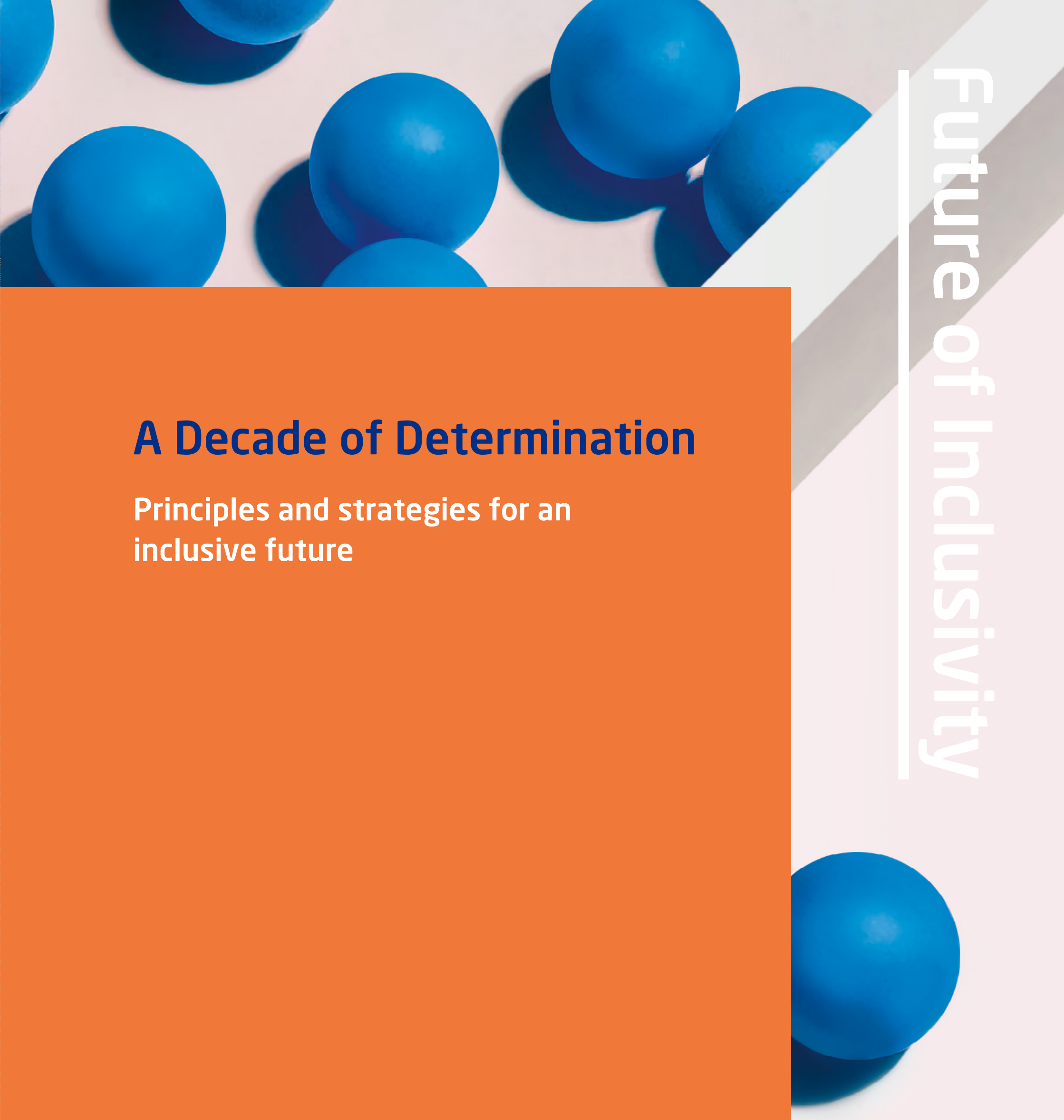


Future of Inclusivity

A Decade of Determination

Principles and strategies for an inclusive future

مؤسّسة دبي للمستقبل
DUBAI FUTURE FOUNDATION

Why is Inclusivity Important?

As Dubai establishes itself as global hub city for businesses, citizens, residents and tourists, it is imperative that policymakers consider the inclusivity of disabled individuals as a key policy priority. Policies to increase inclusivity offer significant economic and societal benefits to cities – conversely the lack of such polices can hold critical 'costs'.

Primarily, polices to foster inclusivity can limit the adverse socioeconomic outcomes faced by people of determination, such as limited access to education and healthcare, unemployment and poverty. The high unemployment rate of Emiratis with disabilities alone makes this a pressing issue - in the UAE around 93% of Emiratis with disabilities are unemployed. People with disabilities are for the most part excluded from the workforce as a result of misconceptions that they are unable to cope with "work pressures and requirements". Restricting opportunities for this segment of the population has the equivalent impact on state resources. Inclusion can also yield 'diversity bonuses'. Research indicates that increased inclusivity is likely to yield beneficial results for both people with and without disabilities. For example, research suggests placing students with disabilities in inclusionary environments causes them to "refine new social relationships with the same-age peer group, and experience more quality programs in a regular education classroom". Inclusion is not only important for the development of students with disabilities but placing them in classrooms with other students is likely to change the negative perceptions, biases, and social stigma that people with disabilities often face.

Neurodiversity can also benefit work environments. For example, according to recent research people with Autism Spectrum Disorder (ASD), can be assets in fields that require the use of pattern-based analysis or mathematical systems. It has been found that including people with ASD helps yield diversity bonuses as they are often able to solve complex problems and identify patterns that others cannot identify as easily. As a result, companies in the private sector began aggressively recruiting individuals ASD related strengths.

Contents

Introduction

The aim of this paper is to identify interventions in the spheres of policy, infrastructure, and technology that might advance the goal of complete societal integration for persons of determination in the city of Dubai in particular, the Middle East and North Africa (MENA) region more broadly, and anywhere else where similar aspirations of inclusivity might be found to prevail.

With that in mind, this report proceeds through four major stages:

1. A definition of the challenge of inclusivity, in both quantitative and qualitative terms
2. An identification of the current global "state of the art" in policymaking for inclusivity
3. An exploration of principles and strategies for policy-making out to 2030
4. The recommendation of a foundational suite of interlocking top-level policy frameworks from which a fully integrated and inclusive society might be constructed

> “Diversity is being invited to the party; inclusion is being asked to dance”

Verna Myers[1]

The first section

defines the challenge of inclusivity.This process begins with a discussion of the statistical and terminological definitions of disability that prevail in various organizations and nations around the world. This is followed by a brief look at the prevalence and circumstances of disability. A significant objective here is to highlight the difficulty in finding consensus, whether regarding the numerical scale of the challenge or the qualitative nature of the difficulties the challenge describes.

Next, the causal factors behind the statistics are discussed in order to understand where disability comes from.
The four dominant causal factors are defined as being congenital, environmental, accidental, and gerontological – the consequence of human aging – and observe some considerable overlap and interplay between them. The gerontological factor is particularly important given the demographic momentum behind aging and the concomitant increases in the prevalence of disability that it is expected to bring.

A discussion of the prevailing “notion of normality” follows, an assumption common to almost all world cultures according to which people with disabilities are seen as aberrations – flawed, imperfect, damaged, broken. The causal factors combined with demographic dynamics demonstrate clearly that, as a well-used activist aphorism puts it, “disability is the biggest minority there is, and it’s the only one that anyone might suddenly join at any moment.”

The second section
identifies the current global state of the art for inclusivity, based on desk research and extensive consultation with sectoral experts from a variety of pertinent fields. This process begins by acknowledging the advancements in medicine, care, and assistive/adaptive technologies made over the last century, resulting in better prospects for people with disabilities than ever before – at least in theory.

The sustained causal factors discussed in the preceding section, in combination with related demographic changes, will inevitably result in an ever-greater number of people being identified as having a disability, whether by the state or by themselves. This is further exacerbated by the broadening of the disability concept to include learning difficulties and chronic mental health conditions, the incidence of both of which are expected to increase in response to the accelerating pace, technological mediation, and competitiveness of 21st century life.

These lessons demonstrate that any hope of preventing or eradicating disability "at source" is likely unfounded, though it is suggested that acting to alleviate systemic poverty offers the best hope of minimizing prevalence over the longer term. More positively, however, it is also clear that adaptation and assistance aimed at making integrated participation in all aspects of society is well within reach. The main pitfall to be avoided in this quest is that of "solutionism," which might be defined as the assumption that there is an off-the-shelf technological solution to every problem.

This is not to dismiss the importance and utility of adaptive and assistive technologies in promoting and enabling autonomous living and dignity for people with disabilities of various types, but rather to recognize that issues around cost, stigma, and customization mean that technology alone is rarely, if ever, the best or only answer. On the contrary, interventions intended to improve the lives of people with disabilities should always be contingent and specific to their case and made in consultation with the individuals in question.

The third section
explores some principles and strategies for policy-making over the near- to medium- term, aimed at developing a significantly more integrated society by 2030. This section begins with a set of overarching principles that are applicable across every conceivable context, most of which stem from what is known as the "social model of disability" – the insistence that the "fault" or dysfunction implied in disability is conceptually located in the social context rather than the individual.

From this conceptual foundation, these principles argue for:

The rehumanization of people with disabilities by treating them first and foremost as people, rather than as passive patients of medical science or technological support

Their participatory representation in decision-making on all policies that affect their lives

Integrating people with disabilities into all spheres of society (which is believed to be the most effective strategy for destigmatizing differences in ability of all sorts)

An approach to policymaking that combines a long-term strategic perspective and commitment with a willingness to experiment, iterate, learn, and adjust when it comes to implementation

Additional specific strategies are then explored that might be applied to four distinct yet overlapping policy contexts: education and early years, employment, domestic, and culture and society.

The fourth section
sets out a foundational suite of interlocking top-level policy frameworks upon which a fully integrated and inclusive society might be constructed. These are produced by reconsidering the goals of the strategies identified in the preceding section, and attempting to distill their top-level intentions into a top-level framework for policy that attempts to affect not just the physical and socioeconomic infrastructures implicated in a given context, but also the social and cultural matrix in which those systems are embedded.

As such, this report recommends:

The full integration of all special needs provisions into mainstream educational institutions and the establishment of a universal regulatory body with responsibility for ensuring the availability of lifelong learning opportunities for people of all abilities (education and early years)

The establishment of a "college of care" intended to professionalize and raise the social status of care and care-adjacent career paths (employment)

The establishment of a policy principle whereby people with disabilities (or their primary caregivers) are always consulted as part of the decision-making process related to the provision of their care and support (domestic)

The universal provision of opportunities to take part in arts and sports activities in all educational establishments for people of all abilities, and the proportional representation of people with disabilities in media (culture and society)

These policies alone will not serve to establish a fully integrated and inclusive society – but after a decade or so of commitment and iteration, they should serve as the foundation upon which that society might be built.

01

Determined Aspirations: Defining the Challenge

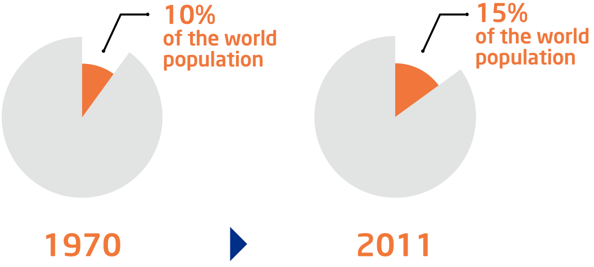
01

Who is “Disabled,” and What Does That Mean?

In 2011, the World Health Organization estimated the prevalence of disability at more than a billion people, or approximately 15% of the world population based on contemporaneous population estimates.[2] This estimate was considerably higher than the estimate of 10% produced in the 1970s, which in turn suggests that a new estimate produced today would perhaps be higher still, in both relative and absolute terms.

Quite beyond the issue of sensitivity in terminology, the question of who counts as “disabled” is more complicated than it might seem at first. Definitions vary between states and institutions, which is one reason why reliable and non-contradictory estimates of the prevalence of disabilities are hard to come by. Put simply, the criteria of counting may vary considerably, with some polities preferring a strictly medical definition, while others opt for a more expansive social definition.

Prevalence of Disability



For instance:

The UAE's definition of "people of determination" defines a person with special needs as "someone suffering from a temporary or permanent, full or partial deficiency or infirmity in his physical, sensory, mental, communication, educational, or psychological abilities to an extent that limits his possibility of performing the ordinary requirements as people without special needs"[i]

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) takes a similar social approach, with its definition of disability including "those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"[ii]

Chinese law begins from a specifically medical definition of disability, focusing on "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. The term 'disabled persons' refers to those with visual, hearing, speech, or physical disabilities, intellectual disabilities, psychiatric disabilities, multiple disabilities, and/or other disabilities"[iii]

---

[i] https://government.ae/en/information-and-services/social-affairs/special-needs

[ii] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

[iii] http://www.cdpf.org.cn/english/Resources/lawsregulations/201603/t20160303_542879.shtml

Differing methodologies of surveying and estimating, and the statistical needs of different governments, further complicate the picture. By way of illustration:

Among citizens of the European Union (EU) aged between 15 and 64, 44 million reported a basic activity difficulty in 2011 (14% of that age cohort)[iv]

The United Kingdom's (UK) Family Resources Survey of 2016/17 reported 13.9 million people with disabilities in the UK (22% of the population as a whole, 8% of children; 19% of working-age adults, and 45% of pensionable adults[v]

The American Community Survey of 2016 estimated the overall rate of people with disabilities in the United States (US) population to be 12.8%[vi]

The prevalence of disability among Chinese citizens was estimated to be 6.5% in 2006[vii]

How much of this variance can be attributed to different counting methodologies and definitions, and how much to different circumstances in the individual countries, is a challenging question. Other nations and regions display their own variances, in such circumstances as statistics are made publicly available at all.

From a population-level perspective, it is not yet possible to demonstrate the extent to which one's economic circumstances may causally affect one's chance of having one or more disabilities, though such a relationship has been repeatedly theorized by academic researchers.[3] However, the evidence is clear that countries with low or middle average incomes exhibit a higher prevalence of disability than countries with high average incomes.[4] What evidence is available suggests that poor people are more likely to have disabilities due to their increased risk of ill health, malnourishment, poor sanitation, unsafe housing, and dangerous work, as well as the prevalence of violence in their context and their lack of access to medical care that might prevent or delay the onset of disability.[5] One clear statistical trend is that people with disabilities are less likely to be employed, and when they are able to secure employment, they will earn at a lower rate.[6]

iv https://ec.europa.eu/eurostat/statistics-explained/pdfscache/34409.pdf

v https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201617

vi https://disabilitycompendium.org/sites/default/files/user-uploads/2017_AnnualReport_2017_FINAL.pdf

vii https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3209727/

Cases and Causes

At a more individual case-by-case level, it becomes easier to consider the causes of disability in a scientific manner. With the strict caveat that this is not an official scientific categorization, but rather a heuristic developed for the context of planning for policy, we might divide the direct causes of disability into four groupings:

1. **Congenital**
   Caused by genetic factors, or by human biology more broadly

2. **Environmental**
   Caused by pollution, climatic extremes, natural disasters, warfare, etc.

3. **Accidental**
   Caused by mishap during activities undertaken for personal, recreational, or industrial reasons

4. **Gerontological**
   Caused by consequences of the human body's aging process

It bears noting that these categories are not distinct or exclusive. For example, "congenital" factors may increase one's likelihood of acquiring what might seem to be simply a "gerontological" disability such as cataracts, the relatively new field of medical research known as epigenetics is devoted to examining the extent to which environmental or circumstantial triggers may modify the expression of a given genetic inheritance.

The conceptual overlap between "environmental" and "accidental" is also considerable. One could argue that industrial accidents, for example, are an environmental issue rather than an accidental one, particularly when it comes to assigning responsibility for any chronic disabilities that result.

The distinction is still worth making, however, even if it is rarely clear-cut in practice. An environmental cause has to do with *where one happens to be*, while an accidental cause has to do with *what one happens to be doing*.

The distinction is worthwhile because, while it is an ethical goal to reduce the incidence of disability overall, curtailing the environmental causes of disability can be perceived as enhancing individual liberty, while reducing the accidental causes of disability might be regarded as constraining liberty. Or, more plainly, people will almost always respond better to being told what things they are now free do without fear of the risks inherent in the environment than to being told what they are no longer allowed to do for fear of the risks of accident.

Perhaps the least discussed of these causal categories is the *gerontological*. This is surprising and risky because gerontological is the category that is both most likely to expand (in terms of absolute numbers and the proportion of cases) and most likely to be directly encountered in a caring context by the greatest number of people. A UN report on the aging of the world population suggests that between 2015 and 2050 the total number of people aged 60 years and over will more than double, from just under a billion to 2.1 billion respectively.[viii]

The dominant gerontological disabilities are predicted to be the partial or complete loss of sight or hearing, various forms of reduced mobility, dementia, and diabetes.[7] For the most part, even the most advanced and/or wealthy societies are woefully underprepared for this demographic surge of disability, whether in terms of accessibility adaptations or in terms of the adequate provision of medical services and care support.

[viii] https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf

NO MORE “NORMAL”

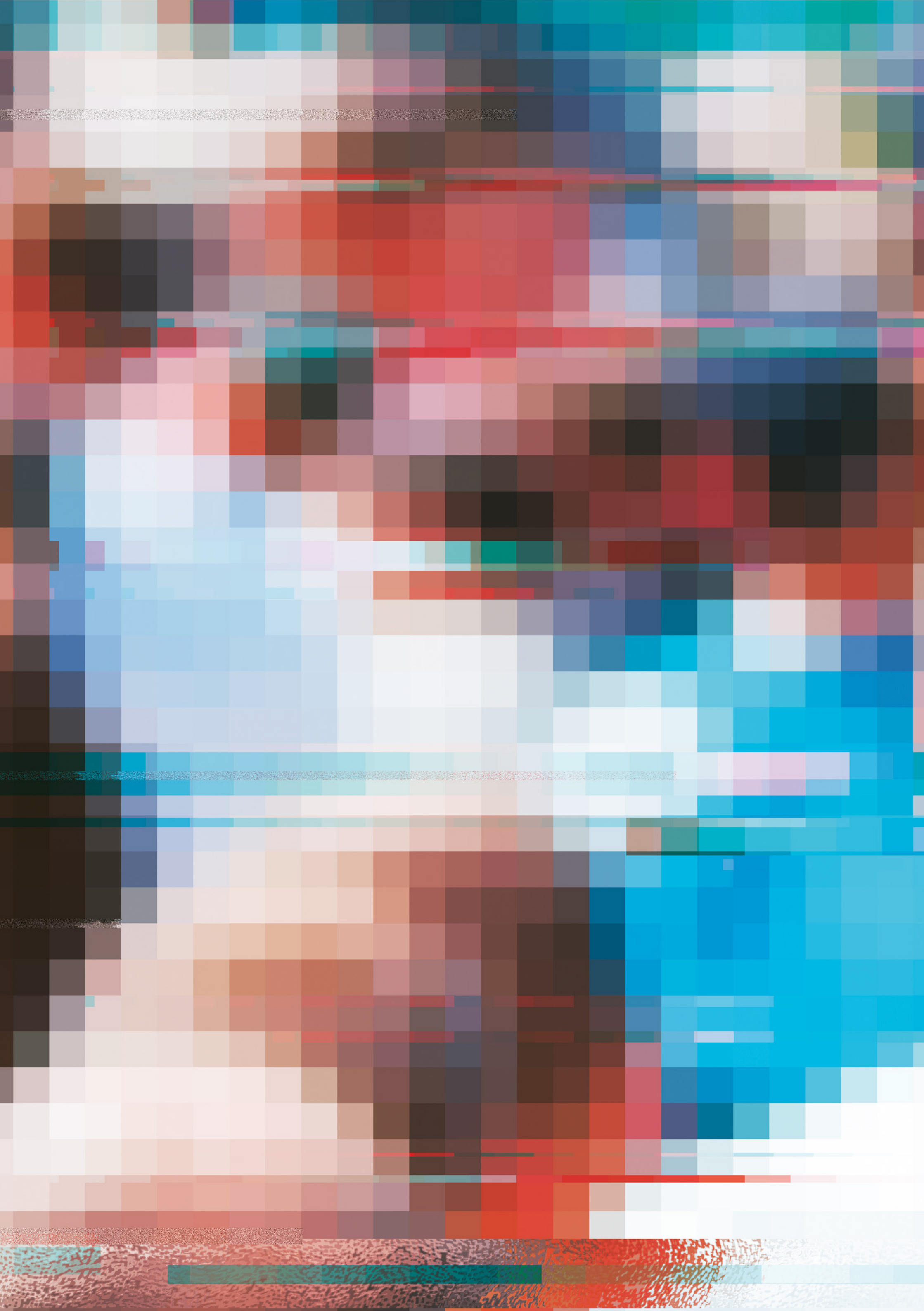
The four causal categories identified above illustrate an important truth: even for those who are currently “normally” able, there is a strong and ever-increasing likelihood of becoming “disabled” in some way, whether chronically (e.g. from gerontological or congenital causes) or temporarily (e.g. from accidental or environmental causes). As a well-used aphorism puts it: people with disabilities are the world’s largest minority, and the only one that any person can join at any time.

Almost every expert consulted in the creation of this report emphasized that the greatest obstacle to the establishment of a fully inclusive society is the pervasive notion of “normal” ability. This notion of normality obscures the truth of diversity and difference. It dissuades people from supporting adaptive and assistive policies and interventions because it allows them to think that not only are these policies and interventions aimed at a minority of people, but also that the minority in question is one that they will never be a member of.

The statistical and demographic trends tell a different story, however. Our abilities, whether physical, mental, or otherwise, are as unique and diverse as we are – and they are definitely not fixed quantities, stable throughout our lengthening lifespans. Designing for “normal” may save costs in the short term, but it ends up stockpiling problems (and costs) over the longer term. Adaptable, accessible environments and technologies can contribute to the resolution of this societal challenge, but in order to mandate the provision of those environments and technologies, the first obstacle to be cleared is the notion of normality. In its absence, it will become obvious that there is no such thing as disability, only differing abilities.

This relates to another theme common to all the consultations for this report – that inclusivity aimed at allowing differently abled people the opportunity to participate fully in society is inseparable from inclusivity more broadly. In the words of one researcher and life-long advocate for the rights of people with disabilities, "A society that is only inclusive for some groups is not actually inclusive at all." The "othering" and stigma attached to disability is indistinguishable from that attached to other differences from the supposed "norm," and indeed are often overlapping (or "intersectional") with them in practice.

Almost every expert consulted in the creation of this report emphasized that the greatest obstacle to the establishment of a fully inclusive society is the pervasive notion of "normal" ability



0

State of the Art: Global Best Practice

2

02

In recognition of the incredible efforts of medical researchers and practitioners, we should start with the good news. It has already been noted that lifespans have increased substantially in the last century due to effective interventions against illnesses related to aging and infant mortality.[8] For example, in the Middle East and North Africa region, average life expectancy was about 46 years in 1960, but had reached 74 in 2017. Furthermore, recent years have seen some significant improvements in the rapidity and accuracy of diagnosis of a variety of congenital conditions (particularly, though not exclusively, related to developmental disabilities),[9] which in turn allow for earlier and more effective efforts to alleviate or otherwise reduce their impact in later life.

Life Expectancy in the MENA Region

Source: World Development Indicators

There have also been considerable advances in therapies, surgeries, and devices aimed at the alleviation or (occasionally) outright cure of severe physical deformities and/or impairments. Orthotics (external physical support devices), prosthetics (artificial body parts), and artificial organs (e.g. hearts) have existed for many years, but recent advances in both technological and surgical sophistication have seen significant improvement in these fields.

Perhaps most obviously to the “normally” abled, however, the explosive adoption and expansion of information technology has brought with it a wide array of adaptive and assistive technologies – many of which are extended faculties of familiar, everyday technologies such as smartphones and computers – that can make life easier and more autonomous for the differently abled. In many respects, then, we might reasonably say that the circumstances and prospects for people with disabilities have never been better.

However, regarding physical disabilities, the accidental and gerontological causal channels are unlikely to reduce in influence any time soon. On the contrary, as discussed above, an increase in the incidence of gerontological disabilities is a demographic certainty. There is little evidence that humans are becoming less interested in activities associated with a risk of accidental injury – though we are much better at avoiding those accidents and surviving the ones that we don’t avoid.

Rather more disappointingly, however, it seems unlikely that environmental causes of disability will wane. While we might hope that armed conflict and terrorism might continue to decline around the world, it seems certain that drastic alterations in environmental conditions and natural disasters due to climate change will provide plentiful sources of human risk in the decades to come.

02

With regards to mental and behavioral disabilities, there is also clear correlative evidence (if not necessarily causal connections) between these conditions and the socioeconomic and technological constitution of contemporary society.[10] As a number of experts in the governance of disability and care have observed, the hypermediated[11] and intensely competitive nature of modern life[12] is sufficiently intense that it causes chronic distress in more sensitive individuals. To say that "modern society is making people mentally ill" would be reductive and inaccurate in scientific terms, but at the same time, there exist plentiful theories linking the rise in mental health problems,[13] and behavioral[14] and learning disabilities,[15] to an increasingly technology-saturated and systematized lifestyle or environment, particularly (but by no means exclusively) in the most "developed" nations.

All of which is to say that there is little or no chance of "stopping" disability at the source. However, it is worth reminding ourselves of the clear correlations (discussed above) between disability and poverty, whether pecuniary or circumstantial, and noting that the implication would be that the incidence of non-gerontological disability is most likely to be reduced by addressing material and circumstantial poverty.

Accepting that the incidence of disability is unlikely to be significantly reduced by medical measures, let alone eradicated, we turn to adaptive and assistive measures by which the differently abled might be given the same opportunities to participate in society. While none of the experts consulted were in any way opposed to the use of technology to support the differently abled, they nonetheless almost universally warned against the risks of "solutionism"[16] – a mindset that assumes even the most intractable social problems might be "fixed" by means of some technological gadget or piece of software.

Perhaps most importantly, the solutionist approach implicitly frames the person with a disability as the site of a "problem" that needs "fixing" – this is a problematic perspective, even when it is held with the best of intentions. Put simply, seeing disability as a problem or flaw in an individual implies that individuals without disabilities are better people. This implication, and the concomitant assumption that disabled people would prefer to be "fixed" in order to be like everyone else, is vociferously rejected by a majority of people with disabilities, and with good reason. It is a dehumanizing narrative and a foundational element of the notion of normality discussed in the preceding section.

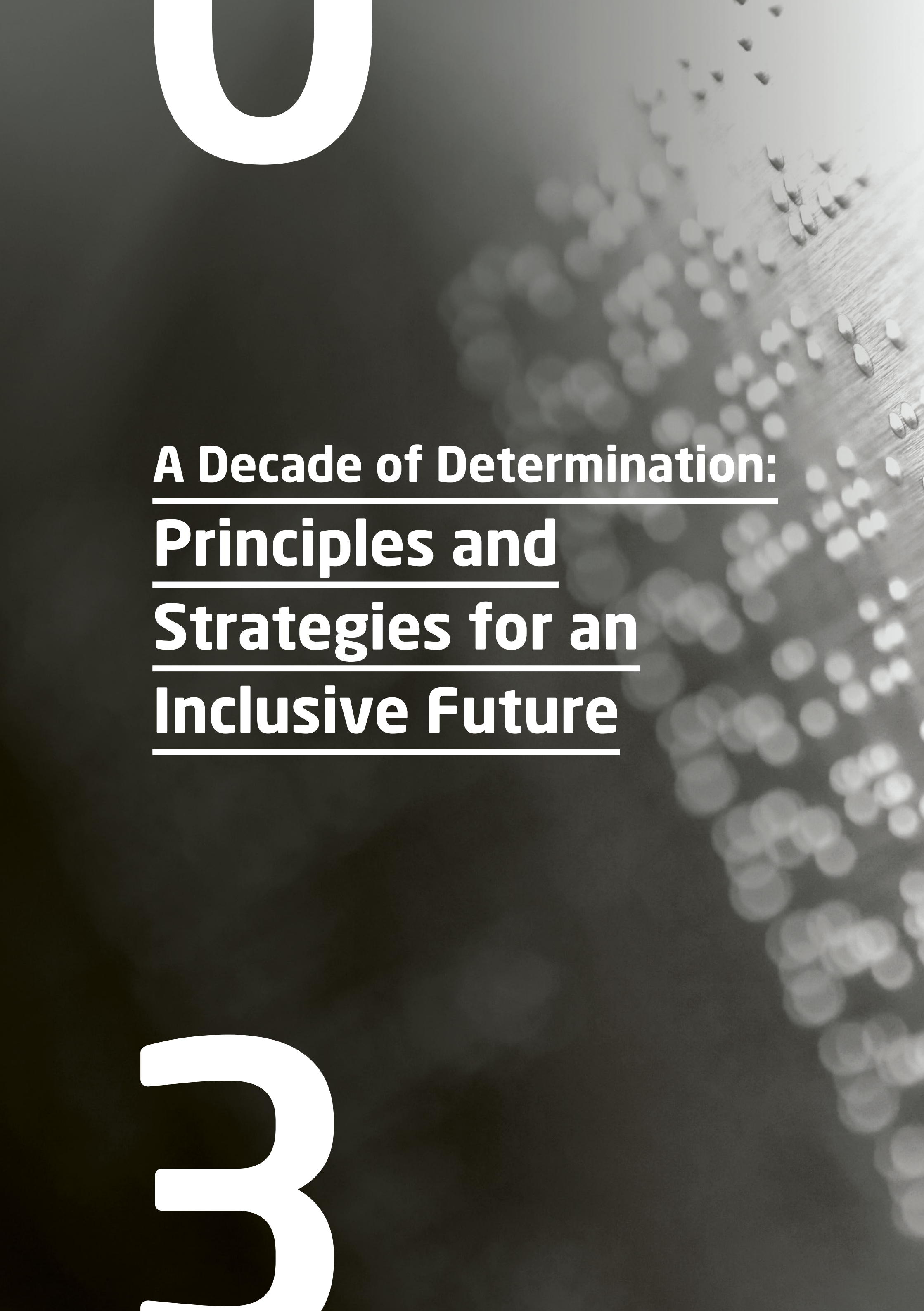
On a more practical level, other issues attend the deployment of technological solutions to address disabilities. As a veteran campaigner for disability rights puts it, once a technology is categorized as being for the support of people with a disability, two things happen almost instantly. First, that technology becomes stigmatized by its attachment to the disability in question, and second, the technology becomes more expensive, as its makers realize they have a captive market. This and other such socioeconomic dynamics are relevant in debates about the distinction between assistive technologies and adaptive technologies.

If accessibility features become completely standardized in architecture, interior design, and civic planning, any stigma around their presence will be steadily reduced, if not negated entirely. Environmental interventions are also proof against the demographic trends in disability already discussed: the more the environment is adapted to accommodate a variety of levels of individual mobility, the fewer problems there will be in accommodating the needs of a growing proportion of differently abled citizens in those spaces (as well as those temporarily disabled due to illness or injury). There is also a cost advantage over the longer term, in that the up-front sunk cost of environmental adaptations is eventually paid off by the reduction in need for individual support solutions and exceptional adjustments. This is particularly evident in public transport systems where differing levels of mobility are designed for from the start, compared to older systems (such as London's underground) where accessibility retrofitting can become extremely expensive.

While it is certainly the case that new technologies and software can be of great assistance to certain people with certain challenges in certain circumstances, our experts were keen to reinforce the importance of contingency in prescribing technologies and therapies alike. In this context, contingency is the explicit understanding that "disability" is not a monolithic category of people with the same set of problems, and that even among a group of people who share a particular disability, the range of actual ability within that category may vary considerably. Co-morbidities – the presence of multiple conditions in a single patient – further complicate the challenge of deciding what interventions might best support or assist an individual.

When it comes to supporting independent and autonomous living in particular, the expert position is very clear: these decisions must be made on the basis of a detailed understanding of the specific case on an individual level, and – as far as is practically possible – should be made in direct consultation with the individuals themselves, with their ideas of what is necessary and suitable to their support being granted the same weight as those involved in the assessment and provision.

Or, to use the language of disability activism: individuals are very likely to be experts in their own disabilities, in a way that medical general practitioners would struggle to become. As such, they are almost always the best people to consult regarding their care.



03

A Decade of Determination:

Principles and Strategies for an Inclusive Future

03

This section explores more specific strategies and tactics that might be enacted to advance toward the goal of a fully inclusive society in the near- to medium-term, e.g. from now to 2030. These are collected within four specific contexts:

1. Education and early years
2. Employment
3. Domestic
4. Culture and society

Much like the causal factors discussed in the previous section, these contexts are not strictly separate from one another. Indeed, a more holistic conception of society – whereby different contexts are understood to overlap with one another and wherein different people may have life experiences that do not follow the linear paths that may have been expected of them – might be considered to be another crucial part of the inclusivity puzzle. The route to inclusivity is therefore less a matter of finding solutions that are transferable between contexts, and more a matter of minimizing the need for solutions in any and every context.

As such, certain general principles of inclusivity are applicable across (and beyond) the four contexts. Building upon the best-practice paradigms outlined in the previous section, these are predominantly to do with political stances or attitudes toward people with disabilities or with the way "disability" is conceptualized. While these principles should not be thought of as a "checklist" that can be followed to ensure an inclusive outcome, they might nonetheless serve as prompts for assessing a proposed intervention before implementing it.

General Principles for Inclusivity

From a Deficit to a Positive Model of Disability

This fundamental principle, which could be thought of as underpinning all the others to follow, is rooted in the experience and activism of people with disabilities. The "deficit model" of disability refers to the traditional conceptualization of people with disabilities as being somehow lacking, deficient, or abnormal. This is sometimes also referred to as the "medical model" because medical science tends to focus on "impairments" or "problems," and reduces the patient to a passive object. The deficit model establishes and reinforces low expectations for people with disabilities, not just in "normally" abled people, but in people with disabilities themselves. As such, it often results in a loss of autonomy, choice, and control over their own lives.

By comparison, the "positive model" – sometimes also known as the "social model" – refers to a recognition that "disability" is a socially constructed category, defined by divergence from a largely mythical average or "normal" level of ability. The positive model therefore broadens its view of the individual to include heightened abilities alongside reduced abilities. This perspective restores the individual's subjectivity and recognizes their right to an agency beyond their status as a passive patient in medical procedures. Additionally, the social model sometimes refers in particular to the related understanding that an individual's disability is very often a function of the ways in which society and the social environment is organized.

These distinctions can appear academic and arbitrary to the able-bodied, but they have been fought for by generations of disability activists, who see them as fair and true depictions of their experience. Their true import for policy will become clearer as they are shown to inform the principles that follow.

03

Don't Fix People, Fix Things

The most direct corollary of the positive or social model of disability is the insistence that if "disability" is to be seen as a problem, then the "problem" lies in the social context rather than in the individual person, and it is the social context that needs to be "fixed."

There is a great deal of political weight behind this argument. After all, history is regrettably well-stocked with horrific examples of attempts to "fix" the problem of people considered inferior or deficient. And while intentionality counts for a lot – few would argue that the medical model is not founded on the best of intentions – our intentions are necessarily shaped by our conceptualizations. This means that if we conceptualize people with disabilities as somehow not completely human, we will end up treating them as such.

There is also an individual psychological aspect to this argument. Put simply, to be a person with disabilities under the deficit model is to be perpetually understood by society – up to and including yourself – as a flawed thing, as a problem in need of fixing. It should be obvious that feeling this way is not conducive to your contributing your best abilities to society, or indeed finding much joy and pleasure in life itself.

Under the positive model, however, the "problem" to be solved is relocated into the environment and/or social context. For example, under the positive model, a wheelchair user doesn't need a "fix" that will allow them to climb stairs. Rather, it is their environment that needs the "fix" in order to make the space in question accessible to this individual and to all of the multiple other individuals who find climbing stairs difficult or impossible.

In terms of developing policies for inclusivity, then, this principle suggests that environmental interventions should always be considered before interventions in the individual.

“Nothing About Us Without Us”

“Nothing about us without us” is a rallying slogan that emerged from disability activism and represents an insistence on genuine participatory representation. If you are going to make decisions that affect people with disabilities, it says, then people with disabilities must be involved in making those decisions. This slogan (and the approach to consultation and policy-making that it implies) is a corollary of the positive model. It represents a refusal on the part of people with disabilities to play the role of a passive object whose fate is to be decided by experts.

This principle suggests that wherever possible, policy interventions for inclusivity should be developed and implemented with the full participatory representation of people affected by the disabilities in question. Token inclusion in deliberations is not sufficient; participation must be extended to the decision-making tier.

Exposure for Integration

Perhaps the most surprising point made by experts engaged with issues of inclusivity was that when it comes to the crucial matter of changing societal attitudes and eradicating the stigma associated with disability, it is still not scientifically proven which methods are most effective. However, the anecdotal evidence in favor of one particular approach is overwhelming – nothing makes faster work of (re)humanizing people with disabilities than encountering them regularly in everyday situations.

Exposure is the key to integration. This is also in keeping with the positive model because it positions the "problem" of inclusivity in the societal collective rather than in the individual with a disability. This principle suggests that, to the greatest extent possible, policies seeking to minimize or eradicate the segregation of people with disabilities are most likely to result in a fully inclusive society.

This process cannot be hurried, however. Re-scripting societal attitudes can take several generations of firm commitment in governance, and decades of progress can be lost very quickly, as has recently become clear with regard to issues of race in Europe and the United States. As such, policy needs to be approached with a mindset of longevity, as addressed in the following principles.

Long-term Change, Long-term Thinking

It is clear that many of the challenges of building an inclusive society are the result of societal path dependencies: long-established habits of thought and governance in which people with disabilities have been understood as abnormal or deficient and treated as a problem to be fixed. For example, the institutionalization of people with learning disabilities and/or chronic mental health issues (in which they might be in effect incarcerated in care homes in order to minimize their exposure to risk in the "normal" world outside) has served not only to exacerbate the disabilities in question, but to enhance the societal conceptualization of people with disabilities as being somehow "other," outside of the norm.

Some of the manifestations of these habits of thought can be addressed fairly immediately. Altering the environment for greater accessibility, for example, is a simple and durable change that can be made. Other manifestations are more subtle, more deeply embedded, and less obviously implicit in an ongoing lack of inclusivity. This is particularly the case in governance, where a focus on minimizing immediate costs and producing easily quantifiable outcomes is almost universal across the developed world. However, recent research strongly suggests that these principles of governance, while well intentioned, have in fact resulted in considerable wastage of funds and the deterioration of service provision.[ix] Many of the nations famed for their hybrid welfare systems have found that this "new public management" (NPM) approach – with its focus on the "delivery" of outsourced services by private contractors – has been far less effective or efficient than promised.[x]

[ix] https://www.instituteforgovernment.org.uk/publications/government-procurement

[x] https://www.centreforpublicimpact.org/mindset-shift-emerging-local-government/

Of particular relevance to the inclusive society is the issue of evaluation metrics – the question of how one determines whether a given policy has been successful. Under NPM, this has tended to focus on the financial bottom line. If a policy or commissioning model results in immediate budgetary savings, it scores well.[xi] This has resulted in substantial underinvestment in infrastructural interventions, with the result that, over longer periods of time, the problems start to return even more strongly than they were before, necessitating a far greater expenditure to address the consequences.[xii] In other words, it is a classic "false economy." By attempting to balance the books in the short term, the NPM approach ensures a far greater financial hit further down the timeline.[17] This outcome is plain to see in the ongoing decline of social care provision in the United Kingdom at the time this report was written. After years of outsourcing in the name of financial prudence, local government bodies are now struggling to bring these services back in-house in order to control both costs and quality of service, which under outsourcing have spiraled and declined respectively.[xiii]

Addressing societal challenges is always going to cost money, but doing things as cheaply as possible at the outset may end up costing more in the long run, whether in terms of money or poor social outcomes, or of both. This principle suggests that the long-term challenge of building an inclusive society requires not just a commitment to funding immediate interventions and sustained programs of support, but also a commitment to measuring the success of those interventions and programs in a manner that recognizes their true value.

In financial terms, this means recognizing that immediate expenditure may only manifest as savings over far longer periods – decades rather than years – but that such savings will eventually eclipse any reductions that might be made to the operational budget. These programs and interventions should be seen as infrastructural investments. But there is also a case to be made for social evaluation metrics, whereby the social good of a given project is not translated into monetary terms of value, but left to stand on its own. Such systems remain predominantly theoretical so far;[xiv] putting one into practice would represent a considerable commitment to the principles of inclusivity and a pioneering move in governance.

[xi] https://www.centreforpublicimpact.org/future-of-government/

[xii] https://www.anzsog.edu.au/resource-library/news-media/beyond-outsourcing-how-governments-can-change-their-approach-to-contracting-services

[xiii] https://www.theguardian.com/society/2019/may/29/bringing-services-back-in-house-is-good-councils

[xiv] https://ssir.org/articles/entry/a_playbook_for_designing_social_impact_measurement

Iterate to Innovate

Related to the matter of evaluation is the matter of strategy. Both must be flexible and capable of keeping long-term goals in mind, even when they're obscured by short-term difficulties.

With a policy goal as broad and complex as that of creating a fully inclusive society, it should be understood from the outset that, while the goal may be clear, there will be many unforeseen obstacles along the way. Making plans is important, but it is equally important to not grow overly attached to them. Most of the experts consulted in the preparation of this report highlighted the necessity of flexible and responsive policy-making, which is able to adjust to new discoveries and experiences. Plans should be reviewed and revised on a regular basis, with adjustments made in response to feedback from end users, as well as those involved in implementation. Much in the same way that front-line practices improve when practitioners are given the chance to be flexible in their methods, policy can benefit from embracing a more iterative and gradual approach.

On a related note, it should be recognized that successful interventions are not necessarily transferable between sectors or contexts, or even between individuals who seem to be in a similar situation. They may be transferable – which means that committing to investigating the extent to which a successful intervention might be translated into other contexts would be a sound strategic principle; it would be less wise to roll out an extensive program based on a few isolated successes. Context and contingency are vital elements in the design of successful and sustainable services, products, environments, and systems. Therefore, successes should be studied closely so that their circumstances are fully understood.

03

Context A: Education and Early Years

It should be acknowledged from the outset that equality of outcomes is effectively impossible – a statement that applies to all efforts toward an inclusive society, but perhaps matters most in the context of education and early years care. Parity of academic or intellectual achievement, even if only an aspiration, is an element of the "notion of normality" already discussed. Ultimately, it sets people of all abilities up to fail.

As such, experts with experience in educational regulation in the MENA region and elsewhere have recommended that de-emphasizing the teleological importance of formal academic qualifications and promoting alternative ends to the means of education would be beneficial to not only the education of differently abled people, but also to the culture in which the education system is embedded. Put more simply, there would be less pressure on people whose gifts are not conventionally academic. This is not to denigrate academic achievement, but rather to recognize it as just one among a number of different and equally valid forms of success.

It has also been suggested that opportunities for learning should be available to all regardless of ability, age, or circumstance. No one should be excluded from the education system, nor pushed to leave it before they feel they are ready. This makes for a more just model of provision and serves to destigmatize non-academic patterns of educational attainment. This would make it more likely that a given individual might return to education, as well as making it more likely that they might succeed on their own terms

In terms of the classroom environment, experts in education and inclusivity alike are united in their opinion that it is crucial to include persons with disabilities in the mainstream teaching environment as early as possible and to the greatest extent possible. Institutions or sub-departments devoted to the provision of support to students with disabilities should likewise be to the fullest extent possible either integrated within or dissolved into schools or colleges that do not discern on the basis of ability.

Student segregation should be avoided, except in such cases (e.g. particularly acute autism spectrum disorders) where integration would be traumatic or disadvantageous to the person with disabilities themselves. Such cases are very rare, however, and it is believed that the vast majority of people with disabilities would benefit hugely from being fully integrated into the mainstream teaching environment – which, after all, is effectively a training ground for society more broadly. For this reason, mainstreaming is to the long-term advantage of everyone, as it reduces stigma through exposure to difference, thus providing all students with the best possible start in life, regardless of their abilities.[18] Such mainstreaming will therefore require compulsory training for educational staff in the correct ways in which to work with students with disabilities, particularly in matters of physical interaction and restraint. There is a fine line between preventing a student from harming themselves or others and unintentionally causing them harm; neither common sense nor tradition are reliable guides in such situations.

It should also be recognized that parents and caregivers of people with disabilities are themselves in need of support, and not only in the form of medical advice. While a medical specialist can advise on the challenges the person they care for is facing, such specialists cannot be expected to advise them regarding the psychological challenges of caring itself. While activists and advocates in the MENA region have expressed a clear desire for readily accessible information (translated into appropriate languages) on disabilities and the conditions that cause them – which might be seen as an extension of the educational function beyond the setting of the school – they have also emphasized that peer support from other parents and caregivers has been invaluable, not only with regards to learning techniques of caring, but also with regards to feeling like part of a community that understands one's circumstances and challenges. These networks are often successfully self-organized, but they could be strengthened greatly through the affordable measure of providing social and physical infrastructure; for example, free spaces to meet and channels through which such groups might advertise their existence.

While equality in outcomes is an impossible goal, a just distribution of resources and support is eminently achievable, provided a commitment is made to both funding and leadership. When it comes to the provision of educational resources in a privately funded system, this presents some challenges. Put plainly, a system wherein fees are paid in proportion to the support and resources required is fundamentally *not* inclusive, as it invites the possibility that some individuals will not get the support they need to flourish because their parents or caregivers cannot afford it.

Many developed states have addressed this issue through taxation-based models of education provision; however, such systems are still dependent on an allocation of funds appropriate to the resources required, and prevailing paradigms are failing to provide enough (see again the "long-term change" section above). In states where the taxation model is inappropriate or politically impossible, alternatives might include a regulatory apparatus that gathers a levy from the fees paid to schools and universities which is used to fund the extra support and resources required by people with disabilities, or a law that schools must charge the same fees to all students, regardless of their level of ability or requirements for support.

It should be noted, however, that the lack of a universal free education program would fall short of the broad definition of an inclusive society in which education is framed as a right rather than a privilege. To charge for it is to divide society between those who can pay and those who cannot. Given the correlation between poverty and disability, this would also impact upon a definition of inclusivity limited to disability – these issues, as discussed above, are profoundly intersectional.

Opportunities for learning should be available to all regardless of ability, age, or circumstance. No one should be excluded from the education system, nor pushed to leave it before they feel they are ready. This makes for a more just model of provision and serves to destigmatize non-academic patterns of educational attainment.

03

Context B: Employment

The most significant obstacle to opportunity in the workplace for people with disabilities is physical accessibility. Of course, there are forms of work that will be fundamentally unsuited to people with particular disabilities – issues of physical mobility will preclude many forms of manual labor, for instance. But all other issues of simple physical ability aside, the main obstacle to including people with disabilities in the workforce is a willingness on the part of employers to accept and accommodate their different needs and requirements in terms of facilities and environment.

Sometimes these differences will be physical, particularly in the case of people with mobility-related disabilities. These are easily accommodated via infrastructural interventions such as accessible architecture, furnishings, equipment, and software – and, as already discussed, making new buildings and public spaces accessible to people with mobility limitations is easily mandated in policy. It can also be surprisingly cheap. Experts in inclusive workspaces estimate that accessibility features might account for a single percentage point of the total cost of a building project.[xv] Furniture that has been designed to accommodate wheelchairs and other such adaptive technologies is readily available, and the majority of modern information technologies have accessibility features built in.

Other forms of disability, particularly learning disabilities or chronic mental health disorders, may require more subtle accommodations, which, counterintuitively, may be harder to enact, as they represent disruptions of the often-unspoken traditions and assumptions of the workplace. For example, individuals with certain types of personality disorders might be fundamentally unsuited to keeping the usual "9 to 5" schedule familiar to office-based workplaces, or to working in a brightly lit open-plan office full of bustle and conversation. However, they may also possess creative or organizational skills that make them valuable employees, and indeed may find their condition significantly improved by feeling that they can make a contribution to society through their work. Finding ways to accommodate such individuals in the workplace is a new accessibility frontier.[xvi]

Business leaders with experience employing such individuals concede that integrating them into a workplace can be something of a challenge from a project management point of view, but only because it is currently out of the ordinary. Much like society more broadly, project management has its own notions of normality, and dislodging them requires sustained effort and commitment. The transition should be relatively swift, however, and the tools are already available. By way of example, managing a team with differing optimal hours of activity should be no more challenging than managing a team across different time zones, which is commonplace in many modern enterprises. The ongoing paradigmatic shift toward project-oriented patterns of work should also make this process easier. It is a short and simple step from treating each project as unique and contingent to treating each employee as such. Technologies such as task management and team communications software can enable and support this sort of "porosity" in the workplace, but researchers from DotEveryone emphasize that technology cannot create it from scratch. As with other aspects of inclusivity, the culture has to come first, with commitment and leadership being seen as particularly important for ensuring that change is substantive and sustained.

[xv] It is worth noting that construction firms are prone to estimate the cost of accessible new-build construction as far higher, which presumably reflects the unusualness of the work rather than its actual complexity; we were unable to secure any informants from the sector who were willing to address this topic. It is widely understood, however, that retrofitting existing buildings for accessibility can be more expensive and troublesome than incorporating such features into new build – but again, not necessarily to the extent that constructors or building owners may claim.

[xvi] In developed nations, the law will often refer to a requirement that employers make "reasonable accommodation" of employees with disabilities, but its interpretation is often left wide open.

[xvii] https://www.ipma.world/self-organisation-a-new-paradigm-for-project-oriented-work-1/

[xviii] https://www.equalityhumanrights.com/en/multipage-guide/changes-policies-and-way-you-usually-do-things

Diverse Workplaces Benefit Everyone

In addition to the benefits of social integration and the destigmatization of difference, some pioneering workplaces argue that inclusivity has business advantages, too. For instance, a diverse workforce should be more innovative because it is less likely to produce obvious, normative solutions to “averaged” problems.

Some employers see the need to accommodate people with differing abilities as an unnecessary or onerous imposition with a potential impact on their bottom line. However, it should be noted by policymakers and other advocates that diverse workplaces are to everyone's advantage, not just that of the employee. The benefits for social integration and the destigmatization of difference have already been discussed, but it is argued by some pioneering workplaces that inclusivity has business benefits, too. For instance, a diverse workforce should be more innovative[19] because it is less likely to produce obvious, normative solutions to "averaged" problems. While it is hard to quantify innovation, the inverse of this phenomenon is more easily spotted: Silicon Valley start-ups (which tend to have highly homogeneous workforces, particularly at the decision-making level)[xix] have shown a notable bias toward producing applications and technologies that suit the sort of people they employ, and no one else.

There is also a governance argument for mandating the inclusion of people with disabilities in the workforce, and it can be seen playing out in many of the supposedly leading economies of the world. Put simply, without opening the labor market to those currently excluded from it by circumstance or prejudice, there will not be enough people to do all the work that will need doing in the years to come. Though it might seem a paradox, this is precisely because the number of individuals effectively excluded from the workforce by disability is growing (as a direct result of demands on the working population increasing), and because social risk is being shunted onto individuals as welfare provision is reduced or withdrawn.

To put it more bluntly, the intensity of modern work culture is resulting in an increasing percentage of individuals being unable to keep up with its demands, whether due to physical, intellectual, or emotional disabilities. This demographic shift is being amplified by the gerontological causes already discussed. As lives become longer, they will inevitably include more "unproductive" years. While countries such as China and Japan are exploring the possibility of dodging this demographic bullet by using robotic workforces, it is uncertain how successful they will be – and such an approach also presupposes a strong pre-existing technological manufacturing sector.

For nations where services have long since overtaken manufacturing in economic terms, however, it seems that the only way to dodge the unproductive years problem is to redefine what "productive" means. One way to achieve that aim would be to raise the profile and respectability of forms of work that were previously treated (and compensated) as menial labor, if they are even considered to be work at all. The revaluation of care work in particular is vital to this transition.

[xix] https://www.wired.com/story/five-years-tech-diversity-reports-little-progress/

03

Context C: Domestic

While there are still occasional reports of impressive and seemingly science-fictional technologies aimed at promoting autonomous living for people with disabilities – the mobility exoskeleton being a persistent example of the genre[xx] – such feats of invention have largely been eclipsed by special applications of technologies that we now think of as mundane and commonplace. But that mundanity is deceptive, for while the smartphone has become a part of daily life for many people in developed nations, that device – and the infrastructure that underpins its functionality – looks almost unbelievable from the perspective of a few decades past.

The miniaturization of microprocessing hardware (and the wireless networking of devices based upon it) have opened up huge opportunities for everyone, but particularly for people with disabilities who wish to live as autonomously as possible. Smartphones and computers are not just devices of communication, but also of control. It seems fairly safe to say that we are only at the beginning of our understanding of what might be done with them.

Some possibilities are now well known, such as text-to-speech and speech-to-text translation systems and the presentation of online media in accessible formats that can be adjusted by the device to suit the needs and preferences of the individual user (such as larger font sizes or closed captioning on video material).[xxi] Some are more innovative, piggybacking on the latest devices to hit the market. For example, the rise of voice-activated virtual assistants has provoked an avalanche of new ideas for assistive systems.

But therein lies cause for caution. Many of the most exciting capabilities of smartphones and domestic information technology more broadly are currently entangled with exploitative business models based on surveillance and data gathering. They also involve the implementation of functions that are invasive, exploitative, unstable, interdependent, and –

perhaps most commonly and most dangerously – poorly designed with an eye to the "average" user and an assumption, often unwarranted, that said user will even read the licensing agreement that they're presented with, let alone actually understand it. To reiterate, *information technologies are devices of control,*[xxii] and control can flow from designer to user just as easily as in the opposite direction, particularly when the complexity of a device and/or its application demands a comparable complexity of design.

These are issues that affect almost all users of modern computing devices, but they are particularly acute for people with disabilities for whom these devices are intended as assistive or adaptive technologies. The notion of "consumer choice" in these arrangements becomes problematic when the choice in question is between, for example, keeping one's privacy and keeping one's autonomy. Privacy in particular is an issue that demands strong and well-designed regulation sooner rather than later – but questions of functional resilience and customization must also be addressed if information technology is to become a trustworthy part of the assistive/adaptive arsenal.

The risk of solutionism is most acute in the domestic space because it is in the domestic context of support for autonomous living that funds tend to be most stretched, with the result that affordable "off-the-shelf" approaches start to look appealing. Experts stress that while such choices are often made with the best of intentions, they can sometimes betray an astonishing lack of consideration for the individual and their context.[xxiii]

[xx] E.g. https://www.suitx.com/phoenix-medical-exoskeleton or https://rewalk.com/. Please note that these links are intended as illustrative examples only and do not represent endorsements by the author of the products in question.

[xxi] It should be noted that standards for website design that enable this sort of on-the-fly adjustment have been long established, with the best-known suite of standards being that specified by the W3C consortium. It also bears noting that adherence to these standards has dropped off in recent years, as accessibility is seen as an easy place to make cuts and restore the bottom line. The triumph of app-based interactions over the "open web" approach that prevailed in the first decade of the millennium is also implicated in this shift.

[xxii] https://thepointmag.com/dialogue/control-groups-william-davies-nervous-states/

[xxiii] https://www.doteveryone.org.uk/project/better-care-systems/

An extreme but illustrative example would be the people living independently with dementia who were provided a "panic button" to summon help, despite being unable to remember what the button was for or how to use it. Another would be the fad for touchscreens in public spaces, which, while helpful for people with some disabilities, can actually serve as a hindrance to people with poor eyesight or motor-control issues.

Technological literacy is often assumed by designers and activists in the assistive/adaptive sectors, but this is a biased way of seeing the world. Even in a country like the UAE, where there is more than one smartphone per citizen,[xxiv] the rate of technological literacy – the competence and understanding of information technology as more than a consumer product or turnkey service – is likely to be much lower than expected. While user interface design has made huge advances in recent years, making it possible for people to use information technologies without understanding them, this means that our devices are increasingly arcane and obscure when in a state of dysfunction, which is statistically more likely in customized or "off-label" deployments. Put more simply, it's fine to rely on a custom smartphone app for your daily support, right up until the app unexpectedly stops working and you have no idea how to fix it.

This issue is compounded by commercial models of software provision and the intentional obsolescence cycles of hardware. If we intend to start deploying smartphones as platforms for assistive and adaptive technologies, then we must consider the necessity of regularly updating and upgrading those devices for all users. As their operating systems and software become obsolete (and thus no longer updated), older devices may become unreliable and insecure, which is obviously unacceptable in a device that is central to someone's ability to care for themselves. There is also the issue of infrastructural dependency. A smartphone can fulfill many functions, but they often require the phone to be charged and have access to some sort of cellular or wifi network connectivity. In regions where connectivity is intermittent and unreliable, these are not a given.

To be clear, this is not to discourage the use of advanced technologies, which offer great opportunities for people with disabilities to live more autonomously. Rather, it is to emphasize their potential fragility. The risk of malfunction is acceptable for those to whom a smartphone is a luxury lifestyle accessory, but not for those whose lives might be literally dependent upon the device. In terms of policy and intervention strategy, then, a sensible rule would be to always look for the "dumbest" possible technology that can achieve the functions required – because "dumb" technologies have fewer ways of going wrong. For example, some service providers are abandoning smartphone-based solutions and returning to the use of emergency phones connected to the landline network. The landline network provides power to the devices connected to it, while a smartphone needs to be charged to work properly.

In terms of more charismatic applications of technology to the care and support of people with disabilities, it is clear that there are plenty of possibilities, even if they do return to the same science-fictional territories as the exoskeletons already mentioned. Japan in particular produces a steady stream of robot prototypes designed to assist with elderly care – but as already mentioned, such approaches to the challenge of the gerontological disability bubble are probably the exclusive preserve of comparatively wealthy nations that also retain a healthy tech-manufacturing stratum in their economic make-up. Elderly care robots also go some distance toward highlighting the extreme cultural specificity of care provision, particularly for the elderly. Fluffy therapeutic robot seals clearly make great headlines,[xxv] but will technological devices with affects and aesthetics closely attuned to the demands of markets in the Far East have the same appeal to users in Dubai, Denver, Doncaster, or Düsseldorf?[xxvi]

[xxiv] https://www.commsmea.com/18171-uae-leads-world-in-mobile-penetration-rate-new-report

[xxv] https://www.wsj.com/articles/SB10001424052748704463504575301051844937276

[xxvi] https://www.bbc.co.uk/news/world-asia-31901943. It should also be noted that beyond the possibility of technological solutions to elderly care in Japan, the social actuality is less utopian. Robots may well replace human carers for those few who can afford them, but the shortage of workers willing to accept the low pay offered in the care sector means that elderly care often falls to family members as unpaid labor, as it increasingly does in many other developed nations

03

These issues can seem somewhat abstract, but experts in the field are keen to underline the fact that the specifics of actual cases can be hugely variable, and that wherever possible, decisions on provision – whether that be the provision of human support and care, of simple assistive devices, or of the most advanced technologies – must always be contingent and tailored specifically to the individual in need and the context in which their need arises.[23] Leading researchers in this field argue persuasively that the most powerful policy action that can be taken in the context of designing services, systems, and products for domestic care is to put the locus of decision-making power as close to the end users as possible and listen closely to what they tell you. As noted above, the most profound (and challenging) cultural shift that needs to be made within professions that work with people with disabilities is the recognition that the individual will in almost every case be the best available expert on their particular condition and the needs associated with it.

Another point strongly emphasized by researchers focused on technology in the care sector was the need to elevate the status and pay of human care work, which – despite the genuine promise of technologies to support autonomous living for people with disabilities – will not be going away. Indeed, even if technology takes an increasingly dominant role, there will still be a necessity for skilled advisors to implement it – skilled in the technologies, but also skilled in taking a caring and considered approach to people whose experiences may be very different to their own. In the Global North, at least, the role of "occupational therapist" has for many years been the butt of jokes and derision, but if the demographic trends continue to play out as predicted, it might become a dynamic growth industry, bursting with new opportunities and challenges. Roles like this – alongside the more direct caring roles, reframed and remunerated as respectable and well-rewarded careers – may be the key to securing a sustainable sociotechnical transition to a fully inclusive society.

Context D: Culture and Society

The representation of people with disabilities in the cultural sphere has two important effects. First of all, it works to destigmatize and normalize disability among the wider population, broadening the notion of normality to include a wider range of people, and portraying people with disabilities as keen and capable of contributing to the society in which they live. Alongside the desegregation of education and workplaces, this sort of exposure has a valuable role to play in changing the culture of fear and otherness around disability.

Just as important, however, is the same effect as experienced by other people with disabilities. Countless people with disabilities have reported the immense sense of personal potential created by seeing "someone like me" doing things in the public eye. Whether they are presenting shows on television or participating in international sporting events, people with disabilities are an inspiration to one another and to everyone else.

If visibility is good, then true representation is even better. In this case, representation means that not only are people with disabilities seen to be participating in social, cultural, or political events, but they are also seen to be representing their own interests. It seems to be a universal desire among human beings to see and hear issues, positions, and opinions that matter to them being treated with seriousness and respect, and this is of course just as true for people with disabilities. However, there is a potential dead end of representation, wherein people with disabilities are only ever asked for their opinion on "disability issues." While well intended, this sort of representation can effectively reduce an individual's public identity to the fact of their disability, which is ultimately counterproductive in terms of inclusivity.

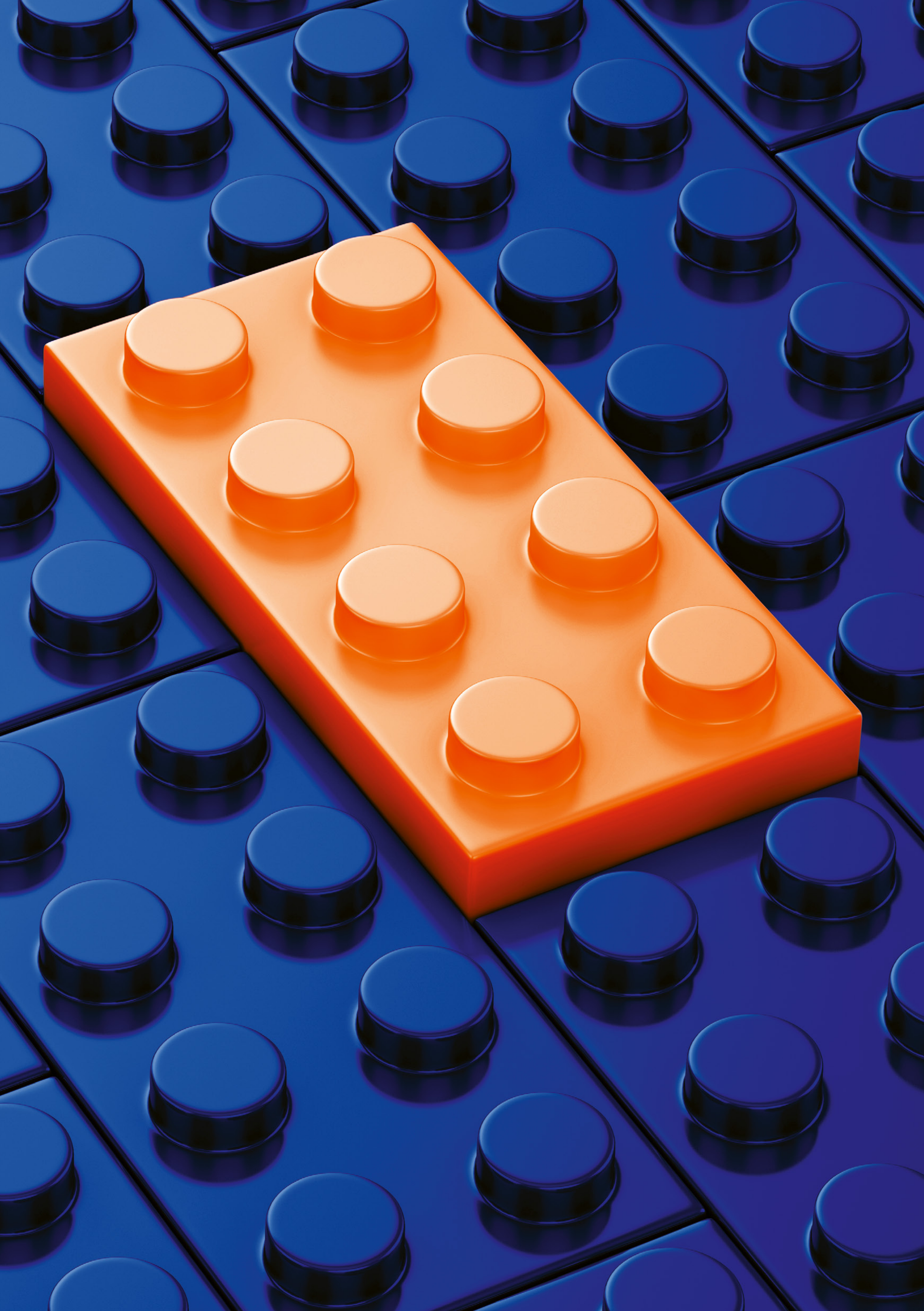
The arts and sports both provide opportunities for people with disabilities to succeed outside of the narrow confines of academic or commercial measures of achievement. Sports in particular offer an opportunity for personal achievement and teamwork, as well as for fame and glory – and, more practically, an outlet for physical energy that for many years was effectively denied under the deficit model. Physical exertion of almost any type was long assumed to be too risky for these supposedly "fragile" individuals. The success of the recent Special Olympics World Games in raising awareness and destigmatizing disability in the MENA region is a case study in cultural exposure, as well as a clear demonstration of the extent to which athletic endeavors can be enjoyed by people of all abilities.

While the achievements on offer in the arts are arguably subtler than those of sports, the arts offer the opportunity for individual expression, as well as an environment that is (at least in theory) more welcoming to different subjectivities and experiences. Perhaps most crucially, the arts function as a social frontier for experimentation and debate, providing a rich space in which disability and its concerns might be represented by those who know them most intimately, as well as the opportunity to challenge prevailing attitudes and start difficult conversations that might still be too contentious for politics or policy.

As such, opportunities to get involved in sports and the arts should be a universal feature of a fully inclusive education system and cultural offer, thus maximizing the likelihood that each individual finds something in which they can take the pleasure of achievement and at which they might eventually excel. A government that commits to providing such opportunities will not only enrich the lives of people with disabilities, but the lives of all its citizens.

04

Determined Futures: An Aspirational Policy Agenda for Inclusivity



04

This section builds upon the findings of the previous section and its four contexts in order to identify for each context an ambitious and aspirational policy (or policies) intended to produce the fundamental cultural changes needed to establish a truly inclusive society. These policy goals are necessarily fairly high-level. The details of implementation are beyond the scope of this report, which is to identify trajectories and directions of travel rather than develop a "road map." Nonetheless, the policies outlined below represent a broad (and interconnected) foundation aimed at mandating the reconfiguration of the physical and social environment in order to remove the most significant obstacles to inclusion while also amplifying opportunities for integration.

Education and Early Years

The most impactful and ambitious policy for inclusive education would be to mandate the full integration of all special needs provision into mainstream educational establishments. The aim would be to creat a system in which the segregation of students by ability is almost entirely eradicated, while allowing exceptions for students whose particular disabilities would make full integration a traumatic experience for them.

In support of this type of integration policy, experts recommend the establishment of a sector-wide regulatory body with responsibility for all provision of learning opportunities, and for making those opportunities available on a life-long basis for individuals of all abilities and social statuses. The reduction and equalization (and eventual eradication) of educational fees should also be included as a longer-term goal.

A truly radical policy for inclusivity in the workplace would be one that not only improves employment opportunities for people with disabilities, but also improves the circumstances of those already working in support of people with disabilities. Experts in caring technologies have recommended establishing a national “college of care,” intended to formalize, professionalize, and raise the social status of care and care-adjacent career paths.

Employment

Full inclusivity in the context of employment will necessitate the careful regulation and management of technologies of automation, which has the potential to radically reshape the opportunities available to people with disabilities, and also to produce entirely new categories of "disability." However, these issues will be addressed in a separate report focused on automation and artificial intelligence.

A truly radical policy for inclusivity in the workplace would be one that not only improves employment opportunities for people with disabilities, but also improves the circumstances of those already working in support of people with disabilities. For this reason, experts in caring technologies have recommended establishing a national (or perhaps regional) "college of care," intended to formalize, professionalize, and raise the social status of care and care-adjacent career paths. These paths would of course include nursing and assistive care roles, but also occupational therapy, pedagogies of care, and more "technical" subjects such as design, research, and development for assistive and adaptive technologies. These careers would not only be aimed at improving the lives of people with disabilities, but would also provide them with pathways to professional achievement; thus, contributing to a general destigmatization of both disability and the labor of care.

04

Domestic

Transformative policies for inclusivity in the domestic context should focus less on specific interventions than on the way interventions are decided upon, thus recognizing both the risks of one-size-fits-all solutionism and the individual autonomy implicit in the social model of disability. A good start would be establishing an overarching policy principle whereby an individual with disabilities and/or their primary caregiver (in that order of priority) is always consulted as part of the decision-making group in any process relating to the provision of their care and support.

This top-level principle will need to be supported with more detailed policies and precedent regarding the suitability and durability of the interventions that are eventually provided. This suggests a policy program closely related to the establishment of the "college for care" (see above), promoting the encouragement and support of social (not-for-profit) enterprises aimed at taking the best and most reliable forms of technology and making them (or close alternatives) as reliable and safe as possible for deployment in domestic support situations.

Culture and Society

Regarding the aim of achieving full social integration for people with disabilities in all spheres of life, particularly in the (most visible) social and cultural spheres, the universal regulatory body for education discussed above should have its mandate extended to ensuring the provision of sports and arts opportunities to people of all abilities in all education establishments. This bolsters the commitment to integration, but also provides the earliest opportunities for people of all abilities to discover and nurture their specific talents and skills, as well as fostering a more creative culture more broadly.

In addition, an affirmative policy aimed at rapidly establishing full proportional and participatory representation of people with disabilities (on all issues, not just "disability issues") in the cultural (e.g. media) and political spheres would serve to support the other policies described above. It would also accelerate the process of acceptance and social integration among the "normally" able, as well as among people with disabilities.

This report acknowledges that the implementation of policies such as these is most certainly easier said than done. Furthermore, enforcing their enactment may be more challenging still. This much can be discerned from even the most casual engagement with the academic literature and cultural discourse in nations where legislation has long-harbored aspirations for inclusivity, but has lacked the commitment and leadership to make it manifest.

Nonetheless, it is worth noting that these are not difficult policies in any technical sense, and they largely concretize principles that most people would concede to be at least reasonable. The challenge inherent in all of them – and inherent to any commitment to inclusivity more broadly – is to stand firm against the interests most heavily invested in the notion of normality. This will require the political courage to stand against the status quo and the political empathy to stand beside the differently abled and insist that they be treated with the same dignity afforded the nominally "normal."

Conclusion

This paper seeks to answer a fairly broad question. Having in recent years undertaken a radical redefinition of disability, perhaps best represented by the preferred official designation "persons of determination", the Government of Dubai seeks suggestions on how a society might be made more inclusive for people with disabilities. The ultimate goal is complete integration, but this report aims to consider first and foremost the relatively near- to medium-term future – what might be realistically achievable in the next decade or so (from the time of writing up until around 2030).

In order to achieve this aim, the research and report were structured around four goals, each of which builds upon the ones before:

1. A definition of the disability challenge in both quantitative and qualitative terms
2. An identification of the prevailing global "state of the art" in policymaking for inclusivity
3. An exploration of principles and strategies for inclusivity policy in the near- to medium-term
4. The recommendation of a foundational suite of interlocking top-level policy frameworks from which a fully integrated and inclusive society might be constructed

Each of these research questions was addressed through a combination of desk research and interviews. The latter were undertaken with experts in a range of pertinent fields and sectors: researchers in ethical technology, care systems, and medical policy; medical scientists; disability activists, advocates, and campaigners; educational policy advisors; designers and futurists.

From a methodological perspective, the extent to which answers to the core questions quickly converged on the same essential arguments regardless of the source was remarkable – an unusual experience, particularly for anyone accustomed to academic research. This phenomenon can likely be attributed, at least in part, to the long and little-discussed history of disability activism, which arguably began to coalesce in the Anglophone West in the late 1960s and 1970s in parallel with the other liberation movements of the time. The "social model" described in sections 1 and 2, for example, emerged from the Union of the Physically Impaired Against Segregation (UPIAS) in the UK.[xxvii]

As such, the work of this report might be thought of as less a scientific endeavor of piecing together a case from scattered evidence, and more a matter of surfacing and bringing together arguments that have been made by people with disabilities themselves for years, if not decades. Those arguments turn out to have very little to do with cutting-edge medicines or technologies, except in very specific cases. Instead, they have a great deal to do with reminding us that people with disabilities are people – no more flawed nor less complete than any of the rest of us and just as entitled to dignity, opportunity, support, and respect.

We should celebrate the fact that societies and governments around the world are increasingly paying attention to the voices of people with disabilities and recognizing that they are the foremost experts in their own lives (as suggested in section 2). But at the same time, it remains clear that there is still a gap between acknowledging that understanding and acting upon it. The goal of full integration is admirable, but it will require a change in attitude not just among the governors but the governed as well. Banishment the notion of normality (see page 19) is as much the responsibility of everyday citizens as anyone else, if not perhaps more so. The Government of Dubai is making a very public commitment to this goal. This report seeks to play a role in helping that project to succeed, thus providing an example that others in the MENA region and beyond might follow.

[xxvii] http://historyof.place/a-place-in-society-maggie-davis-and-the-birth-of-independent-living/

Notes

1. Myers, V. (2011). Moving diversity forward: how to go from well-meaning to well-doing. ABA Center for Racial & Ethnic Diversity.
2. World Health Organization. (2011). World report on disability 2011. World Health Organization.
3. Mitra, S., Posarac, A., & Vick, B. (2013). "Disability and poverty in developing countries: a multidimensional study". World Development, 41, 1-18.
4. Mitra, S., & Sambamoorthi, U. (2014). "Disability prevalence among adults: estimates for 54 countries and progress toward a global estimate". Disability and rehabilitation, 36(11), 940-947.
5. Groce, N., Kett, M., Lang, R., & Trani, J. F. (2011). "Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice". Third World Quarterly, 32(8), 1493-1513.
6. World Health Organization. (2011). World report on disability 2011. World Health Organization.
7. Thompson, S. (2017). "Disability prevalence and trends". K4D Helpdesk Report. Brighton, UK: Institute of Development Studies.
8. Wilmoth, J. R. (2000). "Demography of longevity: past, present, and future trends". Experimental gerontology, 35(9-10), 1111-1129.
9. Rosano, A., Botto, L. D., Botting, B., & Mastroiacovo, P. (2000). "Infant mortality and congenital anomalies from 1950 to 1994: an international perspective". Journal of Epidemiology & Community Health, 54(9), 660-666.
10. Wilkins, W. L. (1972). "Social Stress and Illness in Industrial Society (No. NMNRU-72-56)". Navy Medical Neuropsychiatric Research Unit, San Diego, California.
11. Harvey, P. D., & Keefe, R. S. (2012). "Technology, society, and mental illness: challenges and opportunities for assessment and treatment". Innovations in clinical neuroscience, 9(11-12), 47.

12. Jaco, E. G. (2017). "Mental illness in response to stress". In Social stress (pp. 210-227). Routledge.

13. Thomée, S., Dellve, L., Härenstam, A., & Hagberg, M. (2010). "Perceived connections between information and communication technology use and mental symptoms among young adults-a qualitative study". BMC Public Health, 10(1), 66.

14. George, M. J., Russell, M. A., Piontak, J. R., & Odgers, C. L. (2018). "Concurrent and subsequent associations between daily digital technology use and high-risk adolescents' mental health symptoms". Child development, 89(1), 78-88.

15. Roelfsema, M. T., Hoekstra, R. A., Allison, C., Wheelwright, S., Brayne, C., Matthews, F. E., & Baron-Cohen, S. (2012). "Are autism spectrum conditions more prevalent in an information-technology region? A school-based study of three regions in the Netherlands". Journal of autism and developmental disorders, 42(5), 734-739.

16. Morozov, E. (2013). To save everything, click here: The folly of technological solutionism. Allen Lane Books.

17. O'Flynn, J. (2019). "Rethinking relationships: clarity, contingency, and capabilities". Policy Design and Practice, 2019/2(2), 115-136.

18. Renzaglia, A., Karvonen, M., Drasgow, E., & Stoxen, C. C. (2003). "Promoting a lifetime of inclusion". Focus on autism and other developmental disabilities, 18(3), 140-149.

19. Krause, S., James, R., Faria, J. J., Ruxton, G. D., & Krause, J. (2011). "Swarm intelligence in humans: diversity can trump ability". Animal Behaviour, 81(5), 941-948.

02

With regards to mental and behavioral disabilities, there is also clear correlative evidence (if not necessarily causal connections) between these conditions and the socioeconomic and technological constitution of contemporary society.[10] As a number of experts in the governance of disability and care have observed, the hypermediated[11] and intensely competitive nature of modern life[12] is sufficiently intense that it causes chronic distress in more sensitive individuals. To say that "modern society is making people mentally ill" would be reductive and inaccurate in scientific terms, but at the same time, there exist plentiful theories linking the rise in mental health problems,[13] and behavioral[14] and learning disabilities,[15] to an increasingly technology-saturated and systematized lifestyle or environment, particularly (but by no means exclusively) in the most "developed" nations.

All of which is to say that there is little or no chance of "stopping" disability at the source. However, it is worth reminding ourselves of the clear correlations (discussed above) between disability and poverty, whether pecuniary or circumstantial, and noting that the implication would be that the incidence of non-gerontological disability is most likely to be reduced by addressing material and circumstantial poverty.

Accepting that the incidence of disability is unlikely to be significantly reduced by medical measures, let alone eradicated, we turn to adaptive and assistive measures by which the differently abled might be given the same opportunities to participate in society. While none of the experts consulted were in any way opposed to the use of technology to support the differently abled, they nonetheless almost universally warned against the risks of "solutionism"[16] – a mindset that assumes even the most intractable social problems might be "fixed" by means of some technological gadget or piece of software.

Dubai Future Foundation
dubaifuture.ae
+971 4 516 6569
research@dubaifuture.gov.ae
@dubaifuture