

# Building the Inclusive City

## Victor Santiago Pineda

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Governance, Access, and the Urban Transformation of Dubai



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For love,

The oasis of bliss, peace, meaning, and laughter For my family,

Mother and father, a force of will and a gentle smile Grandmother, unconditional acceptance

Brothers, a bond of strength

For mentors, visionaries and leaders,

Judy Heumann, the godmother for our movement and others who show the way through public service

For teachers and students,

That clear the road toward knowledge

For the parents and advocates,

That battle for justice and dignity

For the future,

That engenders dignity

and

For the restless and generous people of the United Arab Emirates

## PREFACE

As planners, our theories, concepts, and teachings define the ways in which an architect designs a home, a transportation engineer understands streets, a social worker provides community services, and politicians shape policies and laws. In my course "Building the Inclusive City" I like to remind my impressionable students that cities are not fixed; they are evolving systems of systems. These systems transform over time. They shape and are shaped by our values. The ideas shared in this book shape the way cities, nations, and regional institutions work.

In the coming pages, we will explore equity, justice, and access as fundamental values and as catalysts for innovations in sustainable urban development. The rapidly urbanizing city-state of Dubai is the stage where our story unfolds. The story of Dubai, as with any living city, continues to be written day by day. The book covers a range of events that shape the story of disability in Dubai, starting with the founding of the first specialized school for children with disabilities in the 1980s through 2013, when the city's legal, institutional, physical, and social reforms led to the passage of Dubai Law No. 2 on the Rights of Persons with Disabilities. Now more than ever, cities around the world need to focus on access and inclusion. Poor planning excludes and devalues large swathes of people. Ineffective plans limit economic productivity. The estimated 1 billion people who live with disabilities throughout the world deserve better.

My lived experience as a person with a disability drew me to equitybased planning research and equips me with a perspective that uncovers gaps in current research methodologies. This perspective helps me identify fresh approaches to building more equitable and sustainable cities. Although this book focuses on Dubai, a wealthy city-state in the United Arab Emirates, it is not simply about this specific city. This book is about institutions and the role of access and equity in responding to the forces of globalization and urbanization. By studying the urban experience of disability outside the US, Europe, or Australia, this manuscript contributes a more nuanced perspective on the global discourse on the right to the city.

Three insights inform my approach herein. First, disability research, much like other urban or social issues, must be situated in a particular time and place. Second, access and inclusion form part of both local and global planning issues. Third, a twenty-first-century planning education should take access and inclusion into consideration by applying a disability lens to the empirical, methodological, and theoretical advances in the field. This book should be read as part of a larger struggle to define and assert access; it's a story of how equity and justice are central themes in building the cities of the future and of today.

I provide a contemporary history of disability in city planning from a non-Western perspective and provide cultural context for its positioning. This book is an anthropological and urban study of the Emirate of Dubai, its institutions and their revolution, their successes and its failures. I hope this research can help inspire other cities to do more. I am pleased that this book will be available as open access and will help scholars and practitioners reconceptualize disability as a capability deprivation, not simply a medical condition.

By framing disability as a capability deprivation we can build more inclusive and accessible cities. I hope readers like you will use this book to inform their work on metropolitan planning, comparative social development, and urban equity. By bridging theory and practice, I hope to take you on a journey of hopes, dreams, and mostly untapped human potential of persons with disabilities, older persons, children, women, migrants, and anyone else who can benefit from and contribute to the building of an inclusive, innovative, rights-based, barrier-free city.

Berkeley, CA, USA

Victor Santiago Pineda

## ACKNOWLEDGMENTS

This book was a journey, and the journey continues. From my first visit to my last, I continue to be amazed by the generous people and the innovative spirit that characterizes the United Arab Emirates. This book would not have been possible without the support of hundreds of people who have touched these pages and helped give birth to a set of new ideas. These ideas were shaped and continue to shape a global dialogue on human rights and the manner in which dignity and fundamental freedoms are to be guaranteed to persons like me, and many of my most esteemed colleagues, who live with disabilities.

I would first like to extend my sincere gratitude to those that supported me on the journey. My wife and family who patiently and silently waited while I wrote during long hours, sitting by the computer. I also could not have developed this manuscript without the support and constructive criticism of my doctoral committee at the University of California, Los Angeles, that included Vinit Mukhija, Anastasia Loukaitou-Sideris, and Leobardo Estrada. Intellectual influences also include Amartya Sen, Martha Nussbaum, Peter Evans, Kozue Kay Nagata, and Manuel Castells. The basis of this research was born during my time at the University of California, Berkeley and matured further at the University of California, Los Angeles.

Additional scholars that inspire me include Ingrid Robeyns, Marion Iris Young, Edward Soja, John Rawls. This research would not have been possible without the generous support of the US Department of Education's Fulbright-Hays Doctoral Dissertation Research Abroad Fellowship and

Sheikh Saud Al Qassimi Public Policy Fellowship. More importantly, research support from His Excellency Yousef Al Otaiba, Ambassador of the United Arab Emirates to the United States of America, helped offset the costs of editing and making this manuscript accessible to the world through an open access license.

The Mohammed Bin Rashid School of Government (formerly the Dubai School of Government) and particularly Dr Tarik Yousef provided me an institutional and intellectual home. Local disability rights scholars like Dr Eman Gaad, and advocates like Nada Bustami and Majid Osaimi, among others, assisted in facilitating a focus group and recruiting sign language interpretation services.

Local government agencies such as the Dubai Executive Council and Dubai's Community Development Authority actively engaged in discussions. Local special needs centers also welcomed me and provided me with tours of their facilities. In total, over 100 experts or knowledgeable individuals in the field of disability were interviewed and 3 special needs centers were visited. Lola Lopez from Volunteer Dubai provided logistical and administrative support in recruiting and executing the attitudes survey and provided contacts for permission to distribute the instrument at the Dubai Festival City Mall. Marlon Weir and Miriam Rahali provided research and administrative support during the fieldwork phase. Scott Belkin, Sandra Willis, Serida Catalano, Dagnachew Wakene, John Paul Cruz, and most notably Sylvan Doyle patiently edited and revised various versions of the manuscript. I would like to thank my family including, Dr. Sandra Willis, Lizandra Montes, Nada Purkarevic, Maria Pineda, Francisco Pineda, Patrick Pineda, Zachary Kerschberg, and Luis Miguel Gonzalez, among others who patiently spent long hours and late nights supporting and carrying me each step of the way. I would also like to thank my personal heroes Judith Heumann, Ed Roberts, and Dr. Larry Lopez, who eliminated insurmountable barriers and showed me that anything is possible.

There is much that I wish I could have added, and much of this important story still has to be told. Specifically, the story of the rapid progress that had taken place since the launch of the Dubai Disability Strategy in 2015. The past five years have seen tremendous progress, thanks to effective leadership of Aisha Miran at the Executive Council and her capacity to turn a vision into effective and coordinated governance. This is only the beginning of a long journey, and a journey that deserves to be documented, and shared with the broader world. I am excited to see its unfolding in the years ahead as the Dubai Future Foundation, the Centre for the

Fourth Industrial Revolution, and the Dubai Expo 2020 prepare to adopt new paradigms for inclusive urban innovation, and help shape the future of cities.

As a wise colleague told me, "this book is not your last word on a subject but your first." What seemed like a leap of faith turned out to be a twelve-year odyssey. Dubai is and will continue to be a laboratory where the limits of physical infrastructure and social progress are tested. Concepts I developed through this research have already shaped global institutions and helped set targets for the Sustainable Development Goals, the New Urban Agenda, and the implementation of the UN Convention on the Rights of Persons with Disabilities. I intend to support the social development efforts of cities around the world through the Global Compact and Campaign on Inclusive and Accessible Cities (www.cities4all.org), and hope to see the work of the United Arab Emirates offer a path from which social inclusion can be studied not only in the pages of a manuscript but through the realization of a vision for a more equitable and inclusive urban future for all.

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#### CHAPTER 1

## Introduction

**Abstract** Cities around the world are failing people with disabilities, who represent 15–20% of the world's population. These failures exist across every sector of life. Historically, people with disabilities have been treated as objects of charity in need of custodial care. However, urban planners who are well positioned to help usher in a new wave of urban reforms and cities around the world like Dubai are experimenting with more inclusive and equitable policies. These new approaches are fundamentally restructuring urban planning and design. The Convention on the Rights of Persons with Disabilities and UAE Federal Law No. 29 challenge normative approaches to spatial justice and policy. This chapter explores how these innovations seek to remove obstacles for people with disabilities. The case of the United Arab Emirates may at first glance appear to be an atypical case of disability-related development, but its unique position illustrates broader structural challenges and tensions inherent to the process of broad-based, cross-sectoral reforms. Building upon an original innovative framework, this book assesses the transformation of disability rights in Dubai and adds an urban dimension to the Capability Model of Disability by addressing the theoretical gaps that impede social inclusion of people with disabilities in cities.

Keywords Governance • Access • Dubai • Capability approach

- Urban theory Social inclusion People with disabilities
- United Arab Emirates Urban design

#### WHY STUDY DUBAI? SEEDS IN THE DESERT

Dubai is one of the most talked about but least understood cities of our time. In 1999, His Highness (H.H.) Sheikh Mohammed bin Rashid Al Maktoum, the Crown Prince and Deputy Ruler at the time, declared against all odds that Dubai would build man-made islands to rival Manhattan and construct unmatched retail centers that would unite the world in cultural diversity and commercial exchange. With conviction, the Ruler publicly declared that his emirate would become one of the world's most innovative global cities (Al Maktoum 2009). His government labored feverishly to execute his vision and, in record time, Dubai had grown from its humble beginnings as a cluster of fishing villages into a respected regional hub for tourism, commerce, and finance. By 2005, with a reported 25% of the world's cranes and over \$300 billion in development projects, Dubai commanded the world's attention. During the subsequent three years, the Financial Times and the BBC dubbed "Dubai Inc." as "the world's fastest-growing city." However, the situation changed rapidly in 2009. Under the weight of a massive real estate bubble and global financial crisis, Dubai Inc.'s debts imploded. Some building continued, but mostly through the force of inertia. But the opportunity to rethink "Dubai Inc." had come.

I first became interested in the Persian Gulf and the United Arab Emirates¹ (UAE) in 1993 while living in Kuwait with my father, a diplomat, university professor, and journalist. His post as Ambassador of Venezuela to Kuwait also included maintaining relations between my family's homeland of Venezuela and the relatively young federation of the UAE.

My older brother Francisco, who was on the junior varsity basketball team, traveled from Kuwait to Dubai for a match against one of the local high-school teams. He came back with stories that sparked the imagination of his impressionable younger brother, me. Twelve years later in 2005, as the region and nation's expansive urban and economic growth reached record highs, I was engaging in research that documented the formation of the United Nations Convention on the Rights of Persons

<sup>&</sup>lt;sup>1</sup>The United Arab Emirates (UAE) is a federation comprising seven emirates located in the southeast of the Arabian Peninsula in Southwest Asia. It is situated on the Persian Gulf, bordering Oman and Saudi Arabia. These seven states, termed emirates, are Abu Dhabi, Dubai, Sharjah, Ajman, Umm al-Quwain, Ras al-Khaimah, and Fujairah. According to the 2017 World Bank population estimate, the total population of the United Arab Emirates is around 9.4 million.

with Disabilities (CRPD). I began to wonder if the city was real or simply a mirage. Any city with such dynamism would provide a fertile base from which to build in accessibility; it would provide a *tabula rasa* with the potential to become the world's most accessible city.

In 2007, as part of my commitment to documenting, assessing, and supporting the practice of inclusive development, I was invited by a colleague to visit Dubai. This gave me the opportunity to engage with a relatively young and visionary team of experts, government officials, and disability advocates who were charged with the ultimate task—to make Dubai one of the most accessible and inclusive cities in the world. It was exciting, but I was unsure how they were going to pull it off. Could solving accessibility be as simple as simply allocating sufficient funds?

The UAE has substantial resources. It holds the seventh-largest proven reserves of both crude oil and natural gas in the world. Since its independence from the UK in 1971, the UAE has relied on its large hydrocarbon endowments to support its economy, but through concerted efforts over the past several decades, that has begun to change. The UAE is becoming one of the world's most important financial centers and a major trading center in the Middle East. Would this economic advantage prove sufficient in building the world's most accessible city? Three years after my first visit I would move to Dubai to find out.

#### The Federal Structure of Government

Arabic is the official language of the UAE and serves as the main language for government programs and strategy at the federal level. The country's political system is governed by the UAE Constitution, which splits authority between federal and local authorities. Federal authority is exercised through legislation and execution of federal strategies, laws, and mandates (UAE Constitution, Article 120). The individual member emirates have authority in specific areas related to local management and governance such as the provision of roads, commerce, infrastructure, education, health, and employment, among others. At present, the federal system of government includes the Supreme Council, the Council of Ministers (Cabinet), a parliamentary body in the form of the Federal National Council (FNC), and the Federal Supreme Court, which is representative of an independent judiciary.

#### Access Through the Lens of Planning

As an urban planner living in the UAE, I was surprised that my profession had not yet explored this dynamic city-state to a greater extent. But more importantly as a disability studies researcher, I was concerned that urban planners had not developed inclusive conceptual approaches to accessibility; the field had practically ignored disability as a fundamental and central experience of the human condition. A multitude of disciplines such as philosophy, public policy, social welfare, and human development have explored disability as a lens through which to understand social exclusion. Why have urban planners left people with disabilities behind?<sup>2</sup>

Due to its breadth and flexibility, I see planning as one of the few fields that can address and harness the human potential of persons with disabilities,<sup>3</sup> older persons, and all those who may encounter barriers in the built environment. The field of planning encourages scholars to act and shape new approaches to social justice, access, and community development. It has the potential to help bring millions of people out of the shadows and into the light. It has the power to create a radical transformation in the way a city thinks about and acts on two fundamental values for our time: access and inclusion. I thus set out to explore a relatively new phenomenon in urban planning—disability—across various sectors and scales using an intellectual toolkit housed in the fields of policy planning and urban development.

Most disability rights activists I have spoken to in both developed and developing countries have made remarks along the lines of "We're not as advanced on disability rights as the US or Europe" or "You've seen more progress in this field than we have." Through my work, I have had to think a lot about what constitutes progress for people with disabilities. Is progress linked to development? If so, then how? What are the values we are advancing? Peter Hall (2002) argues that development is dependent on changing ideas and norms and is also culturally relative and context specific.

<sup>&</sup>lt;sup>2</sup> It was disappointing to discover that scholars in urban planning, social policy, and international development have by and large failed to address disability as a natural component of the human condition. As such, the three fields are also rather silent on the issue from historical, theoretical, and practical perspectives. Debates around these topics raise questions on the outdated models of disability as well as on government and private sector responsibilities toward the social inclusion of the disabled population. As a result, urban planners are challenged to meaningfully contribute to disability rights and policies.

<sup>&</sup>lt;sup>3</sup>The term "persons" is used in the United Nations Convention on the Rights of Persons with Disabilities rather than "people," although both can be used interchangeably.

Throughout the world, persons with disabilities are often excluded from mainstream society and denied basic rights (Lindqvist 2000). Pejorative approaches are oftentimes entrenched in social welfare systems that perpetuate dependency and stigma or conflict with new technological, political, or social realities. From my frequent visits to the Middle East, I have personally witnessed and experienced various forms of discrimination against persons with disabilities. These range from physical, emotional, psychological abuse to social exclusion and malign neglect. This abuse and neglect is virtually universal and is present in some form even in advanced economies with decades of experience in enforcing disability rights laws. Throughout the book I describe in detail the evolution of urban and disability theory. I also describe in detail the transformation of disability rights in Dubai, and although I highlight early experiences of neglect, discrimination, and exclusion, I also demonstrate areas of more contemporary approaches that have made rapid progress.

According to Nagata (2008), a disability rights scholar and United Nations expert, effects of disability-based discrimination in the Middle East are particularly severe in fields such as education, employment, housing, transport, cultural life, and access to public places and services. Nagata (2008) cites distinction, exclusion, restriction of preference, or denial of reasonable accommodation based on disablement as social realities that effectively nullify or impair the recognition, enjoyment, or exercise of the rights of persons with disabilities. Urban planners have not adequately addressed such issues and have left the disability question unanswered for too long. Advocates with disabilities living in different parts of the world echoed a similar sentiment.

Contemporary research shows compelling evidence that the diminishment of function does not have to equate to a diminishment of agency (Francis and Silvers 2000; Silverstein 2000; Robeyns 2006; Kittay and Carlson 2010). Disability advocates from the Middle East I have spoken with echo existing research (Poortman 2005; Nagata 2008) and say with a sense of urgency that business as usual has not worked for persons with disabilities. In governments across the Middle East public institutions are marred by funding inequalities, duplication of effort, lack of capacity, power, or mandate to meet all of the necessary social outcomes and objectives of equality and employment (social inclusion) that they are mandated to achieve (Humphreys et al. 2003; Caiderwood 2009; Demarco 2009). It really seemed that a new more flexible and more holistic paradigm was needed—one that could be operationalized, modified, and customized to the diverse conditions, customs, and governments that signed onto the Convention. The amount of change required to address these challenges however left me wondering whether solving the disability question in planning and development was too difficult, too costly, or merely an excuse for not embarking upon the path toward justice and greater freedoms as set out by the CRPD.

In the UAE, as in the majority of the world, unnecessary obstacles prevent persons with disabilities from exercising their rights and from being able to fully participate in the range of activities possible in their society. According to the CRPD and UAE Federal Law No. 29 of 2006 Concerning the Rights of People of Determination, federal and local governments in the UAE are required to actively remove physical, social, legal, and other barriers that prevent persons with disabilities from participating equally in public life. Additionally, the CRPD states that persons with disabilities and their organizations should play an active role as partners in this process. However in the first nine years since the passage of Federal Law No. 29, they seldom did, but this has also begun to change. As I will describe later in the book the UAE Constitution defines the basic public goods and services that need to be afforded to persons with disabilities. It also stipulates that these should not be contingent upon nationality (see UAE Constitution 1996, Appendix A; Al-Muhairi 1996).

In 2007, during one of my first trips to the UAE, a real estate developer confided that there was no need for accessibility standards in the Emirates because according to him, "there are no persons with disabilities in the UAE, and if there are, they are too few to matter." As such he argued that "no drastic measures should be taken by the government." According to him, the number of persons with disabilities was exaggerated. He was likely referring to a 2006 government report that stated the "unofficial

<sup>4</sup>Under the general provisions of Article 1, individuals with disabilities will be granted by the Ministry of Social Affairs an official document indicating that "its holder is a person with special needs." This Article is problematic to the equal enjoyment of rights. Requiring that persons with disabilities carry a card issued from the Ministry of Social Affairs would restrict most provisions of the law to nationals and scale down the universal status of *rights* limiting them to a selected group of "card-carrying" beneficiaries. Additionally, such schemes usually work against doubly marginalized groups (in violation of Articles 3, 4, 5, 6, 7, 12, 13, 14, and 33 of the CRPD). Women, children, the elderly, the poor, migrant workers, Bedouin people, and religious/ethnic minorities who live with disabilities would be at a disadvantage and would, under this scheme, not be able to equally realize their rights. The equalization of opportunities for all persons with disabilities in the UAE is an essential contribution in the general and global effort to effectively develop and mobilize untapped human resources.

number" of persons with disabilities in the UAE was estimated to be 3300 people. This figure however only counted the number of disabled individuals who were receiving services for disability through one of the 47 centers regulated by the Ministry of Social Affairs. But in reality, if the UAE has the prevalence of disability equal to international averages, then the UAE has somewhere between 200,000 and 450,000 persons with disabilities<sup>5</sup> (Staff 2005; Salama 2006). According to figures published in the local press, this number is growing due, in part, to the prevalence of consanguinity and maintaining one of the world's highest rates of traffic accidents (Smadi and Sartawi 1998; El-Sadig et al. 2002; Reini 2009; Chung 2010; Shaheen 2010). A wide spectrum of causes beyond the two examples exist and the consequences of disability vary according to the specific socio-economic circumstances and different social services available at the local level. Due to the relative heterogeneity, tolerance, openness, and basic freedoms in the press, negative social factors like neglect, ignorance, superstition, and fear are not as dominant in Dubai or in the UAE as they are in neighboring countries. Dubai, in particular, serves as an ideal case study in understanding the public response to developing and implementing disability rights programs and policies. This is not because Dubai is an atypical case, but because it counters dominant thinking in the area of disability rights. Some of the most common misconceptions in the area of disability rights and policies are summarized in Table 1.1.

#### Challenging and Changing Norms

Toward the end of the 1960s, organizations of persons with disabilities in the US and a handful of other countries started to formulate a new concept of disability (Stiker 1999; Longmore and Umansky 2001; Switzer 2003; Shakespeare 2008). That new concept indicated the close connection between the limitations experienced by individuals with disabilities, the design and structure of their environments, and the attitude of the general population (Batavia and Schriner 2001; Davis 2006; Stewart 2006; Byrne and McLaughlin 2007). As such, the new concepts of disability were closely linked to urban planning, public affairs, and the development of social policies (Hahn 1985, 1986, 1988; Imrie 1996a, 2000; Gleeson 1999; Hall and Kearns 2001). The disability imperative thus

<sup>&</sup>lt;sup>5</sup>This can be referred to as "administrative prevalence." Since 90% of the population is expatriate, there is a lower population prevalence for expatriate adults.

Table 1.1 Common misconceptions in the area of disability rights and policy

| Misconception  | Reality   |
|--|---|
| A nation must be rich to make significant progress on disability rights.   | By cooperating with disabled people's organizations, many developing nations such as Serbia, Uganda, Jordan, Ecuador, and others have improved the participation rate of persons with disabilities despite having limited resources. Other higher-income countries like France may have worse records across different dimensions such as transportation.                               |
| A developed nation has more potential to improve the lives of persons with disabilities than a developing nation. Developing and implementing        | ,   |
| disability rights legislation is purely a domestic process that does not need international laws or international support.                           | implementation of international human rights standards. They also work together bilaterally or multilaterally at the regional level to promote and strengthen national or regional human rights institutions and mechanisms.  |
| Passing legislation will improve the<br>lives of persons with disabilities.  | Laws alone cannot prevent or end gross human rights violations against persons with disabilities. Governments need to promote positive change in policies or actions of government or relevant non-state actors in the area of human rights. This can happen with a strong monitoring agency enforcing strong legislation.  |
| Removing physical barriers in new or existing buildings is too costly and not an efficient use of public funds. Having a small population makes this |   |
| problem easier to tackle.<br>Charismatic leadership is necessary to  | affected populations. Good institutions and the ability to reach the target populations in their local communities are key. This can be a challenge even in countries with relatively small populations.  Oftentimes social change is possible because of a champion at the top. However, disability rights have progressed   |
|  | and been sustained over time through the engaged and prolonged advocacy of parents, self-advocates, allies and academic, research, foundation, and private sector actors working collaboratively with government agencies at both national and local levels.  |
| It is more effective to mandate changes than to engage in a prolonged discussion about changes.  | Too often, mandates and directives fail to adequately incorporate the voices, needs, and capabilities that local communities have to effectively address problems. The disability motto "Nothing about us without us" serves as a reminder that the costs of excluding the population most affected could have negative implications on the projected outcomes and costs of the reform. |

became a planning imperative. The debilitating aspects of disability under the new concepts being developed in the 1970s and 1980s could be partially eliminated with concerted effort and inclusive planning, design, and implementation (Imrie and Wells 1993; Imrie 1996a, 1999; Hall and Imrie 1999; Imrie and Hall 2001).

#### Laying a Foundation for Spatial Justice

The social, political, and historical conditions are substantively different in the UAE from those in the US, Japan, or Europe. Dubai does however provide globally relevant lessons that highlight the pitfalls and shortcomings of what oftentimes were well-intentioned policies and well-meaning efforts by sympathetic government officials. The global disability rights movement and the CRPD brought forth a massive reconceptualization of justice for persons with disabilities on a global level. Evaluating inclusion involves questioning normative approaches to justice. It also helps planners see the critical social and cultural factors, including those based on beliefs and customs, that enable and/or disable people in a given environment.

The UAE and other Gulf Cooperation Council (GCC) countries (Saudi Arabia, Kuwait, Qatar, Bahrain, and Oman) can avoid the mistakes of the US and, at the same time, develop their own approaches to disability theory, policy, and social development faster. They can choose to adapt their own cultural notion of disability or build from existing knowledge in charting their own path for realizing the most tangible rights and norms. The questions that remain are not if and why, but how and when. And this must occur with the knowledge that even in the most developed countries, discriminatory attitudes and social stigma are still prevalent.

## In Pursuit of the Inclusive City

Cities shape how we live and what we can do. They unlock human potential and innovation. Inclusive urban policies can bring millions of people from the margins into the center of city life, and social inclusion is a rally cry for protests from #BlackLivesMatter to court cases on immigration, to emergency preparedness and planning. Too often, however, inclusion is not at the center of urban development. Inequality and exclusion abound, often at rates greater than the national average, at the expense of sustainable development that delivers for all.

From a decade of research, I am convinced that three key types of drivers are needed to combat the rise of urban exclusion and direct cities onto

a better path. The first is political commitment to inclusive urban development at multiple levels, in the face of many forces and stakeholders incentivizing uneven and unequal development. The second is a range of mechanisms and institutions to facilitate inclusion, including participatory policymaking, accountability, universal access to services, spatial planning, and a strong recognition of the complementary roles of national and local governments in achieving inclusive growth (UN Habitat 2015). The third is the role of increasing awareness across society on what inclusion really means. This book explores how these drivers work in unison for persons with disabilities and particularly explores these drivers in one of the most dynamic cities in the world: Dubai.

#### Asking the Right Questions

Approaches toward disability laws and policies are constantly being tested under new assumptions and under distinct political, economic, social, and cultural regimes. More than 180 countries are now committed to promoting, protecting, and ensuring the basic rights and dignities of persons with disabilities. Many are enacting new laws and amending old ones to better align with the principles of the CRPD.

Federal Law No. 29 provides the opportunity to examine the trajectory of successes, and failures of a law. The case study presented in this book illuminates the challenges to and opportunities in effective implementation of international human rights norms at a local level and is structured to specifically answer the following question:

Question How successful has the local government of the Emirate of Dubai been in developing and implementing disability inclusive policies and programs?

The CRPD and Federal Law No. 29 pose challenges and opportunities in implementation. They also challenged governance, social cohesion, and the very notion of citizenship. As a result, this book explores and addresses related questions:

- 1. What frameworks exist to holistically assess the implementation of the law?
- 2. How can local institutions effectively implement the law?
- 3. To what degree have persons with disabilities been engaged in implementing this law?

#### Looking for a Paradigm Shift in Inclusive Urban Development

Federal Law No. 29 is one specific example of how disability rights are being implemented in a wealthy and dynamic autonomous city-state. Perhaps the specificity of an economy that was jump-started by fossil fuels, with a leadership structure based on hereditary rule, could make Dubai's experience implementing disability rights irrelevant to other parts of the world. But this is not the case. Dubai's efforts and outcomes with inclusion closely resemble efforts and outcomes in many other countries around the world. What is surprising is not that our findings in Dubai were not exceptional but rather consistent. It is precisely the attitudes, behaviors, and beliefs of ordinary people that determine the actions of a society not only in Dubai but across the world. People and institutions in Dubai are thus not unique in the way that they have historically responded to disability. Often respondents who were interviewed utilized a medical notion of disability, and by viewing the experience of disability so narrowly, they viewed disability as being an essentialized identity independent of the physical and social environment. In this book I contend that disability is not simply a medical abnormality, but rather a problem in design, or a failure between the agent and his/her environment.

City governments often lack the human resources and the technical skills needed to manage the complex multi-sectoral reforms that are required to eliminate the barriers that prevent persons with disabilities from participating equally in all aspects of public life. Dubai is no different. Although Dubai is a relatively wealthy city with finance, trade, and commerce accounting for a large percentage of its GDP, it faces serious challenges in the administration and coordination of the necessary reforms. These institutional constraints in administrative capacity limit the impact of the laws and, for a period between 2009 and 2014, seriously put in question the viability of Dubai's goal of becoming the world's most accessible city by 2020. I describe later in the book how this changed with the development of the Dubai Disability Strategy and the Universal Accessibility Code of 2015–2016.

Additional complications exist that are particularly unique to Dubai. These include the government's strategic reliance on "signaling" progress through press releases and articles disseminated in the news and through social media. The challenge here is that verbal support of the law is not matched by sustainable budgeting for its implementation. In addition, unique findings from attitudes surveys highlight that dominant social attitudes in Dubai are strongly congruent with international norms along some

dimensions—for example, affording education, health, and employment. At the same time they are somewhat incongruent with regard to affording independent living, as well as ensuring political and public participation. While these particularities are interesting, they also strengthen the argument that Dubai's progress cannot be measured along one dimension, such as simply passing a law or issuing a decree in support of the International Day of Persons with Disabilities. Instead, it must be by concerted, measured, integrated, and systemic initiatives. As such policy reforms or programmatic initiatives must be measurable with key performance indicators (KPIs) that are based on a set of unifying principles. Effective implementation of the KPIs can, over time, transform the entire system of governance.

Ineffective governance is currently depriving persons with disabilities of their basic rights and fundamental freedoms. This is not happening because of some malevolent conspiracy or intentional neglect but rather through micro-deprivations that limit the enjoyment of basic rights. These deprivations limit an individual's agency and, as Sen notes (2000), also limit the individual from "living the type of life that they have reason to value." This book explores the landscape of disability in Dubai and also points to the factors and conditions that would have to change for Dubai to rise to the top of the list of the world's most inclusive cities.

#### An Introduction to Dubai

My host was an energetic local doctor who in 2007 was leading Dubai's first cross-sectoral push to develop disability services. He and his colleague Dr. Sandra Willis, an American trained psychologist and disability advocate, were the first to provide me with the rare opportunity to assess the flourishing twenty-first-century urban anomaly. My host was tasked by the Executive Council of Dubai (TEC) with developing innovative approaches to disability rights and policies for the Emirate. During my first few days, I noticed that Dubai was—by any account—an extreme case. It was constructing citysized mega-projects. Dubai effectively capitalized on and in many ways led the economic transformations taking place across the region. I had asked my host, "What place do persons with disabilities have in all this?" To which he answered, "They have to benefit equally from all the development; they have to be included—that is what my team and I are trying to do."

What truly struck me were not only the articulate intentions of people like my young and generous host but also comments made by the Ruler, Sheikh Mohammed bin Rashid, who had just assumed his role. Dubai was presented as an incubator for tremendous experiments in city planning and regional development. Why not study one government's local efforts to address this timely emerging global issue, inclusion? I was motivated to study the unlikely combination of "inclusion" and "Dubai." Dr. Scott Rains, a friend and colleague, wrote a popular accessibility blog called *The Rolling Rain Report*. His blog entry on inclusive tourism in the UAE further piqued my interest, "Mohammed bin Rashid Al Maktoum of Dubai: A Fair Sheikh for Travelers with Disabilities." In the article, Rains (2005) quotes the Travel Impact Newswire as stating:

The Dubai government says it plans to ensure that the \$100 billion worth of tourism projects emerging in the emirate cater to the needs of disabled travelers and has called on all its stakeholders to join in the creation of a society that cares. Noting that, "we are all at some point in our lives, disabled people," the government says that building a vision for the future as a preferred tourism and business development centre has to include a "future for the disabled as well."

I sensed that the quotes were aimed at attracting disabled tourists and that they may have been falsely attributed to the "Fair Sheikh," Mohammed bin Rashid Al Maktoum. I immediately wondered if the \$100 billion worth of tourism projects would indeed cater to the needs of persons with disabilities or if this was simply a marketing scheme to reach an untapped market demographic. Furthermore, did the "society that cares" cater to the disabled residents as well, or only to its disabled visitors?

Conventional wisdom would say that building an inclusive rights-based city would require increasing the pace of desperately needed social policy reforms. Was this already underway? Were programs being formed to increase institutional capacity across sectors and scales? More importantly, would persons with disabilities participate by sharing their voice and vision for Dubai? In 2005, these were the questions that interested me. These were areas that I believed I could contribute to. Before me was an opportunity to make an impact.

While reading up on Dubai, I discovered that the "future for the disabled" was indeed underway. On September 12, 2006, *Gulf News* published an article entitled, "Law Removes Barriers for People with Special Needs." According to the article, the UAE's first law to protect the rights

<sup>&</sup>lt;sup>6</sup>Up until 2018 the dominant reference to people with disabilities in the UAE was people with special needs. This book attempts to keep historical references in the media to the

of People of Determination was approved by the President, H.H. Sheikh Khalifa Bin Zayed Al Nahyan. The UAE had enacted Federal Law No. 29 of 2006 into law (Salama 2006). According to Wafa Hamad Bin Sulaiman, Director of the Department for People with Special Needs at the Social Affairs Ministry, the law was comprehensive, "matching international standards, providing equal rights, opportunities, and choice for persons with disabilities" (Salama 2006). But what did all this mean? She indicated that Federal Law No. 29 of 2006 in Respect of the Rights of People of Determination<sup>7</sup> removes all barriers to equal opportunities for persons with disabilities and guarantees their right to a decent life and comprehensive care in education, training, health, and rehabilitation (Salama 2006). Those were undoubtedly ambitious goals and I was hungry to find out how they would be implemented, so I kept reading on. The law, she said, guarantees an unspecified job quota for people with disabilities in the public and private sectors, promises improved accessibility to public buildings and residences, and will result in the integration of People of Determination into public and private schools (Salama 2006). By this point, I realized that a unique opportunity existed for me to document and engage with this historic transformation. Dubai was indeed charting a new path, but would it be able to stay the course?

Between 2002 and 2006 I participated in the development and drafting of the CRPD. I wondered to what degree Federal Law No. 29 was based on the principles of the CRPD. I was curious to compare the content of this law to what is commonly referred to as the "Disability Treaty." Here was an opportunity to track the CRPD and its implementation in one of the most entrepreneurial and innovative cities in the world. I had thought about a variety of challenges that would need to be addressed at the local level and often wondered how they could be overcome. A few days later, I discovered that the Dubai Executive Council (a local policy and planning body of Dubai) held a high-profile press conference to announce the launch of an

terminology used at the time. After 2018 people with disabilities started being referred to as People of Determination.

<sup>7</sup>It is important to note that early in 2018, the UAE federal government changed every reference to special needs and people with disabilities to "People of Determination." This included the name of the law itself, which was amended from UAE Federal Law No. 29 of 2006 in Respect of the Rights of People with Special Needs to UAE Federal Law No. 29 of 2006 Concerning the Rights of People of Determination. For consistency throughout this book, I will use the updated name, not the name originally assigned to the law at the time it was enacted.

innovative, cutting-edge local agency branded as *Takamul: A barrier-free society*. The word "takamul" in Arabic means completion, indicating that no society is complete if it leaves out people with disabilities. Takamul was promoted as a "center for excellence on disability issues" and would usher in cross-sector reforms and inclusive and empowering programs for persons with disabilities. Dubai signaled to the world (and to me) that its massive urban, social, and economic transformation would be inclusive of persons with disabilities. During this frenzy, Her Excellency Maryam Al Roumi, the recently appointed Federal Minister for Social Affairs, reemphasized her government's commitment to developing, enacting, and implementing Federal Law No. 29 in Respect of People of Determination and promised to sign the UN Convention on the Rights of Persons with Disabilities. She made good on part of that promise two years later in New York when on August 2, 2008, she signed the Convention on behalf of her government.

By the end of 2008, I had documented progress in the field of disability rights in dozens of countries, including the UAE. I kept thinking about my past visits to the UAE and began wondering to what extent these laws impacted the daily lives of persons with disabilities. To what degree would such laws change institutional patterns and social behavior in the UAE? What had thus far been done and how much farther did the UAE have to go? What barriers could proponents of this law confront and how could they mitigate them? I kept returning to the UAE documenting their progress and mapping out a history and evolution of this extreme urban transformation.

#### Collecting Evidence

This book identifies the implementation and practice of disability rights in the Emirate of Dubai and presents a new evaluative framework for assessing the current state of these rights. The framework is then applied across nine dimensions of public policy: education, health, employment, political and public participation, accessibility, awareness raising, independent living, rehabilitation, and mobility.

After nearly 12 years studying the development of disability rights in Dubai, it has become clear that social change takes much longer than expected. By the time of this writing in 2019, we are beginning to see the early effects of Federal Law No. 29 transforming the country. Most of the data presented, however, focuses on the time period from 2007 to 2014. Future scholars will have the task of tracing the continued developments.

The undertaking was momentous. I collected participant observations, undertook media and content analysis, participated in focus groups, and undertook semi-structured interviews with a variety of stakeholders in Dubai. Official government reports, relevant newspaper articles, and academic journals were also used to assess the current state of disability programs and policies. Field notes from observations, focus groups, and expert interviews strengthened the protocol used for this study by providing insights that further guided my research into the successes and failures of local implementation. In the cases where arguments from absence are presented, I attempt to determine the gap between the content of the legislative measures with the demonstrable lived experience of persons with disabilities. A convenience sample survey distributed at Dubai Festival City Mall provided a local baseline in attitudes toward persons with disabilities. This extended process of conducting surveys, interviews, and focus groups over the period from 2007 to 2019 helped to gain a perspective of how disability is situated in the UAE through various dimensions and at varying scales. This is the first book to provide a detailed account of the social and policy gaps in implementing international disability rights laws at national and local levels in Dubai.

#### Developing a New Theoretical Framework for Assessing Inclusion

A holistic conceptual model called the Capability Model of Disability (CMD) is presented herein as a theoretical framework to address the gaps that impede the social inclusion of persons with disabilities. The CMD that I present builds off other scholars and follows the twin-track approach to inclusive development. It is based on concepts and norms outlined in the CRPD and provides assessment criteria linked to an implementational concept that specifically defines what successful outcomes for disability-related urban policies and programs should be. This framework is informed by the work of my mentor and friend, Nobel Prize–winning economist Amartya Sen, human rights scholar Sophie Mitra, and practitioner Kay Nagata, and other leading figures in philosophy, urban planning, international development, and disability studies.

The CMD offers three fundamental features to the field of urban planning. First, the model characterizes disability as a failure between an individual and their physical, social, or institutional environment along some dimension rather than as a deviation from the norm of human functioning that is independent of the individual's environment. Second, the model

offers a basic (not a comprehensive) development-based framework for inclusive policymaking along the following dimensions—four basic functionings (health, rehabilitation, education, and employment) and five basic freedoms (mobility, accessibility, being included in the community, political and public participation, and awareness raising). Social protection spans both dimensions, but due to limited access to data, it could not be incorporated into the initial fieldwork. Third, the model introduces the concept of salience. In this context, salience refers to the cultural coherence and proclivity for a society to adopt international human rights norms at a local level. These three features frame an in-depth case study that assesses disability rights in the Emirate of Dubai.

#### Developing an Evaluative Framework for Implementation

Implementing comprehensive disability rights legislation like Federal Law No. 29 is an iterative process and as such progress is often difficult to measure. Policies and programs that aim to improve the lives of persons with disabilities routinely fall short of developing the kind of holistic approach that addresses the roots of inequality. I conducted 90 interviews, collected 900 surveys, conducted three focus groups with a total of 80 participants, and participated in direct observations of schools, hospitals, public transportation infrastructure, places of employment, and other government programs in an effort to understand how disability was being addressed and what the real opportunities were for people like myself who may be living with a disability. It was also vital for me to collect and read through nearly a thousand government documents and newspaper articles, which provided primary source material that I could compare against other academic journal articles and books. The case study herein attempts to evaluate the implementation of Federal Law No. 29 and the CRPD at both federal and local levels by assessing:

- 1. Laws: Content of the legislative measure
- 2. Leadership: Executive and budgetary support
- 3. Institutional Capacity: Administrative and coordinating capacity of the implementing bureaucracies
- 4. Attitudes: Beliefs that form the social context and positioning of persons with disabilities
- 5. Participation: Representation of persons with disabilities and their allies

The study benchmarks progress along these key features for three main reasons. First, I developed grounded theory based on findings from interviews and focus groups. Second, interviews with subject matter experts on the CRPD verified these criteria as aligned and fundamental to effective policy. Third, contemporary literature in the fields of public policy, public administration, disability studies, and international human rights law also indicates the validity and necessity of a comprehensive approach capable of generating a more nuanced understanding of institutional capabilities.

The city-state of Dubai presents an opportunity to observe the emergence of a global city as well as government commitment to the needs and rights of a portion of society that has previously been regularly overlooked. The implementation of Federal Law No. 29 thus provides the lens to view how legislation can begin to transform both an environment and the social norms that allow the human potential of persons with disabilities to be realized.

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#### CHAPTER 2

# Understanding Disability in Theory, Justice, and Planning

**Abstract** The experience of people with disabilities living in different countries varies significantly from place to place. Why do some countries excel in ensuring rights for people with disabilities, while others struggle? The answers are linked not only to laws, governance, and accountability but also to salience and the participation of people with disabilities in the issues that most affect them. Successful outcomes for disability-related policies have been inspired by the influential work of authors including Peter Evans, Amartya Sen, Sophie Mitra, and Kay Nagata. This chapter first explores dominant paradigms in social justice and development in planning theory and examines the conceptual pitfalls and failures to address disability-related justice. It then expands on theories proposed by Evans, Sen, Mitra, and Nagata to elaborate on the urban-focused Capability Model of Disability (CMD). The integrative CMD framework effectively addresses a range of nuanced challenges found when cities work to implement inclusive urban policies and programs. The concept of salience is also explored as a novel, more inclusive, and culturally relative developmentbased framework.

Keywords Salience • Disability justice • Planning theory

- Development theory Social justice Disability studies
- Capability Model Social model

### Introduction

From a young age I was surrounded by questions of development and underdevelopment, of capabilities and disabilities. Growing up and visiting family in places such as Caracas, Belgrade, Geneva, and Kuwait, it became clear to me that my experience of living with a disability was radically different as I moved with or visited family from place to place. In these new lands I recall wondering, "Are there other persons with disabilities here like me? What are their experiences, hopes, and dreams? What do they do and what can they become?" By the time I started my undergraduate degree at the University of California Berkeley, I had a powerful realization; my environment shaped what I could do to a far greater extent than my particular impairment. As an adult, I began asking questions about laws, governance, and accountability. Why did some countries excel at providing quality services, while others struggled?

These are fundamentally questions of spatial and social justice and development, and this chapter critically explores these core concepts as well as theories surrounding equity, access, and urban development. I do so by first exploring the ways that the dominant approaches to social justice and development are understood in planning theory and how unjust approaches to planning have negatively impacted the lived experience of persons with disabilities. Second, I explore and expand on the participatory institutions of Peter Evans, the Capability Approach (CA) of Amartya Sen, and the Human Rights Model of Kozue Kay Nagata to illuminate how their work contributes to a disability-inclusive development framework. This framework is then explored in more detail in Chap. 3. With this background, we begin to see the most common pitfalls in conceptualizing, formulating, and effectively implementing disability-responsive development policies. Again, these are policies that are aimed not just for some but for everyone.

# Spatial and Social Justice Theories

Progressive ideas of justice have emerged over the past 40 years to challenge new forms of exclusion, to provide metrics for assessing fairness, and to empower marginalized groups in asymmetric power relationships.

<sup>&</sup>lt;sup>1</sup>Over the past few decades, persons with disabilities benefited from medical advances, political liberalization, and information and communication technologies. Calls for justice have emerged in virtually every country, and disability rights advocates and disability studies scholars are sharing their voices in global debates.

Research by Crocker and Robeyns (2010), Fleurbaey and Maniquet (1999), Harvey (1978), Lefebvre (1991, 1974), Mitra (2018a, b), and Vizard (2006), among others, inform my understanding of human development, economics, geography, and applied disability studies. The term "spatial justice" is used to link together social justice and the organization and utilization of physical space, most notably in the works of geographers David Harvey and Edward W. Soja. The organization of space is a crucial dimension of human society, reflecting social facts and influencing social relations (Henri Lefebvre 1968, 1972). Theorists like Rawls, Young, Sen, Soja, Harvey, Dikec, and others challenge dominant notions of justice, expanding our understanding into new realms. Their findings are of vital importance to persons with disabilities, an omnipresent but invisible sub-segment of every society or social group. However, few researchers have extended theories of justice to explore the conditions and experiences of persons with disabilities.<sup>2</sup> The following section highlights these theoretical gaps, noting that in the struggle to assert and redefine identity and social control, we must also assess the justice of contemporary systems toward developing an inclusive approach to effective disability rights policies.

The capacity and capability of the so-called weak to exercise their rights, agency, and personhood still stands as a key litmus test in the definition of and struggle for justice. New structures of governance promoted by contemporary development theorists also include the role of justice in balancing communal decision-making processes and debates. According to Sen (1999) and Evans (2002), such deliberations can calibrate new socially just values and usher in new approaches to public policy. In exploring the merits of what Robeyns (2008) calls a "capability approach to justice," contemporary development and planning scholars may find innovative approaches to tackling long-lasting problems. The Capability Approach to justice explores the distribution of justice as a fundamental, participatory, and deliberative process wherein social values are developed and implemented by the people most affected. It is inclusive in both process and outcome and as such offers a path toward a theory of social justice that includes persons with disabilities.

<sup>&</sup>lt;sup>2</sup>Notable exceptions are Young, I. M. (1990). Justice and the politics of difference. Princeton, NJ, Princeton University Press. Also Martha Nussbaum, M. C. (2006). Frontiers of justice: disability, nationality, species membership. Cambridge, Mass., The Belknap Press of Harvard University Press. Other disability studies scholars such as Shakespeare, T. (1998). The disability reader: social science perspectives. London; New York, Cassell, and Davis, L. J. (2006). The disability studies reader. New York, Routledge, have addressed the issue of justice from a disability perspective and have applied philosophy to some degree.

#### Contemporary Social and Moral Values

In Social Justice and the City, David Harvey's (1973) questions of social justice are initially approached as if social and/or moral philosophy are distinct fields from which absolute principles can be derived.<sup>3</sup> These ethical principles, once established, can then be used to evaluate events and activities in our contemporary world. Contemporary cities exist in a nexus where economic, technological, and social transformations simultaneously strengthen and erode equality and liberty. Cities are increasingly polarized; larger amounts of wealth, power, and privilege are increasingly being concentrated into the hands of a few, and the gap between the rich and poor keeps widening. Within this contemporary context, it becomes vital to reassess our priorities. What are the dominant contemporary social and moral values? What is the context from which planners and policymakers can make decisions effectively? How can such theories of social justice find practical approaches in policy design, planning, and implementation?

Theories of justice evolve and contemporary approaches incorporate the reality of the theorist's time and place. Over the course of the past two decades, social justice theorists have proposed responses to the economic processes and transformations that were stimulated by competing and complementary forces of neoliberalism and globalization. For many theorists, these two forces are responsible for altering social relations and, in many instances, further marginalizing vulnerable groups. In virtually all parts of the world, persons with disabilities have a long history of neglect and oppression. They have been targets of some of history's most gross human rights violations. A new global movement culminating in the development of a comprehensive international human rights treaty articulates a set of principles that would protect, promote, and ensure the basic dignities and freedoms of persons with disabilities. In what contemporary development and planning theorists have called a post-industrial globalized era, a new set of economic metrics and values trump tribal, communitarian, and/or other traditional social norms. Persons with disabilities are but one minority group that has been impacted by contemporary economic, social, and political transformations.

<sup>&</sup>lt;sup>3</sup> Social philosophy is generally used to refer to philosophy written about societal events and tends to be the writings of classics in literature such as Emerson, Thoreau, Jung, and Schopenhauer. In contrast, moral philosophy is the study of ethics/morality and is thus a separate field from social philosophy. Harvey lumps the two together to more effectively elaborate this social-spatial theory of justice.

Social identities, inequalities, and exclusions are themes that have defined the early part of the twenty-first century. Progressive theorists of justice have sought to illuminate how the phenomenon of exclusion on the basis of gender, race, ethnicity, sexual orientation, or disability leads to injustice. These same theorists, however, have not clearly defined how the phenomenon of inclusion functions or can be sustained.

## Contemporary Approaches to Social Justice

There exists no generally accepted concept or definition of justice, and descriptions of justice are often contradictory. The subject of justice is one of conflict and contest. Miller (1999) states that when talking about justice, we are talking about "how the good and bad things in life should be distributed among the members of a human society." Capability theorists Pierik and Robeyns (2007) suggest Miller's description of social justice is a viable definition on account of its simplicity and that such a simple definition could attract broader support. For example, a policy is described as unjust, Miller argues, when we claim that a person "enjoys fewer advantages than that person or group of persons ought to enjoy (or bears more of the burdens than they ought to bear), given how other members of the society in question are faring" (Miller 1999). Robeyns (2008) argues that theorists of justice primarily focus on the justice of social arrangements and institutions and that justice is often regarded as a matter of ethics rather than of political philosophy. However, Iris Young and other political philosophers disagree (Robeyns 2008), and instead suggest that the very definition of oppression centers on injustices that a group of people suffer from as a means to further empower their oppressor(s).

It is important to note that two dominant traditions exist in social justice literature. The terms "social justice" and "distributive justice" are generally used interchangeably. Harvey and others often use the term "justice" to cover both, but as Robeyns (2008) notes, this can be misleading, since there are debates related to justice that fall outside the scope of social justice. Retributive justice, spatial justice, and other work on procedural justice developed by Iris Marion Young (1990) fall outside this scope and hold promise for new and innovative (non-Marxist) notions of justice to address the challenges of inequality and social oppression.

## Rawls' Versus Young's Theory of Justice

Rawls' theory of justice stems from the egalitarian and social contract tradition. It investigates the basic structure of a just society. Rawls (1971) defines justice as "providing in the first instance a standard whereby the distributive aspects of the basic structure of society are to be assessed." According to Rawls (1971, 1999), each person is to have an equal right to the most extensive system of equal basic liberties compatible with a similar system of liberty for all. Robeyns (2008) suggests that for Rawls, the basic structure of society is a combination of political and social institutions, a cooperative system that allows assignment of basic rights and duties that in turn regulate advantages from this same system. Within this framework, an examination of the basic societal structure allows us to accommodate issues of equality and freedom. Social structures, including laws, may constrain our choices and categorize our functions within a limited framework of mutual advantage.

Rawls believes that social and economic inequalities are to be arranged in a way that benefits the least advantaged members of society. Termed the "difference principle," this arrangement is supposed to apply to a set of basic liberties and social primary goods. Rawls (1999) outlines a set of social primary goods that are necessary to enjoy these liberties, which include (1) basic rights and liberties, (2) freedom of movement and choice of occupation, (3) powers and prerogatives of offices and positions of authority and responsibility, (4) income and wealth, and (5) the social bases of self-respect (ibid. 386). Ultimately, the distribution of these basic liberties and social primary goods has been unfair to persons with disabilities. Rawls relies on social primary goods as the main metric for interpersonal comparisons for the purpose of justice.

However, theorists like Young (1990) challenge the reliance on social primary goods as a metric. Young argues that structural oppression is the fundamental source of injustice, and she is one of the few theorists who mention people with disabilities as a class who frequently endure both injustice and oppression. She suggests that we can learn much about social justice by exploring structural inequality, normalization, and stigmatization. She argues that the historical and contemporary experience of disability is paradigmatic of structural injustice. According to Young, agents, whether individual or collective, have the right to sole authority over their actions only if the actions and their consequences (1) do not harm others, (2) do not inhibit the ability of individuals to develop and exercise their capacities within the limits of mutual respect and cooperation, and (3) do not determine the conditions under which other agents are compelled to act. These three points help us assess the physical and social burdens that limit the choice, voice, and agency of persons with disabilities.

Young expands the meaning of social justice from the morally proper distribution of benefits and burdens in society to the *means* of living, being, and doing. This helps to couch the forms of social oppression into relative forms of social organizations or social processes. Justice becomes procedural as well as redistributive. Young suggests that institutional oppression, often the result of procedures and practices that perpetuate inequality, can bring about injustice. An examination of the *means* and *outcomes* of oppressive or unjust practices is thus necessary to create a framework for internal and external analysis, as such procedures create processes that perpetuate norms and marginalize difference. Understanding the nature of these institutional processes is key to addressing disability and the many forms of social exclusion.

## Sen, Rawls, and Young on Justice

One problem with contemporary theories of justice is that they are often based on "strong assumptions" that may introduce bias or exclude certain groups of people from the theory. For example, it has been argued that Rawls' theory is unable to account for our duties of justice toward the severely disabled (Sen 1980; Kittay 1999; Nussbaum 2006; Kittay and Carlson 2010). Critics have challenged the notion of constituting personhood and the inability to extend justice and rights to those who cannot care for themselves or whose cognitive capacities limit their ability to make conscious decisions and be in active control of their life. Amartya Sen, in his 1979 Tanner Lecture, formulated the first critique against Rawls in this area. Sen claimed that neither *justice as fairness* nor the *difference principle* would give any redistribution to a disabled person on the grounds of one's disability.

Rawls turned to the social contract tradition, where justice is understood as the outcome of *mutual advantage*—that rules of justice are more beneficial for everyone than if each individual were to pursue her own advantage on her own. However, this presents several problematic areas for people living with disabilities and highlights the importance of the interaction between the individual and their environment. A functional limitation for Rawls is a fundamental property of the individual, a failure

that was not addressed by his theory of justice. Egalitarian theories of justice are similarly unable to account for socio-cultural oppression or discrimination. They fail to offer possible improvements or actions that take us to a less oppressive and more just society (Sen 2006; Pierik and Robeyns 2007).

In direct contrast, Young positions functional limitations as a procedural failure of justice, one that inadequately incorporates bodily differences. Young then offers a framework from which to operationalize resistance against five faces of oppression: exploitation, marginalization, powerlessness, cultural imperialism, and violence (Young 1990). These five faces of oppression help set the framework for political actions and policy-based research.

# Capabilities, Human Rights, and the Lived Experience of Disability

Applying contemporary theories of justice to dynamic and interdependent urban systems poses a myriad of complications. Urban infrastructure and mobility concerns are brought to the forefront as the privatization of public space and the creation of closed networks reorganize value creation and benefit distribution to those whose connections matter. Reforming or regulating the volatility of competitive free markets does not solve the inherent dimension of perpetuating inequality that is built into the market system.<sup>4</sup> Such inequalities and forms of exclusion and oppression can be conceived under the framework of Amartya Sen as "capability deprivation." What types of approaches could mitigate capability deprivation? What types of arrangements could increase the capacity of local communities and governments to identify and redress capability deprivations? How are capability deprivations linked to human rights and how are these linked to the lived experience of persons with disabilities? In relationship to Sen's groundbreaking work, development scholars such as Evans, Mitra, and Nagata offer some answers.

<sup>4</sup> Contemporary interconnected networks of social, political, and economic actors perpetuate the paradoxical and simultaneous inclusion and exclusion of powerless, weak, or marginalized people. The dominance of information and communication technologies can perpetuate a surgical accumulation of power and wealth. Technological dimensions of social exclusion further social injustice and inequality at an ever-increasing rate. Trade-offs between different values, power imbalances among different social groups, and interests of individuals and groups may conflict.

# The Capability Approach to Justice and Freedom

Sen's (2000) basic proposition is that we should evaluate development in terms of "the expansion of the capabilities of people to lead the kind of lives they value—and have reason to value." The expansion of people's capabilities depends upon both the elimination of oppression and the distribution of some of the basic tenets of development: the provision of basic education, healthcare, and social safety nets. The Capability Approach as described by Sen offers no concrete steps or list of capabilities that could guide policymakers to assess if progress can be made. It was meant to help inform a new theory of justice that can go beyond debates of resource distribution and approach functional capability (Fleurbaey 2002, 2006). Fleurbaey (2006) suggests expanding and redefining capabilities into refined functioning, which could allow for more measurable indicators to be developed in order to gauge effective social inclusion, active participation, and sustainable change.

Functioning is considered to be the actual achievement of the individual (being and doing). Sen's Capability Approach reveals the limitations of an overemphasis on income and wealth when people's capabilities (i.e., opportunities) and functionings (i.e., activities) are unattended. Sen's Capability Approach places an emphasis on sets and bundles of functionings from which a person is able to freely choose between various alternatives at their disposal. Mitra (2006) expands Sen's Capability Approach to touch on the various ways in which disability can be defined conceptually. The CA highlights two nuances related to issues in disability: deprivation of capabilities and deprivation of functionings. These two concepts run parallel to our basic freedoms and basic functionings that, respectively, seek to address these types of deprivations.

Mitra (2006) additionally underscores the importance of the evaluative dimensions of disability. She notes Sen's reluctance to propose a list of capabilities and functionings to assess poverty and disability-related issues.

<sup>&</sup>lt;sup>5</sup>According to capability scholars, however, Sen never contemplated writing a capability theory of justice. Instead, he simply intended to inform future justice theorists of the link between human capacity (i.e., capabilities) and human functioning, and how the deprivations of human functioning can lead to "unfreedoms." For Sen, "unfreedoms" are states of capability deprivation where basic functionings and doings are denied. *Unfreedoms* for Sen are social deprivations that limit human functioning. Sen takes a relative, not absolute, approach to human functioning. This is important to understanding new models of disability that may inform new theories of justice.

This open-ended question of assessment is thus left to stakeholders to define. So, although people with impairments and disability ought to be involved in selection of criterion of assessment in a participatory fashion, their role remains unclear. She also questions the role of policy in addressing issues in capabilities or functionings, though concludes that needs and points of focus are value-based and vary according to those who are able to define these needs and focuses. These questions and concerns are addressed by the Capability Model of Disability (CMD) (see Chap. 3).

Mitra (2018a) elaborates on the CA as a framework for evaluation of disability and civil rights. She argues for a CA-based conceptualization and operationalization for data collection to advance analysis and insight on issues facing people with disabilities. Her two-layered disability data collection system involves data on deprivations with respect to differential outcomes and opportunities relative to able-bodied people, as well as a stepwise measure of disability (motivated by the CA). The first data layer is used to create comparative assessments of the lives of people with disabilities as a baseline for policy. The second consists of data collection specific to disability (such as emphasis on potential disability and deprivations). However, Mitra does not expand on these indicators of deprivation. Instead they are to be defined and informed by the lived experiences of people with disabilities to identify issues and increase their participatory capacities. This allows for more effective disability-related policy.

Trani et al. (2011) analyze how the CA informs gaps in disability-related research, especially with respect to data collection, policy implementation, and assessment. The authors propose a new measure of both functionings and capabilities by analyzing the gap between the two. They consider the CA's insight on conversion factors such as the ability to internally and externally convert endowments, income, and other social resources into tangible functionings and personal aspirations. Given these new insights elucidated by the CA, data collection and analysis of policy must accommodate nuances with respect to disability. The authors claim that "data collection has to be based on the CA framework from the outset and needs to include values and requirements expressed by community members." In addition, the operationalization of the CA "requires other information, along with identification of resources and constraints, the measurement of the level of availability of commodities, as well as of achieved functionings: measurement of valued capabilities, agency and choice of individuals and communities." Notably, the authors hint at the improvement of measurement of disability and its relevance for policy, but whose stakeholders'

agency (i.e., people with disabilities) has yet to be acknowledged by those in power. This phenomenon is called negation, in which people with disabilities have little to no choice with respect to outcomes that they choose to desire in social life. Thus, these sources provide excellent insight into how a disability-responsive development framework would look. The analysis of these scholars is thus limited by a lack of discussion on the barriers to political participation and effective implementation.

Laws codify human rights principles and thus expand the processes by which capabilities are distributed. This legal aspect is important because human rights inform processes of ethical recognition that shape public policy. These processes further impact expectations and choices toward public action (Vizard et al. 2011; 10). Vizard et al. (2011) draw on Sengupta's Right to Development model to address application to the expansion of substantive freedoms via internationally recognized human rights standards, but nonetheless fail to address the specific method for evaluation. The lack of specificity on how these standards will be reached and who will pay for them is endemic in the global discussion on human rights.

Díaz Ruiz et al. (2015) propose an integration of the CA to assessment of public policies and individual choice. Their study investigates a specific Chilean disability-related policy and its failure to address important constructs identified by Sen that concern people with disabilities. They find that the failure lies in a misalignment with domestic and international laws as well as a lack of connection with concepts such as agency and freedom. The authors also provide an excellent basis for the definitions contained within the CA and its importance for disability policy. The authors maintain that the Capability Approach

takes into account the choices available to an individual. It emphasizes not only what a person is or does, their "functionings," but also the range of capabilities which they can choose from, that is the "set of capabilities" that a person can freely act upon. This perspective captures a person's relationship with their surrounding environment, as well as the available societal opportunities. Due to its comprehensiveness, the CA is believed to complement and exceed other disability models (Trani et al. 2009), which made it crucial to this analysis. (5)

In addition, they draw on Sen's conceptual apparatus of "advantage," which consists of the following: achievement of well-being, achievement of agency (being and doing), freedom of well-being (achievement), and agency of freedom (real opportunities). The authors conclude that in

order to address issues and barriers to the agency of people with disabilities, "the policy requires redesign, scheduled implementation, and furthermore, the political will to position this issue on the policy agenda and advance it in the realm of social protection" (17). One of the telling questions that remain is—how are these rights to be evaluated?

In the following sections I address these shortcomings and develop a nuanced view toward the division of individual, social, and collective responsibility. These approaches require new theoretical and governance frameworks. The right reforms foster new debates and establish procedures that ensure no one is left behind.

## Development Through Participation

Public participation unlocks new capabilities in individuals and in groups, and helps otherwise marginalized individuals address their respective deprivations by influencing the processes of governance and resource distribution. As such, corrective measures that increase social opportunities of education and healthcare can complement individual opportunities of economic and political participation (Sen 1999). Sen states, "If the point of departure of the approach lies in the identification of freedom as the main object of development, the reach of the policy analysis lies in establishing the empirical linkages that make the viewpoint of freedom coherent and cogent as the guiding perspective of the process of development" (Sen 2000, xii). As such, a woman with disability's social position is not inherently influenced by her impairment, but rather by her economic opportunities, political liberties, social powers, and the enabling conditions of good health, basic education, and the encouragement and cultivation of her initiatives.

Evans argues that local knowledge and local deliberations are the core of development and the engine of institutional change. He stresses that the wholesale importing of public policy produces dependency by diminishing the capacity of that society to exercise social choice and "build better institutions" (Evans 2004, 36).6 Evans posits that a state's cycle of dependency can be broken by investing in the participatory capabilities of

<sup>&</sup>lt;sup>6</sup> Evans also states that international organizations, local policymakers, and private consultants combine to "enforce the presumption that the most advanced countries have already discovered the one best institutional blueprint for development and that its applicability transcends national cultures and circumstances. They do this with increasing aggressiveness across a range of institutions" (2004, 32).

marginalized groups. Thus, instead of fully relying on foreign experts to solve domestic problems, a state could invest in developing culturally responsive participatory institutions. Such institutions would elicit and aggregate local knowledge and, in doing so, build the basic capabilities necessary to innovate and realize sustainable solutions (Rodrik 2000; Evans 2004, 36; Pineda 2010).

## Deliberative Development

In this book, urban development is understood as being inclusive if it includes a diverse set of stakeholders in an open process of decision-making. Open decision-making is a fundamental aspect of access, equity, and inclusion. Public sector institutions in Dubai and in most of the world develop plans for public deliberation and exchange of ideas. Amartya Sen sees participation in public deliberations as offering the *only* way to adequately define desirable developmental goals. As he explains, "Processes of participation have to be understood as constitutive parts of the *ends* of development in themselves...An open and public search for agreement or a consensus can be extremely messy and many technocrats are sufficiently disgusted by its messiness to pine for some wonderful formula that would simply give us ready-made weights that are *just right*" (1999, 291). However, Sen remains firm in his belief that technocratic shortcuts must be rejected because consensus draws from valuation and judgment, which cannot be fully automated by technology.

In his paper *Development as Institutional Change: The Pitfalls of Monocropping and the Potentials of Deliberation*, Evans (2004) builds upon Sen's and Rodrik's work, moving the conversation toward exploring the ways participatory political institutions can be implemented in practice and what the impact of a more deliberative process of implementation can be. This approach raises a host of interesting theoretical issues. Evans notes that the developmental consequences of participatory institutions are not well understood, especially at bigger levels, beyond that of a specific community or a project. In fact, he suggests that the most interesting contemporary development efforts are those that attempt to build public discussion and exchange directly into processes of governance. Evans suggests that embedding participation into institutional structures could be called "deliberative democracy," which he defines as a process of "joint planning, problem-solving and strategizing" involving ordinary citizens, in which "strategies and solutions will be articulated and forged through *delibera*-

tion and planning with other participants." This way, "participants will often form or transform their preferences in the light of that undertaking," allowing solutions that would have been obscured or undesirable given initial preferences (Fung 2003, 2004; Evans 2004, 37). If a robust deliberative process could be effective in large enough political units, it would impact developmental trajectories—say, the provincial, municipal, or regional levels—it could be called "deliberative development" (Evans 2004, p. 37). Evans suggests that institutional analysis must consider the manner in which marginalized groups can make claims and contributions to "deliberative development" but does not elaborate on how this should occur.

Sen's idea of deliberative democracy and Evan's ideas of deliberative development provide useful conceptual tools for revisiting innovations in urban governance and challenging existing theoretical arguments about social exclusion, arguments that have influenced how democratic decisionmaking affects developmental strategies and performance.<sup>7</sup> Crocker (2008) sees Sen's ideas about deliberative democracy as a starting point for designing participatory institutions and ensuring that democratic processes are central to development challenges. Could there be a downside to deliberative practices? Could such processes fail to satisfy people's needs, make them less productive, and limit them in any way? According to Evans, no. Responsive participatory institutions improve citizens' ability to make their own choices and foster new growth (Evans 2004, 31). However, he fails to address the real limits of local or regional institutions. His analysis ignores the costs of participation and the limits of institutional capacity to administer and coordinate these deliberative processes. He also fails to account for the ideas, people, and positions that were discarded or deemed unimportant by the broader group.

# The Challenge and Opportunity of Inclusive Development

Development practitioners view the process of figuring out how to take advantage of participatory practices as a unique challenge and opportunity. The consensus is that participation by the intended beneficiaries

<sup>&</sup>lt;sup>7</sup> In Development as institutional change: The pitfalls of monocropping and the potentials of deliberation, Evans (2004) argues that democratic elections and civil rights remain the foundational prerequisites for the flourishing of "thicker" deliberative processes. As "thin" democracy becomes more nearly universal, it becomes more plausible to think about trying to institutionalize something closer to full-blown social choice exercises.

improves project performance (Young 2002; Fung 2004; Poortman 2005; Edwards 2008). However, such ideal conditions are not always reached, as embedded power dynamics need to be overcome and the resulting participation must prove valuable and sustainable and show a contribution to the state's growth. Sen (1999, 33) counters by stating that more participatory regimes produce greater equality without dampening economic growth, leading to greater stability and resilience.

As has been outlined, integrating channels for open discussion and public interchange is a central part of open and democratic decision-making. However, this idea falls short in practice. Deliberative institutions are difficult to administer and may impact the costs of implementing policy. Whether the costs or efficiency rises or falls as a result of embedding public deliberation in technocratic regimes, the bureaucratic process nonetheless is altered. Evans (2004) argues that embedding the deliberative process into existing institutions impacts the supply of public resources. For example, without deliberative processes informing public managers, public investment decisions would be skewed toward the wealthy and connected. Public managers would have a limited understanding of citizens' true preferences. Deliberative processes would be more efficient in uncovering and fulfilling felt needs.

Evans lays out a "local-choice hypothesis" and introduces a broad array of theoretical arguments and related evidence on the developmental effects of distribution, participation, and investment in citizens' capabilities. He suggests that the deliberative development hypothesis does indeed have potential. As I will show later, this becomes even more the case for people with disabilities who are often caught in a web of social stigma, physical access, and institutional neglect by failing to provide alternative text or captioning on website content or sign language at a conference.

<sup>8</sup> First, deliberative institutions must be "socially self-sustaining" in the sense that ordinary citizens are willing to invest their own time and energy in the decision-making opportunities that such institutions offer and are willing to provide electoral support for the parties and political leaders who advocate them. Second, deliberative institutions must, under some set of empirically plausible conditions, be able to overcome the "political economy problem": the opposition of power holders who have vested interests in existing decision-making structures. Finally, there is the "growth problem; deliberative processes must not be so economically inefficient or so biased against investment that they reduce real income growth to an extent that outweighs their intrinsic benefits. If the answers to either the social sustainability question or the political economic problem are negative, then deliberative strategies are infeasible. If the answer to the growth problem is negative, then deliberative institutions are unlikely to be attractive, even to those who value their intrinsic properties" (ibid.).

# Models of Disability from the Perspective of Justice

For persons with disabilities, justice is always contextualized within a framework of laws, landscapes, and social beliefs. Although these factors play out differently in different parts of the world, a steady stream of theorists working at the intersection of disability studies, critical theory, sociology, geography, economics, and philosophy have made major contributions to our understanding of disability as a social phenomenon, not simply a medical diagnosis. A few dominant models include the social model, the medical model, the Nagi model, the International Classification of Functioning, and the human rights model. All these models have been developed to answer, define, and shape our conception of disability. However, this variety of available models can also be problematic. Trani et al. (2011) note that "it is well acknowledged in the literature that three relevant models the individual or medical, the social model, and the biopsychosocial model based on the ICF-lead to different and sometimes contradictory policy implications" (Trani et al. 2011). Thus, the challenge now is how to best reconcile each and understand the process and outcomes inherent with each model. As will be further discussed, each model carries assumptions, costs, and benefits for individuals with disabilities and the broader environment within which they live.

# Understanding the Dominant Models of Disability

In simple and general terms, the social model sees disability as a social construct—disability is not the attribute of the individual; instead it is created by the social environment and requires social change. It is additionally the only model that fully addresses the economic dimension of disability (Mitra 2006).

The medical model (or biomedical model) considers disability as a problem of the individual that is directly caused by a disease, an injury, or other health conditions, and requires medical care in the form of treatment and rehabilitation (Mitra 2018a). The medical model attributes the problem to the individual, who has a condition that is unwanted and that places him or her in the "sick" role with the aim to "cure" or "treat" (Mitra 2006). Such a model is based on "divergence from a capacity of conducting current activities considered as a norm" and thus views disability as an inherently limiting characteristic of the individual (Trani et al. 2011).

The Nagi model identifies functional limitations as the restriction that impairments impose on the individual's ability to perform the tasks of his or her roles and normal daily activities. These roles include family roles (looking after a child), work roles (having a job), community roles, and other interactional roles, as well as self-care activities. Nagi (1991) defines functional limitation as "an inability or limitation in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment."

The International Classification of Functioning, commonly known as the ICF framework, categorizes disability as a health condition where a particular restriction in activity or participation is the result of a particular body function—within a given environment and context.9 Under this model, an activity is the execution of a task or action and participation is the "lived experience" of people in the actual context in which they live (Mitra 2006). The ICF framework is controversial as an evaluation of capacity, as it is restricted to a "standard environment," as opposed to considering what an individual is capable of in a range of environments, a range that may facilitate or restrict an activity or functioning. As such, the ICF fails to acknowledge that ability is relative to the environment in which one functions (Wasserman et al. 2011). The unique opportunity with respect to finding policy solutions to improving the social position of disability is not in discovering a standard for normal functioning, or a standard for the way an environment is structured, but rather in understanding the multiple ways that society defines the standards by which functions or freedoms will be realized.

<sup>9</sup>Cerniauskaite et al. (2011) conducted a systematic literature review on ICF and explored its use and implementation from 2001 to 2009 and discovered that the concept of participation gained more attention when the World Health Organization introduced its description in the ICF in 2001. The ICF became an important conceptual framework in rehabilitation to describe health-related states; its core components—body functions and structures, activities and participation, environmental factors, and personal factors—provided a global and collective language for health and disability. Participation became a source for a better understanding of the possible impact of impairments and disabilities on the life of an individual person. The ICF defines participation as "involvement in a life situation" or as "the lived experience' of people in the actual context in which they live," while the activity is defined as "the execution of a task or action by an individual."

### Rights-Based Models of Disability

Nagata<sup>10</sup> developed a unique set of studies based on what she calls the "rights model" of disability. She provides a framework from which to integrate rights-based approaches to disability-inclusive development. Her work is sensitive to the social and political realities of disability and incorporates development debates. According to Nagata (2008), a rights model of disability should integrate three key perspectives and create a space to operationalize local solutions. Her model recognizes:

- 1. the mutual and dynamic interaction between a disabled individual and their social environments (e.g., social barriers, attitudes, and accessibility);
- 2. the diversity existing among different types and categories of disabled persons and the difference in their needs and priorities; and
- 3. the relevance of the human-rights-based approach to individual disability experiences in diverse local cultures and customs.

What is innovative about Nagata's rights model is the central role that social barriers and attitudes play, as well as the cultural context of diverse individual disability experiences. Nagata's model places critical importance on initially establishing a baseline of the current level of social attitudes. She notes that appropriate national policy and legislation on disability and development must first measure and assess prevalent social attitudes, including discrimination, prejudice, misconception, acceptance, and recognition, in a given society. These baselines "must be established as a prerequisite prior to assessing the effectiveness of any kind of rights-based interventions (for changing society and removing social barriers) in the future, with the ultimate goal of institutionalizing the equal opportunity concept and inclusion among people in those countries" (Nagata 2008: emphasis supplied).

<sup>10</sup>Kozue Kay Nagata has been involved in promoting disability-inclusive development throughout her 24-year career with the United Nations. Prior to her current position at the United Nations headquarters, she served as the disability focal point at the International Labor Office (ILO) Geneva, the UN Economic and Social Commission for Western Asia (ESCWA) (Iraq, Jordan, and Lebanon), United Nations Transitional Administration in East Timor (UNTAET) East Timor, and the UN Economic and Social Commission for Asia Pacific (ESCAP) (Bangkok). Nagata has been extensively involved in the International Convention, the Asian-Pacific Decade of Disabled Persons (2003-2010), and its policy, "Biwako Millennium Framework," as well as in the promotion of the twin-track strategy of disability mainstreaming into various sectors of development (cooperation).

Nagata's research lays out a set of factors that influence personal empowerment for disabled individuals. She also recognizes that universal factors can influence personal outcomes. Her rights-based model lays out the process in which personal versus environmental or individual versus social dynamics of disability and discrimination can be understood, and incorporates human rights perspectives into the local process of development. Nagata's findings show that in Jordan and Lebanon, persons with disabilities are highly stigmatized and marginalized. These individuals want to be part of the development process, and in fact exercising their rights through public and political participation has indeed ushered in changes across society. Nagata revealed that rural areas showed significantly lower results (negative attitudes) relative to respondents who resided in urbanized areas (who in turn showed relatively positive attitudes). Such results also hint at the effect that development can have in increasing the general public attitude toward persons with disabilities.<sup>11</sup>

Nagata's inquiry into attitudes toward persons with disabilities was one of the few on the topic to be conducted in the Middle East and brought to light a set of dynamics that inform my own inquiry. In many ways, Nagata's (2008) study allowed me to reflect on findings that I had confronted in my own research. The rights-based model was predominantly focused on the role that social barriers and attitudes can play in capability deprivation. What types of theoretical concepts could further support this line of inquiry? If we understand disability as a capability deprivation, then how could we measure a given society's propensity to deprive persons with disabilities a set of capabilities? More importantly, how could we address such deprivations in the first place.

#### Conclusion

The work of scholars across the spatial and social justice fields has shapes our understanding of what disability is and how it relates to capability. How society views and understands disability is of significant importance

<sup>&</sup>lt;sup>11</sup> Nagata's primary method of data collection was an attitudes survey and the data was correlated to findings gathered through focus groups. She neither compared her findings to any specific international norms nor elaborated on the ways attitudes could practically be incorporated into the development processes. Additionally, the study failed to highlight the mechanisms that could further empower persons with disabilities to participate equally in the development process. Her research is nonetheless important because it highlights the need to expand culturally relative inquiry into social attitudes, rights-based approaches to disability, and processes for inclusive planning policy formation and development.

and greatly impacts the lived experience of persons with disabilities. These perspectives are also critical to advancing the field of urban planning and capability theory helps to add a more human perspective to how cities should be built. It is therefore important to try and bring forward definitions and models of disability that can begin to shape wider views of disability not purely in terms of deviation from some arbitrary norm of human functioning but instead as a failure of an individual's ability to participate fully in their physical, social, or institutional environment along specifically defined dimensions.

The Capability Model of Disability not only helps to establish a framework for improving the physical and social participation of persons with disabilities but also helps to directly address prejudices and shortcomings in the pervasive (mis)understandings and values of the general public toward persons with disabilities. New policy interventions and design solutions exist when we alter our collective perspective of disability. The social perception of disability can be changed when people understand that the inherent problem does not lay with the individual, but rather in the way our cities are built. This change can significantly expedite progress toward building cities that leave no one behind.

Despite their shortcomings, it is fair to say that I love cities but they don't love me back, yet. Like most urban planners, I appreciate deeply the enhanced cultural, economic, and social opportunities that well-planned cities afford us. We now need to identify and scale up more inclusive and equitable approaches that fully account for the tremendous opportunity and responsibility to build cities that respond to the needs of all citizens.

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#### CHAPTER 3

# What Makes a City Accessible and Inclusive?

Abstract The urban-focused Capability Model of Disability (CMD) presented here outlines three key features for city and urban planning processes: rethinking the relationship between people with disabilities and their environment, a development-based framework for inclusive policymaking along nine policy dimensions, and the concept of salience to measure cultural coherence and likelihood for a society to adopt international human rights norms at the local level. The CMD framework is applied to a set of nine basic primary goods necessary for inclusive urban planning and policymaking, which are divided into basic functionings (health, rehabilitation, education, and employment) and basic freedoms (mobility, accessibility, being included in the community, political and public participation, and awareness raising). This chapter provides insights into what this integrated model looks like and how it addresses endemic challenges that impede full implementation of comprehensive rights, policies, and norms across sectors and scales.

Keywords Basic functionings • Basic freedoms • Implementation

- Human rights Inclusion Equity Access Capability Approach
- Primary goods Human development Community development
- Inclusion policymaking Evaluative frameworks

I have dedicated my life to exploring the dominant debates in policy, planning, and development, with a focus on inclusive urban development. In this chapter, I address these issues and argue that the Capability Model of Disability (CMD) effectively addresses the current gaps in theories of justice, development and urban planning. As discussed in Chap. 2, the rights-based model emphasizes the role that social barriers and attitudes can play to marginalize groups such as persons with disabilities and older persons. However, the rights-based model does not address how policymakers can assess and measure the motivations behind social actions and perceptions. I propose that successful rights-based policy interventions assess the salience of international norms on the local level. Doing so I argue offers a tangible and novel approach to achieve better results. Herein, I explain how the concept of salience fits into a new, more responsive, and culturally relative development-based framework. This chapter offers insight into what this integrated rights-based model could look like and how it effectively addresses the endemic challenges that impede full implementation of comprehensive laws, policies, and norms across sectors and scales.

# SALIENCE IN AN INCLUSIVE AND CULTURALLY SENSITIVE DEVELOPMENT FRAMEWORK

Salience can be used as a tool in planning, policymaking, and development. As a scholar I have been especially interested in how the concept of salience operationalizes a measure for cultural understanding—the proclivity for a society to adopt social change, but also the potential challenges or failures for not incorporating salience. As a practitioner I have explored metrics to measure salience and have argued in favor of their importance. It is, however, a tricky concept to operationalize. Both Sen and Nagata pointed to the importance of social attitudes but failed to incorporate an effective measure. How can we measure social attitudes toward persons with disabilities across cultures and how can we link such attitudes to greater concepts of development? Can salience lead to a new and more integral, comprehensive, and inclusive development framework for persons with disabilities?

# The Central Role of Salience in Implementation of International Norms

Salience plays an important role in the implementation of international norms. Andrew Cortell and James Davis Jr. (2000) point to shortcomings in the methodology of assessing the domestic impact of international law. Their research on salience offers ways to assess sovereign (state) behavior in light of international agreements or treaties such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Cortell and Davis propose that behavior can be analyzed in terms of two national-level factors: the structural context within which the domestic policy debate transpires, and the domestic salience or legitimacy of the norm.

## Domestic Salience or Legitimacy of the Norm

For Cortell and Davis (2000), international norms are prescriptions for action in situations of choice within the domestic political context, and salience refers to the varying strength of the international norm on the local level (*id.* at 68, 69). Salience requires that there is a degree of attitudinal support at a local level that can help drive the norm's legitimacy in the national arena so that the norm can be "accepted as a guide to conduct and a basis for criticism, including self-criticism" (*id.* at 69).

Cortell and Davis (2000) argue that domestic salience is not necessarily helpful in understanding a particular instance of norm compliance. Its utility comes in understanding the factors that promote an international norm attaining an "ought" status in the domestic political arena. The authors found that international norms become salient domestically when looking at five key factors: cultural match, national political rhetoric, the material interests of domestic public actors, domestic political institutions, and preexisting socializing forces. They cite Henkin, an eminent international lawyer, author of How Nations Behave: Law and Foreign Policy (1979). In it, Henkin argues that before a nation observes a law, its people must fully accept its obligations and, by extension, accept the values that underpin the law. He argues that "when international law or some particular norm or obligation is accepted, national law will reflect it, the institutions and personnel of government will take account of it, and the life of the people will absorb it" (Henkin 1979, 60). Henkin notes that compliance or violation of a law ultimately rests on deeply held social attitudes and beliefs. We will explore the function of attitudes and beliefs in later sections.

#### Disability vis-à-vis Domestic Salience

Examining domestic salience within the context of disability rights norms provides a useful indicator for predicting the impact of an international norm in domestic policy debates. Diverse approaches to disability should be seriously considered when developing policy. Identifying a cultural match on disability rights would thus indicate that domestic actors are likely to treat disability rights as a given and would instinctively recognize the obligations associated with disability rights laws and policies. This, however, is often not the case.

Hays argues that culture defines and is defined by the social processes that are learned and perpetuated through society. Karr (2009) builds upon Hays' definition that culture is "all of the learned behaviors, beliefs, norms, and values that are held by a group of people and passed on from older members to newer members, at least in part to preserve the group" (Hays 1996, 333). Like Hays, Karr (2009, 2) argues that "disability can be seen as a trans-cultural (or etic) occurrence in that it is an issue that applies to all cultures. It can also be seen as a culture-specific (or emic) issue, which emphasizes the need for intimate awareness and knowledge of the culture." It is useful to note that in describing how domestic salience can be understood, Cortell and Davis use the term cultural match. Herein, salience is cultural and therefore can be used to describe the preexisting social, legal, or cultural factors that shape the discourse of international norms in domestic policy debates. Salience strengthens the actual impact that awareness raising and public education programs can have in sensitizing the general public toward the issues, needs, and rights of persons with disabilities.

# Cultural Match: Case of "Independent or Community Living"

"Individualism" refers to societies with loose individual ties—everyone is expected to look after themselves, while "collectivism" refers to societies whose members are integrated into strong cohesive groups, which provide protection in exchange for loyalty (Hofstede 1991, 51). Individualistic cultures are found primarily in Europe, North America, and Australia, and demonstrate strong characteristics of autonomy. Collectivistic cultures are found mostly in Asia, South America, the Middle East, and Africa, and are characterized by interdependence and a collective identity (Karr 2009).

Cheloff (2000) studied the influence of religious and cultural values and characteristics on perceptions of and attitudes toward children with disabilities. An individualistic culture showed a greater willingness toward inclusive views regarding community integration and education. In contrast, the collectivistic culture took a more cautious and protective view, limiting the interaction between children with and without disabilities. The individualistic culture also demonstrated more positive views regarding future outcomes for children with disabilities, such as the ability to hold meaningful employment, marry, and have a family (*id.*). Cheloff's and Karr's studies demonstrate the varying perceptions of disability across cultures—many having negative attitudes toward persons with disabilities (intensified by culturally embedded views).

The idea of "self-determination" is similarly subject to cultural interpretation. Turnbull and Turnbull (2001, 56) argue that self-determination is culturally laden and determined by cultural values. Documented definitions of self-determination are mostly rooted in a Western, modern, or Anglo-European orientation and recognize the importance of honoring and respecting one's cultural values (Hanson et al. 1998). Determination and self-determination are foundational to human dignity and human agency. The following chart contrasts some of these modern/Western cultural values and practices with those of traditional cultures in terms of societal approach toward disability (Table 3.1).

**Table 3.1** Contrasting beliefs, values, and practices developed by the US Department of Agriculture and the US Department of Health and Human Services (as cited in Hanson et al. 1998)

| Modern/Western approaches             | Traditional approaches      |  |
|---------------------------------------|-----------------------------|--|
| Personal control over the environment | Fate                        |  |
| Change                                | Maintain                    |  |
| Time dominates                        | Human interaction dominates |  |
| Human equality                        | Hierarchy/rank/status       |  |
| Individualism/privacy                 | Group welfare               |  |
| Self-help                             | Birthright inheritance      |  |
| Competition                           | Cooperation                 |  |
| Future orientation                    | Past orientation            |  |
| Action/goal/work orientation          | "Being" orientation         |  |
| Informality                           | Formality                   |  |
| Directness/openness/honesty           | Indirectness/ritual/"face"  |  |
| Practicality/efficiency               | Idealism/theory             |  |
| Materialism                           | Spiritualism/detachment     |  |

Self-determination is also central to ensuring that the values of justice and access are realized for undervalued, or overlooked, segments of society, such as persons with disabilities and older persons. As such, defining and implementing self-determination through, for example, independent living programs could prove problematic in cultures where one's family establishes one's social role. In those cases, the social role has a social value, and independence or autonomy may actually deprive the individual of their social role and lower their social standing and even quality of life. Therefore, it is important that we understand and respect cultural differences in independent and community living and understand the multitude of ways in which one can execute self-determination (Karr 2009). Turnbull and Turnbull (2001) advocate for more research to conceptualize self-determination representing a broad range of cultural diversity.

## Salience and the Will for Comprehensive Social Sector Reforms

Theories, ideas, beliefs, and cultural perspectives have significant implications for planners and policymakers. Cultural perspectives in particular directly challenge dominant paradigms in the theory and practice of urban and regional planning as well as in social policy development. States struggle to balance opposing pressures of economic growth and social equity. They also often lack the capacity or political or social will necessary to execute comprehensive social sector reforms. Such reforms are further strengthened through an active civil society that understands and mobilizes for them.

Salience serves two important purposes in this regard; it can serve as a catalyst or as a retardant to furthering social sector reforms. Positive salience serves as a catalyst in deliberations on disability policy and can further empower and increase the meaningful participation of persons with disabilities in the implementation and practice of disability rights norms at the local level.

## THE NEED FOR AN INTEGRATED MODEL OF DISABILITY

From 2002 to 2006, I worked with the world's leading human rights experts on drafting the CRPD. Since then I have directed research with advocates, scholars, and practitioners in nearly two dozen countries to formulate innovative and more holistic approaches to disability rights in policy and practice.¹ According to Tom Shakespeare (2008), a disability studies scholar from the UK, disability is a complex, scalar, multi-dimensional phenomenon and any analysis on the topic must take into account the social understanding and construction of disability. The predominant constructions of disability have perpetuated unnecessary and unjust social exclusions, which continue to be widespread and persistent. An applicable or remedial theory of disability should be able to measure the social values, beliefs, and attitudes that devalue and obstruct social inclusion. Most practitioners in the field of disability rights agree that a more integrated and applicable rights-based approach grounded on the principles of the CRPD should be developed. Such an approach should ideally integrate multiple dimensions (or spheres of life) into the policy formulation and implementation process.

Sophie Mitra (2006) addresses this from the viewpoint that disability can be understood as being the result of a variety of factors that includes the individual's personal characteristics such as age, race, or gender as well as their environment and the resources available to them in order to function within that environment (Fig. 3.1).

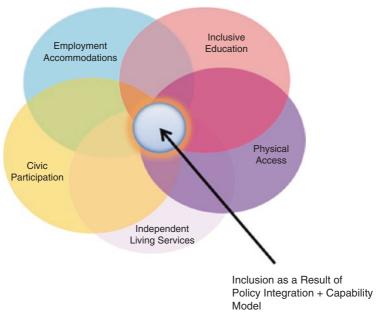
The ultimate goal of an integrated model would be to better achieve social inclusion. Such a model would highlight specific dimensions that can more effectively address the endemic challenges that impede full implementation of comprehensive disability rights, policies, and norms across sectors and scales. It would additionally incorporate attitudes and beliefs as benchmark and target development interventions across multiple dimensions. The result should be a strengthening of the capacities of both institutions and citizens through participatory mechanisms.

# An Integrated Capability Model of Disability

Since Mitra's and Robyn's seminal work on the Capability Model of Disability, other authors have discussed the ways that Sen's Capability Approach (CA) can strengthen the social model of disability. My own contribution to the Capability Model of Disability incorporates both my

<sup>&</sup>lt;sup>1</sup>Many practitioners in the field talk about the fact that the systems are fragmented, weak, or underfunded. Some blame the diverse cultural approaches and understandings of disability or the administrative challenges involved with such reforms. Others cite negative social attitudes or the lack of capacity or funding necessary to implement even the most basic rights.





**Fig. 3.1** A holistic and integrated approach to disability policy requires a coordinated and concerted effort by various agencies and institutions. Identifying and resolving inequality and gaps in outcomes is key to improving the lived experience of persons with disabilities. (Modified figure. Source: Navtej Dhillon and Tarik Yousef. Inclusion: Meeting the 100 Million Youth Challenge, p. 24)

personal and professional experiences. It builds upon all the previous work and addresses a few important theoretical gaps. In this book, when I refer to the Capability Model of Disability, I am specifically discussing the new key elements and a new framework that I feel better integrates concepts of justice, planning, and development. The point of departure for my model lies in the identification of social inclusion through a robust institutional approach to access and governance as the main drivers of inclusive development.

There are three fundamental features that I argue should be added to the discourse on the Capability Model of Disability. These features form a new and more integrated Capability Model of Disability. Such a model

- 1. Characterizes disability as a failure between an individual and their physical, social, or institutional environment along some dimension rather than as a deviation from the norm of human functioning. This model exemplifies the dominant debates in disability studies and can be thought of as an extension to the social model of disability. It fundamentally shows that the concept of a "disabled" person is a social construct and asserts that there is only a capability-deprived person with respect to some physical or social environment.
- 2. **Defines** the concept of salience and uses it to assess cultural understanding and the readiness of a society to adopt international norms across sectors and scales. By doing so, it addresses particular social, cultural, and attitudinal barriers to social inclusion.
- 3. Offers a set of basic primary goods that are assessed through five assessment criteria for policy or primary goods effectiveness. This assessment framework is applied to a set of basic primary goods necessary for inclusive planning and policymaking. The basic primary goods are divided into:
  - a. Basic functionings (health, rehabilitation, education, and employment)
  - b. Basic freedoms (mobility, accessibility, being included in the community, political and public participation, and awareness raising)

These concepts are then brought into discussion within a holistic framework to assess equity. The framework includes the following five pillars:

- 1. Laws: Includes national and international rights and norms
- 2. Leadership: Includes executive and budgetary support
- 3. **Institutional Capacity**: Includes administrative and coordinating abilities of implementing agencies
- 4. **Attitudes**: Beliefs and behaviors of the general population toward targeted groups
- 5. **Participation**: Includes substantive engagement and representation by targeted beneficiaries and relevant stakeholders

# EVALUATING THE UTILITY OF THE CAPABILITY MODEL OF DISABILITY

Mitra (2018) elaborates on the Capability Approach as a framework for evaluation of disability and civil rights. She underscores the importance of the evaluative dimensions of disability and notes Sen's reluctance to

propose a list of capabilities and functionings to assess poverty (and disability-related issues). Mitra stresses the fact that people with impairments and disability ought to be involved in selection of criterion of assessment in a participatory fashion and raises the question as to whether policy should focus on addressing issues in capabilities or functionings. However, Mitra also makes the crucially important observation that needs and points of focus are value-based and vary based on those who are able to define these needs and focuses. These questions and concerns are addressed by the CMD approach.

Trani et al. (2011) help strengthen my analysis by delving into how the CA informs gaps in disability-related research, especially in data collection, policy implementation, and assessment. The authors propose a new measure of both functionings and capabilities by analyzing the gap between the two measures. Trani et al. consider the CA's insight on conversion factors: the ability to internally and externally convert endowments, income, and other social resources into tangible functionings and personal aspirations. Notably, the authors hint at the improvement of measurement of disability and its relevance for policy, but whose stakeholders' agency (i.e., people with disabilities) has yet to be acknowledged by those in power. This phenomenon is called negation, in which people with disabilities have little to no choice with respect to outcomes that they choose in social life. Thus, these sources provide excellent insight into how to develop better policies for people with disabilities with a more integrated CMD framework.

# Defining Desirable Outcomes

The CMD, when applied to policy, can help define, measure, and guide successful outcomes. My model builds off the important work done by many others, most notably by building on the important work of Sophie Mitra (2006). Herein the model addresses how the capacities of both persons with disabilities and the institutions that work with them can build the necessary capabilities to more effectively implement and promote policy coherence. It supports three key outcomes that could help alter the individual's social positioning:

1. Equality of Opportunity: Persons with disabilities are considered to be part of society and are considered equal stakeholders in development. They are afforded full and substantive citizenship on an equal basis with others. Capability deprivation, through the implicit

- and/or tacit denial of reasonable accommodations, is seen as an unjust form of discrimination that could be prosecuted by law.
- 2. Increase Social Role Valorization: Social attitudes toward persons with disabilities are positive, showing no areas of distinction compared to non-disabled individuals. Public information and strategic efforts exist to raise awareness of what persons with disabilities can do in the event that their capability deprivations are omitted. Persons with disabilities encounter no social barriers and enjoy increased understanding from families, communities, and the general public. Their functional *difference* is mediated by reasonable accommodations and an ethos of social inclusion, habilitation, solidarity, and justice.
- 3. Increase Basic Functionings and Freedoms: A set of basic primary goods are identified, thereby paving the way for more targeted approaches toward social inclusion. Basic functionings increase through a closer and more integrated approach to health, rehabilitation, education, and employment. Basic freedoms increase through a closer and more integrated approach to mobility, accessibility, community inclusion, political and public participation, and awareness raising. A robust participatory and community development component is incorporated into the model, with an underlying premise that active participation and engagement by target groups strengthens all other areas that affect them. This participatory element will allow for an increased level of cooperation, accountability, and transparency. This topic will be revisited later in the chapter.

The CMD defines social inclusion in the spirit of the CRPD and identifies capability enhancement and the elimination of capability deprivation as the outcome of all successful disability policies. As was stated above, the provision of rights is strongly linked to the elimination of *capability deprivation*. The CMD applies social justice debates and adds a disability dimension by *defining desirable outcomes for persons with disabilities*. The CMD establishes empirical linkages that incorporate representation, equality of opportunity, and increased social role valorization. It thus offers practitioners a theoretically and empirically grounded framework for policy development and implementation (Table 3.2).

The CMD, as developed and applied here, can help frame the urban dimensions that link individual functions with social and environmental freedoms. The goal of this research is to strengthen the capacities of

Table 3.2 Comparison of Sen's, Nagata's, and Pineda's approaches to the key evaluative aspects

| Evaluative aspect                | Sen  | Nagata   | Pineda                                  |
|----------------------------------|--|--|---|
| Lvuiuuiive uspeci                |  | ixuguiu  |   |
| Well-being                       | Functionings and                           | Human rights and                                 | Capabilities and social                 |
| concept                          | capabilities                               | inclusive development                            | inclusion                               |
| Leading criterion for evaluating | Human capabilities, equality of            | Social awareness, social inclusion, human rights | Functionings, freedoms,                 |
| development                      | outcomes, fairness                         | merusion, numan ngins                            | participation, salience                 |
| progress                         | and justice in                             |  | participation, sanchee                  |
| 18                               | institutional                              |  |   |
|                                  | arrangements                               |  |   |
| Measurement                      | Human outcomes,                            | Scaled attitudes toward                          | Interviews, surveys,                    |
| tools favored                    | deprivational and                          | persons with                                     | focus groups,                           |
|                                  | distributional                             | disabilities, focus                              | document analysis,                      |
|                                  | measures                                   | groups   | and salience to                         |
|                                  |  |  | measure capability deprivations         |
| Agency aspect                    | People have agency;                        | People have weak                                 | People have agency;                     |
| rigericy aspect                  | they are ends and                          | agency; they are a                               | they are the ends and                   |
|                                  | means to                                   | means to development.                            | means toward social                     |
|                                  | development                                | Human resource for                               | inclusion                               |
|                                  |  | economic activity.                               |   |
|                                  |  | Growth is the ends                               |   |
| Mobilizing                       | Individual action                          | Collective action                                | Coordinated                             |
| agency                           | and collective action                      |  | individual, community,                  |
| Voy opening                      | Evenending monals?                         | Immuovino oo sial                                | and state actions                       |
| Key operating goals              | Expanding people's choices (social,        | Improving social attitudes and realizing         | Enhancing basic functionings and        |
| goals                            | economic, political)                       | human rights                                     | freedoms by increasing                  |
|                                  | ceonomie, pontieur)                        | Haman Hants                                      | participation                           |
| Policy concern                   | Emphasis on                                | Emphasis on equality                             | Emphasis on equality                    |
| with distribution                | equality and human                         | and human rights of all                          | and human rights of                     |
| of benefits and                  | rights of all                              | individuals                                      | all individuals                         |
| costs                            | individuals                                |  |   |
| Policy concern                   | Ultimate end has                           | Ultimate end has                                 | Ultimate end has                        |
| with rights and                  | intrinsic value; there                     | intrinsic value; there is                        | intrinsic value; there is               |
| freedoms                         | is a priority for both rights and freedoms | a priority for both rights and freedoms          | a priority for both rights and freedoms |
|                                  | rights and freedoms                        | rights and freedoms                              | rights and freedoms                     |

institutions and citizens as they develop and implement policies based on access and inclusion. Operationalizing the CMD also helps to further point out the differences and benefits of the model vis-à-vis Sen's and Nagata's.

The modified CMD presented herein addresses theoretical gaps to social inclusion and uses the CMD to define successful outcomes and structure disability-related policy approaches. As such, the CMD focuses policy interventions on supporting the ability of the individual within a specific context. This framework also benefited from a grounded theory approach developed through interviews and focus groups. The grounded theory helped identify and define a range of policy interventions across nine specific dimensions. The dimensions were defined through triangulation and pattern matching in coded interviews. These nine policy dimensions offer an integrated and practical lens from which to initiate cross-sectoral reforms. Four of these dimensions (health, rehabilitation, education, and employment) are aimed at increasing basic functionings; whereas the other five dimensions (political and public participation, awareness raising, independent and community living, mobility, and accessibility) are targeted toward increasing basic freedoms. Ultimately, the theory attempts to further equity, social justice, and progress for this marginalized and underserved community.

The Iceberg of Inequality model helps to highlight the primary rights in a hierarchical form. As shown in Fig. 3.2, the basic functionings provide a baseline from which to build and expand capabilities through increasing basic freedoms.

Basic functionings are differentiated from basic freedoms in the following ways:

- 1. *Basic functionings* are understood as primary needs and thus fundamental to the enjoyment of all of an individual's rights.
- 2. Basic freedoms are necessary to expand basic functionings into capabilities, which are in themselves the goal of development. Basic freedoms allow for capabilities and functionings to be converted into social value. They also allow persons with disabilities to live the type of life they "have reason to value" (Sen 1999). Capabilities can also be presented as a function of an individual's basic functionings (BFn) and basic freedoms (BFr):

$$Capabilities = f(BFn + BFr)$$

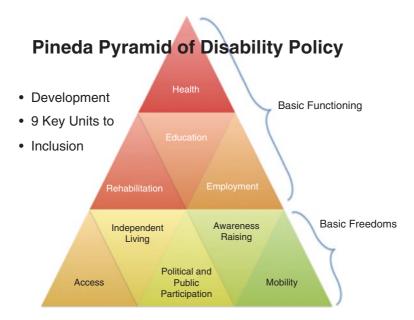


Fig. 3.2 "Iceberg of Inequality" features basic functionings and basic freedoms as organizing domains and as policy areas of interest

# Exclusion as Capability Deprivation

The negative social effects of capability deprivation, as highlighted in the reality lived by persons with disabilities, underscore the enormous cost of not dealing comprehensively with the issue. Sen's research on social exclusion shows that poverty is linked to isolation and marginalization, and oftentimes leads to violence through physical and/or sexual abuse. He also defines poverty as "capability depravity," which is understood as dehumanizing, disabling, and challenging the integrity of already challenged individuals.<sup>2</sup>

<sup>&</sup>lt;sup>2</sup>These perspectives on the importance of dealing with inequality, social exclusion, and poverty of persons with disabilities are mirrored in the differences and views of their origin. By and large, many view disability as arising out of individual tragedy—a tragedy that needs to be addressed through direct support or charity. Alternatively, disability is also seen as a medical abnormality that needs medical and scientific attention to "cure" or eliminate. For adopters of such individualistic viewpoints, social inclusion is only possible under a perfectly "normalized" body and the restoration of full human functioning is seen as the only path toward full citizenship.

# CMD Improves Outcomes

The Capability Model of Disability changes the approach to disability policy and planning in concrete ways. It seeks to remediate past shortcomings and failures not only by providing new approaches to setting and monitoring a baseline, but also by increasing the capacity of domestic actors in implementation. It also provides methods for measuring the domestic salience for international disability norms.

#### Conclusion

In my experience observing disability policy across various countries, I noticed that states with good governance and deliberative institutions increased the capability of social institutions and this in turn fostered more capabilities for disabled individuals.<sup>3</sup> I also discovered that there are persistent negative attitudes and a lack of awareness about the capabilities of persons with disabilities in many countries that derive from a variety of cultural factors, including the unique advantages and disadvantages of individualism versus collectivism in each given society. These negative factors create barriers to changing institutions and contribute to sub-optimal outcomes exacerbated by state policies that do not promote social inclusion for persons with disabilities.

By incorporating domestic salience into a new and culturally specific capability-based model of disability, we can highlight the role that attitudes and beliefs play as either a retardant to social reform or a catalyst to increasing the rate of social and institutional change. Thus, salience must form part of a new and more nuanced assessment of social reforms. The

<sup>3</sup>Sen's concepts of agency, capability, and functionings enable him to argue persuasively for democracy's three-fold importance. *Ethics of Global Development* offers a moral reflection on the ends and means of local, national, and global efforts to overcome these five scourges. After emphasizing the role of ethics in development studies, policymaking, and practice, David A. Crocker analyzes and evaluates Amartya Sen's philosophy of development in relation to alternative ethical outlooks. He argues that Sen's recent turn to robust ideals of human agency and democracy improves on both Sen's earlier emphasis on "capabilities and functionings" and Martha Nussbaum's version of the capability orientation. This agency-focused capability approach is then extended and strengthened by applying it to the challenges of consumerism and hunger, the development responsibilities of affluent individuals and nations, and the dilemmas of globalization. Throughout the book, the author argues for the importance of more inclusive and deliberative democratic institutions. See Crocker, D. A. (2008). *Ethics of global development: agency, capability, and deliberative democracy.* Cambridge; New York: Cambridge University Press.

following chapters explore how governance and access have evolved in the city-state of Dubai, and how key events institutionalized policies and programs that would usher in one of the world's most dynamic urban transformations of disability rights.

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#### **CHAPTER 4**

# The Evolving Transformations of Disability in Dubai Between 1980 and 2012

Abstract To examine the transformation of disability policy in the city of Dubai is to examine how the daily lives of people with disabilities are affected by these policies. This chapter explores in detail the evolution of disability policy in Dubai between 1980 and 2012 in two parts. The first explores the concept of urban transformation by highlighting the role that key legal, political, social, and cultural events played in shaping the evolution of disability services leading up to my first visit to Dubai in 2007. The second offers discussion of empirical findings from extensive fieldwork I conducted between 2007 and 2012. Findings were derived from numerous interviews, surveys, and focus groups aimed at answering the following questions: What steps have planners and policymakers taken to make Dubai more inclusive of people with disabilities, what impact has this had, and what broader lessons can be drawn from the experience?

**Keywords** Participatory action research • Ethnography • Anthropology of the state • Disability studies • UAE history • Evolution of public policy • Medical model • Qualitative methods for disability policy research

# Introduction

On November 10, 2013, the Crown Prince Sheikh Hamdan Bin Mohammed Al Maktoum made an unexpected and bold announcement, "Sign language and braille will be commonplace in Dubai by 2020" (WAM 2013). Dubai—a city for business, luxury, and status—would, according to the Ruler's Media Office, be transformed into a "city for everyone" ("Dubai will be a place for everyone, says Sheikh Hamdan," 2013). I remember thinking at the time that if his declaration proves true, Dubai would in the span of seven years be transformed into an inclusive city, a city where "all responsible service bodies" work to construct "a city welcoming to people with disabilities" (WAM 2013). I was eager to find out how such a complete transformation could possibly occur so quickly.

This was a particularly interesting proposition because in the six years prior (between 2007 and 2012), I documented the rapid rate of urban development and the entrepreneurial and competitive spirit of Dubai. Would best practices in architecture and urban design transform Dubai into the world's most disability-friendly city? I was not so sure, but that goal had deep roots. Designers, planners, and policymakers often fail to adequately consider the evolving transformation of disability and the historical trajectory of how disability is understood and defined socially.

This chapter narrowly focuses on the policies and histories that shape the lived urban experiences of persons with disabilities in the city of Dubai between 1980 and 2012. Although the wider forces of globalization, trade, and commerce clearly affect the urban experiences of diverse constituents, this book will not attempt to detail the implications of Dubai's economic transformation during this period. Other scholars, including Davis and Monk (2007), Davidson (2008), Krane (2009), Salem (2016), Akhavan (2017), Hannam (2018), and De Jong et al. (2019), have all previously explored the economic, geopolitical, and physical transformation of Dubai as a rising global metropolis. Instead, here I focus on the social context of access and inclusion for people with disabilities and the interceding urban transformation during a critical period of economic and institutional change.

This book situates disability policy as the primary unit of analysis within key social institutions to illustrate how Dubai's political and urban transformations shape and are shaped by the people, processes, histories, organizations, policies, and attitudes toward disability. Extensive fieldwork, including interviews, surveys, and focus groups conducted in Dubai

between 2007 and 2012, was aimed at answering the following questions: What steps have planners and policymakers taken to make Dubai more inclusive of persons with disabilities, what impact has this had, and what broader lessons can be drawn from the experience?

While the interrelated concepts of equity, empowerment, accessibility, and inclusion are foundational to the field of urban planning, their application to disability rights is virtually absent in the planning literature. This is especially troubling when we consider the large amounts of literature developed in the burgeoning field of disability studies. There is wide consensus that individuals with disabilities in most major cities confront seemingly insurmountable obstacles when interpreting signage, identifying the presence bus stops, navigating through poorly planned streetscapes, or generally moving around cities without assistance.

In this book, the adjective *inclusive* strictly denotes *inclusive* of persons with disabilities. Thus, an *inclusive* city is one where public services are provided on an equitable basis to persons with and without disabilities. An accessible city is *inclusive* because accessibility allows people to enjoy the same range of rights, privileges, and services regardless of their gender, race, class, age, or impairment. Defining an *inclusive* city this way also implies that an *inclusive* city promotes equity, empowerment, and accessibility as stipulated in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). It should be no surprise that these concepts are transformative and, when implemented, demonstrate how "rights to the city" function in practice.

This chapter is structured into two parts. The first part explores the concept of transformation by highlighting for the first time the legal, political, social, and cultural evolution of disability services in the Emirate of Dubai during its early development between 1980 and 2006. The second part offers a short discussion of empirical findings from fieldwork conducted during the height and slowdown of its growth, namely between 2007 and 2012.

# A City for Some or for Everyone?

Proponents of disability rights may initially be skeptical of Dubai's "City for Everyone Initiative." According to Ahmed M., a leading architect working for Dubai Municipality, "transforming a city from a construction site to a universally designed city is not an easy task" (personal communication, October 20, 2009). However, he is quick to note that "Dubai has

proven the naysayers wrong before." He is referencing the dramatic changes that Dubai has experienced in prior 30 years. Between 1978 and 2008 Dubai was transformed from a sleepy fishing village into a bustling metropolis with world-class attractions such as museums, theme parks, malls, holiday resorts, exclusive communities, wellness hotels, and festival markets (Dehaene and De Cauter 2008; Edensor and Jayne 2011). The ruling family, the Al Maktoums, achieved many of the seemingly improbable goals for the city that they indicated they would: construction of the world's tallest building and largest shopping mall, as well as the Palm Jumeirah development, a 7 km long man-made island that takes the shape of a palm tree (Staff 2008, 2010c, d, e). The government has dramatically improved health outcomes, lowered mortality and morbidity rates, and positioned Dubai as the "City of Tomorrow." Despite these remarkable feats of urban and social development, little is known of how these urban transformations affect the lives of persons with disabilities.

According to the Khaleej Times, the "City for Everyone" initiative launches a new legislative framework. The initiative will develop public and private sector projects that improve public services and infrastructure for people with disabilities. Specifically, these initiatives remove physical barriers and afford persons with disabilities access to all public sector services on an equal basis to persons without disabilities (WAM 2013). A "City for Everyone" would provide "excellent healthcare" to people with disabilities, as well as "supportive social services," and mandates that "all responsible parties" create a "broad societal awareness that contributes to integrating people with disabilities and confirms their participation in community development" (WAM 2013). The rationale for embarking on these ambitious changes is described as "backing the current efforts of Dubai to empower people with disabilities within an overarching framework that contributes to enhancing the effectiveness of existing projects." The article goes on to say that additional initiatives would maximize the participation and integration of this "category" in the community and create new opportunities through which to overcome all the obstacles that may stand in the way of positively engaging and integrating this segment in their social environment as individuals who possess productive and creative capabilities (WAM 2013).

The language used indicates that people with disabilities are a "category" or "segment" of people that must overcome obstacles preventing them from positively engaging in the broader community. This statement simultaneously sets out a vision and mandate that is at once both ambitious and vague. What are the specific obstacles to participation and what new opportunities will be created and by whom? How will the "City for Everyone" initiative succeed and who defines the metrics for its success? Who specifically will create these opportunities? How have planners and policymakers in Dubai designed and implemented opportunities for persons with disabilities in the past? If so, what results have they had? To answer these questions, we must uncover the existing legal, cultural, and historic precedents that can contextualize and add depth to the "City for Everyone." In the next section, I argue that Dubai's "City for Everyone" initiative is not in fact a new initiative; it is rather a purposeful and public re-commitment to fulfilling unmet public mandates, including national and international laws as well as basic local needs.

# A City of Laws, Needs, and International Obligations

Dubai's international obligations complement its political commitment to disability issues. In 2008, Article 9 of the UN Convention on the Rights of Persons with Disabilities recognized accessibility as a human right. This legal instrument fundamentally influences the ways that cities are built, and leaders in Dubai have taken note. From London's full fleet of accessible black cabs to Paris' adoption of tactical museum tours for the blind and Sao Paolo's new accessible transportation master plan, the CRPD is increasingly reshaping urban life.¹ In the 93 countries that have ratified the CRPD, including the United Arab Emirates (UAE), waves of urban and social reforms aim to dismantle pervasive architectural and attitudinal obstacles. Few scholars have set out to document how this golden wave of accessibility is actually being carried out.

The CRPD obligates cities to plan for and meet explicit goals. It reaffirms that *all* persons with *all* types of disabilities must enjoy *all* human rights and fundamental freedoms on an equal basis with others (United Nations 2006). The way cities understand discrimination toward persons with disabilities needs to change. According to the CRPD, local and national governments must protect their residents from discrimination on the basis of disability not only by passing laws but by changing attitudes. According to the former United Nations Special Rapporteur on Disability

 $<sup>^1</sup>$ Additional global agreements such as the Sustainable Development Goals (2015–2030) and the upcoming Habitat III summit (2016) have clear statements mandating that cities be made more inclusive.

Sheikha Hissa Al Thani, a member of the ruling family of the neighboring state of Qatar, "[d]isabled people are more marginalized and more isolated than other people...specifically in the Arab region; they are invisible, because of negative social attitudes" (Reini 2008). One clear example of how people with visual impairments are marginalized is recounted to me by a local advocate named Awatif; she noted in an interview, "the fact that we are denied the right to open a bank account is due to an outdated banking law. This law requires all clients to be able to read a written policy and sign on the dotted line" (personal communication, 2009).

Since 2005, the Ruler, Sheikh Mohammed bin Rashid Al Maktoum, has repeatedly stated that persons with disabilities should be given the support to allow them to contribute to the development of the nation on an equal basis with others (JIWIN 2007; Rains 2005a, b, c; Staff 2010a). The UN Special Rapporteur specifies that people with disabilities should be able to live in a city that entitles them "the same rights to work, education, and health care as everybody else – and granting these rights is a prerequisite rather than a concession [of governments]" (Reini 2008).

On September 12, 2006, and in response to the CRPD, the Supreme Council of the UAE enacted a landmark national law, Federal Law No. 29 (Staff 2009a, b, 2010b).<sup>2</sup> That same day, Gulf News published an article titled "Law Removes Barriers for People with Special Needs" (Salama 2006). According to the article, the UAE's first law to protect the rights of people with disabilities was approved by President Sheikh Khalifa Bin Zayed Al Nahyan. According to Wafa Hamad Bin Sulaiman, Director of what at that time was the Department for People with Special Needs at the Social Affairs Ministry, the law was comprehensive, "matching international standards, providing equal rights, opportunities and choice for persons with disabilities" (Salama 2006). She indicated that Federal Law No. 29 removes all barriers to equal opportunities for persons with disabilities and guarantees their right to a decent life and comprehensive care in education, training, health, and rehabilitation (Salama 2006). The law, she said, guarantees an unspecified job quota for qualified individuals with disabilities in the public and private sectors, provides for improved accessibility to public buildings and residences, and integrates students with

<sup>&</sup>lt;sup>2</sup>Federal Law No. 29 was inspired by the UN Convention on the Rights of Persons with Disabilities. Although the latter is more comprehensive in affording disability rights, Federal Law No. 29 provides essential rights for persons with disabilities. Federal Law No. 29 affects all seven emirates by mandating an ambitious set of civil codes affecting everything from workplace accommodations and accessible public transportation to inclusive education.

special needs into public and private schools (Salama 2006). However, in the subsequent six years since the passage of the law, proponents for disability rights in Dubai bemoan that the Ministry of Social Affairs has failed to adequately implement the law. Khaled A., an Emirati lawyer, noted, "every city in the country, including Dubai, has wasted time" (Khaled A., personal communication, December 25, 2013). Jumana B., a special educator in Dubai, noted that by 2013 the city had made little progress in making schools, places of employment, government websites, and telecommunication, December 30, 2013). What were the factors that impeded progress? How could local institutions at various levels of government effectively respond to these mandates?

The CRPD and its local counterpart, Federal Law No. 29, differ significantly in their approach to social inclusion, and these differences ultimately affect the inclusiveness of city life. Both laws outline a range of actions and responsibilities and highlight the need for cross-sector cooperation. However, upon closer assessment, Federal Law No. 29 falls short on two accounts: it categorizes disability issues as a social protection issue instead of a human rights issue, and it fails to provide implementing agencies with specific regulations. As will be evident in later chapters this would be one of several fundamental institutional challenges to building a truly inclusive and accessible city.

# HISTORICAL AND CULTURAL DIMENSIONS OF DISABILITY IN DUBAI FROM 1980 TO 2012

# The Beginnings of Disability Services in the Emirate of Dubai (1980s–1990s)

Interview subjects working in the government noted that specialized disability programs started in Dubai in the 1980s as the state made gains in its human development, most notably in increasing literacy and life expectancy. Several people interviewed indicated that disability services in the Emirate of Dubai started with the Al Noor Training Center for Children with Special Needs. The Al Noor Training Center opened its doors to its first eight students on November 21, 1981. Al Noor was not a residential facility but a daycare center, with a focus on skills development. It was a charitable entity that could not support the widespread demand for the types of services that it provided. Another center called Five Aces was also

formed during this time. It was a residential facility set up in a rented villa by Jumeirah Beach that could accommodate five students. These two private care centers were the first to provide specialized care and educational services to children with disabilities but others would soon follow.

The Rulers of Dubai, Abu Dhabi, and Sharjah had developed their own efforts in forming "special needs" care centers and funded them from their own purses. In Dubai, H.H. Sheikh Rashid Bin Saeed Al Maktoum donated two beachside villas to form the Dubai Center for Special Needs. It was customary at the time for Rulers to personally respond to pleas from parents to build specialized medical, rehabilitative, and sports facilities for children with cerebral palsy, Down's syndrome, and other congenital or developmental disabilities. The Dubai Center for Special Sports (DCSS) obtained a large facility from the Ruler of Dubai, Sheikh Rashid Al Maktoum. The care provided to persons with physical or mental impairments was commonly offered based on tribal or family ties.

Government services such as more formalized medical care and social security grew to differing degrees in the 1980s as the state formalized its institutions. By the 1990s, H.H. Sheikh Ahmed Bin Rashid Al Maktoum, Commander-Military Command, donated 300,000 sq. ft. of land to build a new facility accommodating 200 students at a new Dubai Center for Special Needs. Additionally, in 1994, the Rashid Pediatric Therapy Center opened up services for what would eventually become 150 full-time students. At this time, there were new approaches being developed that focused on social inclusion and integrating mainstream services in other parts of the world; however, this was not occurring in the UAE. These specialized services were attempting to support students integrate into their communities. The challenge though was that they were not connected to general mainstream programs such as public school placements. While Dubai was making efforts during this time, persons with disabilities were still very marginalized and not achieving independence or job placements. Dubai had started the practice of developing specialized separate services for persons with disabilities but was unable to define, adopt, and regulate proper standards for service delivery.

# New Approaches to Disability Services Forming (1990s-2005)

During this period, disability rights were maturing in different parts of the world. By 1996, the neighboring nation of Kuwait became the first country in the Gulf Cooperation Council to pass specific legislation addressing the education and care of persons with disabilities. By the late 1990s, the UAE was behind its neighbor Kuwait in many regards.<sup>3</sup> During this time, the Kuwaiti government was steadily opening up spaces for civil society and advocacy groups to form. In contrast, the UAE controlled and censored civil society advocacy efforts (even on behalf of persons with disabilities). Kuwait formed a parliament and, through it, provided tempered support to key champions like Munira Al-Mutawa, the Founder and Secretary-General of Kuwait Society for the Handicapped. The UAE meanwhile was preparing for a massive expansion of its economy; it maintained a centralized approach that focused on expanding trade while simultaneously delaying reforms that would open political and public participation.

On October 8, 2009, during the first focus group I conducted with persons with disabilities, their parents, and allies in Dubai, parent advocates commented that their efforts in forming non-profit associations in the UAE were frustrated by the state bureaucracy. Additionally, they commented that conflicting policies toward public associations made it difficult to form advocacy and support groups. Dr. Eman Gaad, a professor of special education at the British University of Dubai and founder of the Emirates Down's Syndrome Association, agreed. She mentioned that the previous policies adhered to by the Ministry of Labor and Social Affairs at the time were so strict that they often prohibited families of children with disabilities from forming voluntary associations. Their budding associations for children with cerebral palsy, Down's syndrome, and others were thus weak and encountered legal obstacles to legitimacy, funding, and social recognition. According to Dr. Gaad, a handful of parent-run organizations such as the Down's Syndrome Association eventually formed through special permission and obtained support from the Ruler's office, but the support came with a cost. Civil society associations were heavily controlled and family associations faced roadblocks and bureaucratic hurdles in carrying out their activities. According to Awatif Ahmad Akbari, a respected disability rights advocate, there were no organizations in Dubai for persons with disabilities that were actually run by persons with disabilities until 2004. Awatif was one of the first leaders with a disability to run an organization that aimed to serve constituents facing the same types of challenges that she herself faced. Awatif has a visual impairment and was able to obtain a leadership

<sup>&</sup>lt;sup>3</sup>According to conversations I had in 2009 at the Shafallah International Forum in Doha, Qatar, with local experts in the field of rehabilitation.

role in Tamkeen, an innovative quasi-governmental initiative. Tamkeen means "enabling" in Arabic, and the organization was set up to empower people with visual impairments. In May 2004, Sheikh Mohammed bin Rashid Al Maktoum, Crown Prince of Dubai at the time, became the founding patron of Tamkeen.

Under his patronage the center became a unique model for an inclusive disability advocacy organization. Tamkeen was unique to Dubai not only because of its commitment toward social integration and empowerment of persons with visual impairments but also because of its governance. Of the three key figures behind the running of Tamkeen—Hamish Mckenzie, Awatif Ahmad Akbari, and Ahmad Almulla, both Awatif and Ahmed had visual impairments. According to Awatif, Tamkeen was one of the first organizations for persons with disabilities represented and run by persons with disabilities.<sup>4</sup> Tamkeen sought to empower the visually impaired (both national and foreign born) through vocational training and leadership development. Awatif eventually went on to run Tamkeen and expand their programs.

# Disability Forms Part of the National Strategy (2005–2013)

In December 2005, Sheikh Zayed Al Nahyan, the President of the UAE and Ruler of Abu Dhabi, approved a National Strategy that had the goal of establishing an integrated course of development across all the Emirates. This happened at the same time that the UAE, and specifically the Emirate of Dubai, was garnering attention from the explosive rate of urban expansion that was taking place. Dubai's boom signaled to UAE nationals and residents that nation-building efforts were well underway. During this time, government officials signaled their intent to use the UAE's economic development to also drive its social development. One of the primary areas of the National Strategy was social welfare. As a result, there would be an increased focus on disability programs and services.

Just as opportunities were opening for persons with disabilities on the planning front, there were also new opportunities occurring from within local and federal government. In 2006, Dubai underwent a major power shift when Crown Prince Sheikh Mohammed bin Rashid Al Maktoum took over the title as Ruler of Dubai and was appointed by the Supreme

<sup>&</sup>lt;sup>4</sup>The only other notable exception was Al Thiqah Club in the neighboring Emirate of Sharjah.

Council as Vice President and Prime Minister of the federal government. In the realm of disability rights, improvements on the ground were coming at an ideal time and with the support of a sympathetic leader. Sheikh Mohammed's cadre of advisors and confidents were assigned new posts and began signaling new opportunities for the country as well as new opportunities for persons with disabilities. Such signals sparked hope for more meaningful empowerment and engagement of disability organizations and their allies (Fig. 4.1).

Anissa Al Sharif, a UK-educated, local social policy expert, was working to support the Ruler's vision for Dubai at the time. She served as the Senior Social Policy Planner at the Dubai Executive Council and was tasked with drafting one of the four key pillars of the 2015 Dubai Strategic Plan. By this time, Anissa Al Sharif knew that there were many segments of the population that were being left out of the Dubai boom. She sought to develop a comprehensive report on the social development needs in the



Fig. 4.1 Sheikh Mohammed during a 2009 Ramadan prayer in his majlis with young persons with disabilities as his guests

Emirate of Dubai. Her study developed an empirical base from which social components of the Dubai Strategic Plan would be developed. According to Anissa Al Sharif, the 2015 Dubai Strategic Plan specifically emphasized the Emirate's commitment to empowering persons with disabilities.

Due to federal-level inertia the process of "decentralization" was well underway in 2006. As a result of the National Strategy, Dubai and Abu Dhabi were pouring hundreds of millions of dollars into building stronger local institutions. In Dubai, these local institutions were called authorities and were being formed under the auspices of Ahmad Bin Bayat, the Chairman of the Dubai Executive Council. Local authorities were charged with implementing the 2015 Dubai Strategic Plan (DSP). They promoted a new, more inclusive vision for Dubai—a vision that, because of the DSP, would include persons with disabilities. In Dubai, working on behalf of persons with disabilities was a family affair. Her Royal Highness Princess Haya Bint Al Hussein (the wife of H.H. Sheikh Mohammed bin Rashid Al Maktoum, Vice President, Prime Minister, and Ruler of Dubai) stated that children of determination were at the top of her priorities and their empowerment was a national duty (Rashid Magazine Therapy 2008, 20).

In February 2006, Dr. Miriam Al Roumi<sup>5</sup> responded to this call when she was appointed Minister of the newly created Ministry of Social Affairs (Staff 2006). Her duty as Minister was to oversee social service reform at the federal level. According to social development expert Anissa Al Sharif, social security and social services in the UAE were at this time weak and relatively underdeveloped. She indicated that most ties in Dubai were traditionally tribal or family based. Cash transfers were distributed directly by individual Rulers. According to interviews up until 2007, the Rulers distributed such social support to petitioners from their personal wealth. This was a time of great institutional transformation, the development of a formalized social security system in the Emirates was only five years old, and local authorities, public policies, and programs were still being formed.

Since the appointment of a dedicated Minister for Social Affairs, Her Excellency Miriam Al Roumi managed a system of social protection that provided direct financial assistance to needy local families. Federal efforts

<sup>&</sup>lt;sup>5</sup> Miriam Al Roumi had served as Undersecretary of the Labour and Social Affairs Ministry since 1999 and had previously run the special needs section at the ministry. She cites her experience in running and overseeing the special needs department as an important factor in supporting the creation of this law.

continued to formulate laws to strengthen social protections mandated by CRPD Article 28.6 According to the UAE's National Report (Emirates 2008) submitted to the UN's Human Rights Council, the Ministry of Social Affairs provides a variety of support services and, by doing so, supports the basic human rights of its citizens.

Several interviewees (personal communication, April 20, 2007, and September 15, 2009) commented that between 2005 and 2006, the United Nations Convention on the Rights of Persons with Disabilities was being finalized in New York and, as a result, the UAE leadership wanted to quickly demonstrate to the international community its commitment to human rights. Notwithstanding the Minister's best intentions, many sources indicated that Federal Law No. 29 of 2006 encountered shortcomings from the time of its inception. Nonetheless, the law was enacted within the context of greater structural changes taking place in the Emirate of Dubai.

# Benefits for and Constraints in Implementing Federal Law No. 29

Leading scholars, advocates, and public sector employees I spoke with between 2009 and 2012 indicate that the city and its policies were characterized as having "attention deficit and hyper-activity disorder." Without a local and federal strategy the government was not able to implement Federal Law No. 29 or tangibly push forward broader social development goals. Up until 2012, most federal-level actors benefited by publicizing their efforts as goodwill or simply as charitable initiatives. This approach is referred to as signaling, but these efforts were not conducted in concert or following any specific goal or strategy. Signaling, if not backed up by concrete actions, is a shortsighted tactic and by itself does not guarantee sustained involvement. In fact, it may prove counterproductive, as efforts are seen as tangential and not a central focus or explicit responsibility.

In this period, federal ministries spoke of consistent progress and cooperation but showed poor results. The key findings that characterize efforts between 2006 and 2012, in these first six years of Federal Law 29, include:

<sup>&</sup>lt;sup>6</sup>Article 28 of the CRPD obligates nations to recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing, and to the continuous improvement of living conditions. Governments must take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

- 1. Laws: Legislative measures characterize disability as a property of an individual independent of her/his physical or social environment. As such these early laws utilize language from the medical not the social or rights-based model of disability.
- 2. Leadership: Sufficient executive support but insufficient budgetary support exists in Dubai to realize the goals set forth in Federal Law No. 29.
- 3. Institutional Capacity: The UAE has sufficient administrative capacity but insufficient coordinating capacity to address disability more holistically in policy, planning, and design.
- 4. Attitudes: Social attitudes are strongly congruent with international norms along the dimensions of education, health, and employment, and incongruent along political and public participation, independent living, awareness raising, mobility, and accessibility.
- 5. Participation: Considerable social and institutional resistance precludes persons with disabilities from participating in public life.

# Analysis of Federal Institutions Implementing Federal Law No. 29

What are the effects of institutional structures on the implementation of rights? Rights cannot be implemented in the Emirate of Dubai in a vacuum. Rights must be understood in the context of the local social, political, and economic structures that define the daily realities of all people. The ways these structures affect persons with disabilities in particular then become a new area for inquiry. Actors and institutions adjust in an opportunistic manner to shifting needs. In the next chapter we will see how Dubai's ability to continuously reform and restructure its institutions and processes provided a unique opportunity to create more inclusive and more responsive systems. The chapter describes and discusses the key functions and actions of federal and local actors in ensuring, protecting, and promoting the rights of people with disabilities along the following key areas: (1) capacity, leadership, and civil society; (2) regulations and process; and (3) implicit and explicit policy objectives as they relate to the implementation of Federal Law No. 29.

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#### CHAPTER 5

# Exploring Functionings and Freedoms in Dubai

Abstract The period from 2006 to 2013 in Dubai was an era of hyper-urbanization and rapid growth. Disability policies, programs, and engagement with people with disabilities were occurring in tandem with the rapid modernization of the city-state. How did these changing physical, social, and institutional contexts impact the lives of people with disabilities across the two separate but interconnected domains, basic functionings and basic freedoms? This time period was also notable for the lack of a comprehensive approach to disability policy and accessibility reforms. Interview respondents indicated that approaches were fragmented and there was a clear gap between what the public sector agencies said they were doing and the type of services and opportunities people with disabilities and their families actually received. This highlighted the importance of advocating for specific actions and policies to ensure the provisions outlined in Federal Law No. 29 and the UN Convention on the Rights of Persons with Disabilities were being achieved.

**Keywords** Policy design • Policy implementation • Contemporary history of disability in the Middle East • Public policy in the UAE

- Inclusive community development Accessibility Exclusion
- Urban policies and programs Participation Nondiscrimination

# Dubai Forms a Foundation for Access and Inclusion

The pressure of rapid economic growth has benefits but also costs and consequences for persons with disabilities. This chapter explores in greater detail the empirical findings and observations I collected through fieldwork in Dubai during the period 2006-2013. This was an era of hyperurbanization and rapid growth. Disability policies, programs, and engagement with persons with disabilities developed in tandem with the modernization of this city-state. What characterized access during this period of transformation? How did the changing physical, social, and institutional context impact the lives of persons with disabilities across two separate but interconnected domains, basic functionings and basic freedoms? In the next two chapters, we will explore how these factors changed between 2006 and 2013, as well as in the subsequent period after the passage of the Dubai Disability Strategy of 2014.

From 2006 to 2013, I studied and participated in the development of the policies and programs that would impact the lived experience of persons with disabilities. The chapter is broken into two complementary sections benchmarking basic functionings and basic freedoms. The benchmarking foregrounds fragmentation but also tremendous potential for continued growth. I begin with an assessment of key findings in four policy areas that I will refer to the four basic functionings: health, rehabilitation, education, and employment. Then I will transition to an assessment of key findings in five policy areas that I will refer to the five basic freedoms: public participation, independent living, awareness raising, access, and mobility.

# BENCHMARKING BASIC FUNCTIONINGS IN DUBAI

Given my earlier discussion of the Capability Model of Disability (CMD) and the context of disability rights in the UAE, I now turn to elaborate on my disability rights framework with a discussion on basic functionings. 1 As described in Chaps. 2 and 3, I adopt the term from Amartya Sen's important work on development. According to him, basic functionings are the actual achievements of the individual, for example, obtaining a university

<sup>&</sup>lt;sup>1</sup>The titles used for this and the following chapter are a reference to Robert Imrie's 1996 work, Disability and the City. This was an influential and pathbreaking book that very much inspired me and my own research. uk.sagepub.com/en-gb/eur/disability-and-the-city/ book229509

degree or competing in the Special Olympics.<sup>2</sup> Sen's Capability Approach (CA) framework reveals the limitations of overemphasis on income and wealth when people's capabilities (i.e., opportunities) and functionings (i.e., activities) are unattended. With respect to my model, Sen's capability relates to the CMD through an emphasis on sets and bundles of functionings from which a person is able to freely choose between various alternatives at their disposal. Mitra expands Sen's Capability Approach to touch upon the various ways in which disability can be defined conceptually. CA highlights two nuances related to issues in disability—deprivation of capabilities and deprivation of functionings. These two concepts run parallel to our basic freedoms and basic functionings that respectively seek to address capability deprivations.

#### Health and Rehabilitation

The UAE has a dual system of healthcare whereby federal and local agencies compete and complement each other in service provision. Since 2006, the UAE has invested considerable resources in developing and providing health services to citizens and foreign workers in the UAE. In 2008, Dubai issued a mandatory health insurance system for citizens and resident aliens (Emirates 2008, 20). This is not a single-payer plan, but rather a mandate to ensure that a private health insurance market is viable. The National Strategy Brief (Office 2006) identifies developing the health sector as a strategic development goal for the UAE. An example of this in practice is the rise in the number of facilities. In 2006, there were 225 public hospitals and clinics for the entire nation. By 2019, there 268 hospitals and clinics in the Emirate of Dubai alone.<sup>3</sup>

Rehabilitation services (physical, occupational, educational, social, psychological, and vocational services) are offered to persons with disabilities in the UAE. These rehabilitation services are provided through three main channels: primarily through the government-run rehabilitation centers linked to hospitals and medical establishments, secondarily through the specialized support and rehabilitation centers, and finally through the adaptive sports programs offered by the Dubai Club for People of Determination.

<sup>&</sup>lt;sup>2</sup> NOTE: Find note/example of Pablo Pineda, or other Special Olympics athletes who also completed a university curriculum.

<sup>&</sup>lt;sup>3</sup> Dubai health authority, Google Maps, and public records were used to estimate the total number of health facilities with the name hospital or clinics in the Emirate of Dubai.

The UAE has the sixth-highest rate in the world of children born with genetic defects (McMeans 2010). According to Dukmak (2009), a researcher at UAE University, there is a serious and growing need for coordination of services, resources, and program sharing in the field of rehabilitation. Many parents feel embarrassed for having a child with a disability and some would rather deal with the problem on their own privately than expose their family to scrutiny by the state (McMeans 2010). According to focus group respondents I interviewed, "There are a lot of people who try to hide it...to be able to face it (in a traditional society) and come out in public is a very brave thing to do." A government employee and academic that I interviewed stated, "as a mother of a child with special needs, I can say that learning to raise a child with a disability in the UAE can be a daunting task. Parents should get help from each other, from the doctors, from social workers, from psychologists on how to work with a child with a handicap." But oftentimes these parents do not know where to go.

# Centers Provide Specialized Supports

On October 5, 2009, I visited the Al Noor Training Centre for Persons with Disabilities. By this time, the Al Noor Training Centre had celebrated 28 years of service, and like most centers I visited in the region, was started by a leading UAE family at the time who had a disabled child. I started by meeting with Deepika, a 29-year-old Fulbright Scholar and Auditory Specialist from India who had been working at the center for the past 3 years. She told me that she came to the center to perform important services as a speech-language pathologist and to conduct some of her own research. She told me that most families face similar challenges in terms of providing their children with the right help and that the biggest problem is access to necessary services. There is also a lack of knowledge in the community of what services are available. Deepika felt that this lack of knowledge and the lack of access stems from societal attitudes in the Gulf. She stressed that such attitudes also affected the center's ability to generate funding and obtain stronger community solidarity.

Mrs. Khatib has been at the center for 11 years and has a background in physical therapy. She points out that Dubai is unique in that over 80% of the population are not citizens but foreign workers. This very large yet "fluctuating" group includes households that are touched by disability. She stressed the need to have Federal Law No. 29 specifically address this population and delineate the rights of non-nationals with disabilities. She admits that this type of policy and reform would be "uncharted waters." Mrs. Khatib noted that extending the law to foreign nationals would also be a stretch because to her knowledge, there was no specific disability policy elaborated in Federal Law No. 29 in any realm of society. According to her, this was urgent because although the law exists on paper, there is still no defined status or specified regulations to enforce. Because of this, she feels that every aspect of Federal Law No. 29 in relation to disability rights is still left open to interpretation. She stressed that unless standards are defined and regulations are developed, the people with disabilities and service providers would not be able to make progress.

# Rashid Pediatric Center for Rehabilitation

The next week, on October 12, 2009, I visited Rashid Pediatric Center for Rehabilitation and met with a head teacher with responsibility for both programming and administration. The walls are covered with art, paintings, and photos. The main hall at Rashid is full of cheerful and bright primary colors. Rashid Pediatric Center was named after the former Ruler of the Emirate of Dubai, Sheikh Rashid Al Maktoum. The center had first caught my eye in 2007 during my first visit to the UAE when I picked up a copy of a comprehensive magazine on disabilities called Rashid. I told the head teacher that I first picked up "Rashid Magazine" on board an Emirates Airlines flight in 2007 and was happy to learn about their efforts. The center has 140 students and 85 staff members. It is a multicultural center that represents over 35 nationalities and accepts students aged between 3 and 20. The head teacher said that the center offers therapy and classes in English and Arabic (as well as Urdu and some other languages). The maximum class size is eight students. The head teacher indicated that the center faces a common issue that affects other similar centers in Dubai; that capacity and resources are stagnant so there is no room for new students or expansion of services due to a lack of funding. According to the center's staff I spoke with during my visit, there are hundreds of children on the waiting list whose needs cannot be met.

The center also has a "best buddy" program where students from general education schools come by after their classes to play games and socialize with the children at the center but she mentioned that there were not many Rashid students that visit regular classrooms. Each Rashid student has an Individualized Education Plan (IEP) that is assessed on a regular basis and modified if necessary. Therapy makes up the majority of each student's curriculum as most of the students at the center have a "cognitive (learning) disorder."

During my interview, I learned that the school did not have a standardsbased curriculum and that the Ministry of Education provided no clear oversight on learning. Focus group participants complained that Rashid and other centers couldn't offer recognized diplomas. My host mentioned that the average developmental age of the students is eight years old and that academics do not play a major role in the curriculum, although it is provided to those that can "process it." The head teacher noted that her curriculum focuses on socialization. I found it strange that a group of children with ages that range from 8 to 15 who had hearing impairments were studying "what things are made out of." I asked why they are studying this if they had a hearing impairment and not a cognitive impairment. Though she couldn't answer, the head teacher mentioned that about a fifth of the 29 students have no inherent cognitive impairments but are at Rashid because of neglect, abuse, or other reasons.

# Challenges to Rehabilitation

According to the head teacher at one of the country's leading pediatric rehabilitation centers, many initiatives in Dubai are launched with too much fanfare and too little follow-through. This excitement builds up when members of the Royal family endorse an initiative. One interview respondent stated, "Important things are discussed but too often are not realized. The inactivity and lack of action are endemic." The head teacher echoes this and states that efforts are inconsistent, and "the lack of tangible effort on behalf of the 'backers' leads most new initiatives to lose momentum, there are too many shortcomings across multiple levels." The process of achieving social inclusion is missing. She summarizes the predicament that the centers face as follows: "There's a will, but no way."

An example she gave was related to building codes. Architects visited Rashid a few years ago and came to explain the new building regulations that were being developed to guarantee access. She was frustrated that she never found out what happened from that visit. According to her, there is still no regulation or standardization of building codes. As such, most efforts in the field of disability rights become "unsustainable initiatives." She mentions that this is due to the fact that the law has not been developed—it does not have regulations and still needs to be applied.

The head teacher I spoke with believes the failure in application is due to the lack of administrative and coordinating capacity of the Ministry of Social Affairs. The Ministry of Social Affairs regulates and supervises the activities including working hours of the centers. She cited that the school days are entirely too short and as head teacher, she can only keep students between 8:30 am and 1:15 pm despite having ample buses, drivers, and assistants that would allow for younger and older students to be dismissed at different times, which, for example, would allow older students to stay at the center for a longer period than younger students.

# Athletic Training and Sport Rehabilitation

There is a vibrant community of athletes with disabilities that receive support, train, and compete in adaptive sports programs. The Dubai Club for Special Sports (now called the Dubai Club for People of Determination) serves as the primary meeting point for persons with physical disabilities to get together and develop their self-confidence and self-esteem. During an interview I conducted in 2009, Majid Al Osaimi, the Secretary-General of the sports-based UAE Federation for People of Determination, said that

The UAE has participated in every Paralympics since 1992, earning 19 medals including 4 gold medals. The dominant approaches to disability rights are through services and programs that are based on rehabilitation and sports. There is a strong prejudice toward treating people with a disability as being sick and needy. We want equal treatment and the basic services to improve our position in society. In sports we are champions and have brought back medals from the Beijing, Athens, and Atlanta Paralympics.

He has since gone on to serve on the Dubai Higher Council for People of Determination, and to represent the UAE in sports and human rights conferences raising awarness of disability rights.

Rashid Saeed, a young 23-year-old man with cerebral palsy, has virtually grown up benefiting from the services offered at the Dubai Club where he serves as an Ambassador for Adaptive Sports and Health. Besides improving his physical and coordinating skills, this offers Rashid the opportunity to travel and attend competitions in a variety of sports.

# Jumpstarting Inclusive Education

According to official government statements I reviewed between 2007 and 2014, the UAE implemented a number of programs to establish an advanced, up-to-date educational system in keeping with current educational technologies and advancing students to higher levels of education (Emirates 2008, 19; KHDA 2014). These efforts indicated a commitment of the State to be responsive to the needs of students with

disabilities. According to the Human Rights Commission Report generated by the United Nations, people with disabilities are entitled to the same rights as others but are being denied those rights by many private schools in the UAE. However, prior to 2009 efforts were sparse and guidance was very basic. Between 2009 and 2013, a slow but steady effort by the Knowledge and Human Development Authority (KHDA) worked to assess and address significant gaps. Efforts by the KHDA focused on outreach, education, accommodations, and on undertaking cost assessments of inclusion. Unfortunately, during this period the patchwork approach to the implementation of Federal Law No. 29 led to schools and charities that did provide meaningful education and support services to persons with disabilities to become heavily oversubscribed.

#### Inclusive Education in the UAE

Public and private schools in the UAE and in Dubai have divergent pathways to inclusive education. Federal Law No. 29 assures the rights of persons of determination to receive an equal education.

Special Education Reforms began unfolding in earnest in 2008–2009. By 2009, national students with different types of disabilities were starting to be enrolled in regular public schools. However, the developed policies designed to address service gaps that most private and public schools in the UAE faced in this period were ill-equipped to accommodate a broader number of children with physical, sensory, development, and/or intellectual disabilities on a consistent basis. Special education is provided for a select group of students in select public schools. Only specific physical, neurological, developmental disorders or intellectual disabilities, or high achieving students would be accommodated through pilot programs. In the period between 2009 and 2012, these students started to benefit from a general education classroom experience but not in a way that was comparable to their non-disabled peers.

Most of these early reforms were being led by Ms. Noura Ibrahim Almarri, the Director of the Ministry of Education's Department of Special Education in cooperation with two of her colleagues from the department. The Special Education Department at this time set the foundation for establishing more inclusive programs. According to the 2009

<sup>&</sup>lt;sup>4</sup>In 2010, the Ministry drafted a new set of standards for inclusive education that set off a series of changes in local policy. Authority, U. M. (2010). UAE Yearbook 2010. UAE Yearbook. N. M. Council. Abu Dhabi, UAE Media Authority: 230.

Special Education Standards,<sup>5</sup> the focus on inclusive (as opposed to "special") education is reflected in the department's vision and mission statements. The Department, however, was very small, understaffed, and underfunded according to Ms. Noura Ibrahim Almarri. She does not have a staff to help the schools deliver on their mandates.

By 2010, the Ministry of Education's Department of Special Education was tasked to plan, execute, follow, and supervise inclusive and special education programs with trained personnel. The department's three staff members had to ensure that all students received an appropriate, individualized education based upon their strengths. Although the department developed standards and provided awareness of and capabilities to implement Federal Law No. 29, students with disabilities were routinely being denied admission to public and private schools and encountered barriers to employment or tertiary education. The Ministry sought to provide educational assessments and training of teachers in diagnosis and early intervention. By 2012, these goals were not being realized due to limitations in executive leadership, institutional capacity, and lack of broad partnerships and participation from targeted groups. According to participating teachers, these early initiatives were ineffective. The first set of guidelines did not sufficiently ensure that both general education and special education teachers would share the responsibility of educating students with disabilities.

One of the major institutional challenges I encounter between 2006 and 2012 is that out of the thousands of public and private schools in the UAE, there are only a handful of schools that accept students with disabilities. They also tend to add additional costs and pass on the added expenses to the disabled child to accommodate, as one interviewee suggested these expenses were "for the expense and maintenance of their special need." Schools engaging in such discriminatory practices and are in clear violation of Federal Law No. 29 and the Convention on the Rights of Persons with Disabilities (CRPD).

# Ensuring Dignified Work

By 2008, the UAE had one of the highest percentages of imported labor in the world; 250,000 employers employ 3,113,000 foreign workers of more than 200 nationalities (Emirates 2008, 16). The number of persons with disabilities in the workforce was unknown; statistics were not kept so

<sup>&</sup>lt;sup>5</sup>The Special Education Standards were revised in 2017. This is discussed in more detail in the conclusion of this chapter.

progress would not be measured until better statistics could be developed. According to several interviews corroborated by focus groups conducted between 2009 and 2012, the employment rate for people with disabilities, however, has steadily increased and attention from both the public and private sectors has increased. A few leading companies are seeing positive results by deploying best practices in inclusive employment.

# Frustrated Voices on Employment

Morad Ali Shadeed is a wheelchair user and Jordanian national who lives and works in Dubai. His employment is full-time and his remuneration is lower than his counterparts who work similar hours and similar jobs. Additionally, his office is on the second floor in a building without an elevator and he has to drag himself up and down the flight of stairs each day. According to Morad, his colleagues and his employer commend him for his efforts and his work, but nonetheless he feels that "things are not right. I will never get a promotion or advance at the company." He has sought other employment but has not been able to secure anything so according to him, "I am just going to have to shut-up and keep working." This experience of discrimination based on disability was not unique to Morad. Masoud M. Al Khouri also has felt it at his work. Masoud is a manager with a hearing impairment and notes that too often he is passed up for promotions. He confessed that he works hard and during our second focus group held at the Dubai School of Government, he confessed that he felt he was being discriminated against by his employer on account of his disability.

According to a political scientist who in 2009 served as a professor at the Dubai School of Government, there is a long way to go for the UAE to effectively regulate employment for persons with disabilities. One of his students, Amal El Robee, agreed. Amal conducted a national study on the vocational aspirations and realities of persons with disabilities in the UAE, the Ministry of Labor had not contributed in any meaningful way to developing or implementing employment protections for persons with disabilities. In speaking with individuals on the topic I noticed that most respondents seemed to note that although there are no explicit legal restrictions limiting the employment of persons with disabilities, the lack of protections again discrimination based on disability in effect limits their equal participation in work. However, discrimination on the basis of disability goes against Articles 16 and 18 of Federal Law No. 29 and also Article 20 of the UAE Constitution. The constitution stipulates that the state, "shall furnish the appropriate facilities for that by providing legislations protecting the rights of the employees" (Bitar 1971). One UAE resident with paraplegia stated, "We need specialist employment services that go beyond mandating quotas to be included in the mainstream labor market." Additional attention with a clear strategy was needed in this period to protect persons with disabilities from neglect and abuse.

This is well described by the director of a Dubai center that provides employment readiness training. She shared a story of the real opportunities that people with disabilities have, "Much positive momentum exists, and there is fertile ground from which to build off. The government agencies seem supportive, there is willingness. But I just don't have the way to fully carry out real changes." When asked to elaborate, she just said, "there is a will, but there is no way. It's a complex issue and there is often no progress." She was talking about the social and institutional barriers that limit people's choices and by doing so limit their freedom to take action. Like the previous assessments on basic functionings, I next turn to look at a category of policy areas in the domain of basic freedoms.

# BENCHMARKING BASIC FREEDOMS IN DUBAI

Basic freedoms highlight the underlying structures that facilitate an individual's choice and agency. They support an individual's ability to participate on an equal basis with others in society. Basic freedoms elevate the inherent dignity of the individual. The notion of freedom is that you don't have to think about negotiating your existence or your preferences. Basic freedoms grant you the right to act upon the world, be seen, enjoy, and shape your environment (whether it be in the physical world or through accessing digital content online). Freedom includes such basic rights as the opportunity to board a train or be able to use a sidewalk to avoid risking your safety negotiating oncoming traffic on the street. Freedom includes the right not to be discriminated against.

The literature on basic freedoms exists in the context of human rights, development, and disability justice. Vizard et al. (2011) attempt to bridge the conceptual gaps between Sen's capability approach and an international human rights framework to inform the ways these concepts can have practical public policy applications. For example, human rights inform "processes of ethical recognition and political campaigning, integration into public policy, and broader processes of social transformation that affect expectations, behavior and choices...[and integration of] human rights standards and principles into broader public action strategies" (10).

Vizard et al. highlight the need for state evaluation with respect to results achieved in international obligations and policy evaluation to measure compliance with human rights laws. The authors draw on Sengupta's mode of the Right to Development (2002, 2004). This model's application to the expansion of substantive freedoms via internationally recognized human rights standards sets important new mechanisms in place for measurement and evaluation of development (Sengupta et al. 2005).

The following sections highlight fieldwork findings around basic freedoms and illustrate some of the important early factors that would develop between 2006 and 2013 and become prerequisites to creating what Dubai is today. This section enables an exploration of the choices that individuals with disabilities have with respect to five domains of basic freedoms: participation, awareness, mobility, independent and community living, and accessibility.

# Public and Political Participation

During the period 2006–2012, the UAE began a process of gradually opening political participation. Initially, the Federal National Council (FNC) began to increasingly acquire legislative and representative legitimacy. The State adopted a clear timetable of gradual steps so that each stage of opening participation could be evaluated independently. Tellingly, during this period the Services for Educational Development, Research and Awareness for Inclusion, also called SEDRA, a non-profit group supporting persons with disabilities, supported the election campaign of a woman with a disability to the FNC. Although she did not win, it served as a statement that women with disabilities could play a role in political and public affairs.

In the UAE, associations, clubs, civic and volunteer networks, and trade councils for expatriates are the primary means for realizing political and public participation. These activities were heavily regulated and are seen as strengthening social cohesion among the various and diverse local and foreign residents of the emirate (Emirates 2008). Public and political participation of persons with disabilities in this period was weak and according to an Emirati named Ahmad, "this lack of meaningful participation in the decisions that affect us is keeping us stuck." Ahmed's view was echoed by others including those from the focus groups who stressed that the absence of a vibrant community of non-governmental organizations impacts the development of disability rights. Participants a series of focus groups I conducted in 2009 at the Dubai School of Government included parents and professionals as well as persons with disabilities. Parents and professionals stated that they wanted to participate more meaningfully in policy development, by sharing their opinions and experiences with the Ministry of Social Affairs. Participants wanted a more open and transparent manner to engage and felt left out and ignored. Parents particularly felt frustrated by the lack of clarity, professionalism, or simply a response to an inquiry. Many parents talked about how they sought out support or answers to basic questions to no avail.

Experienced residents like Mouna, a special education teacher and mother of a child with cerebral palsy, did not hold out much hope for rapid change in this area as she indicated that her opinion was irrelevant to the authorities. She stated, "our experiences are not important to them." She indicated that she felt ignored by the people working in the ministries. They want to attract consultants from abroad because they assume anything developed in the UAE would be based on old policy documents, old language, and old approaches. "This is absolutely not true…there are a lot of people like me that could contribute, but have gotten tired of fighting."

Specifically, according to Mouna, "the lack of voice, capacity, and power of persons with disabilities limits what can be accomplished here." She said that most efforts undertaken in Dubai were fragmented, meaning that most initiatives are either ad hoc proclamations by Sheikh Mohammed or key members of the ruling family. Those initiatives rarely engaged substantively with persons with disabilities and where they did, they were often uncoordinated efforts of parents of children with disabilities. By 2012, adults with disabilities had not yet claimed any meaningful role in developing and shaping policy. A fact that would soon begin to change.

# About Us Without Us: Federal Law No. 29, a Missed Opportunity

The most prominent example of a missed opportunity to adequately and substantively engage persons with disabilities occurred in early 2006 when the UAE was considering the development of a comprehensive law addressing the rights of persons with disabilities. The newly formed Ministry of Social Affairs expeditiously sought persons with disabilities to share their thoughts. A common thread emerged throughout the three focus groups I conducted in October of 2009, namely that of a missed opportunity to demonstrate substantial engagement and participation. Persons with disabilities and their allies affirmed that the Ministry of Social Affairs did not substantively engage persons with disabilities in their drafting of a law for persons with disabilities. Their effort fell short. Participating with the Ministry of Social Affairs, according to one vocal participant, "was superficial

and not real." Other participants mentioned they were frustrated that their comments were not incorporated and there was no follow-up on the meetings that were set. Even local government agencies and local officials were not informed of the pending law's announcement and local disabled leaders were not included in reading final drafts of the text.

After the law was declared and the press conferences settled, the Ministry of Social Affairs was to set out a work plan for the implementation of the federal law and was mandated to form national committees to identify priority areas and develop regulations. However, there was not sufficient ownership or engagement with other ministries or even with service providers across the emirate. Seven months after the law went into effect, one top official informed me during an interview that persons with disabilities would not participate in high-level committees implementing Federal Law No. 29 because there were no persons with disabilities in the UAE qualified to serve on such committees. Upon raising the issue of representation, he reconsidered his statement and asked me to connect him with qualified candidates. He was simply unaware that there were lawyers, doctors, and professors in the UAE who have disabilities. The next day, his office publicly announced that over 50% of the committee members should be persons with disabilities.<sup>7</sup> However, even six years later, little was done to ensure persons with disabilities were actively engaged. The committees set up to implement Federal Law No. 29 had no budgets, power, or administrative support. The committees that would have had representation were in effect never fully activated.

# Community and Independent Living

After living in the UAE for a few months, it became clear that the concept of independent living is foreign to the general population. Asma, a young woman who is a wheelchair user, indicated that she does not agree with Western notions of independence and shed light on a cultural dimension that I had ignored. During a private interview, she stated: "independent living sounds like a punishment, why can't I live with my family." Although some people with significant disabilities in the UAE are not able to imagine living their lives on their own terms with equal choices to the rest of the population, others yearn for it.

<sup>&</sup>lt;sup>6</sup> Personal interview in April 2007 with a senior deputy in the Ministry of Social Affairs.

<sup>&</sup>lt;sup>7</sup> Personal interview in May 2007 with a senior local-level government official.

# Hala's Story

Hasbrouck (2008a) wrote a column about a young local Emirati woman named Hala. She shares Hala's story to illustrate how Hala is empowered to live the type of life she has reason to value. Hasbrouck notes that Hala, instead of depending solely on help from her family, directs the time and manner of her care. By doing so, Hala develops enough self-confidence to pursue a career or start a family, knowing that she can meet all normal expectations with help from personal assistance services (Hasbrouck 2008a). Personal assistance services are common in the UAE as a large portion of the Emirati population has domestic workers. Domestic workers help with child care, housekeeping, errands, driving, and cooking (Hasbrouck 2008a). Domestic workers also provide support to disabled family members; however, the idea of a person with a disability directing their own care is still rather underdeveloped (Hasbrouck 2008a). In addition, a personal assistant could help with transportation and personal needs at school or work. In fact, by using personal assistance services, disabled Emiratis could meet all the social, economic, and civic responsibilities of daily life (Hasbrouck 2008b). Hasbrouck effectively argues that there are many Arab and Emirati pioneers with disabilities who like Hala have come to understand that the "disability" lies not with themselves but in "how society affects them." Thus, limiting beliefs affect the real choices people with disabilities have to live the type of life they have reason to value.

# Hussain's Story

A young local Emirati with a neurological condition I met in August of 2010 exemplified the neglect and abuse that is perpetrated behind closed doors. I met Hussain at the Dubai Mall, a place where he says he can enjoy himself and meet friendly people. Hussain mentioned that he has a hard time meeting people because his life is different. He mentioned that his life is different because he is a person with a disability. He is treated differently and was taken out of school. He cried for two weeks when he was taken out of school because he lost his friends. Due to his disability, it was becoming increasingly difficult for him to read and neither his family nor his teachers provided any modifications to allow him to continue to be able to do so.

Shortly after he turned 15, his mother married him off to a Filipino woman whom he had never met. Due to his condition, he uses a wheel-chair to get around and a diaper because he does not have aid to assist him 24 hours per day. The woman was to take care of him, but he soon realized

that this was not really the case. She was, in fact, a servant for his mother. A year later, he was married to his second wife, this time against his will. He was then subsequently married to a third wife, again at the insistence of his mother. He cried for two months because he had not been given a choice and because he did not want to marry these women. Hussain has no voice and no choice in the affairs of his life. According to him, his mother makes all the decisions about his life and his three wives ridicule and mock him. He has no intimate relationships with any of the three wives and says that during family events he is usually marginalized. He said that his mother and wives do not respond positively when he asserts his wishes and tries to leave the house as much as possible because he cannot stand being there. Hussain is completely without recourse and assistance. His basic needs are met but he essentially has no freedoms. The prevalence of the rehabilitation or medical model of disability limits and counters the promulgation of a more modern "rights-based" model of inclusive education to take root. Hussain's story exemplifies what happens when the rights-based perspectives on disability are not protected, promoted, or enforced.

# Dana's Story

The challenges facing persons with disabilities in Dubai are multi-faceted and counteract full social inclusion. In talking to locals who had disabilities, I understood that the traditional culture in Dubai limits the choices and freedoms of many groups, especially women, migrant workers, children, and the elderly, not just people with disabilities. To try and further understand the reality of options open to persons with disabilities in the city of Dubai, I asked some local friends the following question—"If the dominant culture does not even support a woman's choice to live independently, then how could a woman with a disability live independently and be included in the community, is this even possible in the UAE?" But despite the cultural and political challenges that are present, I was somewhat surprised to hear that they can.

Dana Nashawati is a Syrian national born in Dubai. She is blind and works at the Emirates Airlines customer service center answering phones. She goes to school at night and lives with a friend. She is active and has learned how to navigate the city on her own. Through the encouragement and support of her family, Dana has developed a strong sense of selfconfidence. She tells me that "the entire city is now in my head. I can get around and know where things are. The taxi drivers are so surprised when I tell them where to turn or how much farther or how much closer I want them to go before I get out. Sometimes people don't believe me when they find out I am blind." For Dana, living independently is clearly important, "I want to make my own choices, I want to be free and go where I want when I want without having to ask for any favors and Dubai's metro system now makes this easier." Dana's comments indicate that independent living is strongly affected by an ability to enjoy the services of the city on an equal basis with others, especially transport services.

### Marriage Fund for Independent Living

The Marriage Fund was established in accordance with Federal Law No. 47 of 1992. It aims to encourage the marriage of citizens to other citizens, provide financial grants to citizens of limited means to help them to bear the costs of marriage, participate in achieving familial stability in society, and to conduct cultural, social, and behavioral awareness campaigns. The Fund is structured as a marriage incentive and also targets persons with disabilities. This fund gives grants of no less than 60,000 dirhams to the deserving among young Emirati adults (Emirates 2008, 22). The fund is also extended to persons with disabilities. According to the National Media Agency, two mass weddings for people with disabilities took place in the UAE. The Prime Minister Sheikh Mohammed bin Rashid presided over one of these mass weddings in 2008 and awarded each couple 70,000 dirhams to start their lives. These mass weddings allow people with disabilities a chance to advance into adulthood without the burden of organizing private wedding events, which can be cost-prohibitive for some families. Referencing the challenges to create an independent life in the community, Mohammed, a man with hearing impairment from Dubai, said, "We are a rich country and the government can do more. If you are married, the government gives you a house, but many disabled people do not marry, so it's tough for us." He continued by stating, "bad ideas toward people with disabilities prevent us from getting married, and we don't have the chance to work like others."

In 2009, Dr. Eman Gaad served as the Director for Disability Services and worked closely with Dr. Maryam Matar, the General Director of the Community Development Authority (CDA). They told me that social protection systems in Dubai need to focus on the needs of persons with disabilities and address issues of neglect, isolation, and segregation. On April 26, 2010, at the invitation of Dr. Matar and Dr. Gaad, I gave an hour-long lecture on living in the community to 40 key managers working at the CDA. The talk focused on bridging the gap between policy and practices, especially related to the issues that limit community and

independent living. Participants asked questions about developing and measuring quality community-based services. According to Dr. Matar, CDA was a new entity tasked with creating a meaningful difference for persons with disabilities.<sup>8</sup> The CDA works toward promoting and raising social standards in the local community and increasing the role of citizens in the community by cooperating with concerned entities in order to achieve the goals of the development sector and to develop the basic structures necessary for this. Since 2008, the CDA has worked to develop the programs, policies, and standards based on its five strategic goals: promotion of national identity; social protection; social inclusion; social empowerment; and social cohesion in Dubai. These areas continue to pose challenges to community integration. According to Dr. Gaad, this is due to strong family traditions that separate persons with disabilities from the rest of society due to a sense of shame. She said that disability has traditionally been viewed as a public shame and is only occasionally seen as something special. Participation is, therefore, primarily limited to adaptive sports and recreation. She stated optimistically that "this is changing, changing fast, but not quite as fast as I would like." Shame and social stigma create an altered understanding of the real choices people with disabilities have and the ways in which they can execute their basic functionings and freedom.

# Awareness Raising

Shortly after I arrived in the UAE, I noticed the unique role the media played in stimulating public discussion. Freedom of speech and assembly is controlled and according to colleagues at the Dubai School of Government, the media is known to practice self-censorship. Disparaging remarks against the Ruler or the Ruler's family is prohibited by custom and according to a surprising decree issued in March of 2009, reports disparaging or threatening the economic security or economic standing of Dubai would be prosecuted. Within this context, the media serves a critical role in spreading awareness and ideas among the local and diverse expatriate populations as long as it does not directly criticize its leaders or their policies. From my own experience, I noticed that the media was very

<sup>&</sup>lt;sup>8</sup>The CDA is a government entity founded in 2008 and mandated with enhancing the social development in Dubai to achieve the Dubai Strategic Plan 2015 that was announced by H.H. Sheikh Mohammed bin Rashid Al Maktoum on February 2007.

interested in my research and during the six key months of my fieldwork (April–October 2009) I was interviewed ten times, appearing in seven English speaking newspaper articles and three English speaking radio segments. There were also over a dozen articles published about my research in both Arabic and English. This experience made me understand the interest and need in effectively engaging the media to promote, protect, and ensure the rights of persons with disabilities.

According to popular Emirati columnist, Sultan Sooud Al Qassemi, the media has become an unlikely ally in promoting disability as a rights issue. Sultan himself writes on contemporary economic, political, and cultural events in the UAE and has covered disability issues on occasion in his articles. He notes that it is a shame that there is, in general, a low degree of awareness about disability issues among the public and through our conversations between 2009 and 2013, he revealed his commitment to helping bring awareness to disability issues through his articles. Sultan understands well that the government signals its intent to the population and then generates buy-in through multiple channels of dialogue that include traditional media, social media, and the Ruler's council. These processes increase awareness and generate social discourse that shapes the nature of pending policies and programs.

### Mechanisms for Raising Awareness

Staff writer, Ramona Ruiz, has written on disability rights issues for the *National*, the most widely circulated English-language daily in the UAE. She indicated that the human-interest stories linked to disability are usually presented positively in the English language media and tend to get widely read. The media analysis I conducted for this case study also tended to support her statement. My analysis of the local media included a review of over 300 English language newspaper articles published in the UAE between 2006 and 2010. The articles overwhelmingly indicate that the portrayal of persons with disabilities in the UAE media is relatively positive and often state that rights are being implemented and that incremental progress is being made.

Al Rifli is a young man with a visual impairment who hosts a youth-focused television program on a local Arabic-language channel. Through his work, he hopes he can do his part to change attitudes in Emirati society. Specifically, he wants to raise pressing social issues that young Emiratis face; one of these issues being the lack of understanding and opportunities for persons with disabilities. He acknowledges that persons with disabili-

ties are seldom seen in public let alone hold jobs. According to him, "they just need to be given the chance" (Swan 2010). He notes that in the area of awareness raising, "The Government [is] trying to solve this problem and provide support." He stresses that most Emiratis with disabilities, "think that they can't do anything. They don't have the support to keep going. The family doesn't encourage them to live a normal life; they just keep them at home" (Swan 2010).

The lack of community awareness and involvement may also be a barrier to rehabilitation services for individuals with a disability in the community. The Dukmak (2009) survey results identified that parents' lack of awareness of rehabilitation services prevent children from being properly treated and an absence of campaigns on rehabilitation services or telephone hotlines to guide and advise parents limits the effectiveness and reach of the services. This, in turn, limits the effectiveness of the State in protecting the rights of children to access rehabilitation services. Dukmak (2009) argues that the lack of awareness could limit the provision of and subscription to family services. The lack of knowledge by parents about available services and lack of information with regard to resources can be eliminated according to Dukmak (2009) by increasing the visibility and accessibility of such services in community settings. Dukmak (2009) concludes that increased advertising and promotion should target consumers through pamphlets, newspaper, magazines, talks, and seminars (Dukmak 2009).

### How Models of Disability Shape Awareness Raising Efforts

In 2009, a group of people with disabilities participated in a focus group that I was running at the Dubai School of Government. They stated that efforts to generate a substantive change in attitudes have been largely ineffective. Persons with disabilities wanted to see more sustainable measures to combat stereotypes, prejudices, and harmful practices relating to persons with disabilities and they wanted these efforts to reflect their direct experiences not related through an intermediary. However, a Deputy Minister that I spoke with at the Ministry of Social Affairs at the time would disagree. He noted that the Ministry had arranged public information campaigns and published journals on this topic and had been making great efforts to educate the public. One vocal focus group participant was a long-time advocate and disability rights campaigner named Haidar. Haidar, a wheelchair user stated that every public effort to raise awareness had been ineffective and suggested that one of the primary reasons for this was that most public awareness campaigns are not designed by or in coordination with persons with disabilities. Haidar eventually developed his own campaigns including riding a solar-powered wheelchair across the country to raise awareness.

Throughout every aspect of society, and through different channels, both negative and positive perceptions of persons with disabilities co-exist. However, another participant, Nada Al Bustami, stated that changes are indeed occurring: "Over the past ten years, things have really changed in terms of perception. The community is much more responsive, there is much more awareness, but negative stereotypes still persist." Awatif Ibrahim Akbari agreed, stating further that the negative and persistent stereotypes, prejudices, and harmful practices relating to persons with disabilities are not effectively combated. Focus group participants like Nada Al Bustami shared cases where employers, school principals, or family members would continuously resist requests such as accessible toilets, extended time on exams, or simply the opportunity to form a family. The resistance exists on such occasions when an individual may want to assert his or her rights. These assertions come into conflict with dominant notions of who should be afforded rights and how those rights should be accommodated.

### Accessibility and Mobility

After spending nearly six months in Dubai in 2009, I became increasingly concerned that there were no real experts that I could find that understood accessibility and usability of the built environment, ISO 21542:2011. I was delighted when I met Issasm El Aloui, a German-trained architect who recently moved to Dubai. During an interview he mentioned that "Dubai missed a unique opportunity to build a 21st century city by not developing or enforcing building standards in the area of accessibility." El Aloui moved to Dubai in 2008 and was frustrated with the lack of clear guidelines on accessibility. He mentioned that "The entire building code in Dubai is 19 pages, and in Germany the codes to build only a bathroom are 200 pages." The lack of uniform standards characterizes Dubai's ad hoc approach to accessibility.

# Accessible Signage

From my own experience noting signage on public buildings, I found a wide variety of different styles being used. Some buildings use simple, easy to understand signage. This is important not only for people with low vision or intellectual disabilities but also assists in the signage being more easily read by everyone. Implementing, promoting, and enforcing signage available in language and graphics that are easy to read and comprehend

benefits the hundreds of nationalities and tourists that come through Dubai. Accessible signage, adequate degrees of color contrast, and signage in braille were present in all large public meeting facilities including malls, the metro, hotels, and conference centers.

### Training on Accessibility

Although Dubai is a regional/global hub for tourism, finance, and services, there seemed to be no accessibility training programs in the Emirate of Dubai. This became increasingly clear when I organized a meeting with Tamdeen, a construction management company working on some of the biggest development projects in Dubai. Anwaar Al Shammari is the Director of Tamdeen and supervises the master planning of Dubai TECOM, Healthcare City, Academic City, Sports City, and Internet City, among others. Anwaar is also a recent graduate of architecture. She shared with me that neither she nor any of her colleagues received coursework or training on access issues. According to her, architecture programs in Dubai do not include access or universal design into the architecture curriculum. She added that the relevant stakeholders are not sufficiently trained on accessibility indicators and the government currently mandates no training. She had hoped that my research would illuminate some barriers or gaps that may be present in some of her own development projects since she and her colleagues did not have a clear idea of the accessibility requirements in master planning. I mentioned that there are opportunities to have such training provided by both the tertiary education system and private companies and consultants in the field of architecture and design. Ms. Al Shammari noted that without government enforcement, accessibility issues will not be acted upon.

### Transportation and Roads

I had the chance to meet Mattar Al-Tayer, the Chairman of the Board and Executive Director of the Roads and Transport Authority (RTA), in May 2009 during an annual one-day conference on barrier-free tourism. Al-Tayer presented the Transport Strategy for People with Special Needs in Dubai in front of 50 professionals interested in lowering the physical barriers to Dubai's tourism infrastructure. Al-Tayer mentioned that the RTA had taken the lead in implementing Federal Law No. 29. He said this was accomplished by developing a comprehensive strategy to enhance

accessibility in all modes of transportation (Al-Tayer 2009). Al-Tayer indicated that the RTA had conducted interviews with 259 persons with disabilities and found that of those interviewed, 80% were limited in their activities due to transportation system constraints. Additionally, the RTA study found that 95% of the interviewed respondents said that accessible transportation is important for a better quality of life (Al-Tayer 2009). On account of these findings, the RTA undertook a comprehensive approach to transportation accessibility. According to Jumana Nabti, a transportation planner in Abu Dhabi, "An inclusive transportation infrastructure is one in which accessibility was integrated into all aspects of work. Dubai realizes that it needs to make changes."

### Improving Mobility Through Human-Centered Design

The RTA is responsible for the road network, as well as managing the transportation services in the Emirate. Tabitha Decker, an urban sociologist and visiting scholar at the Dubai School of Government, noted that the design of sidewalks and the existence of physical barriers in the city are problematic for persons with disabilities. In order to rectify this, the comprehensive RTA strategy began identifying the location of all physical barriers and established priority areas due for modification. In such areas, barriers would be removed and accessible design features would be implemented. The goal was to increase the total number of miles that are accessible and available to pedestrians, mothers with strollers, the elderly, and persons with disabilities. As Issasm El Aloui noted, "Access helps everyone in Dubai not just persons with disabilities." Jumana Nabti noted that Abu Dhabi had created a plan that was more comprehensive than Dubai but in the end, she stated both plans were aimed at the same goal; removing unnecessary barriers from the built environment (Fig. 5.1).

Between 2006 and 2013, I encountered insurmountable accessibility challenges all over Dubai. One prominent example was in Jumeirah Beach Road (JBR). JBR is a promenade lined with beachside shops and residences. The sidewalks contained a variety of obstacles that prevented me from enjoying the promenade on an equal basis with others. Barriers included protruding posts, a lack of curb-cuts, and uneven surfaces, among others. The beach runs parallel to Jumeirah Beach Road and I was happy to see that there was a mile-long boardwalk alongside the beach. When I



Fig. 5.1 Proposed changes as stipulated in the RTA's comprehensive Strategy for People of Determination; examples from Jumeirah Beach Road, Dubai

tried to approach the smooth cement boardwalk, I realized that there was no path to get to it, this boardwalk was surrounded by sand, limiting my ability to reach it and my ability to enjoy it.

In 2015, a 10-foot path was built that connected the sidewalk to the boardwalk and hence allowed wheelchair users an additional mile of accessible public infrastructure. Such gaps in planning and design could be caught in the future through the permitting process only if standards are put into place that stipulate that all public facilities should be made accessible on an equal basis to persons with and without disabilities. The RTA has already started this process and has presented some of the ways in which they will be identifying and modifying the built environment (Fig. 5.2).

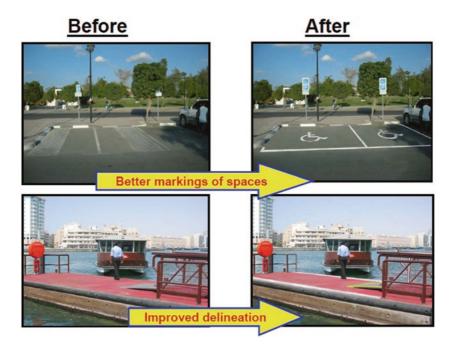


Fig. 5.2 Proposed changes as stipulated in RTA's comprehensive Strategy for People of Determination; examples show improved markings and delineations

### Public Metro and Public Buses

In September of 2009, Dubai became the first city in the region to have an integrated public transport system fully accessible to people with disabilities. All modes of public transport (including the Dubai Metro, public buses, marine transport, and even some taxis) now meet the mobility requirements of the Road Transport Authority with respect to people with disabilities. After using both the bus system and the Dubai Metro, I realized that this system was indeed markedly superior to anything available in the region. The efforts put into this infrastructure to ensure ease of use have led to remarkable results (Fig. 5.3).

<sup>&</sup>lt;sup>9</sup>I have visited the following countries in the region, Egypt, Lebanon, Saudi Arabia, Qatar, Oman, Yemen, Syria, and Kuwait. Dubai's transportation is also easier to use than the transportation systems that I have used in Paris and New York.



**Fig. 5.3** Proposed changes as stipulated in RTA's comprehensive Strategy for People of Determination; examples of wider air-conditioned bus stops

According to Tabitha Decker, increasing access to transportation modes such as the Dubai Metro is important because it opens up the city to persons with disabilities. All of a sudden, they can access new places in new ways. Places that were off-limits are now on the map. Increasing efforts to map the accessible walking environments have been taken on by the RTA.

Challenges and barriers exist in the areas surrounding the bus and metro stops according to persons with disabilities who use the public transportation system in Dubai (Ahmed 2010). "Facilities for 'special passengers' are excellent within the stations and the trains but the access and exit areas on the roads need urgent improvement as they are dangerous for handicapped people," said Kaltham Obaid Bakheer Al Matroushi, Manager of the Ladies Section at Al Thiqah Club for the Handicapped (Ahmed 2010). Kaltham was among the 13 volunteers who were invited to participate in the study organized by the Rail Agency of the Dubai Roads and Transport Authority to identify gaps in the Metro's facilities (Ahmed 2010).

Badriya, a hearing-impaired teacher, suggested that at least one of the staff members at each station should be trained to deal with passengers who, like her, cannot hear. "It is difficult to communicate with the staff to seek any help or guidance," she said (Ahmed 2010). Abdul Redha Abu Al Hassan, Director of Rail Planning and Development at the RTA, said that the study aimed to further improve facilities for people with disabilities. He noted that the stations are designed with a "barrier-free access system" to make the metro accessible to all regardless of any physical impairment following best international practices (Ahmed 2010).

### Dubai Taxi

The RTA has purchased and runs a small fleet of three wheelchair accessible vehicles. Two of these vehicles were used between 2006 and 2009 in pilot programs testing different rates, fees, and dispatching systems. During my visits to Dubai, I have come to greatly depend on these vehicles and have been able to see that the RTA has adjusted their approach to this service over the years by changing from a fixed charge fee for pickups to regular metered fees. The vehicles have a steady demand from about 20 regular clients in Dubai. The taxis can travel to any emirate in the UAE and, like regular taxis, are also available for rental on a daily rate of \$200 per day. In August of 2010, the RTA purchased two additional accessible vehicles to add to its fleet. According to Mohammed, the senior of three "special" drivers, "The taxis are popular with tourists who use wheelchairs in Dubai" (Fig. 5.4).

### Live Assistance

Dubai's position as a luxurious tourist destination gives it a unique advantage in terms of the availability of live assistance and intermediaries available to facilitate such things as opening doors, guiding customers through crowded areas, and so on. In this regard, Dubai also provides persons with disabilities with a unique and ample supply of live assistance in public places. During the months of March through October 2009, I noticed that such intermediaries, trained and untrained, were available to facilitate my own access to public buildings and facilities. Thus, it can be inferred that other persons with disabilities could greatly benefit from this unique characteristic of Dubai's tourism and leisure-based service sector. Live assistance afforded ease of access. Morad Ali Shadeed and Hussain



Fig. 5.4 Two of the five accessible vehicles owned and operated by the RTA

Al Rahma, both wheelchair users, mentioned that there are always people available at the malls, hotels, or at restaurants to help with getting in and out of vehicles, buildings, residential or retail establishments, and airports.

### Access to Information

During my time in the UAE speaking with numerous people about disability issues, it was clear that when talking about access, most people with and without disabilities failed to equate the concepts of equitable accessibility to information. Most often when speaking about accessibility, people primarily equate it to the provisions of accommodations in physical infrastructure such as ramps and elevators.

Information and Communications Technology (ICT) accessibility has become a key area of importance for cities around the world. As increasing volumes of information are stored and accessed online, it becomes vital that people can easily access this information whether they are at home or via mobile devices. This is of particular importance for persons with disabilities and the elderly, who often rely on access to information, such as public transport or city services information, to enable them to move around their cities and lead fulfilled lives away from their homes. Dubai, like other major cities around the world, has recognized the importance of this area and is making efforts to improve digital inclusion but also suffers from the common problem that many of these efforts remain separated from one another and lack a cohesive integration of efforts and services. Without accessibility standards, comprehensive planning, and careful guidance of these efforts, ICT programs risk leaving persons with disabilities further behind.

Between 2007 and 2013 I spoke with Fadi Salem, a researcher working at the Mohammed bin Rashid School of Government, formerly the Dubai School of Government about the technological shift taking place in Dubai. Dubai is positioned as a "leader in E-Government" however, he recognizes that ICT infrastructure does not currently take into account the needs of persons with disabilities. Abdullah Saeed Rashid Al Suwaidi, the Deputy Minister for Social Affairs, notes that the ministry has been working on improving this. He cites an example in the field of telecommunications where the Ministry of Social Affairs launched a project with Etisalat, the dominant telecommunication company in the UAE. The joint initiative would make telecommunication services accessible to the deaf by providing video calls where individuals could sign to each other and see the video feed in real time. This early engagement in the topic would later in

2017 develop into digital accessibility standards for the emirate as well as an Emirate-wide initiative called Smart Dubai, which would require all government websites to comply with the WCAG AAA rating, the highest standard in digital accessibility.

### Mobility

Dr. Hisham S. Farahat is the director of sales for Al Masood Mobility, a leader in the sale of mobility-related products. He affirmed that insufficient efforts have been made to promote the development of a comprehensive range of mobility products for persons with disabilities. He shared several stories of children who had lived their entire lives without mobility devices, developing greater medical complications and being denied the opportunity to leave their own home. He mentioned that most people were not aware of the range of mobility products that are currently sold in the UAE and the products that are available in the US, the UK, Japan, or Germany but not yet available in the UAE.

According to Dr. Farahat, persons with disabilities in Dubai do not have many opportunities to receive training in mobility skills. A notable exception to this is the Tamkeen Vocational Education Center for Individuals with Visual Impairments. More advanced or specialized assistive technologies are for the most part not available for persons with disabilities and are very expensive. Furthermore, very few centers exist that can provide assistive technologies such as customized wheelchairs, fitted prosthetics, electronic or environmental controls, automated door openers, or customized vehicles.

Federal Law No. 29 specifically forbids discrimination in obtaining a driving license for persons with disabilities. As a result, two of the 50 centers for instruction in driving are now offering specialized driving courses for drivers who as a result of paralysis or leg amputation may choose to use modified hand controls on their vehicles.

### CONCLUSION ON BASIC FUNCTIONING AND FREEDOMS

In regard to the provision of services that span health, rehabilitation, education, and employment for persons with disabilities, the period between 2006 and 2013 was notable for its lack of formulating a comprehensive and consistent approach. Teachers, parents, and persons with disabilities indicated that approaches were fragmented, and each school had a different level of readiness.

Throughout my discussions, it was clear that there was a gap between what the public sector agencies said they were doing and the type of services and opportunities that children with disabilities and their parents actually received. This highlights the importance of advocating for and enforcing basic functionings to ensure the provisions outlined in Federal Law No. 29 are actually enforced and disability rights are achieved in the UAE.

This chapter also underscored the impact of participation and awareness on the ability of a society to create policies and implement plans that affect persons with disabilities that actually consult and include them in that process. Everyone should have the opportunity to participate in civil society and decision-making should include the consultation and leadership of those that the decisions most affect. When it comes to urban planning and ICT, persons with disabilities have a lot to gain but also a lot to lose from policies that ignore them entirely or do not adequately include them in their development.

Key to addressing these challenges is the development of strong awareness among the public of the effects that urban planning, policy, or design can have on the prospects for marginalized people in society to live independent and fulfilling lives. There is, however, evidence that attitudes in the UAE are shifting in a positive direction toward this greater awareness and understanding of how cities can be improved to benefit a greater number of people. As these attitudes continue to evolve and the built environment of the UAE continues to be transformed, greater freedoms for individuals will be realized. This will affect not only how people can make use of urban space but also directly affect the number of people able to actively participate in civil society, seek meaningful employment, and contribute to the cities in which they live.

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#### CHAPTER 6

# Laws, Rights, and Norms

**Abstract** Legal systems reflect the cultural norms that shape laws with respect to disability and access. By taking a theoretical and empirical approach to disability rights, it is possible to assess how basic functionings and freedoms are affected by laws, rights, and norms. This chapter examines how the Convention on the Rights of Persons with Disabilities (CRPD) and Federal Law No. 29 differ significantly in their approach to social inclusion (i.e., social protectionism vs. human rights) and assesses what levels of progress were achieved in the implementation and enforcement of the national laws at local levels. In many instances, Federal Law No. 29 can be seen to have fallen short of the guidelines outlined by the CRPD. At a fundamental level, the federal law characterizes disability as a failure in the capacities of the individual regardless of their environment. A clear example can be seen in the federal law which emphasizes a protectionist approach to independent living and community involvement, in stark contrast to the CRPD's Article 19 that outlines a rights-based model. Dubai's local-level law on disability passed in 2014 presents a strong alternative by shifting the focus to rights, equity, and access.

Keywords Federal laws of the UAE • Local authorities of the UAE

- Institutional capacity Rights-based policies in the Middle East
- Barrier-free Accessible Inclusive Urban planning Human rights Urban transformation Leadership Disability strategy

### Introduction: From Theory to Global Framing

I now transition to another important element of my framework. In addition to an analysis of basic functionings and freedoms, there are various pillars that serve as evaluative criteria for assessing progress on disability rights. These five pillars are laws, rights, and norms; executive and budgetary support; administrative and coordinating capacity; attitudes and beliefs; and representation and participation. In the next two chapters, I will address each of these significant pillars and explore how they help frame a broader understanding of disability in the UAE and other parts of the world.

In this chapter, I explore the concept of legality and its role in disability justice in the context of the UAE. Legal sources help illuminate how cultural forces shape inclusive laws with respect to disability and access. In this sense, critical legal theory provides a useful framework to analyze various manifestations of legality that assume authority, politics, immutability, and neutrality are all-natural products of a legal order. Critical legal theory also questions the epistemologies and genealogies of intellectual history that dominate our ways of understanding legality.

# LEGALITIES AND ACCESS TO JUSTICE

Boyle (1985) addresses legal realism by explaining and critiquing modern European social and cultural schools of thought, whose impact continues to influence what we consider to be possible within legal systems. He proposes a definition of legal realism as the interpretation of legal systems as subjective entities whose inconsistencies are a product of legal actors' socio-political-economic contexts. Marxist legal scholars condemned legal systems for the ways in which they functioned as a cultural apparatus of the superstructure, that is, the mechanisms by which the desires and needs of the ruling economic class were facilitated and coordinated. Furthermore, a tension arises in legal scholarship when attempting to study the nature of legality: on the one hand, there exists a structural master narrative that lawyers and all others only serve to articulate. On the other hand, legality may be interpreted as a phenomenological construct in which judges and other legal actors must symbolically and individually interpret and understand the codes and texts that, in turn, reshape legal systems.

Calabresi (2003) analyzes legal thought by categorizing the field into four approaches. In doing so, he asserts that legality must be studied in conjunction with other frameworks and disciplines. The legal system, Calabresi argues, perpetually integrates values exogenous to systems of

legality via legislature or groups of people rather than purely by legal scholars. This gives an insight into the field of legal studies as neither predictable nor strictly coherent; the exogeneity of cultural and social values continuously alters the legal system through complex mechanisms not just limited to legislatures. The normative legal approach emphasizes the enforcement of rights via institutions, while neglecting the role of values within legality.

For people with disabilities in many parts of the world, institutions and the systems of legality have failed to adequately account for disability justice. Throughout the world, seeing justice or injustice in the context of disability becomes a key element in the process of individual or collective empowerment. As such, legal analysis should focus on the capacity of institutions to reform or reinterpret legal norms. Deemphasizing a positivist tradition and unveiling the role of norms and ideologies pushes for a separation of the study of rights from the study of value formation in legal systems. Understanding the underlying values of a legal system thus allows for a new range of institutional approaches to unfold.

Kratochwil (1991) takes a more specific approach, addressing the role of norms and rules on international laws. He claims that norms are shortcuts for human behaviors because they inform our reasoning processes. Kratochwil contends that laws are characterized by practical reasoning, which is in turn informed by normative contexts. He argues that norms are in place to "simplify choices for actors with non-identical preferences facing each other in a world characterized by scarcity" (13). Emphasis is on the ways in which the role of norms is analyzed by reshaping underlying assumptions and premises of previously utilized frameworks and practices. Thus, we can rethink the use of normative language and the rhetorical processes that inform it in order to understand the implications for the legal system. Kratochwil illustrates how the reasoning processes behind norms and rules are manifested in the production of laws both domestically and internationally. We must, therefore, reemphasize the role of normative and deliberate language toward the ends of producing inclusive and equitable laws.

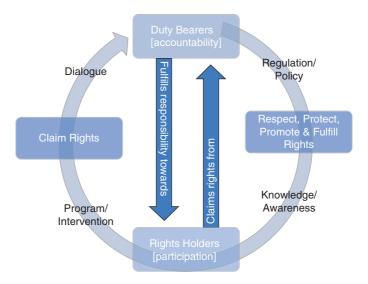
# Treaties and Sustainable Development Goals: CRPD and SDGs

Persons with disabilities continue to face discriminatory practices and systemic, attitudinal, and environmental barriers in police and judicial systems that prevent their full access to justice. There is also a lack of disability

awareness among the police, legal officers, and laws that limit their legal capacity and equal recognition before the law. These pervasive barriers exist while persons with disabilities are at a higher risk of violence and discrimination and thus have higher needs for justice.

Norms and standards relating to access to justice for persons with disabilities are set out in a series of binding and non-binding instruments at international and regional levels. States ought to explore the barriers to justice that persons with disabilities face, and set out legislative approaches to overcoming them. Finally, states need to identify rights holders and duty bearers in relation to persons with disabilities and assess their capacity to promote the full realization of disability rights (Fig. 6.1).

The Convention on the Rights of Persons with Disabilities (CRPD) explicitly applies the right of access to justice in the context of disability. Specifically, Article 13 of the Convention directs State parties to ensure effective access to justice for persons with disabilities on an equal basis with others. It also includes the provision of specified accommodations that facilitate their effective role as direct and indirect participants such as the appropriate capacity building measure for those working in the field of



**Fig. 6.1** Diagram showing duty bearers fulfilling responsibilities to rights holders through regulatory policy, knowledge and awareness, program interventions, and dialogue. Through these steps rights holders can claim their rights

administration of justice, including police and prison staff. Provisions of the CRPD beyond Article 13 are also relevant to access to justice. They outline requirements to ensure equality and non-discrimination; equal recognition before the law; liberty and security of the person; freedom from exploitation, violence, and abuse; and respect for private and family life.

# THE LIVED EXPERIENCE OF DISABILITY IN THE CONTEXT OF BASIC FUNCTIONINGS

### Post-2013 Approach to Disability Inclusion

The remainder of this chapter illustrates how norms, discourses, social understanding, and the lived reality of persons with disabilities were shaped by the implementation of Federal Law No. 29. In the following sections, I look at how the implementation of the law as well as the commonly identified lack of means to enforce it, influenced a range of different sectors within UAE society in respect of the four basic functionings: health, rehabilitation, education, and employment. I then discuss how the implementation of the law impacted on the five basic freedoms: public and political participation, community and independent living, awareness, accessibility, and mobility.

Under the auspices of the My Community a City for Everyone initiative and in support of Federal Law No. 29, H.H. Sheikh Mohammed bin Rashid Al Maktoum, Vice President and Prime Minister of the UAE, issued Dubai Law No. 2 of 2014 for the protection of the rights of persons with disabilities in the Emirate of Dubai. The law was developed to demonstrate that persons with disabilities are entitled to all the rights prescribed to them, that they are respected and treated with dignity, and that their potential as empowered and productive members of society is recognized. The law calls on all concerned parties in Dubai to provide essential and basic services to all persons with disabilities such as the following: affordable healthcare and rehabilitation services; inclusive quality education at all stages; public services, which includes the use of roads and public transportation; facilitated access to public amenities; and ensuring that their surrounding environment is easily accessible. The Dubai law is also aligned and in accordance with the UN CRPD (2006), ratified by the UAE in February 2008.

The new law and "My Community" initiative stipulated the establishment of the Higher Committee for the Protection of the Rights of Persons

with Disabilities to be led by H.H. Sheikh Mansoor bin Mohammed bin Rashid Al Maktoum. The aim of this committee was to implement the articles of the local law and supervise the implementation of the Dubai Disability Strategy (DDS) 2020 that outlines the role of private and public sectors and civil society institutions in supporting and implementing this strategy along with its requisite objectives, goals, and strategic direction in transforming Dubai into a disability-friendly city by 2020. Government entities, committees, and offices in Dubai have combined their efforts to help develop successful, tangible, and practical steps to support the related legislations and laws.

In 2017, the UAE Government launched the UAE National Policy for Empowering People of Determination. The policy aimed to promote an inclusive society by referring to people with disabilities as "the determined ones" and establishing an advisory council along with dedicated official representatives in government institutions. Not dissimilar to the Dubai Strategy, the Six Pillars of the National Policy address health and rehabilitation; education; vocational rehabilitation and employment; outreach; social protection and family empowerment; and public life, culture, and sports.

### From a Medical to a Rights Model in Health and Rehabilitation: Seeking a Cure or Ensuring Rights?

The CRPD stresses that persons with disabilities have a right to the same range, quality, and standard of free or affordable healthcare as provided to other persons. Additionally, the CRPD mandates states to provide health services needed specifically because of their disabilities. These include early intervention and services that aim to minimize and prevent further disabilities, which are especially important for children and the elderly (Article 25[b]). In contrast, Federal Law No. 29 limits most provisions of health to UAE nationals with disability categories that have been "qualified" and defined by the government. When a state demarcates disabilities as qualified or unqualified, they help define or limit the range of rights that are afforded to qualified individuals.

In signing the CRPD, the UAE was agreeing to ensure that health professionals in the UAE help raise awareness of the human rights, dignity, and needs of persons with disabilities through training and the promulgation of ethical standards in healthcare. In contrast, Federal Law No. 29 lumps the notion of awareness raising into early detection and diagnostic

program development, remaining silent on much of the substantive and meaningful legislative content that could direct tangible change. An example of this can be seen in the area of protecting patient rights. During a focus group discussion, participants complained that the UAE has no strong provisions for patients' rights. A young woman with a disability named Fatima stated that "if consenting family members and healthcare professionals have low expectations about a disabled woman's ability to marry, she may be sterilized with the consent of her father." Focus group participants thus stressed that such failures in legal protections of patients with disabilities needed to be addressed.

### The Building of Inclusive Education Systems for All

With Dubai's plans to be one of the world's most accessible cities by 2020, the Knowledge and Human Development Authority (KHDA) launched the Dubai Inclusive Education Policy Framework in 2017. It outlined ten standards for inclusive education that need to be implemented in all Dubai private schools by 2020 and required schools to allot a specific budget for facilities and resources to realize the goal of providing inclusive education for all students in private schools. Fees, which were once double or triple the cost of enrollment for children with disabilities depending on the nature of the need, must now be reasonable and reflect respectable value for the money designated by efficiency of delivery and effect on student results.

### Dubai Inclusive Education Policy Framework: Ten Standards for Inclusive Education

- 1. Identification and Early Intervention
- 2. Admissions, Participation, and Equity
- 3. Leadership and Accountability
- 4. Systems of Support for Inclusive Education
- 5. Special Education Centers as a Resource for Inclusive Education
- 6. Cooperation, Coordination, and Partnerships
- 7. Fostering a Culture of Inclusive Education
- 8. Monitoring, Evaluation, and Reporting
- 9. Resourcing for Inclusive Education
- 10. Technical, Vocational Education, and Training (TVET) Higher Education and Post-School Employment

In line with international conventions, treaties, and goals such as the CRPD and the Sustainable Development Goals (SDGs), the efforts toward building an inclusive education system in Dubai will require the development of new policies and mechanisms to improve the currently weak infrastructure. Such efforts ought to be grounded in the firm belief that:

- all children can learn and have the fundamental right to an education in the least restrictive environment providing equal opportunities;
- school systems ought to be able to educate learners with appropriate support mechanisms; and
- all benefit from a better quality of education, as improvements are realized.

### A Journey from Social Burden to Human Capital: Attaining Gainful Employment

Although employment discrimination based on disability is prohibited under Federal Law No. 29, little has been done to spell out specific provisions. The language used in the law is ineffective—as indicated by phrases such as "Special needs shall be taken into account upon undergoing the tests of competency to have the job for people concerned with the provisions of this law." The malleability of the language used here, that seems to encourage vague interpretation as a substitute for clear direction, is unfortunate and is detrimental to the supposed goals of the law.

Federal Law No. 29 does not characterize disability as a failure in agency but as a failure in the functions of the individual irrespective of their physical or social environment. The law is thus based on the medical model and stipulates that responsibility for employment issues should rest not with the Minister of Labor but with the Minister for Social Affairs/Community Development. It mandates the Minister for Social Affairs/Community Development with developing additional regulations with other concerned authorities. What is needed is increased coordination and discussion on the issue from a policy perspective.

Article 18 of Federal Law No. 29 clearly states that future legislation will regulate "the working hours, vacations and the other terms related to the work of persons of determination." The law states that at the recommendation of the Minister of Social Affairs/Community Development, the Council of

<sup>&</sup>lt;sup>1</sup>The problem with this statement is that the Minister for Social Affairs cannot develop regulations for nor regulate with authority for the Ministry of Labor.

Ministers will at a future date discuss and decide upon the specific quota of persons with disabilities to be employed. These provisions are hinted at in Article 27 section 1(h) of the CRPD but disability rights scholars generally discourage the use of quotas.<sup>2</sup>

Dubai has an opportunity to protect the employment rights of persons with disabilities if it sets a standard definition that discrimination against persons with disabilities will not be tolerated and will be punishable and enforced by fines. Shortcomings of such programs are that although promotions do exist, protections do not. Ensuring the rights through fines, penalties, and administrative injunctions is the missing key. The law is silent on these points. As such, Federal Law No. 29 should be amended to include the proper incentives and penalties. Specific injunctions should be stipulated for monitoring and enforcing the implementation of the law.

# THE LIVED EXPERIENCE OF DISABILITY IN THE CONTEXT OF BASIC FREEDOMS

### Post-2013 Approach to Disability Rights

Community and Independent Living in the Context of a Collectivistic Culture

Federal Law No. 29 is relatively silent on supporting persons with disabilities to live in the community with choices equal to others. In the UAE, persons with disabilities do not currently have access on an equal basis with others to housing and community-based services. The issue of independent and community living is based on the fundamental choices that persons with disabilities have or should have relative to where they live out their lives. In the UAE, people with disabilities are not obliged to live in a particular living arrangement. Specifically, Article 9 specifies that individuals with disabilities should adapt himself or herself to integrate into society. The legislation characterizes the disability as occurring within the individual, irrespective of the individual's environment, instead of characterizing the disability as a failure in agency of the individual due to barriers in the physical and social environment.

<sup>&</sup>lt;sup>2</sup>Temporary special measures can be adopted to redress the past disadvantage of persons with disabilities but which may be intended to operate only for a period of time. For example, a government might set targets or quotas for the employment of persons with disabilities with the goal of removing the quotas once the targets have been achieved. See <a href="http://www.un.org/disabilities/default.asp?id=236">http://www.un.org/disabilities/default.asp?id=236</a>

Federal Law No. 29, Article 9, takes the protectionist/rehabilitative approach to disability in contrast to Article 19 of the CRPD that is oriented around a rights-based model. Although Federal Law No. 29 could be improved by adopting the rights-based capability model articulated in the CRPD, the failure of the UAE to successfully implement Federal Law No. 29 in relation to independent living has more to do with the Council of Ministries and their delegates (established training centers and institutions) who are supposed to be taking the lead. Federal Law No. 29 should be amended to specifically provide for increasing choices to the manner in which persons with disabilities can live so that they may realistically be able to choose to form their own families or living near their families but independent of them.

Between 2006 and 2014, persons with disabilities did not live independently and were not being actively included in the community. This could be the result of the lack of support services and the cultural, political, and economic structures that define disability and citizenship. Like in other parts of the world, substantive citizenship in the UAE is afforded to an Emirati male that is employed or financially independent and has the capacity of forming a family. Substantive citizenship is more difficult for unmarried local women, older persons, and persons with disabilities. It is nearly impossible for foreign nationals to attain. This clear demarcation of citizenship and culture is indicative of the spectrum of salience between the international norms of the CRPD, the national norms of Federal Law No. 29, and the domestic norms of Arab culture and family tradition. Laws, culture, and politics all play a role in defining the social position of persons with disabilities and other marginalized groups. Their emancipation, therefore, depends on the restructuring of imaginaries and narratives around autonomy, human agency, tradition, religion, politics, and power. Awareness and attitudes are key factors in this social transformation.

The DDS recognizes the need to establish Centers for Community/ Active Living (CCL) with the aim that such platforms may promote leadership, representation, and universalized disability awareness. To date, however, the charged Community Development Authority has not commenced the planning of such critical service delivery. This requires that it be able to promote self-advocacy and share knowledge of all available programs/opportunities via the ongoing exchange of information with others CCLs in the region and around the world. I certainly hope that by 2020, Dubai will embark, if only on a modest scale, on a center that can serve as a hub for exchange at a minimum and as a catalyst for empowerment and self-advocacy at best.

# A Voice of Determination to the Once Voiceless: A Paradigm Shift in Disability Awareness and Advocacy

Article 8 of the CRPD on awareness-raising is considered by international disability rights scholars as being key to facilitating education, employment, accessibility, political and public participation, and other rights. As I have mentioned previously, Federal Law No. 29 heavily embraces the medical model of disability and thus does not characterize disability as a fundamental failure between the agent and their physical or social environment; instead, it characterizes disability as being the property of an individual. A person with a disability is understood by the law to be a deviation from the norm, thus needing rehabilitation to integrate into society. This is evident in the manner in which awareness raising is dealt with in Federal Law No. 29. The law does not raise this issue as a separate article but instead mentions it in the context of health. Article 11 states that awareness raising must concern itself only on the types of impairments instead of on the types of physical and social barriers that exist in society. The law thus understands the disability to be the property of an individual independent of their physical and social environment. Article 11 goes on to state that awareness raising should be the responsibility of the Specialized Committee on health. This statement is incongruous with the spirit of awareness raising that is reflected in Article 8 of the CRPD that states that awareness raising should be focused on providing equal opportunities in every aspect of life. Article 8 states that efforts should foster respect for the rights and dignities of persons with disabilities.3

Federal Law No. 29 should be amended to mandate specific efforts in the area of awareness such as awareness training and the role of the media in promoting rights and dignities but failed to do so. Rights promotion is raised in Articles 3 and 4 of Federal Law No. 29 and Article 39 states, "This law shall be published in the official gazette" (2006). Hence the law also fails to indicate who besides the Ministry of Social Affairs shall promote the law and specify the ways it is to be promoted.

In line with the explicit Dubai Law No. 2 statement that respective authorities "will have the duties and powers to: raise awareness in society of the rights of Persons with Disabilities under this Law and the legislation in force, and organize the awareness and education activities and campaigns

<sup>&</sup>lt;sup>3</sup>Federal Law No. 29 could have mentioned awareness training and the role of the media but such efforts can be further stipulated in regulations or standards issued by the Council of Ministers

required for this purpose," the Executive Council's Department for the Policies and Programs for the Rights of Persons with Disabilities launched a wide-scale awareness campaign designed to normalize disability and bring the lived experiences into the normal spheres of life—from home life and parenting to sports and cultural events, education, and work environments. Data from the Dubai Social Survey on the public perception of disability from 2015 to 2017 documents a 10% average increase in awareness of the issues people with disabilities face in daily life to the belief that people with disabilities should be included in society.

The declaration in 2017 by the leadership that people with disabilities ought to be addressed as People of Determination shook the community to the core. Evidence of the transformation was evident in language and signage, propelling retailers among others to put the statement of declaration in public spaces such as public beaches and malls, banks and schools.

### Universal Accessibility and Mobility on Paper and in Practice

Article 23 of Federal Law No. 29 delegates the authority for promulgation of building codes and implementing them (i.e., monitoring and enforcement) to the Council of Ministers. However, the Council of Ministers has not taken action on this specific mandate and a national building code that would accommodate the needs of persons with disabilities was never developed. This is politically challenging since each emirate has near-complete autonomy on land use and real estate development. However, the failure to develop the building codes was in violation of Article 23 of Federal Law No. 29. The delay to draft a unified set of federal building codes would also postpone efforts to effectively monitor and enforce Federal Law No. 29. Without monitoring and enforcement, Federal Law No. 29 had no real efficacy.

Article 23 could have provided a framework for developing regulations that are based on inalienable rights rather than simply protections. Unfortunately, it does not. The drafters of Federal Law No. 29 did not see disability as a dynamic context-specific experience, where the environment played a key role in limiting an individual's choices and opportunities. The drafters of Federal Law No. 29 understood disability only in medical or essentialist terms, placing the lived experience of disability squarely on the individuals irrespective of their environment.

Federal Law No. 29 also falls short in describing how access is to be achieved. By comparison, Article 9 of the CRPD specifically notes that the

identification and elimination of obstacles and barriers to accessibility shall apply to a wide variety of areas. The CRPD also specifies that accessibility should include information and communication as well as other electronic services. Despite this, Federal Law No. 29 is silent on access to information, digital services, and other key aspects of the country's future development.

Dubai Law No. 2 stands strong in its objective to provide "Accessible Environments to ensure that Persons with Disabilities enjoy all their rights under the legislation in force," with explicit mention of access to places of worship and to public places; using roads and means of public transport. In an attempt to meet the obligations set in the law, the Higher Committee appointed the Dubai Municipality and the Road and Transport Authority to develop the Dubai Universal Design Code to define how the built environment and transportation systems in the Emirate will be designed, constructed, and managed to enable one to approach, enter, use, egress from, and evacuate independently, in an equitable and dignified manner, to the greatest extent possible, in line with the Universal Design concept.

In 2017, the Government of the Emirate of Dubai began to implement the Dubai Universal Accessibility Strategy and Action Plan (DUASAP). Fifteen relevant governmental and semi-governmental local entities in Dubai were mandated to prepare a three-year (2018–2020) sectoral implementation plan to retrofit existing buildings, infrastructure, and facilities to ensure a barrier-free and fully inclusive physical environment. The ten priority sectors include Education, Healthcare, Recreation, Culture and Arts, Sports, Religious Services, Transportation, Retail and Commercial services, Justice and Judicial Services, and Tourism. The Global Alliance on Accessible Technologies and Environments (GAATES), an international non-profit organization that promotes the accessibility of technologies and the built environment, was directly involved in the development of the policy. Using five strategic elements, Dubai has moved quickly to transform its infrastructure (built environment and public transportation) by 2020, ensuring that its code is enforced and implemented.

Mobility is mentioned in Article 20 of the CRPD and is referred to explicitly in Article 10 of Federal Law No. 29. Both articles cover assistive devices and mobility aids such as wheelchairs. Again, Federal Law No. 29 takes a medical approach in identifying a series of medical conditions that limit an individual without taking into account the individual's environment. The CRPD approaches the right to mobility in a way that characterizes the disability as being relative to the individual's social or physical

environment. Federal Law No. 29's emphasis on training should be directed not only toward persons with disabilities but also to staff, encouraging technologies that are facilitated at a time and manner of choice by the person with disability. Some efforts in this regard include innovations, hack-a-thons, and the deployment of wayfinding apps and specialized services such as Be My Eyes, or Aria that could transform mobility. In conjunction with the universal design standards, technology and mobility training for people with disabilities could open new possibilities for more equitable public participation for all.

### Conclusion

Legal systems reflect cultural and societal norms that shape the laws that are developed with respect to disability and access. Reemphasizing the original theoretical approach to disability policy and rights, I have discussed the importance of basic functions and basic freedoms to inform my framework and examined how laws, rights, and norms are all affected by the basic freedoms and functions.

It is telling that between 2006 and 2014, disability was continuously characterized as a failure in the capacities of the individual regardless of their environment. Regulatory mandates were slow and ineffective, and by 2014, the Emirate of Dubai took on a unique role in spearheading the Dubai Disability Strategy to advance on the local level a range of disability programs and policies that would go beyond Federal Law No. 29 and provide a functioning framework for sustainable progress. Ultimately, the contrast in the way independent and community living is understood emphasizes the challenges of eliminating the protectionist approach to care and the cultural and institutional challenges of developing substantive citizenship for persons with disabilities based on inalienable rights and not a clientelistic social order dependent on relations of political patronage.

In many instances, Federal Law No. 29 falls short of assuring basic rights. For example, accommodations for those with disabilities are not defined and specific requirements or guidelines required by the CRPD are missing from the law. Federal Law No. 29 has, in practice, denied persons with disabilities the opportunity for an equal standard of education, an equal standard in employment, and an equal standard in access. This is not to deny the great advancements and achievements of Dubai and diminish its place among the most accessible and inclusive cities in the region, but rather to highlight a missed opportunity.

Dubai has made concerted efforts to align its strategic objectives with the global agenda. In fact, the leadership in Dubai has a vision and commitment to ensure that Dubai is transformed into a disability-friendly city by 2020. The inspired vision is to make Dubai an inclusive, barrier-free, and rights-based society that promotes, protects, and ensures the self-determination of people with disabilities or, as aptly reframed in October 2017 by H.H. Sheikh Mohammed bin Rashid Al Maktoum, the Vice President and Prime Minister of the UAE and Ruler of Dubai, "People of Determination."

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### CHAPTER 7

# Laws Are Not Enough: Unlocking Capabilities Through Innovations in Governance

**Abstract** Many factors beyond the legal system determine the ultimate success or failure of implementing comprehensive accessibility policies and programs. There are two main drivers for inclusive urban development: political commitment to inclusive practices, and the mechanisms and institutions needed to administer and facilitate them. This chapter explores how the narrative and conditions that determine equity and access in cities are shaped. There is a clear need globally to strengthen administrative and coordinating capacities and improve connections between cities and their citizens. This chapter highlights the importance of creating and disseminating information regarding accommodations, assistive technologies, and training throughout schools, community centers, advocacy organizations, and other social institutions. It defines leadership (executive and budgetary support), institutions (administrative and coordinating capacities), attitudes (beliefs), and participation (representation) as central evaluative criteria for evaluating progress at the local level. It also highlights how attitudes and cultural beliefs may produce negative associations of people with disabilities by assuming high dependency and individual fault, rather than pursuing policies aimed at equity, access, and inclusion.

**Keywords** Evaluative criteria for inclusion • Leadership • Institutional capacity • Budgetary support • Participation • Representation of people with disabilities • Public administration • Equity • Access • Inclusion • Attitudes • Beliefs

### WHY LAWS ARE NOT ENOUGH

Many factors feed into defining success or failure when deploying a comprehensive policy or program on access and inclusion. In this chapter, I explore how leadership (through executive and budgetary support), institutions (through administrative and coordinating capacities), attitudes (and beliefs), and participation (and representation) shape the narrative and conditions that determine equity and access in cities.

### Understanding the Role of Leadership

Leadership in this section is defined through executive and budgetary supports. Public administration theories have had a large impact on executive and budgetary support literature. Wildavsky (1986) and Baumgartner et al. (2014) tackle the fluidity of the policy process and how individual and collective actions shape institutions and budgets. Wildavsky develops a cultural and normative theory of budgeting and uses comparative examples of various levels of analysis to construct explanations for how budgetary processes interact with other political domains. An important premise of his argument is that political cultures contextualize and embed preferences about ways of organizing social activity and, hence, different budgetary behaviors. In other words, resource allocation in any given context epitomizes the prevailing structures and modes of power. He emphasizes the multi-faceted importance of budget and monetary allocations such as enabling public policies, program implementation, and budget constraints. Wildavsky additionally observes that resource scarcity structures political and collective actions and that a budget is more than "a mechanism for allocating resources," with "the aim to obtain desired objectives at the lowest cost...and for pursuing efficiency" (8). Instead, budgets also structure social value and replicate valued social processes. Ultimately, Wildavsky argues that analysis of a governing body's budget allocation can serve as a lens to examine the dominant cultural and ideological imaginaries (zeitgeist) as manifested through political choices and mechanisms for shaping social life.

Baumgartner et al. build upon punctuated equilibrium theory to develop insight into the broader policy process. Punctuated equilibrium theory emphasizes how the evolution of public discourse affects the acceptance or rejection of the status quo; this allows for examination in opportunities for policy change or reversal. The theory utilizes a multiple streams

framework to contextualize policy within a process. For Baumgartner et al., this contextualization to a great extent defines what is created by explaining how policies are conceptualized, measured, and executed. However, neither Wildavsky nor Baumgartner et al. raise the issue of social value creation explicitly. They do, however, agree that stability and change in public policy preferences (unlike previous theories) is shaped by shifting social and political tides that adapt to change in the public understanding of existing social problems. Both Wildavsky and Baumgartner inform our understanding of executive and budgetary support and allow us to conceptualize how the allocation and distribution of power and wealth can contribute to fostering more equitable and inclusive outcomes for persons with disabilities and other marginalized groups.

### Understanding the Role of Institutional Capacity

To study the public policy process in Dubai is to study the various interactions between the actors, agents, beneficiaries, and exogenous events that all affect policy creation and outcomes. The role of civil society in shaping the dominant cultural configurations in the pursuit of building the elusive "inclusive city" is increasingly important. However, in a place where social or advocacy groups are not organized, underfunded, or weak, we must resort to understanding public sector institutions and their capacity to act.

Civil society organizations engage in advocating for the rights and wishes of the public. For people with disabilities, local organizing is very important. Civil society groups in many countries work with governments to deliver services and contribute solutions to inequalities across diverse areas; from training to transportation. Organizations run by individuals who live with disabilities carry influence and can help mobilize allies to help foster greater commitments.

Administrative and coordinating capacity is particularly important in Dubai considering the breadth and scale of social, economic, political, cultural, and technological changes that have shaped the twenty-first century. These huge shifts bring forth new needs, new capabilities, new risks, and new rewards. Due to these emerging complexities, Farazmand (2009) argues that the uncertain nature of the global environment indicates that traditional approaches are unable to meet many of the new challenges ahead. Public administration increasingly has to be rethought, both in its processes and outcomes.

Farazmand emphasizes the role of adaptive strategies to foresee and mitigate dynamic and unpredictable changes. He asserts that strengthening the public sector and its services "must be done externally through laws, legislation, and reclamation of the appropriate role for government as the guardian of society in domestic and international affairs...[as well as] internally by engaging citizens, community organizations, and other organizational institutions in governance and administration..." (1012). Thus, Farazmand calls for greater flexibility in both the public sector and civil society. Transparency is a crucial component of this strategy; it considers the importance of citizen participation, trust, and confidence in governmental practices.

Schout and Jordan (2005) examine the strength of coordinating capacities in the European Union (EU) by examining environmental policy. By analyzing the EU's governing system, he sheds light on the EU's self-interpretation of governance as loose centralization and emphasis on network-led steering via self-organization of administration. However, the author indicates that administrative capacities diminish because of challenges to coordination. He suggests an emphasis on strengthening secretarial roles to scrutinize relevant agendas, monitoring of progress, and auditing of required administrative capacities at multi-sector, multi-state levels of governance.

It is important to strengthen administrative and coordinating capacities to improve services for people with disabilities. In addition, the accessibility of information regarding service providers is crucial to addressing a range of barriers. Unfortunately, however, supervisors and leaders often lack the knowledge and awareness to accommodate services for those with disabilities. For example, the final report of the Jumpstarting Inclusive Education Workshop held in the UAE recommended continued training with groups of principals, supervisors, and teachers to strengthen their existing knowledge. This would allow them to learn how to better accommodate and support effective education and inclusion of persons with disabilities.

The lack of awareness in employment services is the result of ineffective coordination between direct agencies and bureaucracies. This is typically caused by ineffective coordination between bureaucracies. In addition, the pervasive role of ableism and cultural negativity affects capacities for self-representation and the voice of people with disabilities. Thus, in order to meet standards for basic freedoms and functions, there needs to be an increase of internal capacities for administrators and bureaucrats to address the needs of persons with disabilities.

### Understanding the Role of Attitudes and Beliefs

Attitudes and beliefs are important to disability policy and inclusion because they directly and indirectly shape courses of social action. Political attitudes and cultural beliefs typically produce and reproduce negative associations of persons with disabilities by superficially assuming high dependency and individual fault (vs. policies that are aimed at empowering).

Several authors have looked at the role that attitudes and beliefs play in regard to disability policy. This includes observing how increased levels of inclusion occur due to the ways in which they directly and indirectly determine courses of social action. Albarracín et al. (2005) identify three factors that interchangeably influence attitudes. These are termed affect, beliefs, and behavior. Affect is the moment of initial impact and feeling that people experience given any set of objects or events. Beliefs are mental shortcuts for associating an object or event with a given characteristic. Behaviors are defined as the actions of an individual. These factors reciprocally affect and are affected by attitudes; thus Albarracín et al. conclude that attitudes are not set in stone.

Forester (1993) draws on a wide theoretical tradition to argue that the policymaker's work is a contentious political process and relies on the importance of persuasion. The author raises the question of whether "our language does not [just] simply mirror or picture the world but instead profoundly shape our view of it in the first place" (1). He concludes that policy arguments are selective, both shaping and shaped by regimes of power that include beliefs, attitudes, and values. Attitudes and beliefs shift with respect to an individual's perception of their environments. However, they are also a product of the discourses and worldviews circulated within those environments; thus, people's beliefs both shape and are shaped by the socio-cultural context in which they are embedded.

Furthermore, Baumgartner et al.'s edited collection (2014) highlights the importance of social constructs in the realm of policy creation. Social constructions can be defined as the (typically negative and unrealistic) pre-existing notions, assumptions, stereotypes, associations, and representations of groups, populations, and histories. These social constructions tend to be the product of dominant regimes of truth, or the cultural spirit of the times, circulated by discourses, social structures, practices, the media, and so on. Ultimately, these constructs manifest themselves throughout all sectors of society, including policy and law. Not only do these constructs, "impact the material welfare of target groups [in policy

practices] but [they] also influence their social reputations, political attitudes, and participation patterns" (105–106). Thus, groups lying at the margins of society (via exclusionary policy practices due to preexisting social constructs) are typically deemed unworthy of political inclusion and participation in policy.

This lack of political power decreases the likelihood of culture-wide change. Such rethinking of social constructs could occur through the implementation of policies related to marginalized groups and redefining their needs and characteristics. The author concludes that "policy designs impact public and elite opinion, the social construction of target groups, the distribution of political power, resources, and even the legitimacy of various knowledge systems" (108). With respect to disability policy, political rhetoric and cultural discourse produce negative associations to people with physical or mental disabilities by superficially assuming high dependency (vs. policy that is aimed at empowering, etc.). These arguments highlight the importance of the interchanging dynamics between beliefs and attitudes about marginalized groups and policy processes. By being inclusive with our policy processes, we can contribute to the rethinking of preexisting attitudes and beliefs about marginalized populations.

# Understanding the Role of Participation and Representation

Robust participation and representation processes are crucial to creating more inclusive and accessible policies. Fagence (1977) highlights the importance of participatory and inclusive decision-making in urban planning processes. He begins by foregrounding the importance of nuanced and cautious cultural translation of inclusive decision-making within domestic and international settings. In addition to various benefits, this ensures the unified implementation of decisions with minimization of unintended consequences via cultural barriers. Fagence paraphrases Burke (1968): "planning agencies and the general citizenry [should try] to achieve a consensual precision on the interpretation of 'citizen participation', how the concept may be operationalized, what resources will be required, what the various decision-making responsibilities will entail and where they may be properly located" (3-4). This form of collaborative planning minimizes the room for error in the conceptualization of the citizenry's desires and the actions of planning agencies.

Fagence notes that the higher diversity and decentralization of interests that are represented within planning strategies results in more innovative decisions. Methods for planning should emphasize the interaction with and creation of public consultation techniques that increase public support and participatory input. All these recommendations for citizen participation in planning purposes are crucial to our understanding of unequal power dynamics. The author points out that participatory decision-making is important for power equalization in the public sector. Systemic exclusion of populations whose power lies in the margins of society is that whose input is most crucial to planning processes.

# Leadership, Modernization, Social Protection, and Human Rights

The role of human rights in the official government rhetoric can be understood as part of the UAE's efforts at signaling modernity. Social development is a strategic objective of the UAE Federal Strategy and as such state development is linked to achieving the nation's social development goals. Social development is linked to the Federal Government Strategy and the Federal Strategy Brief of 2007, which is fully detailed in the UAE 2021 and Dubai Strategy 2021. The Federal Strategy Brief of 2007 highlighted social development as the first of six national priorities. However, by 2013 after four years of nursing a recovering economy, it became clear that the outcomes fell short of the intended goals.

The Strategy Brief displayed a telling tagline of, "Leadership, Integration, and Excellence." Natasha Ridge, Professor at the Dubai School of Government, noted that the UAE uses a tactic she referred to as "strategic signaling" to promote or present progress to stakeholders. In essence, the government signals its intentions in priority areas through press releases, strategy documents, and public speeches. This pattern is most often seen in the social sectors (like education) where the government wants to show national and international stakeholders that the UAE can lead the discussion, that they are part of the solution, and most importantly that they should command equal respect. Ridge notes that in this case, these signaling efforts aim to demonstrate that the UAE is not a developing country but a developed country. However, when signaling changes the discourse but stalls in implementation, an additional force is needed to push it through the bureaucracies of the individual emirates.

Ridge notes that the use of signaling in promoting social development programs and social protection schemes does not directly improve lives. This fact was evident in the second focus group I held at the Dubai School of Government in 2009. Participants there shared their frustration with disability rights in the UAE. According to stakeholders I spoke to, persons with disabilities, their families, and allies felt that Federal Law No. 29 has had little to no effect on their daily lives. I was surprised to find that well over half were either unaware of Federal Law No. 29 (enacted in 2006) or did not know where to find out more about the law. This was confirmed in a national study¹ conducted with 111 persons with disabilities. The study showed that only 10% of respondents were aware of Federal Law No. 29 and only 2% of the respondents were familiar with the content of the law (Alawadhi and Mousa 2009). Almost all foreign nationals I spoke with who live with disabilities stressed their interest in better understanding the implementation of Federal Law No. 29.

Morad, a Jordanian national who uses a wheelchair, and Dana, a Syrian national who is blind, are two foreign-born residents who have disabilities and work in Dubai. Both Morad and Dana expressed their hope that Federal Law No. 29 would protect them from abuse and discrimination and ensure them equal opportunities. This attitude is in contrast to most locals with disabilities who seem to conform to their conditions.

Hussain Al Rahma is 21 and stopped walking at the age of 9 due to a neuromuscular condition. Hussain exemplifies what many other nationals with disabilities I spoke to feel. He is unable to imagine that things in his life could change and said that with respect to his rights, "things are not in my hands." Hussain's story is indicative of a general malaise and feelings of disempowerment that exist among young locals in the UAE, feelings that are amplified for those that live with disabilities.<sup>2</sup>

<sup>&</sup>lt;sup>1</sup>The study tool was an interview survey. The study was conducted in four of the largest emirates: Abu Dhabi, Dubai, Sharjah, and Fujairah. The survey was conducted by a number of specialists from the Tamkeen Center in Knowledge and Human Development Authority and the Department for Disabled Welfare Management in the Ministry of Social Affairs. The questionnaire was assessed and arbitrated by Ahmad Almulla, head of External Relations at Tamkeen Center, and Nazem Fawzi Mansour, a specialist of Disability Science and specialist of speech and language disorders in the Ministry of Social Affairs.

<sup>&</sup>lt;sup>2</sup>The story of Hussain is explored in more detail in the Community and Independent Living section in Chap. 5.

# Institutional Capabilities in the Context of Basic Functionings

# Administrating Open and Accessible Health and Rehabilitation Systems

Cultural and context-specific factors add to the complexity and unresponsiveness that characterizes the delivery system for health services in the Emirate of Dubai. Dr. Sandra Willis, who in 2010 was the Chief Advisor on Mental Health and Disability at the Dubai Health Authority (DHA), stated that the DHA was formed in 2006 as part of the process of developing a twenty-first-century healthcare system. The Dubai Health Authority's vision was stated as: "Excellence in health and healthcare in the Emirate of Dubai and a people-focused health sector in which individuals, businesses, healthcare providers and government work together to achieve world-class results." Although the vision for the healthcare system in the UAE was clear, interviews with healthcare professionals and persons with disabilities revealed that the vision was still a long way from being properly realized.

By 2012, a range of healthcare initiatives were still in their infancy. A senior official at the Dubai Health Authority confided that the health sector in Dubai was plagued by inefficiencies in scale and regulation. According to parents of children with disabilities that participated in focus groups I conducted at the Dubai School of Government, the health sector in Dubai, "is far from achieving world-class results for everyone, this is even more so for our children who have disabilities. We don't know where to go or who to see, there is very little information for us. Parents of children with disabilities are desperate in Dubai." This frustration is not a secret.

Persons with disabilities in focus group discussions suggested that the health sector is indeed relatively underdeveloped when compared to other sectors such as the economy or tourism. One local Emirati with a mobility impairment admitted, "I don't trust the local hospitals, if you need to be seen in the UAE, make sure you go to the American Hospital." People I spoke with in interviews and focus groups who had disabilities also generally seemed to favor visiting private hospitals if they could or even organizing to leave the UAE to visits experts abroad if they had the means.

For many years, the Ministry of Health has failed to provide habilitation and rehabilitation services at the earliest possible stage. Consequently, the local government of Dubai has sought to develop its own initiatives in

this area. By 2015, the Ministry of Social Affairs still did not offer sufficient habilitation and rehabilitation services based on the multidisciplinary assessment of the person's individual needs and strengths. The current habilitation and rehabilitation services are not capable of providing all of the necessary support for persons with disabilities to participate and be included in the community and in all aspects of society. Habilitation and rehabilitation services are available to persons with disabilities in local communities, including in some rural areas of neighboring emirates. Persons with disabilities usually are not informed about and do not have access to assistive devices and technologies pertaining to habilitation and rehabilitation. Rehabilitation professionals and staff do not receive comprehensive initial and continuing education and are not regulated. No minimum standards exist to license or certify who can be considered qualified to practice rehabilitation services in the UAE or in Dubai.

Interview respondents overwhelmingly confirmed that shortages in rehabilitation services were affecting individuals with disabilities and their families. Such shortages are not solely attributable to a lack of financial resources (as is the case in many developing countries) but rather to a lack of laws, political priorities, and the capacity of institutions to effectively develop and administer community-based rehabilitation programs. Dukmak's (2009) research suggests that parents have difficulty accessing rehabilitation services and that they need better access to information and knowledge about rehabilitation services in the UAE. Dukmak's recommendations are consistent with my own. Workshops are needed to show parents where to look for public services and general information. Peer support and parents support groups could also allow affected families to share experiences, resources, and information about rehabilitation services in the UAE. These could be organized to include visits to rehabilitation centers and institutions for individuals with disabilities. Dukmak's research also noted that the media plays a major role in providing information on rehabilitation services. His results show that an overwhelming percentage of parents (90.1%) felt that the media has a significant role in empowering parents.

Collaboration is needed in the working relationship between rehabilitation service providers, regulators, and parents. Service providers have identified many barriers in providing services for individuals with disabilities, including policy and administrative issues, lack of resources and service availability, lack of community awareness and involvement, and culturally sensitive service provision. Parents, on the other hand, should

be given an increased influence regarding the rehabilitation services provided to their children. As such, the status of rehabilitation still falls short of allowing persons with disabilities to attain and maintain maximum independence: full physical, mental, social, and vocational ability; and full inclusion and participation in all aspects of life. Such should be the goals of the Department on Disability Services at the Ministry of Social Affairs.

## An Ongoing Journey from Exclusion to Integration and Inclusion: Education Policy to Improve Educational Opportunities for All

Federal Law No. 29 and the UAE Constitution provide persons with disabilities the right to education. Nonetheless, federal laws and social norms still enable persons with disabilities to experience discrimination by being routinely excluded from the general education system on the basis of their disability. Both the Convention on the Rights of Persons with Disabilities (CRPD) and Federal Law No. 29 have requirements ensuring, protecting, and promoting the right to education but the local law falls short on several fronts. People with disabilities until very recently were regularly denied the opportunity to receive a mainstream education due to a variety of physical, social, and administrative barriers.

In 2008, the Ministry of Education (MOE), under the leadership of Dr. Hanif Hassan, launched a campaign for inclusion in schools under the "School for All" slogan and established the Department of Special Education. The National Project for the Inclusion of People with Special Needs (2008) focused on environment, facilities, and equal opportunities. Fifteen public and private schools participated and 50 students with special educational needs and disabilities enrolled in mainstream schools. The project yielded variable results due to a variety of reasons including limited resources, human capacity, and specialist support. Ultimately, the project resulted in 12 students with hearing impairments being sent abroad to study and 20 students placed in employment. The project is now expanding to the rest of the UAE. As of 2015, 156 public schools across the UAE participated in the project. Supported by Her Highness Sheikha Fatima bint Mubarak, the Supreme Chairperson of the Family Development Foundation and Chairwoman of General Women's Union, the National Project for Inclusion is aimed at achieving complete integration of people with disabilities into society at the social, educational, health, and environmental levels.

Education is both a federal and a local issue. On both levels and across the entire system, the provision of education is highly differentiated. It is also discriminatory toward persons with disabilities as it is inaccessible at many levels. For example, only some development skills are available to children and young persons with sensory impairments. Instead, educational efforts by the Ministry should promote independence and social development of the students with impairments. Students with disabilities should have the opportunity to learn braille or sign language in school in a manner that is appropriate and sensitive to their local culture (e.g., Arabic Braille or Arabic Sign Language). Additionally, schools routinely fail to offer options such as alternative script; augmentative and alternative modes, means, and formats of communication; orientation and mobility skills; or sign languages as required by the CRPD. Persons with disabilities do not have access to peer support and mentoring, which would help promote positive self-image and increased socialization. All such efforts should also be tracked, measured, and incorporated within a greater and legally enforced framework for creating a sustainable system for inclusive education.

Inclusive education is a system of education in which all pupils with special educational needs are enrolled in ordinary classes in their district schools and are provided with support services and an education based on their needs. Inclusive schools are based on the basic principle that all schoolchildren in a given community should learn together, so far as is practicable, regardless of their impairments or difficulties. They should recognize and take into account the diverse needs of their pupils, adapt to different styles and rhythms of teaching, and provide a quality education through the appropriate use of resources and study plans as well as partnerships with the community.

There is insufficient knowledge among teachers, principals, and supervisors about adjustments, accommodations, support, and services available to facilitate the effective education and inclusion of persons with disabilities within the general education system. International consultants have been brought in to the Ministry of Education and the Dubai Knowledge and Human Development Authority to set up plans and conduct workshops on inclusive education. Such programs are just the beginning of a long road but may prove ineffective if local capacities are not strengthened. There exists little administrative training for education and administrative staff. This lowers their ability to take on the required administrative and coordinating tasks needed.

The Ministry of Education collaborated with my organization, the Victor Pineda Foundation, to develop a pioneering program to equip educators with the knowledge and tools necessary to embark on the process of including students with a diversity of abilities in mainstream school environments (Pineda 2010). I helped run a three-day training workshop for mainstream principals, supervisors, and teachers with a team of local and international experts on inclusive education entitled, "It's About Ability - Jumpstarting Inclusive Education in the UAE" in 2009, held at the UNESCO Regional Center for Education Planning (Pineda 2010). The workshop served as a cornerstone for the deployment of the inclusive education initiative and for the implementation of Federal Law No. 29 across the entire public school system in the UAE (Pineda 2010). Through this process, we were able to map out a system-wide plan for supporting inclusive education. The workshop set out to provide participants with the ability to understand and explain the benefits of inclusion as well as the ability to identify, address, and eliminate barriers to inclusive education in their school. Additional exercises allowed teachers and principals to develop their own methods to facilitate inclusion and understand accommodations in the classroom. The workshop allowed participants to understand the difference between integrated and inclusive education and use that understanding to develop and execute a personal and communitywide plan for inclusion.

In small group settings, the principals and supervisors discussed a range of administrative challenges and opportunities. It was clear that better coordination between principals and teachers could help support better outcomes across schools. Additional resources and training could also support their teachers and allow them to deliver better results in the classroom. The teachers discussed the format and structure of teaching with an Individualized Education Plan (IEP). Participating educators then reconvened to identify barriers to inclusive education and offer solutions as a group.<sup>3</sup> According to statements made by the general teachers during the Jumpstarting Inclusive Education workshop, too many general education teachers and principals pass on the responsibility of educating children with disabilities to special education. The IEP should recommend the necessary curriculum modifications, classroom accommodations, or give

<sup>&</sup>lt;sup>3</sup>Schools (Pineda 2010). To learn more, see FINAL REPORT—It's About Ability Workshop: Jump Starting Inclusive Education in the United Arab Emirates, The Victor Pineda Foundation and Ministry of Education (UAE).

modified or alternative assessments required of both the general education and special education teachers (Ministry of Education 2009, 9).

Persons with disabilities in the UAE should be seen as assets and partners in helping to spread a culture of human rights through education. The UAE is aware that teaching and spreading the concepts of human rights is a basic human right. Other factors are related to the complexity and unresponsiveness that characterizes the delivery system for education services. Education professionals should be made aware that those individuals with disabilities, their parents, and allies need to be informed about the special education services available in the country and the importance of these services to promote inclusive education in the UAE.

By 2015, the Community Development Authority (CDA) in the Emirate of Dubai, the Department for Special Needs Services at the Federal Ministry for Social Affairs, and professionals and service providers were well aware that individuals with disabilities, their parents, and allies need continuous training and education that was based on principles of empowerment and empowerment-oriented support services. The advancement and momentum gained after 2018 with the Federal Strategy for People of Determination was a big step in the right direction. However, personal care assistance funding, peer support networks and mentoring, community-based advocacy, dialogue, and debate, as well as the provision of assistive technology and durable medical equipment that supports must continue to be strengthened to sustain and build on the progress.

# Institutional Capacity in Employment

Persons with disabilities were up until 2015 not involved in developing policies and standards in the employment sector. Additionally, the lack of role models of successful people with disabilities and the state's relatively weak engagement with policy formulation and analysis are linked to the unresponsiveness that characterizes the employment sector. Focus group participants reported issues related to discrimination in salaries that could be improved by standardization in salary structures. They also lamented a lack of access to meaningful and professional training for furthering development of self-confidence and marketable skills.

Sheikh Mohammed, the Vice President of the UAE and Ruler of Dubai, has historically personally funded vocational and continuing training programs in his emirate. Certain employment programs are provided through rehabilitation centers that receive some funding through the Federal

Ministry of Social Affairs. Vocational efforts developed through vocational rehabilitation too often fail to provide a sustainable or continuous approach to service provision.

The provision of equipment that assists persons with disabilities to gain or maintain employment is difficult to find or expensive to procure and, according to interview respondents, usually dependent on benevolence by the Ruler or other civic leaders. Assistive technologies play a key role as they can often allow people who may otherwise struggle to find employment to access a far greater variety of roles. For this reason, assistive technologies should be on the basis of the employment strategy for the UAE. The provision of transport services to allow persons with disabilities to easily travel to and from work is another strategy that can significantly improve employment opportunities.

HR professionals and mainstream training centers should be made aware that individuals with disabilities, their parents, and allies need to be educated about the professional and training services available in the country, the importance of these services for the UAE, and how to access them. Additionally, there should be more knowledge about how to identify the providers of employment and training services. Information regarding reasonable accommodations, assistive technologies, and vocational training should consistently be communicated. For those not able to work in open employment, sheltered workshops can play a valuable role in allowing people to contribute while still receiving a level of support. Clearly, these types of targeted training programs and workshop environments require dedicated funding and management to be effective but are not currently being widely supported in any meaningful way.

# Institutional Capability in the Context of Basic Freedoms

# Institutional Capacity in the Context of Public and Political Participation

In the public and political realm, the general population does not participate in any meaningful regard in the affairs of the state. And this reality is even more pronounced for persons with disabilities. The UAE is a federation of seven autonomous emirates; the seven Rulers each have total authority within their emirate. There are no elections and there is only limited representation through the development of the Federal National Council.

Additional structural and cultural factors limit the participation of persons with disabilities. These are related to the complexity and unresponsiveness that characterizes the representative legislative process and the relative control the state exerts on the third sector. Stimulating growth of the third sector would provide additional impetus for a variety of activities. The state is apprehensive of this and as such has created specific channels from which to regulate non-profit organizations.

Dubai runs one of the most open and transparent governments in the region. There are measures in place to prevent discrimination against persons with disabilities but the higher councils are organizations of the government. Barriers to participation in public office are more the result of the political system than particular discrimination. In the government's new expansion and trial of publicly appointed representatives, there is room for supporting or appointing a candidate with a disability to serve on the 40 member Federal National Council. Such action would show that marginalized populations have representation in governance and can make contributions to their country. It would also demonstrate the gradual evolution of the UAE's commitment to democratic processes. Measures taken to encourage participation have failed because of a lack of leadership and because involvement did not apply to all persons with disabilities. The state's lack of engagement with civil society organizations across and beyond the three main categories of impairments (auditory, visual, and physical) and the overrepresentation of parents and underrepresentation of self-advocates provides inadequate representation of interests and results in a sub-optimal process and outcome for all.

From my experiences living and working in the UAE as well as conducting surveys and focus groups in the region, it is evident that disabled people are still viewed by many as outcasts and outsiders. Many consider them to be different and possibly even irresponsible or incapable of carrying out public responsibilities on an equal basis with the general population. This relative distrust of persons with disabilities directly affects the opportunities afforded to them in the area of political and public participation, lowering the general public's expectations of their achievements and indirectly limiting their engagement with public affairs.

In general, professionals should be made aware that more education on the rights of persons with disabilities is needed, particularly for parents, allies, and community members and that such information and understanding of rights is especially important for the individuals themselves. Information regarding basic rights can be communicated through mass media, rehabilitation centers, health clinics, special education centers and schools, ordinary schools, community development authorities, local advocacy organizations, parents' associations, independent living centers, telephone hotlines, and family physicians. However, the UAE limits the ability of civil society organizations to carry out activities or campaigns without government approval. It is illegal to assemble and form civil society organizations and obtaining these licenses can be difficult and costly for persons with disabilities.

A unique way to stimulate representation would be to appoint four or more persons with disabilities to the 40 members Federal National Council. Government leaders, policymakers, and non-profit professionals should be made aware that individuals with disabilities should benefit from and contribute to national debates and nation-building, in support of Princess Haya's efforts. Political and public participation allows for increased accountability and inclusiveness to be operationalized. The Ruler's office should signal the importance of meaningful public participation by persons with disabilities by encouraging further leadership development by persons with disabilities. Information regarding basic rights and further leadership development should be provided to all organizations working with people with disabilities.

Finally, a concerted effort should be made to put persons with disabilities in charge of centers and organizations that serve them. Increasing representation of persons with disabilities in the governance of these centers would go a long way toward showing that persons with disabilities can govern themselves and contribute to their communities.

### Institutional Capacity in Community and Independent Living

People with disabilities are not seen as holders of rights. Far too often they are seen as problems, as opposed to problem solvers. Principal contributing factors include the predominance of cultural-social-family ties and traditions that assign value to family solidarity and look down upon the Westernized concept of family emancipation. Additionally, the weakness of community-based services for people with disabilities perpetuates psychological considerations such as alienation, fear, and social isolation. These factors prevent many persons with disabilities from pursuing their own lives apart from their families, as well as contributing to issues when they attempt to pursue building their own families.

Top-down planning related to community inclusion and independent living appears to be problematic and the Ministry seems to be experiencing long delays. This could be due to a lack of access to adequate knowledge relative to drafting specific regulations and standards (and in monitoring and enforcing compliance) for the independent living facilities in their administration. However, it would be a mistake to simply blame Federal Law No. 29 as currently drafted. It is important to recognize that tradition has a dominant effect on social norms and too often people with disabilities remain bonded to their parents out of necessity and not always out of choice.

The voices of persons with disabilities, or of the determined ones, are resounding louder and more definitively than ever before. This is particularly impressive given that there are explicit measures in place that restrict the establishment of non-governmental organizations and thus the building of a burgeoning civil society. Disability advocacy is thus in its infancy and does not hold an expansive space in the public domain. To make progress in this area, community inclusion, as well as independent living, should be linked to the social development mandates of the National Federal Strategy. Doing so evolves the existing approaches and enables local- and federal-level solutions. A coordinating body such as a community and independent living council could work to guide and stimulate work in this field.

A glimmer of hope exists as new efforts to coordinate state action on disability issues advance. The "My Community...City for Everyone Initiative" has already stimulated the development of 13 new programs across the city of Dubai. Furthermore, these programs support a new local-level law, Dubai Law No. 2, to protect the rights of people with disabilities in Dubai. This law, when supported by a strong implementation strategy and budgets, has the potential to bring much-needed reforms (Table 7.1).

# Institutional Capacity in Awareness Raising

Dubai provides a unique case in which to study awareness and public attitudes toward the human rights and dignity of persons with disabilities. Although the government recognizes these rights, it currently does not properly enforce them. As such, clarifying what disability rights are is fundamentally important to their enforcement. The status of persons with disabilities within society is still very low and their role in public life is

**Table 7.1** Key objectives of Dubai Law No. 2 of 2014 show a rights-based framework taking place in the Emirate of Dubai; this indicates a shift from a medical to social model of disability framing policy

| $\Upsilon ear$ | Law, decree, or mandate   | Objective  |
|----------------|---|--|
| 2014           | Dubai Law No. 2 to protect the rights of people with disabilities in the Emirate of Dubai | The law supports Federal Law No. 29 of 2006 concerning the Rights of People of Determination Addresses architectural and social barriers Fosters human capital development for persons with disabilities Preserves dignity and protects against all forms of discrimination and abuse Sets up a high committee to oversee coordination and cooperation across all government sectors |

limited. This is because the human rights and fundamental freedoms of persons with disabilities are not fully understood, universally recognized, or respected.

The media in Dubai plays a central role in all public discussions and public debates. Censorship linked to protecting the economic and social standing of the UAE exists but such restrictions would not regularly affect persons with disabilities. The Federal National Media Council tracks articles and actions on behalf of the government that promote the rights of persons with disabilities in the UAE. On their website, they host these and tag articles dealing with People of Determination.<sup>4</sup>

Although guidelines do not formally exist in relation to the portrayal of persons with disabilities in the media, coverage is generally fairly consistent with protecting the human rights and dignity of persons with disabilities. This could be because the media is well developed in the UAE and incorporates international best practices in English language reporting. Nonetheless, the drafting of specific guidelines in this area could work to strengthen and make more consistent the messaging that promotes people's rights and dignities as is mandated by Article 8 of the CRPD. This is especially important in Arabic language reporting, which has been noted

<sup>&</sup>lt;sup>4</sup>News articles monitored by the National Media Council, under the general heading of Social Development. The council tracks articles along 35 categories; one of these categories is "Disabled." See <a href="http://www.uaeinteract.com/news/default.asp?ID=37">http://www.uaeinteract.com/news/default.asp?ID=37</a>

to be weaker in its approach and more disparaging in its language. Arabic language guidelines would help avoid such embarrassments if the national media council enforced these guidelines. Since communications channels are not centralized, the National Media Authority and the Ruler's media office could disseminate such guidelines. All government agencies could also review these guidelines to increase consistency in government communication.

Local traditions illuminate how people approach and understand the role of disability in society. Culture and traditions can mobilize parents to identify and meet their children's needs; inversely it can impede a parent's efforts at seeking out support (Dukmak 2009). The UAE should address awareness by broadening the scope of disability history and deliver fresh and dynamic perspectives on the way that disability has been used to legitimate and understand norms, social relations, inequality, and oppression. This should include discourses on disability in Islam, including historical research into individuals, groups, and institutions, as well as representations/constructions and perspectives on disability through time and culture.

Persons with disabilities should be included in the development, marketing, and public outreach initiatives that aim to increase awareness. Increased training of persons with disabilities in communication and media should be strengthened. Only consumer or disabled driven measures will effectively promote the capacity and contribution of persons with disabilities, it cannot be done "for us" it has to be done "by us" or "with us." Until that happens, the messages will continue to fall short of their objective and highlight the potential contribution of persons with disabilities to the workforce and labor market.

# Foundational Elements to Accessibility and Mobility

Access to the built environment as well as access to information and communications technologies is central to ensuring, promoting, and protecting the freedoms, rights, and dignity of persons with disabilities. Despite its clear importance; planning, architecture, web development, real estate, and technology professionals were essentially not engaged in this regard until 2016. Only recently have they been made aware that individuals with disabilities have rights and that those rights will be enforced by the government through penalties and fines. Education and awareness regarding accessibility standards and guidelines are important, and corrective measures should be pursued if those rights are not respected.

There currently exists only a limited capacity to identify barriers and obstacles to accessibility in public facilities and services. The only measures in place are essentially *ad hoc* appeals and responses. This lack of a formal process proves to be a very costly, haphazard, and ineffective way of dealing with such problems. There are no appropriate or comprehensive standards and guidelines for the accessibility of public services and facilities in the Emirate of Dubai.

According to Issasm El Aloui, an architect and planner working in Dubai Municipality in 2009, the local government had on file a 19-page document that refers to all building codes under the jurisdiction of the municipality.<sup>5</sup> According to him, these guidelines provided the municipality a minimum set of standards that were not promoted and often not enforced. Such weak standards attracted criticism for being weak, vague, and nonspecific. By 2010, the neighboring Emirate of Abu Dhabi has mandated that the International Building Codes (IBC) be used in all new construction in Abu Dhabi, but did not develop their own codes. In 2017, the Government of Dubai's The Executive Council launched the Dubai Universal Design Code. The purpose of the Code is to regulate the design, construction, and management of Dubai's built environment and transportation systems. The Code specifies a set of standards and shows how people with disabilities and others can approach, enter, use, egress from, and evacuate independently a range of public places from buildings to bus stops. The Code leverages European, American, and Asian accessibility standards to ensure the built environment is constructed and utilized in an equitable and dignified manner, to the greatest extent possible, in line with the Universal Design principles. Currently, the Dubai Universal Design Code is on its way to becoming the Federal standard for construction.

Standards and guidelines for accessibility do not necessarily apply equally to all government and private entities providing public services and facilities. The hotel sector is challenged by provisions to ensure 10% of all rooms incorporate inclusive design features. Government entities must continue to seek out knowledge, to build capacity, and generate awareness of the progress they are making. Accessibility standards once passed need to be effectively measured, promoted, and enforced equally

<sup>&</sup>lt;sup>5</sup> Just before publishing this manuscript, I came across a larger more comprehensive document entitled Dubai Building and Construction Codes for 2004. These codes, however, failed to mention access or accessibility in the context of disability or special needs.

for public and private entities. Non-compliance should be adequately reported, identified, and resolved through formal administrative and judicial processes.

With regard to improving mobility services, factors such as a lack of locally based technical skills and knowledge are related to the complexity and unresponsiveness that characterizes the delivery system for mobility services. Social workers, rehabilitation and healthcare professionals, special educators, and service provider professionals should proactively promote mobility products and services available in the country. This includes both awareness programs identifying service providers and how these can be accessed as well as advertising ways of making these products and services more widely available in the UAE.

The Ministry of Community Development and the Community Development Authority in Dubai are not capable of implementing widespread changes in the mobility sector directly. However, their role as a purveyor of information would have a great impact on the local community of persons with disabilities in Dubai and the greater UAE. Additionally, the CDA could implement innovative partnerships with local organizations and invest in scaling up mobility solutions like wayfinding. Such services could include training professionals in the field of rehabilitation and special education and mobility training for individuals with physical, hearing, and intellectual disabilities in conjunction with the ecosystem of local organizations and service centers.

#### Conclusion

Local experts that I interviewed in 2013 and again in 2014 indicated that, in the four years between 2009 and 2013, little to no substantive progress had been made in the implementation or enforcement of the national laws on the local level. The evidence points to the fact that for a majority of government workers, disability is seen as a priority, and as an area that requires renewed attention. However, the concepts and specific guidance on how to bring about meaningful change are only now taking shape. The persistent challenge is that disability is still poorly understood and disability studies or disability rights advocacy does not have a proper platform or home in Dubai. Unless the dominant perception of disability changes from a medical abnormality or tragedy completely independent of the physical and social environment, to a failure between an individual and his/her environment, little meaningful progress can truly be made.

Additionally, the Emirate of Dubai has sufficient administrative but insufficient coordinating capacity to address disability from a development perspective.

An additional two factors must also be addressed: the lack of robust policy-based research on disability; and the prominence of marketing policy intentions. Furthermore, when public attitudes are brought under scrutiny, we begin to uncover that dominant social attitudes in Dubai are strongly congruent to international norms along dimensions of basic functionings (affording education, health, and employment) but are strongly incongruent along with basic freedoms (affording independent living, and political and public participation). When these factors are combined—the lack of policy-based research, the lack of sustained funding, and the lack of understanding and awareness of key areas such as independent living and public participation—this in effect deprives persons with disabilities of their rights. Furthermore, it deprives them of the basic capabilities for contributing to their city and enjoying the type of life that they have reason to value. Additional work needs to be done to continuously assess progress across sectors and scales. Doing so will allow local officials to implement more targeted interventions. Transformative actions can be stimulated by the "City for Everyone" initiative, and such efforts can substantially improve outcomes.

For example, the "City for Everyone" initiative should establish a stronger autonomous council led by people with disabilities to monitor and assess progress and build capacity across different sectors and scales of government. Additionally, all substantive efforts must ensure that persons with disabilities participate in the development of policies and laws that affect them. I argue that only when the interconnectedness of multiple barriers is identified can planners begin to steer contemporary cities toward more inclusive urban futures. Understanding the history of past efforts also provides additional context and allows government officials to avoid repeating costly mistakes. Measuring this transformation is highly relevant at the national and sub-national levels. Assessing performance in disability rights at these levels is of critical importance. Doing so helps cities determine the progress made and evaluate the impact and sustainability of urban policies.

The past ten years have seen an immense shift in perception and mindset on the rights and inclusion of people with disabilities. Just a decade ago it was not unusual to know and hear of families that would not reveal publicly that they have a family member with a disability. This would essentially result in a person being confined to the family home under the care of full-time hired help, rarely integrating even in larger family functions, gatherings, or travel plans. The shame associated was palpable. However, today it is possible to think that such occurrences and mindsets are the exceptions rather than the rule. Public perceptions have shifted markedly, as has been confirmed by the Community Development Authority's Dubai Social Survey, now in its fourth iteration since 2008.

Dr. Sandra Willis stated that three key events took place that catalyzed the significant shifts in the perceptions of people with disabilities in Dubai and the UAE from a medical and charity model to a rights/social model. First, it was the direct engagement of the leadership with the disability community. She recalls the impact of first seeing the images of the Dubai Crown Prince, H.H. Sheikh Hamdan Bin Mohammed, and his brother, H.H. Sheikh Mansoor Bin Mohammed, playing wheelchair basketball with people with disabilities and other top government officials in Dubai. The second was the announcement by H.H. Sheikh Mohammed bin Rashid, the Vice President of the UAE and Ruler of Dubai, announcing that all people with disabilities will be referred to as People of Determination. Finally, the hosting of the Special Olympics World Games in the UAE was transformative in shifting attitudes and highlighting the talents and capabilities of people with disabilities.

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#### CHAPTER 8

# Charting Access and Inclusion in Future Cities

**Abstract** How can access and inclusion become an integral part of the cities of the future? Initiatives such as Smart Dubai hold the answers to making infrastructure investments that deliver economic and social advantage to all of a city's people. This chapter looks at the concept of the "Smart City," namely cities that use decision making, planning, and infrastructure to achieve vastly improved connectivity, efficiency, and access to city services. However, the Smart City also needs to be an accessible city. The Dubai Disability Strategy created a framework for shared governance and measurable progress toward ensuring that Dubai would become an inclusive, rights-based, barrier-free city for people with disabilities. By integrating accessibility standards into the procurement process and standardizing national platforms in line with global access requirements, the government of Dubai can leverage technology to bridge the divide between people with disabilities and those without. The success of the Dubai Strategic Plan and the Dubai Disability Strategy have created a blueprint for inclusive public policy and spurred new initiatives at the federal level. Dubai's local law and strategy is reforming federal institutions. The scaling up of local practices promises to be a catalyst for an even greater commitment to building accessible and inclusive cities across the region.

**Keywords** Accessibility standards • Bridging the divide • Local law of Dubai • Smart City • Dubai Disability Strategy • Barrier-free • Inclusion • Access to city services • Equity • Connectivity • Efficiency • Local practices • Smart Dubai • Global access • Global cities

### SMART CITY DUBAI

The UAE leadership is united in their understanding that the most important infrastructure investments that cities can make deliver both economic and social advantage to all of its people. Where concrete and roads were once the hallmarks of city development, today citizens demand a far more responsive government, one equitably leveraging the promises of our twenty-first-century digitally connected society. Dubai has made major investments in building out a state of the art program called Smart Dubai to provide improved services, more efficient processes, and greater equity for all, including persons with disabilities.

Investments in more inclusive digital infrastructure result in people being more productive and having access to government services that are more responsive to the needs of citizens. Dubai has also invested considerable resources in becoming the world's "smartest" and now also the most accessible city. In doing so, they may be gaining a competitive advantage over other cities that are slow to implement the technological and policy changes that deliver more connected and empowered people. In listening to city leaders in Dubai and around the world, one key message appears; they are all driven to provide all their constituents with an improved quality of life through better and more personalized services, whether or not they have a disability.

Before we explore Smart Dubai, let's define our key terms. "Smart City" is used to describe the types of infrastructure investments that allow for improved connectivity, efficiency, and access to services within cities. The Smart Cities Council defines a Smart City as one that "uses information and communications technology (ICT) to enhance its livability, workability, and sustainability." ICT includes the full range of modern smart devices, sensors, and software that maximizes the potential of technology to improve the ways that cities operate and for people to access a city's full range of environments and services. Not only do they allow for more efficient operation of city services such as energy or water systems, public transport networks, or public safety, but they are often also the deciding factor on whether persons with disabilities or elderly persons can

independently utilize a city's services rather than being completely reliant on external assistance, or worse, being forced to remain confined to their homes. Until recently most global discussions on Smart Cities left out persons with disabilities.

Dubai is fully aware of the importance of becoming a recognized Smart City and due to the Dubai disability strategy of 2015, one that is accessible and inclusive. The Smart Dubai initiative was launched by Sheikh Mohammed bin Rashid, Prime Minister of the UAE and Ruler of Dubai, in 2013. The primary aims of the program were to transform Dubai to a Smart City by linking the city's services and improving access to them via smart devices, providing high-speed wireless internet in public locations, and installing a series of sensors throughout the city to provide live information. The program has the lofty aim of making Dubai the "smartest city on the planet," which it will achieve via a mandate that outlines four key pillars and six dimensions.

The four pillars are:

- 1. Efficient—optimized use of resources
- 2. Seamless—integrated daily life services
- 3. Safe—anticipate risks and protect people and information
- 4. Impactful—enriched life and business experiences for all

The six dimensions are defined as a series of strategic initiatives and partnerships based on improvements across the areas of economy, living, governance, environment, people, and mobility. Note that although neither list prioritizes access or inclusion, there are entry points in the pillars (seamless, impactful) and dimensions (living, people, and mobility).

Both the pillars and dimensions, however, clearly state that the Smart Dubai's aims include improvements in inclusiveness and the life experiences of *all citizens*. The steps which the program is taking to achieve these goals include hubs that unify government services, a customer experience lab to improve the accessibility of these services, as well as a "happiness meter" voting program to determine people's levels of happiness across different regions within the city on an ongoing basis. The Smart Dubai customer experience program showcases kiosks that feature universal design to ensure the government services kiosks are usable for persons with various types of functional needs.

The Smart Dubai program is a continuation of other innovative programs that have been previously developed and implemented by the Dubai government to drive global competitiveness. These included the Dubai

Government Excellence Program, launched in 1997, which aimed to prioritize service excellence, as well as the Dubai eGovernment program, launched in 1999 to boost internet penetration in the emirate at a time when global internet penetration was less than 5%.

The success of programs such as Smart Dubai in effecting the real quality of life improvements for persons with disabilities lies in remaining accountable to the stated aims to improve the life experiences of all citizens, irrespective of if they have difficulty hearing, seeing, remembering, or have challenges with manual dexterity. Metrics are being put in place to accurately show that these improvements are occurring and being used by persons with disabilities and that the programs themselves continue to evolve and follow an iterative, continuous improvement process on inclusive design and usability. Aligning these types of programs with internationally recognized and broadly adopted ICT accessibility frameworks and standards is vital and the Smart Cities for All Global Initiative that I cofounded with my colleague James Thurston is helping cities to become smarter and more accessible.

### Bridging the Digital Divide in Inclusive and Smart Cities

Dubai should have a vested interest in leading the dialogue on the role of technology in building smart, accessible, and inclusive cities. By building in accessibility standards into their procurement process and standardizing digital platforms in line with global access requirements, Dubai is bridging the divide between people with disabilities and those without. Digital accessibility standards like US Section 508 and the European Union's EN 301549 ensure the availability and usability of web and mobile content to all. Although the city and national governments are continuously developing accessibility-related regulation and compliance mechanisms, accessible and inclusive cities can create a market for and incentivize enterprises to bridge the digital divide. Through strong regulations and enforcement mechanisms, Dubai is building an inclusive digital ecosystem with private firms working across the public sector to deliver accessible and inclusive solutions. Companies operating in the UAE now have opportunities to strengthen their accessibility offerings, enabling them to improve the customer experience, appeal to new customer segments, and enter new markets to achieve end-to-end accessible outcomes.

#### Design for Humans

Human-centered design, or inclusive design, is creating a new cultural mindset and engineering approach that initiates and drives the creation of inclusive solutions and digital experiences. Cities and companies that deliver inclusive solutions have a broader and more universal appeal. They provide frictionless experiences and by doing so increase their influence and reach. The power of inclusive thinking is a mindset shift that helps ensure all products and services integrate inclusion and accessibility into city policies, processes, and operations. At a minimum, this requires accessibility training for developers and the active and meaningful engagement of people with disabilities and disability professionals. Microsoft and Apple are also leading the way in inclusive design and incorporating inclusive design practices into public sector solutions.

### Artificial Intelligence and the Dubai Future Foundation

Artificial Intelligence-enabled technologies are creating new interfaces and convergence between assistive and mainstream technologies that can cater to a wide set of needs and abilities, as long as they are trained to be inclusive. Dubai is home to the world's first Museum of the Future, and through the Dubai Future Foundation is leveraging AI to empower people with disabilities. Some areas of interest include assistive robotics; content translation and voice enablement; image and video identification; and mental health.

# Workforce Marketplaces, New Industries and Standards

Cities like Dubai and businesses like Microsoft that have made a commitment to accessibility and inclusion are not merely creating new products and services; they are shaping new marketplaces and even seeding new digital industries. Changes in technology standards, ethical norms, government mandates, and privacy are currently defining the contours of an ecosystem-driven digital economy. Users, customers, and increasingly talent can always move. Cities can opt to exclude a significant segment of the population and can make life more challenging for people with disabilities or they can make intentional steps toward leading the inclusion revolution.

### Inclusive and Accessible Cities of the Future

Global trends are now demonstrating that technology holds undeniable opportunities for cities that make accessibility an integral part of their digital infrastructure, online services, e-government platforms, and the way they do business. Cities and businesses that prioritize accessibility can experience what Accenture is dubbing the *accessibility advantage*. This allows them to attract and retain talented workers, develop breakthrough innovations in services, reach new markets and demographics, and keep pace with rapidly evolving accessibility standards in the shifting technological landscape.

For cities to advance their digital inclusion position, they also need to shrink the digital divide and consider these actions:

- 1. Understand the implications of accessibility on everything they do
- 2. Celebrate inclusion as a core value
- 3. Design accessibility into core strategies and measure progress over time
- 4. Transform urban design and development processes to feature accessibility and inclusion as key components of urban innovation and resilience
- 5. Build a diverse ecosystem of partners, including local and national linkages and cross-functional task forces continuously advancing policies and programs that advance access and inclusion

#### Conclusion

In the past 30 years, a range of structural changes transformed political priorities and put into place some competing ideas of what Dubai was and could be. Starting in 2005, these changes included new approaches that moved disability services from the margins toward the center of planning and social policy. This move also signaled to the world that Dubai was committed to ensuring that the highest standards were met in the provision of public services and that these standards included people with disabilities. This helped to alter the vision of Dubai, bringing into focus the various changes that needed to be made to accommodate a wider range of people who had for too long been excluded from participating in public life.

Through ratifying the United Nations Convention on the Rights of Persons with Disabilities, 90 countries and many rapidly modernizing cities across the world have taken on this particular challenge. Although Dubai's transformation from a fishing village to a global hub is unique, the city nonetheless must continue to address the need for infrastructure, mobility, and quality public services. In Dubai, as in most cities, unnecessary obstacles prevent people with visual, hearing, or mobility impairments from participating equally in employment, civic, religious, cultural, or family-related activities.

Addressing the needs of people with functional limitations is inherently complex. Disability challenges planners and policymakers to confront difficult urban issues. By sustaining practices that promote social exclusion, planners and policymakers are unwittingly perpetuating unnecessary barriers through outdated practices, policies, or prejudices. Choices in urban design, transportation, housing, and public infrastructure can include or exclude entire populations. Attitudes toward diverse constituents also matter, as they shape and are shaped by the presence or absence of people with disabilities. Within the dynamic and changing forces of globalization, disability rights increasingly embody the progressive ideals of equity, access, and social justice. Planning scholars and practitioners are powerful allies in promoting, protecting, and ensuring that people with disabilities can exercise their rights and participate equally in city life. They play a key role in not only altering the built environment (i.e., removing unnecessary barriers) but also actively promoting the participation of persons with disabilities as a targeted underrepresented group.

When launched by the Government of Dubai's Executive Council in 2015, the Dubai Strategic Plan (DSP) and the Dubai Disability Strategy (DDS) initiated the process of shifting the region's dominant social welfare models of service delivery toward rights-based social development approaches. Doing so reframed the functioning of entire systems and confirmed disability rights and inclusive public policy as a multi-sectoral and cross-functional policy priority. According to many participants I spoke to, it was a journey that involved intense debate and discussion.

Reframing the approach of existing systems required a massive reprogramming and new forms of budget allocations that prioritized social inclusion, social cohesion, and mainstreaming disability in the monitoring and evaluation framework across nearly two dozen government departments. These included reforming policies and programs across education, health, social development, municipal affairs, police and safety,

sports, social protection, disaster preparedness, and even water and power. The success of the DSP has created a blueprint in inclusive public policy and has spurred new initiatives aligned with the DSP and DDS at the federal level. Dubai's approach to inclusion is scaling up and reforming national institutions. This is creating an even greater commitment from virtually every sector across the UAE. This nation that began as clusters of coastal fishing villages has transformed into a nation of cosmopolitan global cities that espouse and define "inclusive" modernity with a conscience.

When I first arrived in Dubai in 2007, I encountered a city-sized construction zone and a frenzy of developers building the future at any cost. In the subsequent years as I dug deeper, I encountered thoughtful and committed leaders, with a generous spirit inspiring all their people to work hard and claim it. Future-focused cities like Dubai understand that failure to align domestic policies and programs with the broader frameworks like the Sustainable Development Goals (SDGs) or the Convention on the Rights of Persons with Disabilities (CRPD) risks creating norms that fall short of our collective potential. Sheikh Mohammed notes, "What we aspire to create goes beyond the present, and calls upon us to unleash our imagination on what is possible and what we can achieve."

This case study on Dubai was developed to provide evidence and equip scholars and policymakers with new conceptual approaches, empirical evidence, and methodological considerations and to hopefully make a fundamental contribution toward unlocking more inclusive urban futures for the nearly one billion people who live with disabilities. Ultimately, disability is an important demographic, cultural, political, economic, and social reality in the kaleidoscope of urban diversity. A kaleidoscope that allows contemporary planners to not only see but also construct the elusive *inclusive* city of tomorrow.

What has been achieved in Dubai in the years between 2015 and 2019 has broadened my imagination of what is possible. When a city plants the seed of accessibility, public perceptions on the importance of equity and inclusion in that city also take hold. Dubai is a unique case study, not by being exceptional or unreplicable but because it illustrates a city's challenges and opportunities, successes, and setbacks. More than anything, however, it demonstrates perseverance in the belief that all people, including persons with disabilities, have the right and the responsibility to help shape our more inclusive urban future. Dubai has embraced the task of transforming its approach and ensuring that this future is accessible to all.

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