabled/living with a disability?

Goals

Which goals has the company defined specific to disability inclusion and how are business leaders measured against these goals?

Training

Does your company provide disability inclusion training for its managers and employees?

Employee Resource Groups (ERGs)

Does your company have a disability-specific Employee Resource Group (ERG) in place with an executive sponsor?

Digital Accessibility

Has your company undertaken a review of the accessibility of its digital platforms and content?

If not, does the company have a plan to undertake a review over the next calendar year?

We knew from the outset that asking our global partners and companies to publicly disclose the percentage of their workforce who Self-IDentify as disabled was one of the most critical yet complex asks we had made.

Since the inception of the Valuable 500, we have seen many organisations both within our partners and companies and in the wider business community making great strides toward collecting and analysing Self-ID data but we have also seen tremendous hesitancy to publicly report this data out of a fear of it not being good enough, or close enough to where organisations think it should be. We saw many leaders and passionate disability inclusion advocates confused as to why disclosure rates were so low and questioning what they were doing wrong.

We held discussions across various geographies and learned that there are nuances and intricacies related to how to approach this work successfully and in a way that is respectful of world views, not just western-centric views. We also heard from the investment community that there would be no resistance to ingesting disability performance data into index rankings, ESG ratings, etc. if companies were willing to disclose it and provide it in a format that could be standardised and vetted. We also recognised that this work had to be informed and led in partnership with the disability community to ensure we got this right.

Data for the sake of data does not serve the disability community well and in some cases can do harm. It does not provide pathways to meaningful employment and career progression, it doesn't catalyse change in the way society perceives disability, and it doesn't dismantle ableist systems that impact individuals on a daily basis. Data with intent does, and can be a powerful instrument of change. This document was designed to give you the insights and tools to nurture that intent and benefit from the many positive outcomes of undertaking this work.

Credit: This work was produced by the Valuable 500 and Authored by Former Chief Innovations Officer, Rhiannon Parker.



Fundamentals

Self-ID As A Process

Common goals of corporate Self-ID efforts are to better understand the composition of an organisation's workforce, identify employee needs, connect individuals with peers who have similar lived experience or identities, and provide resources. Gathering and analysing Self-ID data also enables the establishment of a baseline which can be measured and tracked as organisations set tangible goals and formalise commitments to increase disabled representation in the workforce.

In a corporate setting, Self-IDentification (commonly abbreviated to Self-ID) is a generalised term which refers to processes organisations use to invite employees to share demographic information about themselves. Organisations commonly use an online survey or similar methodology to invite employees to participate. Others may integrate Self-ID into human resource information systems and/or onboarding initiatives.

Self-ID may or may not be anonymous. While each organisation will have its own rationale for whether or not a Self-ID process is anonymised, it is our position that anonymising the data is a best practice in regard to data governance, the likelihood of employees participating, and protecting individuals from discrimination or inequity. In many jurisdictions, data protection and human rights legislation may also prevent the collection of disability-related data if it is not anonymised.

When it is at its best, Self-ID either includes or sits adjacent to efforts to understand the sentiment of employees in the workplace.

Unfortunately, employee sentiment is often overlooked or omitted from Self-ID methodologies. Focus on employee sentiment provides leadership with the opportunity to assess, benchmark and compare how employees with varying identities feel about and experience the workplace culture and take action to improve employee sentiment on behalf of the entire workforce.

For example, if a Self-ID survey which includes employee sentiment shows that there is a statistically significant difference between how disabled employees feel about their work environment, interactions with leaders and peers, perceived opportunities for progression, etc., compared to other employees, this provides meaningful data and insights. Without asking these questions or explicitly collecting this data, these differences may never be detected.

Self-IDentification in an organisational setting should not be confused with efforts directed toward complying with legislated or regulatory disability employment quotas, nor should the datasets be aggregated or compared. Disability employment quotas and considerations relevant to Self-ID in the workplace will be addressed under Legal considerations.

"I endorse the premise that Self-IDentification, or Self-ID, in a corporate context is an empowering tool that allows employees to communicate their demographic information voluntarily. We see its application in varied forms, whether it's implemented through online surveys, HR systems, or even during the employee onboarding process.

The choice to anonymise the Self-ID data is an aspect that I think is open to debate, differing across organizations. My standpoint, however, is unambiguous: anonymisation of the data is not just a prudent practice, it is the cornerstone of effective data governance. Beyond this, I believe it bolsters employee participation and provides crucial protection against inequity and discrimination. From my perspective, anonymization of disability-related data is not just a recommendation, but a requirement in many jurisdictions due to data protection and human rights regulations.

I interpret corporate Self-ID initiatives as opportunities – they are chances to obtain a deeper understanding of the workforce's composition, ascertain the needs of employees, and facilitate connections among individuals with shared identities or experiences. They also aid in resource allocation, ensuring that support is provided where it's needed most."

HANNAH OLSON

CEO at Disclo

Self-ID Characteristics

Self-ID characteristics can include gender, race, ethnicity, sexual orientation (LGBTQIA+), disability and/or neurodiversity, amongst others. An organisation may choose to invite individuals to Self-IDentify through a single process or multiple processes such as a single survey or many surveys (i.e. a survey focused on all lived experiences and identities vs. a survey specifically focused on disabled identity). They may also choose to ask these questions as part of a one-time orientation process or on a recurrent basis. This gives organisations flexibility to focus on a single demographic or aspect of an employee's identity, or on various aspects of how employees Self-IDentify.

Calculating Self-ID

One of the reasons disability performance data has not been integrated into mainstream data sets such as financial indexes, DEI indexes, and ESG ratings, is because there is a lack of standardisation in the way the data is calculated.

For disability data to be useable by data providers, trusted by quality assurers, and factored into rankings that allow organisations to be rewarded in capital markets, it is not necessary that all companies use the exact same methodology. It is however essential that organisations are transparent about how they arrived at their numbers.

Consider the following examples:

Company A: sends a Self-ID survey out to 50,000 employees and receives responses from 22,542 employees. Of these 22,542 employees, 1,964 employees Self-ID as disabled.

The company chooses to calculate the percentage of their workforce who Self-ID based on the number of people who responded to the survey rather than the number of people who the survey was sent to.

In this scenario their reported Self-ID percentage would be based on the following formula:

$$\frac{1,964}{22,542} = 8\%$$

Company B: sends a Self-ID survey out to 50,000 employees and receives responses from 35,588 employees. Of these 35,588 employees, 4,000 employees Self-ID as disabled.

The company chooses to calculate the percentage of their workforce who Self-ID as disabled based on the number of people who were sent the survey.

In this scenario their reported Self-ID percentage would be based on the following formula:

$$\frac{4,000}{50,000} = 8\%$$

In the previous example, both companies report 8% disabled representation within their workforce, yet these statistics are based on completely different calculations. Also consider that if Company A calculated the same way as Company B, their Self-ID percentage would be 4%, and vice versa if Company B used the same calculation as Company A, their Self-ID percentage would be 11%. This is a concrete example of how clarity surrounding disability data is critical to it being widely accepted and ingested into investor grade data sets.

As with the choice to anonymise Self-ID data, there are many factors which influence how organisations choose to calculate Self-ID. Data may have been calculated one way from the beginning of Self-ID implementation and a company may be hesitant to move away from presenting data in ways that are not comparable to previous years. It is not necessary for all companies to calculate the data in the same way, ask the same questions, or operate in complete alignment. However, it is imperative that they are transparent regarding the data analysis methodologies used. This transparency allows data providers and analysts to normalise the data and facilitate benchmarking with a high degree of confidence and certainty.

The Psychology Of Self-ID

The psychology of Self-ID is influenced by how the disability community experience the world. Regardless of geography or culture, we see examples of how disability is still associated with pity, sadness, sorrow, and assumptions that persons with disabilities are “less than”. Business has a fundamental role in refuting these assumptions and harmful views toward disability by creating opportunities for disabled talent to be seen and contribute within the global economy.

It is critical to understand that identifying as disabled or not is a conscious choice made by an individual. Therefore, disabled identity cannot be assumed. An individual may have a medical condition or a functional or visible difference and not identify as disabled. Others may assert that barriers in society are disabling and actively choose not to own a disabled identity. Both perspectives are valid.

It is also important to note that disabled identity is not static; the way people perceive their identities can and does change over time. Disabilities can be temporary, situational, and vary in degree depending on a multitude of factors.

"Everyone has an individual journey to identifying as disabled. For me, the initial diagnosis of sight loss didn't register as me being disabled. It was still me, I just had some challenges with sight. It is only later on when seeking support and needing to complete a form for government assistance that I was presented with the question of if I was disabled. My initial thoughts were of rejection to the notion that I am disabled, I don't want to be known as disabled. I didn't see myself as disabled. My view of disability (at the time) was someone in a wheelchair not someone with sight loss. I was also aware of societal attitudes towards disabled people.

After the initial shock, I looked at it logically, I needed assistance and needed to stay employed to support my family. I knew I had to acknowledge I was disabled on the form to get the support I needed. After sending the form off, I still rationalised it in my mind that I wasn't disabled – it was just how the law saw me. It took time to process that identifying as disabled isn't a bad thing, I am not less of a person. It took time, because I also needed to process and accept my loss of vision. My life was changing, I wasn't in control and it was scary – identifying as disabled felt like another loss, another acknowledgement that I was less of a person.

Over time, I have realised that being disabled is not being less, it isn't a barrier if you accept that you need to change your approach. Identifying myself as disabled opened my world to talking with others and seeing that society is creating the barriers, not my disability. I look back and realise

how uninformed I was, how narrow my view was and how the media and society have set that perspective. I have since built up my confidence to be myself, be there and represent disability in the room. It has helped others open up and see that being yourself, letting colleagues know that you are disabled doesn't make you less of a person or less able. It's not easy, but I do encourage anyone who hasn't Self-Identified, to do so. It is only through representation and reporting that we can change the perception within society and ensure our children grow up in a more inclusive world."

TIM DIXON

Head of IT Architecture, Group IT at Intertek

Self-Identifying as disabled or disclosing a disability is not the same as providing detailed medical information. Many people with disabilities within our ecosystem speak openly about how important it is to establish boundaries around requests they receive from strangers, peers, managers, etc. to disclose medical information and histories in their day-to-day interactions within the workplace. Whether this applies to a wheelchair user, someone who is blind or has low vision, hearing loss, a traumatic brain injury, etc., there should be no expectation that disabled employees need to educate others on their condition, discuss the history of how they acquired their disability, or answer intrusive questions. Respecting medical privacy is particularly important in the workplace as there is often a requirement for access workplace accommodations and/or reasonable adjustments.

“Asking a disabled person to prove their disability is asking them to disclose the parts of themselves that are most frequently rejected, looked down on, and seen as less than. There is a valid fear that they will no longer be seen as a capable employee. There is valid fear they’ll be seen and treated as a legal risk. There is valid fear they will lose their income. People very rarely go through this often traumatic process with significant downsides when it isn’t necessary.

While companies have a legal right to ask for verification that an ADA-qualifying disability exists when the disability is not apparent or previously known, documentation is not required, and it is rarely truly necessary. When medical confirmation is necessary, choose a humane and respectful process, with the undertone that the employee is valued and capable. The main focus in the discussions should be on what barriers exist, and what accommodations will effectively remove those barriers. That doesn’t come from a doctor’s note, it comes from a conversation with the employee.”

JULIE HARRIS

Executive Director of Stilbe

Across the many conversations we have every day with the disability community, we are encouraged and energised to see the many ways that people with disabilities across all geographies are stepping into their disabled identities with pride. Despite the many barriers that are perpetuated by legislation and policy, social norms, and health inequity, people are owning their disabled identities more openly,

actively combatting stigma and ill-informed perceptions, and demanding more in regard to human rights, career opportunities, and access to the built and digital environments. We look forward to how our vibrant community continues to gain confidence and experience the evolution of their disabled identities.

Neurodivergence Vs. Disability

Many current conversations pertaining to disability inclusion centre around the distinction between neurodivergence and disability.

An increasing number of organisations and individuals want to know whether they should formally categorise neurodivergence as a disability or not, and whether neurodivergence should be considered as an aspect of mental health or not. As with any disabled identity, the distinction between a neurodivergent and/or disabled identity is fundamentally an individual choice. Not all neurodivergent people identify as disabled or perceive their neurodivergence as a disability. However, many do. Therefore, our position is that it is not up to an organisation, DEI practitioner or other party to categorise these identities, it is up to the individual.

In the context of Self-ID and addressing the disability data void, inviting employees to disclose both neurodivergent and disabled identities is recommended as this approach offers a richer understanding of the workforce than if it were not included.

Mental Health

Mental health must be given the same degree of consideration as physiological health. It must also be recognised as a facet of the disabled experience – not as a global trend that began in 2020. Historically, sustained levels of discomfort surrounding mental health as well as a disproportionate focus on disability as a physical experience mean that many employees work without requesting accommodations, sharing their experience with management, or leveraging benefits that focus on mental health in fear of judgement.

Consider a situation in which a colleague arrives at work with a broken leg and the comfort with which peers are able to express sympathy and show care for their well-being. Contrast this with a colleague who is visibly and/or vocally living with depression, who some co-workers misinterpret as cumbersome, and difficult to work with or approach. As support structures are developed to address mental health, ingrained stigma must be faced with candour and empathy.

It has been our observation that mental health conditions or diagnoses are often referenced or used as descriptors of negative behaviours which trivialise or misrepresent the experience of those lived experiences. Examples include referring to oneself or specific negative traits as “OCD”, “on the spectrum”, “crazy”, “bi-polar”, “schizophrenic,” etc. These references to mental health perpetuate inaccurate depictions of how others truly experience day-to-day life and sensationalise specific symptoms of various mental health conditions.

As employers look for ways to support and destigmatise employees’ mental health, it is important to be mindful of perpetuating a

culture that excitedly offers “mental health days”, quiet rooms, meditation apps, etc. while simultaneously failing to offer an employee with chronic depression to request flexible hours or the ability to join virtual meetings with the camera turned off.

A consistent theme we hear from the disability community is how exhausting it is to have to mask one’s experiences or identity. Whether this refers to masking in the form of suppressing the desire to stim, or forcing oneself to make eye contact to adapt to business culture norms, maintain a sustained presence in sensory rich social environments, appear energetic or upbeat, or maintain privacy around medications, it is important to understand that flexibility and “soft adjustments” to work structures, policies and practices can have a significant impact on employee experience, productivity, and retention.

Issues that have long been taboo are now being confronted, but there is a long road ahead to normalise openness around mental health across the corporate sector, and this normalisation is a goal of the Self-ID process.

Embracing workers’ mental health can reduce churn and increase productivity which in turn benefits the long-term health and success of any business.

Evolving Yet Persistent Models of Disability

The way society perceives disability has a direct impact on nearly every aspect of life for persons with disabilities. For much of the 19th and 20th centuries, societal views and norms were influenced by the charitable and medical models of disability.

The **charitable model of disability** is based on the assertion that persons with disabilities are helpless and unable to live full, self-sufficient, and independent lives. The charitable model of disability calls for help, caregiving, pity and sorrow as primary means to “support” the disability community who are often positioned as a source of inspiration. Even as of today, we still see many indicators of how deeply woven charitable model thinking is in global perspectives on disability. These perceptions of disability and the emphasis on helplessness come at the cost of autonomy, respect, and access to human rights, amongst other key aspects of being able to participate fully in society and the economy.

The **medical model of disability** perpetuates the view that there is something inherently wrong, deficient, less than, and/or problematic with an individual who is disabled. In situations where equal participation in society, the community, the workplace or any other facet of day-to-day life is limited, the medical model points to an individual’s impairment(s), functional difference(s), deficiency(ies), or condition(s) as the causal factor. The focus is on “fixing”, “curing” or “healing” the individual to address such barriers.

The **social model of disability** challenges these viewpoints and positions barriers in society as the causal agent which limits individuals’ access

to physical environments, resources, opportunity and autonomy. The social model states that it is society’s responsibility to actively work toward removing barriers for persons with disabilities. It is important to note that many people choose not to identify as disabled because they view disability as a result of social and environmental barriers. We are as supportive of anyone who chooses not to identify as disabled as we are of those who identify as disabled with pride.

We have seen tremendous change associated with social model thinking – cities, municipalities, and nations solving environmental barriers, governments enacting legislation to require access to digital offerings, global thinktanks posing tough questions about what a future that includes AI means for the disability community, etc. However, we still have a tremendous amount of work to do. For all the progress social model thinking has catalysed, many disabled thought leaders and others have pointed out that there is a lack of human agency associated with the social model. This is to say that if the removal of barriers to full participation in all aspects of life are deemed to be society’s responsibility, this means that catalysing change is incumbent on society funding, enacting, and advocating for this change without meaningful contribution from the disability community themselves.

The **human rights model of disability** complements the social model by asserting that a disabled individual can use their rights to dismantle inaccessible systems and play an active role in ideating, innovating and engineering ones that benefit everyone. The disability movement has a rich history of supporting and being supported by individuals, activists and advocacy groups with intersectional identities who have leveraged human rights to deconstruct outdated and harmful social norms, legislation and barriers to accessibility.

Holistic Views Of Disability

“Whether it is in consideration of disabled representation in marketing and media, customer service delivery, or accessibility of digital or built environments, it is important to recognise that disability goes beyond mobility. We point this out because we have observed a disproportionate amount of focus on mobility-related disabled imagery and the way disability is represented and understood globally. We have also observed trends specific to industries where the focus on mobility is more prominent than other types of disabilities.

The travel and tourism industry is an example of how disability inclusion, accessibility, and other related topics are overwhelmingly geared toward people with mobility-related disabilities. It is not uncommon to hear from blind or D/deaf travellers who are offered wheelchairs during travel and need to remind customer service agents that their disability is not related to their ability to move independently, or travellers who are unable to access important information due to a lack of captioning, or neurodivergent guests who are offered accessible rooms that have been designed to meet a completely different set of needs than their own.

Holistic disability inclusion requires that the diverse experiences of people with chronic illness, cognitive and learning disabilities, and all other forms of non-visible disabilities are recognised as equal members of the disability community. In addition to ensuring people with non-visible disabilities are not left out of the conversation, it is important to take time to understand some of the

shared life experiences. We hear often from people with non-visible disabilities that their disabled identities are challenged, questioned, or undermined.

Whether this applies to a wheelchair user who intermittently uses their wheelchair when their energy levels are low or when their balance is off and is called out for “faking” a disability, someone with a stoma bag being chastised for using the disabled facilities in a public setting, or someone with partial or low vision who doesn’t fit the stereotypes we see in the media, we need to understand that there is no one better equipped or more experienced in determining what disabled identity consists of than the disability community itself.

This seems like a simple concept; however, the disability community is routinely left out of discourse, policy development, innovation, user testing, risk management, and feedback on the very things that impact their ability to equitably participate in society.

This is why the mantra Nothing-About-Us Without-Us is fundamental of any work related to disability inclusion or improving disability performance. We have to also recognize that there should not be a single story about disability inclusion.

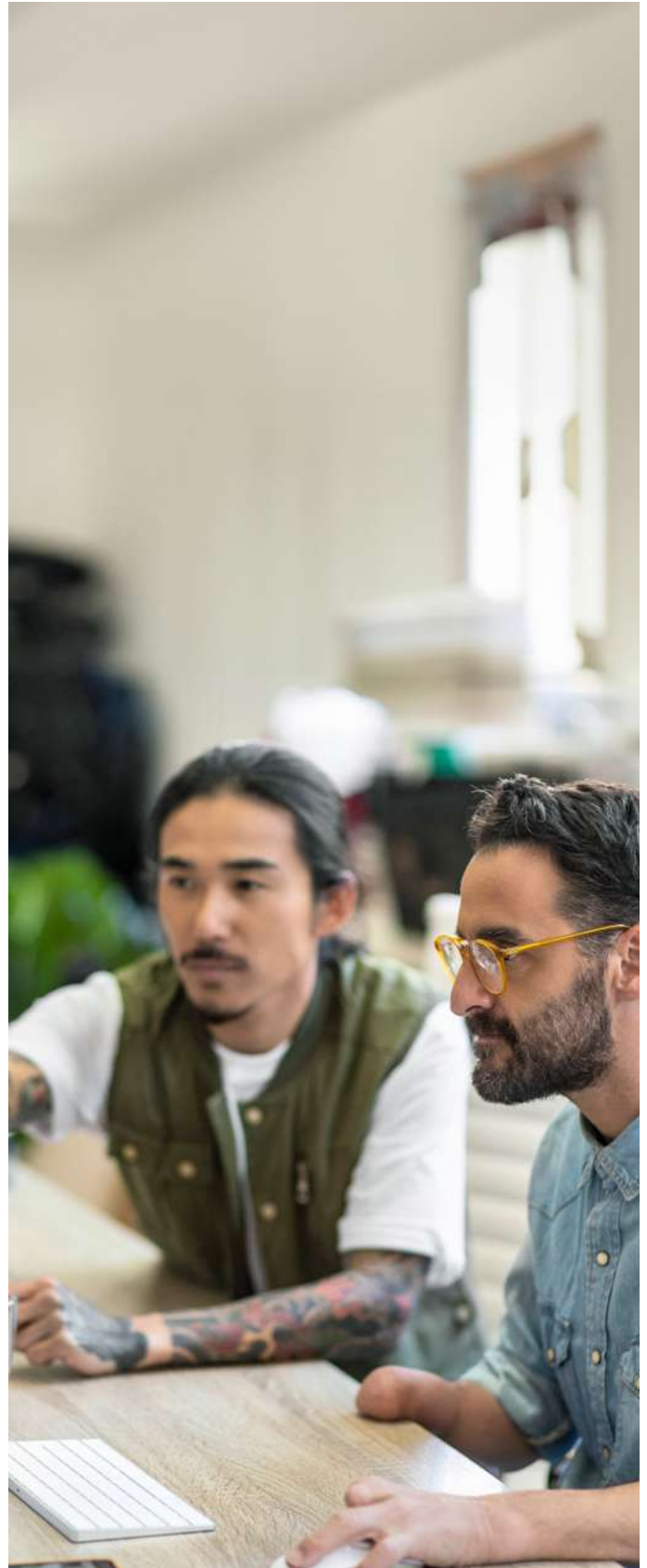
There should not be a singular point of view that is accepted, while other views are sidelined. Part of the holistic view means finding the courage to accept that different cultures express their celebration of disability inclusion differently and that there should not be a dominant single story of disability.”

FATMA AL JASSIM

Disability Inclusion & Accessibility Consultant

In the context of disabled representation in the workplace, it is important to recognise that employees with apparent disabilities may be more likely to self-disclose because of the fact that their disability is visible and they have, out of necessity, had significant experience with disclosing in the past. Because many disabilities have visible markers of their presence such as a wheelchair, signing in one's sign language of choice, the presence of a guide dog, etc., this undermines an individual's autonomy and ability to choose to whom and if they disclose.

The goal of any Self-ID process should be to ensure that employees with all types of disabilities are considered and invited to participate in ways that are respectful of their lived experience.



Building Cultures Of Trust

The foundation of any successful Self-ID process is the establishment of reciprocal trust between an employee and the business they work for.

From the perspective of an employee, this means that for an individual to feel comfortable sharing information about their personal identity (which can often include information about their health or other legally protected characteristics), they must have a clear understanding of how their employer intends to use that information to support them as an individual. This includes having an understanding of what the goals are of introducing Self-ID within the business and of what their employer intends to do with the information they share, and having confidence that the data they share will be protected, be subject to appropriate data governance processes, and not used against them in a harmful or discriminatory manner. Organisations who undertake Self-ID processes with the intent of acquiring demographic data rather than extending care to their employees see limited success in building trust with marginalised employees.

Employees will also expect that there is a fair exchange in value whereby the employer acts with their best interests in mind to create systems, processes and resources that address needs specific to their identity/identities.

"If you're looking to rebuild the trust of your junior and/or marginalised-employee populations in your workplace, that often starts by offering them resources, support, power, authority, and agency that senior and/or advantaged employee populations may not immediately benefit from. I've seen this countless times. Senior leaders ask a grassroots DEI council what they need to feel comfortable working for the good of the organisation, and the requests they receive come as a surprise. Resources specifically for Black and brown folks. Protections specifically for LGBTQ+ employees, disabled people, and neurodivergent people. Specialised support for healing from racial trauma directed at junior women of colour.

How about an all-company workshop, or crowdsourcing a resource we can ***all*** benefit from?" is the common counter-suggestion from senior leaders, and the swift response to that is a resounding "NO.

...The bare minimum needed to rectify these past and often present harms that disproportionately harmed marginalised communities is reparative and restorative efforts that disproportionately support and undo harm done to marginalised communities. Hence, the first step to rebuilding trust is recognising that disproportional harm must be addressed by disproportionate benefit to those harmed."

LILY ZHENG

Disability Inclusion & Accessibility Consultant

From the perspective of the employer, there must be a baseline level of trust which assumes that employees will act in good faith and disclose accurate data about their identities. There appear to be several myths or widely held beliefs that, if given the opportunity, employees would disclose a disabled identity to gain an unfair advantage or access workplace accommodations that are not actually needed. When we look at disability disclosure or Self-ID at a global or even country-level scale, we have not seen data or evidence which supports these assertions. On the contrary, we can witness the positive outcomes achieved when employers extend trust to their employees.

Perhaps one of the most significant barriers to building reciprocal trust as it applies to Self-ID is the requirement for formal diagnoses or medical documentation. This is also one of the most contentious topics to be explored when implementing and continuously improving upon Self-ID within the workplace. We have seen many examples of organisations that require medical documentation, formal diagnoses, or other forms of “proof” for employees to gain access to workplace accommodations or even for their disabled identity to be acknowledged or formally recognised. Many times, the requirement for medical documentation serves the purpose of helping an organisation determine whether they are legally obligated to provide reasonable adjustments or not, rather than approaching requests from a place of care, increasing productivity, or providing support. We have also seen examples of organisations who have adopted “trust-based” models of Self-IDentification and disclosure and have made a conscious choice not to require documentation.

There is not a one size fits all recommendation for how organisations should approach the question of whether or not a diagnosis is

required or the specific conditions under which this is appropriate. However, the disability community have been explicit in their feedback that using diagnoses or formal medical documentation as a means of gatekeeping access to workplace accommodations or acknowledging their disabled identity erodes trust and decreases the likelihood of them participating in Self-ID within the workplace.

It is important to recognise that there are many reasons why an individual may consciously choose not to pursue a formal diagnosis and that this decision is irrelevant to whether or not their disabled identity is valid. In the case of mental health, persistent stigma still exists around diagnoses, and in many countries, waiting lists for assessments and formal diagnoses can be years long and involve significant time and cost. Individuals may also make a conscious decision not to pursue diagnoses because of previous negative interactions with medical professionals or inequitable health services.

Whether a diagnosis relates to mental or physiological health, it is important to remember that many symptoms and aspects of how a person experiences their life and a work environment occur regardless of whether a diagnosis has been sought and received. This fact raises questions on the relevance or necessity of medical documentation. As an example, if someone experiences intrusive thoughts, the severity may ebb and flow over time, and may be triggered by stress or other factors. Symptoms may become significant enough to disrupt daily functioning, require time off work, or require support from a therapist, etc. In this example, the ways in which intrusive thoughts affect an individual are present whether a diagnosis is present or not. The same can be said for many other aspects of mental and physiological health.

Advocates of trust-based models rightfully question what the formal documentation or diagnosis have to do with the validity of someone's disabled identity. We recommend examining these perspectives and incorporating them into corporate Self-ID methodologies.

Foundations Of Trust

The fundamental starting point for all organisations is to approach disability inclusion from a place of care and curiosity that is well informed by progressive models of disability. No matter what level of organisational maturity a business is defined by, prioritising meeting the needs of disabled employees is essential.

It is critical to remember that trust is either established or eroded from the moment a potential employee interacts with a business for the first time. Well before HR has the opportunity to expose a candidate to disability-inclusive hiring practices, those candidates will have interfaced with the company's website and digital assets, social media presence and other facets of the organisation's digital offerings. If these assets are not accessible, this makes an implicit statement that an organisation's commitments may be aspirational rather than tangible. Candidates may have also visited retail or office locations which they were unable to access in the same ways as non-disabled customers or guests, or seen ads where disability was either not present or not appropriately represented.

"Social media and websites are often the first impression that someone has of a brand, even if it has a physical location.

If you're not making your digital content accessible, what are you telling your clients and customers with disabilities?

Accessibility is even more vital for accounts that exist to serve the public. If you're an elected official, an emergency service, or a healthcare provider, what kind of crucial information are you excluding disabled folks from by not making your content accessible?

How does that exclusion impact their health and safety? The repercussions of inaccessible digital content are far more serious than most people probably realise."

ALEXA HEINRICH

Many organisations and their leaders find it overwhelming to know where to start and lean toward large-scale initiatives aimed at improving disability performance within their businesses. While these types of undertakings have the potential to have significant impact, it is important not to overlook the value of simple gestures of empathy and care and the genuine desire to understand disability on a more personal level.

"It is common for people to know more about an individual than to know the actual person. "That one over there has [insert diagnostic label here]." "She's the one who always needs help." "He can't hear all that well." "That little guy goes to a special school. Nice kid."

A lot of this knowing about is made possible by a generally clever and safe use of words. The jargon and the rhetoric help us keep a comfortable distance from intimacy. And prevent us from having to display our awkwardness.

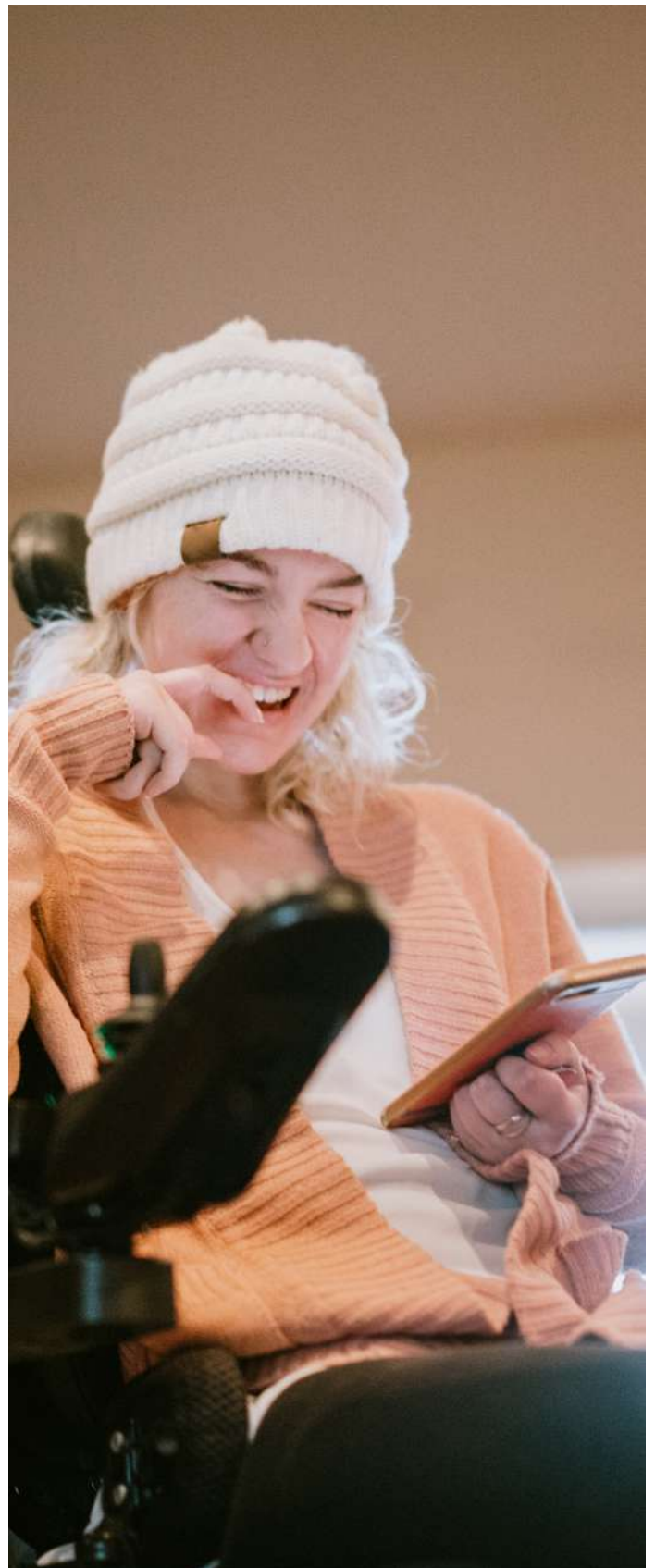
We don't like not being ourselves. And that happens a lot in DisabilityLand. We find ourselves off balance.

Visitors in this terrain don't generally have a lot of social practice with disabled individuals. They get good, instead, at pretend closeness. Too friendly. Too right in your face. Laughing at the joke just a little too much.

And certainly relieved to have what was never really an interaction done with."

ALAN BRIGHTMAN

DisabilityLand



Reasonable Adjustments

Another important consideration for Self-ID is to recognise that an individual's success in the workplace may depend in part on continuous opportunities to access the right adjustments or accommodations to support their functional needs and role requirements. A functional difference is when an individual thinks, communicates, senses, moves, operates, or comprehends in ways that are different to what society has deemed 'normal' or 'natural'; as a result, systems in place often lack the support necessary for those individuals to be successful. Functional differences can be visible or non-visible; equally they can be permanent, temporary, and/or situational.

"Disability equality is only possible when organisations combine being barrier free for groups with similar access needs with making the reasonable adjustments for individuals which enable them to contribute on an equal basis.

It is puzzling, given the business benefits, which include enhanced productivity and employee engagement, that so few organisations are even attempting to deliver adjustments fairly and to an acceptable, explicit, and consistent quality standard, worldwide.

Too many organisations settle on an ad hoc basis for just meeting a bare minimum compliance standard rather than enabling every colleague to thrive. Denying an adjustment to a disabled colleague in Argentina because you can legally do so, when you would provide that same adjustment if they worked in the UK, constitutes unfair treatment, and is ultimately bad for business.

Would you require your left-handed CPO to provide a medical certificate before giving her a left-handed mouse?"

SUSAN SCOTT-PARKER
OBE

There are many names for the ways in which organisations support their employees or through which employees communicate their needs. Common references include reasonable adjustments, workplace accommodations, accessibility requirements, ergonomic adjustments, etc. We will use these terms interchangeably throughout this resource.

It is our position that making reasonable adjustments is an ethical and often a legal imperative.

We have seen many examples of compliance and data-driven cultures gone wrong whereby the requirement to provide disability or medical data – to prove you are disabled enough to trigger a legal obligation – is used as a gatekeeper or restricts access to reasonable adjustments. This conveys the message: “We will only treat you fairly if compelled to do so by local law.”

When reasonable adjustments are managed well, they are done in a way that both implicitly and explicitly states that the organisation trusts its people and is committed to giving all employees the tools and flexibility they need to be productive in their work. Disability-inclusive organisations support accommodations as key facilitators to removing barriers and enabling colleagues with disabilities to participate equitably in all aspects of their work environment.

A recent analysis by the US Department of Labor of survey data from 2019 to 2022 reports that nearly half of workplace accommodations made for people with disabilities can be implemented at no cost, and where there is cost, the median is just \$300. In addition to gathering information about the costs of accommodations, the survey explored employers’ motivations for making them, their effectiveness and the benefits they produced. The report includes the following findings:

- More than half of employers made accommodations to retain valued employees.
- 68.4% of employers said the accommodations made were either very effective or extremely effective.
- The direct and indirect benefits of making accommodations included retaining valuable employees, improving productivity and morale, reducing workers’ compensation, and training costs, and increasing workforce diversity.

This formalised research supports what the disability community have repeatedly communicated: the vast majority of workplace accommodations are either free to implement or involve low cost.

We recommend that all organisations adopt the following recommendations from Business Disability International. These 12 Critical Success Factors are tangible steps organisations can take to ensure workplace adjustment service lines are designed effectively and efficiently:

1. A named senior executive is responsible for ensuring the service meets explicit performance standards and drives continuous improvement.
2. A named service manager is responsible for ensuring that the Workplace Adjustment (WPA) service, end to end, meets these standards.
3. There is a well-publicised single “door” of entry to the service.
4. There is a “real” speed of delivery standard – case studies show that it is reasonable to set a standard that states it will take no more than 14–20 days from when adjustments are first requested to when they are delivered and operational.
5. The line manager does not pay and does not drive the service for their team member/s.
6. Employees are trusted to self-refer and are not routinely required to prove they have a disability in order to get the tools, accessibility or flexibility that they require.
7. There is a well-publicised central catalogue of approved “hard” adjustments, i.e. technology, assistive devices, furniture.
8. There is a well-publicised catalogue of approved “soft” adjustments: i.e. flexitime, rest breaks, medical appointments, disability- related absence.
9. Passports or workplace adjustment agreements capture what has been agreed and delivered for the employee, so they need not renegotiate with a new manager.
10. Procurement requires key suppliers, including facilities management and IT support, to meet the adjustment and accessibility-related performance standards, enabling the “end to end service” to deliver promptly and effectively.
11. The impact of the service is routinely documented, including the cost benefit associated with reducing absenteeism; enhancing productivity and employee engagement; and reducing management and legal costs associated with grievances and litigation.
12. Adjustments are clearly positioned as a managerial responsibility, not a medical one: medical interventions are kept to a minimum.

Adjustment / Accommodation Data

Anonymised data related to the provision of workplace adjustments/accommodations can serve as a source of rich insights on disabled representation in the workforce. It can also help inform leadership on the degree to which an organisation has succeeded in operationalising disability performance.

For example, if a Self-ID initiative is launched but yields very low response rates, reviewing anonymised data associated with the number of workplace accommodations provided annually may help provide perspective. For example, if Self-ID disclosure is low but there were a high number of accommodations requested and provided, this may indicate that there is work to do in creating a culture in which employees feel comfortable disclosing. Anonymised accommodation data may also help predict or explain varied Self-ID participation rates across different geographies.

If various geographies are defined by high rates of accommodation requests and high rates of Self-ID participation and others are defined by low numbers of accommodation requests and low Self-ID participation, this may point to the need for more awareness and education on the availability and pathway to accessing accommodations to drive higher Self-ID participation.

In regard to operationalising disability performance, if a high proportion of accommodation requests were provided within 14–20 days, this likely indicates that systems and processes are effective at facilitating workplace accommodation requests and support a culture in which employees feel confident in disclosing their disabled identity or lived experience.

We recommend exploring the ways in which Self-ID disclosures and accommodation/adjustment data can be layered to provide a more complete picture of disabled representation in any workplace.



Training

One of the most significant things a leader can do in support of advancing disability inclusion at a system level is to invest time, effort, and funding into ensuring their workforce is educated on disability inclusion and specific ways to support disabled employees.

Providing or mandating disability inclusion training is a great example of how business has the power to catalyse global change. As a reference, the combined total of employees across the Valuable 500 at last count was over 22 million employees; most Valuable 500 companies are multinational organisations, many with employee counts in the tens of thousands and many with supply chains comprised of hundreds of thousands of suppliers. Providing employees, contractors, and suppliers with training based on the social and human rights models of disabilities represents a tangible means of dismantling previously held notions on disabled lived experience and identity, and as we have heard from the disability community and companies alike, is a foundational element of building a strong culture of trust.

In the majority of organisations, disability inclusion is either absent from DEI training, or appears as a brief reference within generic DEI training initiatives. The importance of providing training that is disability-specific and is led by persons with lived experience cannot be overstated enough. Another strong message from the disability community is related to the importance of hiring outside experts and trainers to provide disability-specific training rather than asking employees to lead training sessions themselves. We listened to many shared experiences of situations where disabled employees were called upon to educate their

peers, develop content and strategic plans, and solve specific issues. Some disabled employees enjoy this and welcome such opportunities; however, many communicated that advocating for disability inclusion and/or educating their peers came at the cost of sharing personal stories, medical history, and lived experience.

Training does not need to be formalised to be effective. Discourse and knowledge sharing within our Self-ID working sessions revealed that simple content focused on the fundamentals of disability theory and models, and storytelling from peers, disabled creators and advocates are effective. The outcomes of these learning approaches are to generate awareness, build empathy, and foster a work environment which is conducive to building trust.

Organisations who have committed to investing in disability-specific training have also reported that these perspectives enable them to better serve and understand their customers and access market segments they had not considered before. This can mean simple things like becoming aware of and familiar with assistive technology disabled employees and customers use, incorporating stories about the life hacks and ingenuity people rely on to navigate barriers to accessibility, or stories about how simple changes to work processes and expectations can make a significant impact on productivity, performance, and job satisfaction. Honest conversations from neurodivergent employees on things like the emotional and energy deficit that comes from masking in a work environment, sensory overwhelm, and being required to be on camera, etc. are great examples of how training can help bring more awareness to specific lived experiences.

“A culture of acceptance and respecting differences, as well as a degree of flexibility, is very important for any disabled employee to thrive.

Building such a culture requires awareness across all levels of the organisation, coupled with other initiatives. Ultimately, systemic change to hire and motivate disabled employees is a long-term investment.

The effort, time and resources are significant, but the development potential is truly astronomical.”

PREETHAM SUNKAVALLI

Manager, Business Transformation at Mahindra Group

Employee Resource Groups

Employee Resource Groups or ERGs refer to voluntary, employee-led communities that may or may not be formally supported by an organisation. ERGs are often organised on the basis of shared identities, interests, or backgrounds with the goal of supporting employees by providing opportunities to network and create a more inclusive workplace. ERGs often start out as grassroots efforts led by passionate advocates or people with lived experience seeking to build a sense of community, generate awareness, and provide resources to others. Organisations use many naming conventions to refer to ERGs. These include business resource groups, DEI councils, affinity groups, inclusion resource groups, or network groups.

In progressive organisations, ERGs mature into recognised functions that benefit from executive sponsorship, allocated budgets and

formalised, remunerated roles responsible for their activities. In mature ERGs such as these, it is also common to see the establishment of sub-communities or groups which represent and support individuals with intersectional identities or those with specific lived experiences. In regard to disability, it is important to note that ERGs are not just focused on personal lived experience of disability. They can be for parents and carers of disabled children, spouses of people with disabilities, and others whose lives are touched by disability.

When they are at their best, ERGs adopt a community-first approach. This is to say that the focus of the ERG is to foster the establishment and growth of identity-led communities and a sense of connectedness rather than supporting ERGs with the goal of leveraging and/or gaining access to disabled lived experience and perspectives. We have seen many examples of how ERGs that do not adopt a community-first approach can actually erode cultures of trust in situations where passionate advocates of, and for, the disability community are utilised as an unpaid source of expertise, innovation, strategic advice and peer support. In these cases, burnout is very common and can have negative impacts on employee performance because participation in and leading ERG activities eclipses those required in their primary role.

“Disability ERGs go beyond mere advocacy. They are an untapped resource of individuals who know all too well the barriers presented within your organisation. They are community and an opportunity for many disabled individuals to feel a sense of belonging.”

JAMIE SHIELDS
AMS

As a global collective with representation across 41 headquartered countries and 64 industries, we have noted that ERGs are not common across all geographies. Thus, many organisations are unaware of the concept of an ERG or the benefits of having them in place. In these geographies, discussions relating to ERGs may give the impression that they must be formalised, well thought out and established initiatives rather than an employee-led effort to connect as a community.

It is important to note that taking a community first approach may be achieved through other means than ERGs that are culturally relevant in a specific geography. Non-western countries have much to offer regarding ways of working and new thought leadership that represents global perspectives.

For example, in Japan, the concept of *wa* (和) is an important cultural value which loosely translates to the concept of “group harmony”. In the context of the workplace, *wa* can be expressed in the form of taking care of and meeting the needs of all members of a team, and prioritising group values and the welfare of the community over individual ambitions or desires. Just as we have highlighted the need for more thought leadership from those with intersectional identities, it is critical that the way we approach disability inclusion incorporates global and culturally unique perspectives.

#PositivelyPurple is another global movement that celebrates and draws attention to the contribution of employees with disabilities around the world. More importantly

#PositivelyPurple has been connecting disability Employee Resource Groups (ERGs) and networks around the world – building disability confidence from the inside out and driving a movement for change. PurpleSpace have been leading this movement since 2017: as a mark of respect to

the UN International Day of Persons with Disabilities (IDPD) held annually on 3rd December.

Operationalising Disability Performance

An overwhelming majority of conversations on disability inclusion in the workplace are had through the lens of DEI, if they are had at all. Employees at all levels of organisations have communicated that they feel lost as to how they can participate in enacting change. For many people, conversations around being an ally or “stepping up” are intangible or lack meaning in the context of their job duties, the remit of their role, or their areas of expertise. In contrast, tangible actions like a supply chain manager adding a disability-specific question to an RFP or adapting service level agreements, an IT developer engineering systems to be accessible from the outset, or social media teams ensuring ALT Text and captioning are added to all images and videos online are work activities that are relevant, actionable and meaningful to them. We need to see more of this. Anyone, anywhere within an organisation that communicates with others through media, software, presentations, and/or websites, can take tangible action to ensure that everything they do are respectful and accessible.

With the above examples in mind, a goal of this document is to make the case for moving beyond a singular focus on disability inclusion as a DEI construct and to operationalise disability inclusion. What we mean by this is to catalyse a paradigm shift whereby Valuable 500 companies expand the concept of what disability inclusion means to include actions and effort that drive productivity and profitability, reduce risk, optimise efficiency and increase the likelihood of recruiting and retaining talent, etc.

"Many of us who work on technology accessibility talk about the concepts of "shift left" and "born accessible."

The idea is that you think about how you make your workplaces, your products and your culture fully inclusive from inception, not as an afterthought.

Instead of treating disability as something "special" that is dealt with only when a stakeholder encounters a barrier, you mainstream the inclusion mindset; you make it table stakes.

It's one reason I did away with the Accessibility Champions awards at a company I worked for. The new approach was that you shouldn't get a trophy for doing your job properly – that's what your pay check is for. Though we didn't get there by the time I left, the next step was to include assessment of how well you handled this part of your job, making it part of your performance evaluation and determination of your compensation. Now that would have gotten tangible results!"

LARRY GOLDBERG

Accessible media & technology consultant

Representation

In the context of this document, disabled representation refers to the act of ensuring persons with disabilities are present and identifiable in all aspects of society in ways that are consistent with how the disability community perceive themselves. This can be interpreted in many ways. It can mean companies creating toys, publishing literature, and producing media based on characters their disabled audiences can relate to and aspire to be.

It can mean casting disabled talent behind and in front of the camera, so the world consumes media which portrays authentic depictions of the lived experience of disability. It can mean seeing disabled models on the runway or on the cover of mainstream media publications. For organisations who do ensure persons with disabilities are represented across all facets of media, PR & advertising, it is important that the representation is authentic and informed by how the disability community perceive themselves. Often times, the way disability is represented in the media, advertising and PR, stock imagery, and even in person at events, can be reminiscent of medical and charitable model thinking.

In the context of business, disabled representation can also refer to workforce composition – from seeing peers with disabilities working in all functions in the organisation, to board level leaders who openly identify and speak about their lived experience. It can mean showing up to a conference or event and encountering multiple other disabled attendees. It can also be as simple as having the experience of working with a deaf colleague who communicates via a sign language interpreter or with a blind colleague who uses assistive technology and getting comfortable with those peer-to-peer interactions.

Inclusive Language

“Language is one of the most important signals that we have to demonstrate our acceptance or rejection of a person’s identity.”

EMILY LADAU

The language we use to talk about disabled identity matters and is central to building cultures of trust. Even more importantly, the language we use to define disability impacts employees’ willingness to engage in Self-ID processes and in some cases may even influence whether an individual perceives themselves as disabled. The language individuals use to describe themselves and the disability community is very much a personal choice. Some people prefer identity first language such as “disabled employee” or “autistic person” whereas others prefer person first language such as “employee with a disability” or “person with autism”. Out of respect for different preferences, we have used both identity first and person first references to disability throughout this document.

We recommend holding space for personal preferences within the workplace as well.

“It is important to respect personal preferences, whether one prefers identity first language or person first language, to create an inclusive environment that accommodates individual choices within the workplace. I personally introduce my disability as: “I am a person with a disability and even in this sentence, the word person comes first.” I identify as such so that people understand that I will need assistance and let people know I am not asking for special treatment, just looking for an inclusive experience.”

TUCKER DUPREE

Colleague Experience Lead at BP

When we speak about disability using a lexicon which is overwhelmingly negative, this immediately signals how disability is viewed by the individual using that language or as a representative of an organisation’s culture. As an example, consider the contrast between the phrase “wheelchair user” and “confined to a wheelchair” or “wheelchair bound”. This example demonstrates how language is a carrier of negative views and stereotypes on disability driven by medical and/or charitable models. These stereotypes signal that disability is tied to sorrow, pity, and a limited ability to live a productive life. Economic participation in the workforce is a great example of how the disability community and business can challenge and deconstruct these stereotypes. Having a person with a disability employed in a role specific to operations, finance, procurement, IT, HR, marketing, or any other function within an organisation demonstrates that persons with disabilities can thrive in these roles and that assistive devices are simply facilitators rather than limitations.

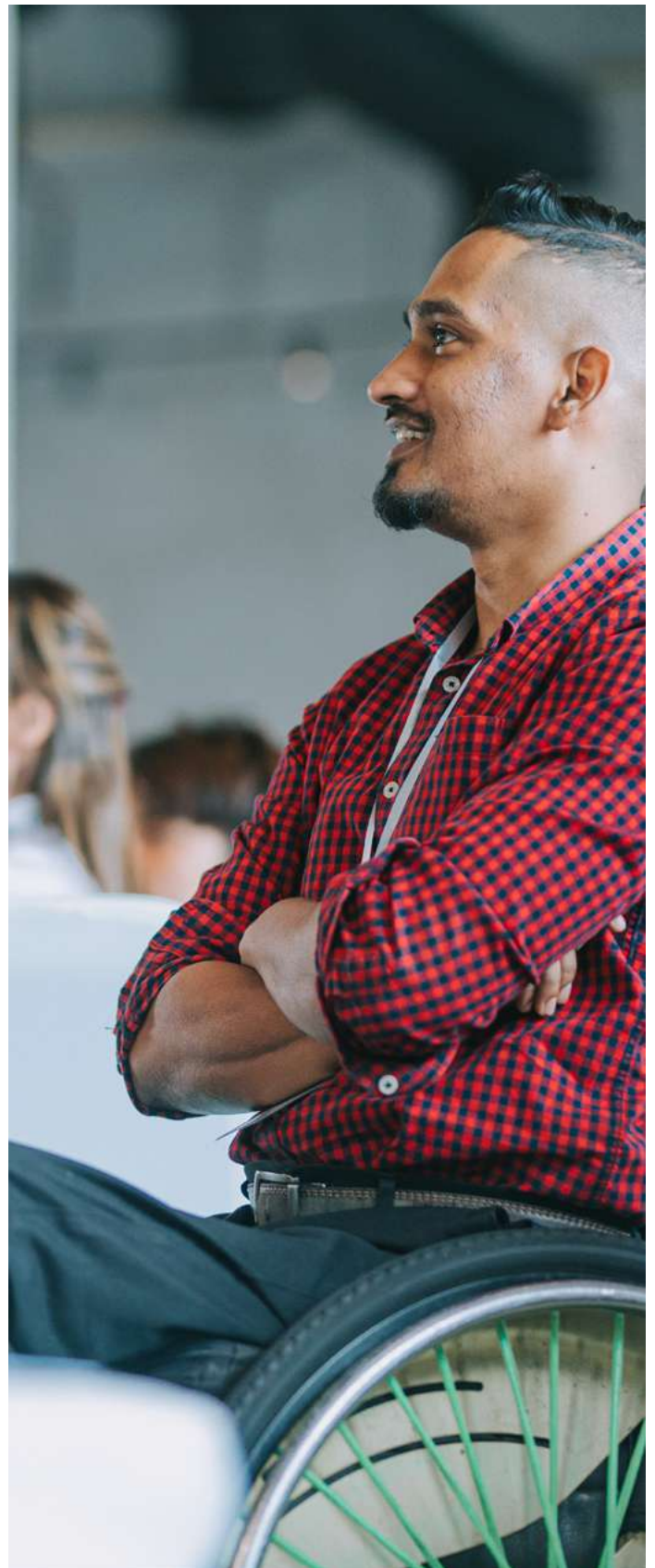
However, if barriers in recruiting, retention and career progression persist, it makes it difficult for the disability community to access these opportunities.

Phrases and words like “bound to”, “confined to”, “suffers from”, “impaired”, “dysfunction”, “atypical”, “abnormal”, and “disorder” are examples of common language used every day which carry and perpetuate ableist perspectives toward the construct of disability.

As we all examine the language we use to describe disability or to reference certain behaviours and experiences, it is important to recognise that ableist language is something that is stubbornly woven into the words, idioms and phrases many of us have learned over the course of our lives. Part of actively dismantling ableism is to consciously choose to use language in a different way.

It is easy to become overwhelmed with the feeling of not knowing what to say and to be concerned whether our language can cause offence. It is our position that it is important for us all to set realistic expectations for ourselves as we work to remove ableist language from our vocabulary, and when slip ups do happen, to acknowledge them and move on.

Self-reflection, accountability, and the desire to do better are more important than perfection.



Below is a list of definitions of disability that are used across various geographies. These definitions demonstrate various degrees of ableist language and references to harmful models of disability. As you read these definitions, please consider how the language used in definitions and ways disability is referenced and discussed can erode trust.

Japan

Persons with disabilities are those who, because of physical, intellectual, or mental (including developmental) disabilities or other impairments of physical or mental function are subject to considerable restriction in their vocational life, or who have great difficulty in leading a vocational life, over a long period of time.

Germany

Persons are considered “disabled” if their physical functions, mental capacities, or psychological health are highly likely to deviate for more than six months from the condition which is typical for the respective age and whose participation in the life of society is therefore restricted.

Australia

Recognises the definition of disability as including those who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various attitudinal and environmental barriers, may hinder their full and effective participation in society on an equal basis with others.

Israel

A person with a physical, mental, intellectual (including cognitive) impairment, either temporary or permanent, which substantially limits a person’s ability to function in one or more main areas of life.

India

A disabled person is a person with long-term physical, mental, intellectual and sensory impairment, which in interaction with barriers (social, communicational, cultural, economic, environmental, institutional, political, attitudinal or structural) hinders his/her effective participation in society equally with others.

UK

A physical or mental impairment that has a substantial and long-term negative effect on your ability to do normal daily activities.

China

One who suffers from abnormalities of loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal.

Ireland

A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of enduring physical, sensory, mental health or intellectual impairment.

Mexico

Any person who, due to congenital or acquired reasons, has one or more deficiencies of a physical, mental, intellectual or sensory nature, whether permanent or temporary and which, when interacting with the barriers imposed by the social environment, may prevent their full and effective inclusion, on equal terms with others.

Implementation Success Factors

Leadership Engagement And Transparency

The curation of this document was informed by conversations with the disability industry, disabled employees, creatives and entrepreneurs, and DEI and operational practitioners within the Valuable 500 companies who have been actively involved in work related to Self-ID related. Across the hundreds of interactions with all parties, a common theme that emerged was the importance of leadership engagement and support of Self-ID processes. Whether it is announcing the launch of a Self-ID process, or annual invitation to participate, we heard time and time again how important it was that C-Suite leaders and their senior leadership teams spoke openly about their support for Self-ID, spoke personally to why they were asking employees to participate, and spoke about how the organisation intended to support employees with disabilities. Employees are acutely aware of the responsibilities and workloads carried by their executive leadership teams; therefore, leadership-led launches signal to employees that disability inclusion sits as a priority alongside these accountabilities. Disability inclusive organisations include disability performance in the bonus or remuneration criteria of their leadership teams. This is another example of how leaders operationalise disability inclusion and require accountability across their organisations.

From the inception of the Valuable 500 to where we sit today, we have seen numerous examples of how important it is for leaders to speak openly about their own personal lived experience or the proximity of disability in their lives. Like any employee, the choice to do so is an individual one, but when leaders demonstrate the courage to disclose their disabled identity or life experience internally within their organisation or more publicly, it fosters trust in meaningful and powerful ways.

“When people rightly say that the majority of disabilities in the workplace are not visible – I know it. The impact may sound small, I sometimes speak with a loud voice in meetings or need to sit in a certain part of a room, but at any stage of a career, the self-consciousness this creates can be intimidating. In the past, I have shared my own experience with EY teams, and I found that voluntarily coming forward makes a huge difference. That transparency creates a recognition that “we see you” and that you belong.”

JULIE TEIGLAND

EY EMEA Area Managing Partner; EY Global Leader

Humility And Honesty

One of the most consistent messages communicated by the disability community is the importance of humility and honesty as it applies to individual leaders' and organisations' disability performance. This can mean many things – it can mean intentionally sitting in the discomfort of recognising that progress is not as advanced or as comprehensive as it should be. It can be acknowledging that despite good intentions, formalised cost structures, and dedicated roles and responsibilities within an organisation, there is still work to do or that people have been let down. It can be actively acknowledging and challenging harmful views or belief systems held, and it can be publicly disclosing data that is a lagging indicator rather than a leading one.

What we have learned is that the world's largest and most recognised brands both within and outside of the Valuable 500 dominate the market fiscally and reputationally because they are the best at what they do. Excellence is woven into their corporate DNA and often it is deeply uncomfortable to acknowledge or even recognise that disability performance is not 100%. However, leaders need to face this discomfort head on in order to create meaningful change within their respective businesses. The sheer scale of the disability population globally should be motivation enough – excluding 16% of the world's population is never good or ethical business.

Part of the path to curating this document was to create safe spaces and environments for leaders and employees to speak honestly about the complexities of the disabled experience, fear of not doing enough or getting it right, add the risk associated with stakeholder activism, cancel culture and litigation.

We hope that an outcome of interacting with this resource is to acknowledge that the work of improving disability performance may never be done and will certainly not be defined by perfection.

Despite this, setbacks should not be a deterrent to continuous improvement.

Internal Communications

Messaging from disabled employees, consultants, and corporate communications practitioners alike asserts that internal communications are an essential ingredient of successful Self-ID processes. The hallmarks of successful internal communications strategies include approaching Self-ID as something that is worthy of well thought out, consistent communication that starts well before employees are welcomed to participate in a Self-ID survey or data gathering initiative.

Disability Inclusion Awareness

For many organisations, this means starting with the training and awareness described above to ensure that all employees understand the fundamentals of progressive models of disability and the importance of ensuring that environments, customer service delivery, products and services are accessible to all, and understand the proactive steps the organisation has put in place to provide workplace adjustments/reasonable accommodations to everyone. The awareness phase of internal communications is also often focused on making employees aware of the presence of Employee Resource Groups or other identity-led communities within the business.

Signalling Intentions

Once a threshold level of awareness on the fundamentals of disability inclusion has been achieved, many organisations move on to internal communications aimed at sharing leadership's intentions and the expected outcomes of Self-ID. Understanding disabled representation within the workforce must come from a place of empathy, care and the genuine desire to remove barriers on behalf of disabled

employees. We have seen many examples of Self-ID initiatives that have seen limited success because leadership failed to signal that a Self-ID initiative was more than a simple data acquisition exercise. Notable topics disabled employees want to have certainty on are:

- Understanding how sharing personal information about their identity is going to benefit them and the organisation.
- Having confidence that leadership is committed to acting upon the things they learn if employees take the time to provide feedback on their disabled lived experience.
- Clarity on whether or not the survey is truly anonymous. If not, certainty that participating won't put them at risk of discrimination, harassment, or stalled career progression.
- Understanding what organisations intend to do with the data provided and who in the organisation has access to it.

Announcing the Launch

A hallmark of successful Self-ID campaigns is a formalised, C-Suite-led launch. Self-ID launches hold tremendous potential as creative exercises which allow for heightened awareness and adoption of brand values, purpose, and identity. When the messaging is curated effectively, they also serve as an opportunity to demonstrate that leadership is committed to addressing disability-specific inequity or lagging performance.

Sustaining Momentum

Once a Self-ID initiative has been launched, it is important to understand that continued success and engagement cannot be assumed. Formalised efforts to keep the concept of Self-ID and the company's intentions associated with understanding disabled representation in the workforce must be communicated. Our research revealed that making use of multiple platforms and means of communication were essential to ensure as much engagement as possible.

Cross Pollination

Weaving disability inclusion and the desire to understand disabled representation in the workforce throughout concurrent communications campaigns was also a common success factor amongst companies who had achieved success with Self-ID. We heard many stories of how Self-ID implementation started with formalised C-Suite led campaigns and was intentionally made relevant to other ongoing communications initiatives. These included examples like International Women's Day, to celebrate and generate awareness of the nuances of female and gender fluid disabled identity, neurodivergence adjacent to STEM awareness and education, discussions on mental health, neurodivergence and disability related to the benefits of flexible or remote working, etc. What these approaches have in common is that they keep the conversation on Self-ID going and create opportunities for people to connect with the concept in meaningful ways.

Tracking Progress and Data Transparency

Once Self-ID has been successfully implemented, it is critical that progress is communicated on an ongoing basis. As

with other aspects of Self-ID, transparent communication is best achieved across multiple platforms or media. These can include company townhalls, internal business updates, posts on an intranet or internal social channel, and public disclosure instruments such as annual reports and accounts (ARAs), sustainability, ESG, or impact reports. Many employees have expressed frustration with participating in Self-ID processes which lack transparent communication of disabled representation in the workforce.

Representing Intersectional Identities

"Intersectionality is defined as the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequalities."

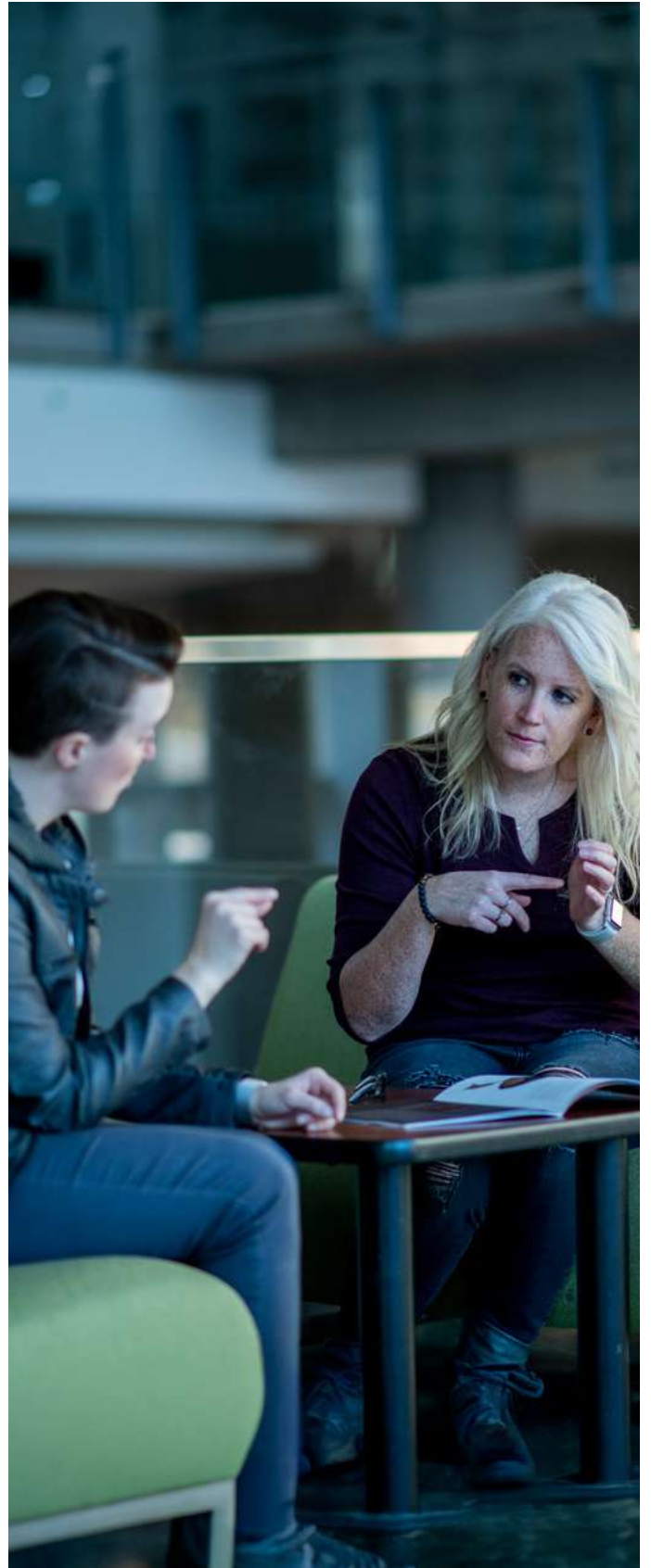
KIMBERLÉ WILLIAMS CRENSHAW

“Simply put, these are captured in the depth of the relationships between employees. The ability to connect, establish trust, engage with conflict, or avoid it, and elicit collaboration or curiosity. These are attributes that, like respect, although not captured in a KPI performance, certainly deeply affect it, and go on to affect retention rates and/or ‘quiet quitting’ and in the long run, the organisation’s bottom line. In the long run, the organisation’s bottom line is based on its ability to accept the intersectional nature of who these employees are, the willingness to embrace it and the active nature to bridge the gap where they do exist.

So, when we talk about intersectionality, a one size fits all approach does not work and it is naïve to expect one line manager to bear this responsibility or one C-suite executive to champion this cause. It is an organizations’ responsibility to ensure there is buy in from the top, but more importantly, every person hired and retained within the organisation is held to values of inclusion, respecting, and engaging with colleagues within their uniqueness and seeing that as the organisation’s strength.”

DR. ELSA ZEKENG

Founder, SökerData



Legal Considerations

We found it notable that perceived legal barriers dominated many conversations we held on Self-ID and were often cited as the reasons organisations were not actively working to better understand disabled representation in the workforce. Concerns over whether businesses were legally required to provide accommodations and the cost implications of workplace adjustments also dominated this area of discussion.

A country-by-country review of legislation related to disability data is beyond the scope of this resource. However, due to the many inaccurate perceptions surrounding the lawfulness of collecting disability data we encountered, it became apparent that a primary goal of this resource would need to be to dispel common myths or misunderstandings to clarify what are and are not legitimate jurisdictional legal challenges to approaching Self-ID.

An important aspect of the work we undertook to produce this resource was to open a dialogue with companies within the Valuable 500 who were well advanced on their Self-ID journeys. There was a wide continuum of experience related to corporate Self-ID initiatives; a handful of our companies had launched Self-ID in 50+ countries, and many had done so in more than ten countries. Some were implementing Self-ID for the first time and others had been progressing this work for multiple years. Some were seeing representation of employees with disabilities reported in numbers which align closely with the WHO's data on the global disability population (16% as of 2023), whereas others were seeing numbers below 1%.

Regardless of this disparity in approaches taken and the data outputs, the overarching conclusion we reached is that in **most countries our 500 companies operate in, there are legal**

means through which Self-ID can be implemented. In countries where legal constraints were prohibitive, we saw examples of other means of assessing disabled representation. The analysis of anonymised data associated with the number of workplace adjustments/accommodations requested each year is an example.

We highly recommend that all organisations track and analyse data on how workplace adjustments were provided, the cost of these adjustments, and the amount of time it took to provide them to employees.

In addition to providing insights into how employees with disabilities experience the workplace, workplace adjustment provides an avenue to gather meaningful disability data in legally restrictive jurisdictions.

Our research also established that risk and compliance, regulatory, and legal teams are central to organisations' ability to facilitate Self-ID processes. Despite the critical role these functions play, many organisations do not possess the in-house expertise to advise, support or contribute meaningfully to implementation. Furthermore, the lack of concrete expertise can often serve as a blocker to Self-ID processes being established at all. Given that globally, disability data is legally governed differently regarding declaration, assessment, communication, treatment and retention, it is essential that organisations establish formalised roles and responsibilities dedicated to monitoring and interpreting the legislative landscape which is constantly evolving.

In the context of legal considerations, it was compelling to facilitate conversations between companies who, at the outset of the working sessions, believed Self-ID wasn't possible in a specific jurisdiction, with companies who were able to demonstrate otherwise. The brokerage of knowledge between Valuable 500 companies resulted in many lessons and insights being shared. This included challenging overly conservative interpretations of anti-discrimination acts, codes, employment laws and regulations and providing evidence of how it was possible to operate in compliance. We look forward to our 500 companies engaging in continued discourse to dispel inaccurate interpretations of the legal landscape.

Data Considerations

A legitimate legal consideration for collecting, processing, analysing and storing Self-ID data is to ensure that data is governed in compliance with relevant legislation specific to each operating jurisdiction.

In relation to regulations such as the General Data Protection Regulation (GDPR) in Europe, we encountered widespread assumptions that it was not lawful to collect disability data. In fact, GDPR compliance was one of the most frequently cited reasons for not collecting Self-ID data.



“If the lawfulness, value and transparency for such process was evident, wouldn’t it become a no-brainer to disability inclusive employers and employees with disabilities to collaborate on their joint purpose in a safely and respectfully designed disability Self-ID process?”

It is regrettable that companies as well as employees still have misconceptions about the opportunities and benefits for Disability-related Data and General Data Protection Regulation (GDPR) which define well the opportunities for how Self-ID of persons with disabilities can be realised in secure and meaningful ways rather than prohibiting such process to exist.

It is crucial for disability inclusion to succeed in a managed way that factors in favour of it can be understood via data and analysis in relevant context, like at the workplace. A first step for organisations to take is regular education to all employees about data protection regulations and disability rights applied locally as well as also within the full scope of a multinational’s activity. This can happen as part of yearly mandatory trainings, as the case for my employer ever since I joined for GDPR. This knowledge enables several crucial steps as once: firstly, higher chances of trust of the data subject providing personal data in well-designed transparent processes respecting such regulations, and secondly, confidence of the data controllers and processors on how regulatory compliant processes are handled correctly. This way, risks and misunderstandings can be reduced on both sides and processes on Self-ID for employees with disabilities be enabled.

As a start, it should be clear that the Self-ID process ensures that the consent is “freely given” and on a voluntary basis, specific to Self-ID as an employee with disability, informed and unambiguous about the type and purpose of these data. In addition, the process must respect all principles of Article 5 of GDPR, i.e. that it specifies explicitly the purposes and usage (Purpose Limitation Principle) of the data provided, explaining in a transparent way all steps of processing, rectification, storage, retention and means of deletion. It needs to be ensured that solely data “adequate, relevant and limited to what is necessary in relation to [that] purposes for which they are processed” are collected respecting the “Data Minimisation Principle”. Purposes need to be clearly and transparently linked to the interest of the workforce, especially employees with disabilities, and the anonymised reports be available to them.”

ALEXANDRA K. NOTHNAGEL
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However, an in depth review of Article 9 of GDPR (which specifically addresses sensitive personal data such as disabled identity), revealed that if organisations acquire the data via a lawful means of processing, assess and mitigate risks unique to data controlling and processing, and maintain appropriate data governance processes in regard to who has permission to have access to the data and the specific circumstances under which data can be accessed, Self-ID data can be collected in a compliant manner. Gaining and documenting explicit consent that was freely given, specific, informed and unambiguous is central to ensuring compliance, as is the right for employees to withdraw consent at any time and request to see what data the company holds on them.

As previously mentioned, anonymity of the data is central to many organisations' ability to maintain regulatory compliance with relevant legislation. Many organisations within the Valuable 500 and in the wider business community have elected to use third party data processors in order to effectively maintain anonymity and ensure adequate data protection and governance and data storage place. There is no one size fits all for all organisations; each of these considerations are unique to the businesses evaluating them.

Many discussions related to disability data lead to discussions of the Disability Pay Gap, management, leadership and board composition.

While it is important to highlight the fact that pay inequity and disabled representation are key issues to be assessed and addressed, it is important that the pursuit of this data does not come at the cost of anonymity or proper data governance practices.

To provide context to how this may transpire in a corporate setting, consider a situation in which an anonymous Self-ID survey was sent out to 1,000 people and 25 participants' responses show that they identify as disabled. If the survey included the opportunity for participants to provide information on other Self-ID characteristics such as gender, age, sexual orientation, etc., current management tier (manager, leader, C-Suite, board member, etc.), when analysed, the data set, although still anonymous, may give away information individuals provided with the understanding that it was private and protected. For this reason, data governance practices such as establishing a minimum sample size and limiting how and by whom the data can be analysed and correlated are key to maintaining data privacy and being able to truly preserve anonymity.

Disability Employment Quotas

According to the International Labour Organization (ILO), as of 2019, 103 countries across the world have quota systems in place which require organisations to provide threshold levels of employment opportunities for people with disabilities. These thresholds are typically expressed as a minimum percentage of the workforce which must be comprised of disabled workers, and specify an employee count which renders the organisation responsible for compliance. 33 of these countries identified (32%) have quotas backed by levies or fines. Many organisations find themselves under pressure to meet these quotas and avoid fines, which serves as a distraction to understanding and supporting their workforce. It has also been noted that many times disability quota systems have dedicated talent pipelines which lack meaningful opportunity or progression for individuals who formally Self-IDentify via federal initiatives.

All organisations undertaking efforts to measure disabled representation in the workforce must understand that there is a clear distinction between corporate-led Self-ID, and Self-ID undertaken to comply with country-level disability employment quotas. In our opinion, there are also tangible reasons why the two data sets would be expected to differ, sometimes drastically. This is an important consideration given that differences in the two data sets have been misinterpreted as an indicator of poor data quality or integrity.

From our research and conversations across the globe, we learned that many individuals are hesitant to disclose a disability at the federal or company level due to the following reasons:

- Restrictions on personal autonomy such as the number of hours permitted to be worked.
- Requirement to demonstrate and medically document “degree of disability” based on various scales or weighting systems (for example, in Germany and France).
- Frustration with talent pipelines that do not offer meaningful opportunity or progression.
- Time intensive, costly, and personally invasive disclosure requirements.
- Fear of becoming ineligible for insurance policies and benefits. Fear of discrimination from line management, HR, or colleagues.

Many countries enacted disability employment quotas in the post-war era to create opportunity for individuals who acquired disabilities as a result of war-time service. Advocating for more progressive approaches to increase disabled representation in the workforce is a key role business can play. For a comprehensive review and classification of disability employment quotas, please review The International Labour Organization’s report on Promoting Employment Opportunities for People with Disabilities.

The Path Forward

This document, in addition to providing disabled-led perspectives and recommendations on how to approach this work, serves as an invitation to start where you are and acknowledge that many other organisations are in the same position. It was not written as a resource with a concise set of recommendations; rather it was written as a resource to come to at various stages of engaging in work aimed at understanding and increasing disabled representation in the workforce. We hope that the recommendations, perspectives, and insights within this document will also serve as tools to help break down the many barriers to progress and to disability data being meaningfully integrated into business performance criteria.

An important consideration for the format of this offering was to hold space for disabled entrepreneurs and consultants who hold deep expertise in this area. As you explore how your organisation is working to build cultures of trust, to use disability inclusive language, engage in successful implementation, and navigate the legal landscape, we recommend actively seeking out consultants, advisors, and innovators with disabilities to inform and progress work within your respective organisations. Your business will be the better for it.

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Google is one of 15 iconic leaders within the Valuable 500 committed to co-investing and co-creating system-level change solutions aimed at enabling full and equitable participation for the global disability community. Google led the inclusive design sprint methodology which brought together the companies within the Valuable 500 who were most advanced on their Self-ID journeys. This process facilitated knowledge transfer, innovation and ideation, and critical analysis of resources required to simultaneously serve the needs of business and the global disability community.

Deloitte.

Deloitte is a fellow iconic leader within the Valuable 500. Deloitte are committed to using their brand and business principles as a force for good.



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Key Influences

This document is as much a celebration of the individuals and advocacy groups who show up every day for the disability community as it is a resource for businesses who are committed to understanding more about disabled representation in their workforces and how to approach this work. Below is a list of some of the reading materials, media, and resources which have informed, inspired and guided the creation of this document. While this is not intended as a formal list of suggested resources, we want to celebrate and amplify the work of the disabled thought leaders, entrepreneurs and activists who have invested their time and energy to create awareness and educate others.

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- [Not Special Needs. March 21 – World Down Syndrome Day. YouTube.](#)
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- [TedTalks: Wanda Diaz Merced – YouTube.](#)
- [Authentically Reflecting Disabled People – Google All In.](#)
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