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The future challenge of the ADA: Shaping humanity's transformation

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Abstract

Through a meta-review of global trends and the contextualization of the 25th anniversary of the Americans with Disabilities Act (ADA), the author proposes that a change of strategy and focus is required to achieve the ADA's aspirations. The argument is made that the disability community and inclusion effort must participate in a leadership role in shaping the current transformation of society, including three broad systemic factors: (a) design and development, (b) research and evidence, and (c) education and learning, to avert widening disparity and address risks that affect all members of the global society.

ADA and the Future

The positive impact of the Americans with Disabilities Act (ADA) over the past 25 years is undeniable, both for persons with disabilities and for society as a whole (Blanck, 2016a, this issue). However, to date, the disability community and ADA efforts have been largely responsive to barriers and breaches of inclusion, equity and accessibility commitments. For the next 25 years and beyond this will not be enough. To realize the aspirations of the ADA, we need to do more than catch up, patch and fix; or the gap will continuously widen for persons with disabilities (Blanck, 2015a, Vanderheiden, 2006).

Few people would disagree that we are experiencing accelerated change in all areas of life spurred on by disruptive technologies and global connectivity (Tapscott & Williams, 2008). With greater speed and magnitude come expanded opportunities and risks. Early choices

propagate at a far faster rate, making it more difficult to fix once momentum is gained (Castells, 2011). It's relatively easy to redirect a slow moving buggy; with a fast moving truck you want to help navigate the vehicle; if you are on the sidelines you will be left behind, if not run over. As a community invested in inclusion for people with cognitive and other disabilities, we need meaningful, pervasive participation in architecting the changes affecting our society. To help guide the direction of our society as a whole means we need expertise, foresight and influence to participate proactively, not reactively (Blanck, 2014). Full participation in steering these fast-moving technical disruptions that are transforming our lives will set society's course toward optimizing opportunities and minimizing threats for all (Treviranus, 2014b).

It also is not enough to trust that the vanguard will keep everyone in mind, even when inclusion is a commitment. Accessibility, for example, is a precarious value; almost everyone agrees it is important, but often it is the first thing that is compromised when there is a time or budget crunch or when other priorities arise (Harper & Yesilada, 2008). Moving forward, ADA-related legislation and regulations should be the rearguard, primarily to catch the laggards. Our focus and attention should be on strategic systemic intervention to guide the inevitable transformation of at least three foundational areas: (a) systems and processes of design, development, and production, (b) research methods and means of gathering evidence, and (c) systems and processes of learning and education.

The Inclusion Imperative

We have no choice but to broaden our focus. Given this evolving transformative era, we have neither the power nor the speed to create meaningful impact through current strategies, particularly when there is a significant increase in disability through aging and better survival rates. We must go beyond treating the outbreak of barriers, and beyond preventing new barriers

for people with disabilities. To achieve meaningful impact we have a time-limited opportunity to trigger inclusive health, education, employment, prosperity and well-being for everyone, by helping to steer our society toward practices that sustain inclusion and self-determination by default (Blanck & Martinis, 2015).

This is a tall order, but evidence is mounting that by promoting inclusive design and the conditions for inclusive participation we are doing just that (Blanck, 2014, 2015b). Accessibility may be equated with designing for diversity and respecting human difference (IDRC, 2013). The benefits of diversity are well documented and acknowledged in fields such as physics, biology and economics (Samuelson, 1967, Jones, 2012). Complexity scholars and researchers warn against the risks of monocultures, disparity and lack of inclusion (Page, 2010). Researchers in societal well-being and health show that inclusive and equal societies are healthier, wealthier, wiser and more innovative (Wilkinson & Pickett, 2009, Page, 2007). This assertion has been supported by prominent economists and the World Economic forum (Piketty, 2014).

From a global perspective, perhaps the most important challenge our civilization faces is inclusion, and our greatest redemptive asset is diversity (Treviranus, 2014). There is a realization that increased connectivity leads to an entanglement of even the smallest choices. Whether we label phenomena as ripple effects, tipping points, or butterfly effects, we are becoming aware of the larger, systemic impact of our words and actions (Gladwell, 2006, Downes, 2009).

With greater connectivity and mobility comes complexity in every domain (Page, 2010, Goldin & Mariathasan, 2014). As we become collectively conscious of the risks of health disparity, the environmental impact of careless waste, the corrosive effects of economic disparity, and terror that arises out of social fragmentation, our civilization will thrive or fail based on the capacity to be inclusive (Global Risk Report, 2015). With respect to our collective

futures moving forward, we seem to have three general paths we can take in our approach to diversity and inclusion:

1. Protecting the lucky few

We can choose to support disparity. A lucky few will hold the majority of wealth and opportunity. As the few must increasingly protect their wealth and security from the excluded, this choice comes with escalating security costs and associated constraints on our freedom and self-determination. Competition also escalates as the choice of who is privileged and who is not has huge stakes. This means that the standard for who belongs to the privileged will become more narrowly defined, leading to risky monocultures that are more vulnerable to threats, leading to greater instability as "superpowers" vie for dominance.

2. Charity

A seemingly more humane approach is the charity model. In this model, the included support those who are excluded through charity, public social services and episodic acts of private munificence. As these charity measures are influenced by political forces, as well as by appeals to empathy or pity, those that are excluded must persuade the included that their needs are great, if not the greatest. This intensifies the power imbalance as the excluded are encouraged to become more dependent on the included. It results in divisiveness among the excluded as there is competition for limited charity resources and attention. Charitable impulses wax and wane and become less sensitive to stimuli, meaning that the appeals must escalate in intensity and continuously refresh to avoid "charity fatigue" (Moeller, 2002).

3. Inclusive Participation

A third choice is to recognize the value of diversity and design society such that everyone can contribute their personal optimum. This requires moving away from mass design to designing for

diversity and enabling participation from the full spectrum of members. It requires a proactive and integrated approach to inclusion design, thinking about inclusion before decisions are made and conventions set, and assuming that exclusion is never an option in any planning.

The disability inclusion movement is positioned to guide the choice between dystopian scenarios of ever-rising disparity necessitating mounting security, equally untenable disempowerment and dependency of one part of our society on another, or meaningful inclusion, participation and multi-perspectival knowledge, leading to innovation and evolving, dynamic resiliency. Unlike other groups, the disability community permeates economic strata, geographic boundaries, cultural, ethnic and racial divides. With global connectivity, this can be leveraged into a significant influence. The disability community represents the largest global minority and is personally relevant to all decision makers (UNESCO, 2013).

Systems and Processes of Design, Development and Production

The first process that we must address is design and development. In this transformative era, design of systems, tools, practices, processes, services is a powerful tool. Our complexity and connectedness means that each design decision we make regarding emerging technology and practices takes us in the direction of greater inclusion or greater exclusion and each design choice propagates, making it more difficult to turn back or redirect. While conventions are fluid, we have a critical challenge and a time-limited opportunity to support inclusion of human diversity in design, or risk lock-in of conventions that cause new barriers (Lanier, 2010).

The dynamics of connected and entangled global networks means that emerging technical practices introduce more than opportunities and challenges, but also powerful vicious and virtuous cycles. Addressing any factor in the system can cause an amplified and escalating reaction. As a positive example: enabling an individual with a disability with experience in using

screen readers to participate in IT development in a company has impact on all technologies that are generated by that team (Blanck, 2014). If what is developed is a development toolkit, the impact will be evident in all future software created using the toolkit (Harper & Yesilada, 2008). As a negative example: while digital systems and networks have transformative qualities that can address barriers, they can also accentuate exclusionary pre-digital tendencies. Search engine optimization strategies, social media "likes," "most popular" ranking, and recommender functions create an overwhelming popularity echo-chamber on the net. The popular becomes more popular while the unpopular disappears (Treviranus & Hockema, 2009). Similarly, network trading and global markets can amplify the echo-chamber of wealth. Market and consumer analytics causes a proliferation of popular or trending products (Sunstein, 2009).

Because "Big Data" strategies replicate the flaws and biases of traditional research methods, evidence-based governance based on Big Data and data analytics can create an echo-chamber of political and policy influence (Treviranus, 2014a). Those that have get more, those that don't have get a winnowing of choices, resources and influence. Global networks can exacerbate this, but designed correctly they also hold the key to addressing these pre-digital conundrums. If present at the decision-making table, the informed disability community can help steer innovation toward more inclusive approaches before conventions are locked in.

Current systems of commercialization, that prioritize mass production, large consumer bases, and competition to lead in the sale of high-demand products, are not well-suited to designing for diversity (Becker, 1971). Mass produced products and pricing dependent on economies of scale marginalize unique demands. Products that cannot leverage economies of scale are expensive and variation in production is costly. This is an acceptable condition if the special products represent discretionary goods and services, but this comparative pricing

becomes highly problematic if most of a consumer's essential needs are special, such as housing, transportation, clothing, tools, computer interfaces, services, educational supports and other products and services of daily living, as is the case for many people with disabilities. What is the impact on spending power for the majority of people with disabilities and their families who live below the poverty line and are struggling to "make ends meet"?

Could the solution be to seek economies of scale in specialized products such as assistive technologies by addressing market fragmentation and consolidating demand through the globalization of products for people with disabilities? Will the increased incidence of disability brought about by aging increase demand to sustain a separate assistive technology industry and drive competitive pricing?

There are two issues with this potential scenario: the nature of the disability market and the challenge of interoperability with quickly moving digital systems. First, people with disabilities are the outliers in the market. Their needs are extremely diverse. Disability is accompanied by a lessoning of the degrees of freedom to adapt to a sub-optimal design. Seeking economies of scale may work for pseudo-majority requirements within the disability market, but if the assistive technology market is to reach the margins each product must become more specific and diverse thereby confounding any economies of scale. Exploiting economies of scale in this market only intensifies the disparity of the consumers who are left stranded at the edges.

Second, while certain relatively static manufactured products, such as canes, may find economies of scale, in the digital realm assistive technologies must maintain foolproof and dependable interoperability with mainstream products, as they are intended to bridge the gap between standard interfaces and the requirements of individuals with disabilities. It is challenging to remain interoperable with software and hardware systems that are updated almost

daily, whose provenance is hard to determine because of the distributed nature of software and network development, and whose specifications for interoperability may be trade secrets. The reliability and currency of computer access systems for people with disabilities is tenuous at best and dependent on agile adjustments in response to mainstream products. Mass production to achieve economies of scale lessens flexibility and responsiveness within the supply chain, making the task even more challenging. This conundrum cannot be addressed through a separate or segregated approach such as an assistive technology industry leveraging economies of scale. What is needed is an integrated approach if we are to address disparity. This implies changing the mainstream approach to design, development and production.

The relative diversity of individuals with disabilities also presents a challenge to the design of accessibility regulations that govern the digital domain (Treviranus et. al. 2011). Enforcement and compliance evaluation requires testable criteria (Blanck, 2014). It is impractical to establish and enforce the relative criteria needed by the diverse group of people who face barriers to access. This compels regulators to create fixed homogeneous criteria in a quickly changing, highly heterogeneous domain. This leads to the perception that accessibility is antithetical to innovation, aesthetics and diversification, which could not be further from the truth. The resulting conundrum is intensified by the slow pace of legislative change. One area that is most affected is the area most in need of proactive intervention: digital inclusion or "eQuality" (Blanck, 2014, Treviranus et. al 2011).

Fortunately, we are at the cusp of a disruption of the conventions of design, production and marketing. Firstly, there is a nascent culture shift in design. Mainstream designers are recognizing the innovation that occurs when designing, not for the typical or average, but for the edges (Brown, 2009). The standard tools of design such as personas, use cases and scenarios are

moving from capturing the typical or average consumer to capturing "extreme users." These design firms recognize that by addressing the needs of the margins you encompass the needs of the majority (Donovan, 2013). It is unclear whether this trend will permeate the industry but even companies such as Nike are dabbling with this notional shift (Kassenbrock).

More significantly, emerging technologies such as affordable or consumer-grade 3D printers and accompanying 3D capture technologies help to significantly reduce the barrier to personalized manufacturing. Systems are emerging that enable the additive printing of everything from clothes to food. It is predicted that it will be possible for every household to have the equivalent of a mini-factory to download 3D designs, make necessary modifications and produce personalized variants of required products (Lipson & Kurman, 2013). This trend is bolstered by a drive for greater environmental sustainability (reduced shipping costs, reduced waste through production overruns), the ability to create more complex and intricate designs, and the agility and flexibility this brings to industrial design.

Added to this is the Internet of Things (IoT) instrumentation of our environment (Vermesen &Fries, 2013). These add "smarts" and connected monitoring and sensing to everything in our environment from fridges to surveillance drones, to our vehicles and city streets, to personal devices that monitor fitness and health. The associated risks are ominous, including the loss of privacy, and the vulnerability to fraud and misuse, especially for people who are most vulnerable to cognitive barriers, increasing the imperative for people with disabilities to be active in navigating this new territory (G3ICT, Blanck, 2015). The opportunities are also undeniable, these innovations will increase the specificity of our 'smarts' regarding optimizing our environment and tools to meet our unique needs. These technologies will likely reduce the necessity to estimate, clump and cluster around a majority or norm and reveal the full

spectrum of diverse human characteristics. Combined with 3D printing (or 4D printing which adds the temporal element), we can produce technologies that intelligently respond to our changing needs (e.g., supports that adjust to our patterns of movement, medicine that automatically calibrates to our vital signs) (Self-Assembly Lab).

Associated with these disruptions are changes in the dynamics of markets. We are moving from an economy that is driven by mass marketing of products (and the associated waste and debt these encourage) to a market where the consumer plays an active role (Rifkin, 2014). Whether it is prosumerism, multi-sided platforms such as the Android platform or eBay, or sharing economies such as Uber and AirB&B, economies are becoming more demand driven. This leads to a diversification of demand as consumers are free to express their individual needs and preferences (Treviranus, 2014b, Rodriguez & Blanck, 2016, this issue), which may lead to a diversification of supply and production. A global accessibility effort referred to as AccessForAll or the Global Public Inclusive Infrastructure and encompassing projects such as Cloud4All, Prosperity4All, Floe (Flexible Learning for Open Education), AccessForAll Ontario, Preferences for Global Access and others are capitalizing on digital adaptability, network-enabled collective production, utilities that enable the discovery and refinement of awareness of personal requirements, and global platforms that connect consumers at the margins with producers and suppliers at the margins, to deliver one-size-fits-one products to consumers with disabilities (Lewis & Treviranus, 2013, Vanderheiden et. al. 2013).

Despite these opportunities presented by technologies, it may still be the case that individuals with disabilities are relegated to the role of consumer or passive recipient rather than active participant in decision making, design and production, thereby blocking a full virtuous cycle. Unless the modes of production or authoring themselves are inclusively designed, people

with disabilities cannot participate as authors, designers and producers (Treviranus, 2008). Component libraries, game development kits, mobile app authoring environments, and "next-generation" software development toolkits democratize the design and development of software and mobile applications. Maker systems and hardware kits enable the creative exploration of the internet of things (Morin, 2013). While some of these systems are designed to be usable by children, work still needs to be done to make them accessible (Brunchnews, 2015).

Similarly organizations and governance bodies that design and develop standards, specifications and policies that guide these emerging systems include entrenched conventions and customs that prevent inclusive participation. Whether it is meetings in inaccessible venues, prohibitive expenses of membership and travel, inaccessible collaboration tools or information; the disability perspective is excluded to the detriment of people with disabilities, but also to society as a whole. The Web Accessibility Initiative of the World Wide Web Consortium, a notable exception, recognizes participation of the disability and accessibility community in the W3C from an early stage has played a large part in the success of the Web (Treviranus, 2014).

Research and Evidence

As our traditional systems of design, development and production are not constructed to take human diversity into account, neither are our systems of research and evidence. These foundational underpinnings of our civilization are critical to the inclusion of people with disabilities as they influence all aspects of our life, whether by guiding our individual and collective decisions, determining public spending, or informing our health care. The human proclivity toward confirming expected patterns and predictability, and the aversion to change and dissonance, are embedded in our tools of objectivity. Statistical analysis is designed to detect patterns, eliminate noise, and find the norm in a data set. It is used to corral diversity and tame

complexity. While these may be necessities to ease human understanding and to guide human decision-making, these have taken precedence over recognizing diversity and have created increasingly risky blind spots and exclusions (Taleb, 2012).

This is especially risky for persons with unique conditions, unusual circumstances or individuals who are in uncommon contexts (Armstrong & Deadman, 2008). Increasingly, in a connected and highly interdependent world, the important questions involve complex, shifting and evolving factors that defy generalization. Traditional research generally tests a hypothesis with a representative sub-group and then applies the findings to the group as a whole. Outliers such as people with severe disabilities are so individually unique and divergent that it is usually impossible to find a representative group or sub-group (Treviranus, 2014a). However, this extends well beyond people with disabilities, everyone finds themselves as an outlier in some set of measures, and experiences the resultant mismatch.

In many realms (e.g., education), for individuals at the margins empirically-based "solutions" pose a problem, solutions can be a set-up for failure–or another set of expectations not met. The better empirical support for the solution, the more policy makers, service providers or educators are invested in the success of the solution, and the greater compunction to dismiss or distance exceptions by pointing to deficits in the non-conformant client/employee/student rather than the solution; and the more devastating the failure. As with all choices, there is an institutional propensity to rationalize choices once they are made (Agócs, 1997).

This is not to deny or downplay the importance of finding commonality. When exploring the area of human diversity in any depth, we bump up against the interplay of diversity and commonality. However, commonality is frequently imposed or assumed (e.g., all women.., most

blacks.., most teenagers..., most seniors…). This type of commonality when applied to the individual instance at the edges is often found to be superficial, transient or false.

However, there is an uncanny human phenomenon that occurs when very diverse people come together in an environment where diversity is accepted–they often find a deeper and more meaningful commonality. The same phenomenon of finding genuine commonality by supporting diversity can be observed in our research and co-design methods (Treviranus, 2014a). This mismatch of sanctioned traditional research methodology with the domain of disability also puts academic and research efforts addressing disability at a disadvantage, whether it is in matters of academic publishing or research funding, which privilege statistical power and high impact measures. This means that people with disabilities are not only excluded from mainstream research, but also there is an inherent implicit bias against research or publishing that involves this highly heterogeneous group.

As in design, development and production the domain of research and evidence is being disrupted by technical innovations and associated new practices. These traditional approaches to research have garnered powerful reinforcements with the rise of Big Data, data analytics and the associated zeal for evidence in large numbers. By seeking only innovative simple solutions with high impact we discount complexity, inevitable change, and, more critically: diversity. However, new data analysis tools, monitors, sensors and Internet of things smarts also provide the opportunity for a fundamental shift toward personalization. This has the potential to enable each individual to act as their own representative research sample or subject. We can become investigative scientists to discover what works best for us as unique individuals. Even temporal and contextual generalizations can be avoided with contextually-aware data gathering. This is

referred to as small and thick data and the limits are being explored by groups such as the "quantifiable self" movement (Estrin, 2014).

The Internet of Things will cast a pervasive net to capture all the data associated with our daily lives. We are in the process of determining how to add meaning to this vast new glut of information. How will this transform our notions of privacy, how do we ensure this information is not misused, how can we leverage this new source to not only make machines smarter but to make ourselves smarter? This awareness must encompass the full range of human difference. It seems natural to seek simple answers, clean conclusions, "cut and dried" advice. It appeals to our sense of order, our aesthetics and even our intuitions about truth. However, in the human realm, conclusions and solutions inevitably come with exclusions and compromises (unless they are vacuously all-encompassing). At the margins there are no easy answers, quick fixes, average or typical patterns. It is a complex, messy, unstable territory. But the margins are where we find the greatest diversity and creativity. The messy, complex and unstable breed resourcefulness and innovation (Meyer &Rose, 2005, Gladwell, 2008).

Learning and Education

Lastly, one of the most important levers for long lasting systemic change is our education system. Paradoxically, our institutions of formal learning are the most resistant to change and most discriminatory with respect to human diversity. Diversity is seen as an issue to be addressed, not an important outcome to be fostered. This does damage to learners, squanders human potential and puts our society at risk (Meyer & Rose, 2008).

The ADA, and associated legislation (e.g., IDEA) are to ensure that diverse learners can participate in education (Zirkel, 1993). There is broad acceptance that education is a right not a privilege and there is also a general recognition that societal and individual well-being,

democracy, security and prosperity benefit from education for all members of our communities. However, despite a changing economic reality our education systems continue to be architected to foster conformity, minimize diversity, normalize and standardize learning outcomes.

It no longer serves us, in today's economy and connected society, to produce graduates that are replaceable copies of each other. Beyond contested foundational "building blocks" we don't all need identical skills and knowledge. In our connected communities we can depend on others (if not on ever more capable machines, and computers), to fill in anything we haven't adequately learned or have forgotten from our schooling. In our social and crowded society, we need to go beyond tolerating or respecting diversity, we need to prize and learn to orchestrate and create synergy out of our diversities. We should shift focus from how we are each better or worse in the same skills, to the unique, evolving set of talents, passions and competencies we each bring to tasks at hand.

To produce the diversity and inclusion required by our current reality represents more than a renovation of education; the implications are broad and deep. We need to stress collaboration over competition while maintaining optimal challenge to spur learning. We can't depend on mass approaches, we need to personalize learning at a deeper level–not just the pace, path and mode but also the goals of education. It is the disability community that has pioneered this new model of learning.

Conclusion

As a global disability community, foundational systemic strategies do not seem to be on our roadmap and among our longer-term aspirations. Under the ADA presently, primary focus remains (and rightly so) on defending rights and battling barriers. However, we are uniquely qualified to help to create a world where such defense is obviated by a more fundamental

change. Over the next twenty-five years of the ADA, we must leverage disruptive opportunities to contribute our insights and deep knowledge of human variability. This is needed to guide the inevitable transformation of society and to disrupt old habits of exclusion.

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