Ambivalent Inheritance: Down Syndrome and Kinship Futures in Jordan

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Note on Language

Transliteration

Arabic words have been transliterated to most faithfully convey my interlocutors' styles of informal, everyday speech. Long vowels and emphatic letters are marked with diacritics, as per guidelines provided by the *International Journal of Middle East Studies* (*IJMES*). Diacritics are also used to denote ʿayn and hamza (ʾ). Those familiar with Arabic will recognize the predominance of urban, Palestinian dialect variations in the text, as well as colloquial grammar structures. Arabic terms and loanwords are set in italics. As per *IJMES* guidelines, words found in the Merriam-Webster dictionary are not italicized, nor do they receive diacritics (e.g. fatwa).

Disability language

When working and thinking with disability communities, questions of language are of the utmost importance. Throughout the dissertation, I employ identity-first language (e.g. "disabled people" rather than "people with disabilities") when writing in my own analytical voice, following the precedents set by disabled activists and academics in North America (Brown 2011). I maintain the person-first description for Down Syndrome, however, as I have yet to encounter a grammatically sound rendering of the identity-first format. When conveying direct speech from Arabic, I use the closest translation of the speaker's intent, resulting in a mixture of person-first and identity-first language.

Abstract

This dissertation traces the emergence of Down Syndrome in contemporary Jordan and explores how certain forms of embodied difference become disabling in different contexts. Down Syndrome is a relatively new idea in Jordan. Its dissemination and uptake are tied to burgeoning biomedical, therapeutic, and educational industries, as well as to the significant presence of human rights-focused organizations that operate locally and internationally. The emergence of Down Syndrome is also tied to growing disability communities that connect people around the world through Facebook, Instagram, and other social media platforms. This research explores how Down Syndrome fits into a context where strong models of gender and sexuality shape performances of personhood, and where the resources channeled through kinship-based networks vastly outstrip state-centered support systems or citizen-based identities. Drawing on twenty months of ethnographic research based in the capital city of Amman, the chapters that follow trace how ambivalent and potentially violent practices of kinship comingle with acts of care to unevenly transform the actors connected through them.

Families and individuals in Jordan situate and experience disability – real or potential – through embodied relationships of kinship and faith. These affective ties intimately shape entanglements of self, society, and temporality, which I theorize through the concept of *kinship futures*. Families mark the passage of time and imagine the future in terms of shifting, embodied capacities for providing care. Down Syndrome emerges through these existing and anticipated relationships. In turn, fears about sustaining family-based economies of care remake Down Syndrome in the present. Kinship futures encompass relationships of moral accountability forged

at the nexus of human mortality and divine authority, and they create value and hazards for disabled and nondisabled people alike. Ultimately, Down Syndrome operates as a node where various registers of difference coalesce, providing a powerful lens for understanding how family, gender, politics, and power shape the boundaries and meanings of personhood in contemporary Jordan.

Chapter 1. Introduction

I. Counting disability, making disability count

Less than one month after my arrival in Jordan, the Washington Group on Disability

Statistics convened in the capital city of Amman for their Thirteenth Annual Meeting. I attended

the event's opening with my newly established research contact, Imm Zahra.[1] Upon becoming

parents, Jordanian women and men commonly assume the teknonym (*kunyeh* in Arabic)

"mother-of" (*Imm-*) or "father-of" (*Abu-*). While the first-born son takes precedence in this

naming practice, couples without sons will often be identified through the name of their oldest

daughter. Zahra was neither her mother's firstborn son nor her oldest daughter. Yet, many of the

women in Imm Zahra's social circle, myself included, refer to her by the name of her youngest

daughter.[2] In the wake of Zahra's postnatal diagnosis of Down Syndrome, Imm Zahra decided to

mobilize, and she founded the al-Nur society to connect and support families across Jordan. It

was through this work that she found herself attending events like the Washington Group

conference, which was held at an international hotel in downtown Amman near many of the

government's administrative hubs.

The Washington Group was established in 2001 under the auspices of the U.N. Statistical

Commission City Group. It seeks to "address the urgent need for cross-nationally comparable

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[1] All names in the dissertation are pseudonyms.
[2] I preserve the *kunyeh* throughout the dissertation. To minimize confusion, I use the name of the child most immediately present in the material at hand. Not all women embrace this naming practice, and some reject it entirely. Among my research participants, however, the *kunyeh* was common and unproblematic. I write the formula with *Imm* (mother)*,* rather than *Umm*, to convey a sense of the dialect pronunciation.

population-based measures of disability. Its mandate is the promotion and coordination of

international cooperation in the area of health statistics, focusing on disability data collection

tools suitable for censuses and national surveys" (The Washington Group 2018). Hosted by

Jordan's Higher Council for the Affairs of Persons with Disabilities (HCD) and the Department

of Statistics (DoS), the Washington Group played a part in developing Jordan's 2014 Population

and Housing Census. Ultimately delayed until the fall of 2015, the census incorporated extensive

use of tablet technology and GIS mapping software, receiving support from both the USAID

Jordan Census Project and United States Census Bureau. This most recent census included, for

the first time, a disability-specific question set developed and tested by several of the

Washington Group's 123 member states (Jordan News Agency 2013). The introduction and

celebration of the disability module reflects increasing local, national, and transnational interest

in gathering reliable quantitative information on disabled people.

Heterogeneous definitions, measures, and methods of data collection have historically

resulted in wildly divergent rates of reported disability (Mont 2007). Developed countries almost

always report significantly higher rates than those of developing countries, and survey

instruments tend to report higher rates than census data collected from the same population

(Mont 2007). Jordan's 2004 census, based on the self-identification question, "Do you/does

someone in your family have a disability," reported a 1.2% prevalence rate (Mont 2007, 8). This

number falls strikingly below the World Health Organization's overall estimated disability

prevalence rate of 15%, which drops to 11% for developed nations and rises to 18% for lower

income countries (World Health Organization 2011).[3] International and local disability groups

hailed the census's improved technology and methodology as opportunities to gather better data

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[3] The Center for Disease Control places the current disability prevalence rate in the United States at 22% (2017).

on disability in Jordan, the collection of which then leads to somehow improving the lives of disabled people.

A number of disabled people attended the Washington conference as both employees and participants in various community initiative and organizations across Jordan and Amman in particular. Some of these advocates are also members of prominent local families, a factor that strengthens their organizing capacities. In looking around the room, however, I noted a particular absence. "Imm Zahra," I whispered, "There's no one here with Down Syndrome." Imm Zahra looked around, scanning the room for a familiar face. "You're right. And they're not even speaking Arabic!" she said with a laugh. She glanced up at the speaker on the podium, who belonged to a well-known, elite Jordanian family. Observing the various dynamics of the gathering, I was struck by a certain irony. Intent on studying Jordan's local disability world (Ginsburg and Rapp 2013), I instead found myself in a remote outpost of Washington D.C.

Over the twenty months of fieldwork I conducted in Amman between 2013 and 2015, I occasionally attended similar disability-related conferences, events, or celebrations. I usually, however, tried to sidestep these invitations. The provenance of individuals whom I would come to recognize as key influencers in Jordan's disability activism and advocacy, the formal occasions felt distinctly removed from the day-to-day routines and struggles of families, which is where I situate my research. The local rhythms of everyday life in Jordan certainly intersect with the transnational disability movements and practices exemplified by the Washington Group. Families debate the nature of disability, argue about representational stakes of changing terminology, and try, on individual and collective levels, to harness the opportunities that disability presents as an emerging identity. The perceptibly global dynamics and possibilities inherent in these issues sharpen local attentiveness. When formal events convened to assess a

new law or celebrate the inauguration of a global campaign, however, they felt acutely removed from the actual complexities families encounter as they attempt to forge everyday inclusive spaces and practices for their children. Such gatherings seemed to belong to the realm of public discourse that Paul Dresch describes as *mujamalah*, which he likens "in many a context, [to] 'polite waffle'… or, otherwise, in a low key American sense, 'bullshit'" (2000, 112, 117). The lively and antagonistic debates between audience members and experts that I watched unfold at more than one event of this kind suggest that others shared in my assessment.[4]

As they attempt to advocate for rights, services, and resources, most families of intellectually disabled children in Jordan directed their energies into reconciling and recognizing disability in the domain of kinship, itself a deeply political project.[5] The urgency of this project emerges quite clearly from my interlocutors' own accounts of what it means to have a child with Down Syndrome. I first met Abu Amer while he accompanied his son to a local farmer's market that offers intellectually disabled children and adults space to congregate and socialize. I explained that I was an American student doing research on the experiences of families who have members with Down Syndrome. Abu Amer nodded vigorously to convey his approval of my research topic. "Ask me anything!" he replied enthusiastically. Then, without pausing, he began reflecting on his son's life and their family's experience:

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[4] If *mujamalah* marked interactants as formal acquaintances who were obligated to perform the rituals of distance and flattery (MacDougall 2017), a distinct kind of openness and intimacy emerged between family members of disabled children. Despite varying degrees of familiarity, the affective and experiential ties of disability made relative strangers comfortable enough to address and criticize formal public officials with the frankness – and fury – of friends.

[5] Veena Das and Renu Addlakha introduce the concept of "domestic citizenship" to capture the entangled politics of kinship and disability that shape women's life trajectories across their respective fieldsites in India (2001). They describe domestic citizenship as an attempt to, "(1) displac[e] citizenship from its conventional association with publics defined through civility and (2) displac[e] domesticity from its conventional place in private, particularistic loyal ties" (Das and Addlakha 2001, 530). I have found their work on this concept to be provocative in thinking through the social politics of disability in Jordan.

> The most important thing, the fundamental thing, is that his family accepts him (*inū al-usra yataqabbalū*). In Arab society, often times if the woman gives birth to a sick child, the husband leaves. Not me! The most important thing is the mother and the father, then the [extended] family – siblings (*al-imm wa-l-ab wa baʿadayn al-usra – al-akhwān)*!

Abu Amer drew out the final long vowel in *al-akhwān* for dramatic emphasis, his voice rising with emotion. He then threw his hands up into the air and continued:

> My siblings have daughters, so they didn't want Amer to be seen, because they want their girls to get married. [He then pantomimed locking someone behind a door and throwing away the key]. This is how Arab society thinks. If someone is disabled, the family is disabled (*izā fī wahad muʿāq, al-usra muʿāq*).

Abu Amer repeated his list, adding new components and ticking his fingers off one by one to end with his palm outstretched in the air: "the father, the mother, the family, neighbors, society (*al-ab, al-imm, al-usra, al-jīrān, al-mujtamaʿ).*" Somewhat belatedly, he then added, "and another problem, there's no support from the government (*mā fi daʿam hukūmiyya*)." Essentially, during this conversation, Abu Amer drew me a map. On this map he located disability in a web of social relations, linking the nuclear family to extended kin and potential future kin through marriage, and then to neighbors, society, and more belatedly, the state and governmental bodies. Trying to parse out how disability, and Down Syndrome specifically, generates and imperils relations between these actors and institutions in contemporary Jordan forms the heart of this dissertation.

II. Kinship futures

Time is central to dominant framings of disability, which usually rely on medicalized terms relating to onset, chronicity, and permanence. While understandings of illness emerge in relation to potential cure, disability precludes such a relationship. It is through the *absence* of disability and disabled persons, argues Alison Kafer, that the future is imagined as progress. Futurity, Kafer argues, is deployed in the "service of compulsory able-bodiedness and able-

mindedness" which then loops back to shape the lives of disabled persons in the present (2013, 27). The future that Kafer crips[6] in her work, however, belongs to a specific time and place. Communities imagine their futures on different terms, in relation to the particular ideals, and across varying temporal scales. Disability and futurity possess local histories and belong to grander cosmologies.

Families in Jordan bring Down Syndrome into being through what I am calling *kinship futures*. While the birth of a baby invites parents and family to imagine and dream about the future, the birth of a baby with Down Syndrome, in Jordan, occasions urgent and immediate questions about family reputation and marriage. What will happen between spouses? What will happen to the marriage prospects of siblings and cousins? What will happen to an individual with Down Syndrome *after* the marriages of their siblings and cousins? Families wonder what kind of person a child with Down Syndrome will become, and they imagine possible futures in terms of the lineal and affinal relationships that their child will or will not be able to create. Geoffrey Hughes writes that "for all of their diversity, my Jordanian interlocutors were nearly unanimous in thinking of marriage as a key moment for the social reproduction of families, communities, and Jordan itself as a nation-state" (2015, 3). Down Syndrome changes this key moment, but this moment is already changing across Jordan and the broader Middle East. These larger developments have their own potential implications for individuals and families living with Down Syndrome.

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[6] Crip studies and crip theory have emerged out of dissatisfaction with earlier disability studies scholarship's lack of intersectionality. Often described in parallel to the emergence of queer studies and queer theory from the earlier domain of LQBTQ-studies, the term "cripping" can be understood in relation to "queering." Cripping seeks to address and push back against inequalities, racism, and heteronormativity within disability studies and disability activism (McRuer 2006; Samuels 2017; Schalk 2013).

Many families criticize and position themselves against marital anxieties that they nevertheless describe as unavoidable part of their culture (*thaqāfa*). In setting up this tension, they demonstrate how kinship continues to provide a critical means for cultivating wellbeing and survival in contemporary Jordan. Men and women, in their respective roles as spouses, have different resources at their disposal to negotiate and mitigate the threat of stigma that accompanies the birth of a disabled child. These resource differentials potentially put them at odds with each other, in some cases threatening their own marital ties. As an allied marital unit, spouses also have various resources at their disposal to manage their broader kin and social networks together. Although I initially tried to represent marriage as one chapter, a finite moment or life stage, this ultimately proved impossible. Marriage courses throughout the dissertation just as it does throughout social life and politics in Jordan, forging – and damaging – connections between spouses, children, kin, friends, and even strangers.

Fears about marriage and collective family reputation make certain disabilities emerge through Jordan's local political economy of care, which is grounded in the entanglements of kinship and statecraft that Andrew Shryock and Sally Howell describe as "house politics" (2001). Families mark the passage of time in terms of changing kinship roles, and kinship roles take shape and evolve through embodied capacities for providing and exchanging care. The development of a lifelong condition that might impair a child's capacity to provide future care can affect immediate and extended networks of kin. Families respond to these uncertainties in a variety of ways, often making fraught and unpredictable calculations in their attempts to sustain kinship futures. These attempts can extend to include, or even come to depend on, the labor

performed by various non-kin, such as therapists, doctors, tutors, and foreign domestic workers.[7] In the absence of reliable, adequate state-sponsored social services, and coupled with neoliberal policies exacerbating socioeconomic vulnerability across the country, families' abilities to shape and protect their kinship futures remain key determinants in the lives of disabled persons.

The horizons of kinship futures also extend beyond death, encompassing relationships of care that bind family members to each other and create a sense of shared moral accountability before God. Families embed disability in a politico-moral project grounded in local realities of religion and kinship, which are, in turn, shaped and informed by each other. At different moments in the life course, and in different ways, people in Jordan connect disability to the nature and meaning of good deeds, the inevitability of divine Judgment, and the wisdom of seeking refuge in God. Caring properly for family shapes individuals' own assessments of their relative position on the path to heaven or hell, and it also impacts social status and moral reputation in everyday life. In the context of my research, being good to one's family did not need to be described as Islamic, but being good to one's family made one a good Muslim. I use the lens of kinship futures to examine these imbrications of disability, care, and morality.

Religion, class, and capital offer practical and moral strategies for challenging disability stigma among kin and in the community, albeit in ways that are not always predictable or consistent. Many families, special educators, and therapists in Jordan push back against an abstract classist narrative that designates the poor as inherently antagonistic toward disability. Kawthar, an employee at the Society with experience working in the special education sector across the Middle East, described this to me in the following way. "The problem in the Arab

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[7] Almost none of my interlocutors employed foreign domestic workers, but wealthier families frequently rely on such labor. I did in fact meet several caretakers, almost all whom were from the Philippines, through one specific program that attracted primarily upper class families.

world is *al-fikr* (thinking). Economic level doesn't determine people's ideas. There are rich

people who hide their children and poor people who recognize that [disability] is something from

Allah and their child is a human being with rights." Where the rich and the poor converge,

however, is in thinking through disability in terms of kinship.

III. Narratives of change and progress

Jordan is a small country located in the dynamic and volatile region known today as the

Middle East. Roughly the size of Maine, it is bordered by Syria, Lebanon, Palestine, Israel, Saudi

Arabia, and Iraq. In the 2004 Population and Housing Census, the country's total population

registered at 5.1 million. By the close of 2015, this number had exploded to 9.5 million

inhabitants, almost half of whom live in the capital city of Amman. Noncitizens comprise almost

one third of the country's current population, 1.2 million of whom are refugees of the Syrian

civil war that began in 2011.[8] The demographic shocks caused by displacement, occupation, and

war have shaped the country's history, beginning with the Palestinian *Nakba* in 1948, the Six-

Day War in 1967, the Gulf War in 1990, as well as the U.S. invasion and occupation of Iraq in

2003.[9] As a result of each of these conflicts, Jordan has absorbed large numbers of refugees (and

returnees in the case of the Gulf War) in short periods of time.

Against this backdrop of continuing regional turmoil, however, the quality of public

health in Jordan has continued to improve over the past half century. Like most Middle Eastern

and North African nations, Jordan is currently in the middle of a demographic transition from

high to low mortality and fertility rates (Bel-Air and Ababsa 2013; Bloom et al. 2001;

Puschmann and Matthijs 2012). For Jordan's more affluent, oil-rich neighbors to the east, such

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[8] These figures come from the 2015 census (Department of Statistics and UNICEF 2016).
[9] One could go further back and begin with the resettlement of Circassian populations by the Ottoman empire in the late 19th century (Shami 2009).

as Oman, the Emirates, Saudi Arabia, and Kuwait, rising rates of diabetes, obesity, cancer, and inherited blood disorders have sharpened state biopolitical machinery through various forms of surveillance and control (Beaudevin 2013; Trainer 2012). These rates continue to increase in Jordan as well, but a lack of capital has hindered the establishment of widespread screening or intervention programs. The major exception to this is a recent premarital screening program for Beta thalassemia, which began in 2004 (Alkhaldi et al. 2016). Overall, Jordanians today enjoy longer life spans while suffering from increasing rates of non-communicable and chronic disease. This juxtaposition is embodied, felt, and a topic of frequent discussion. Both older and younger generations recognize the indicators of improved health all around them. At the same time, they experience what they describe as uniquely new aches, pains, and bodily risks. These macro level contexts shape how families encounter and make sense of Down Syndrome.

Bodily disruptions, configured and recognized differently across time and place, generate meaning and demand social practices to contain them. This is because the symbolic richness of bodies makes them "good to think with" (Douglas 1966; Scheper-Hughes and Lock 1987; Turner 1984). "As the locus of personhood and the material manifestation of self," writes Julie Livingston, "the human body is at once a profoundly moral and historical site" (2005, 2). In her research on debility[10] in Botswana, Livingston's interlocutors made sense of the present – fraught with social, economic, and bodily crises – by "remembering a past in which such suffering was hardly possible" (Livingston 2005, 1). This narrative process generates what Livingston describes as the "moral imagination" (2005, 1). Tine Gammeltoft also draws on the imaginary to analyze the enthusiastic embrace of selective reproductive technologies in Vietnam. The vigorous promotion of pregnancy termination that Gammeltoft witnesses in cases of

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[10] Debility "denotes both the frailties associated with chronic illness and aging and as the impairments underlying disability" (Livingston 2005, 6).

suspected fetal abnormalities reflects and reproduces entangled conceptions of the ideal

Vietnamese citizen. Personal and collective traumas of war, fears about genetic damage in the

wake of Agent Orange, and insecurities wrought by economic liberalization compel families in

Vietnam to minimize the risks of giving birth to a disabled child by any means possible

(Gammeltoft 2014, 154–55).

Both Livingston and Gammeltoft's work illuminates how historical crises shape

embodied experiences of vulnerability, which in turn materialize through narrative form. The

moral imagination articulated by my interlocutors in Jordan, however, revolves around promises

of material, social, and moral development – however incompletely realized. This progress-

oriented outlook exists in striking tension with other local and regional narratives centered on

deterioration, stagnation, and hopelessness (Al-Mohammad 2012; Matthies-Boon 2017; Schielke

2008; Schielke 2015). "Before," according to a common narrative I encountered during

fieldwork, "there were not so many people with Down Syndrome." In the words of an older

woman whose son with Down Syndrome was nearing his late thirties, "It's because they all died!

They didn't know then what they know now about their nutritional needs and about their heart

problems. There wasn't any care!"[11] Her analysis speaks to a widespread belief that while people

with Down Syndrome have always existed, their capacity for basic survival and emergence in

public social life reflect dramatic improvements in local practices of medicine, hygiene, and

nutrition.

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[11] This belief was often coupled with the perception that high rates of disability prevalence are endemic and also increasing, due to both genetic and environmental factors. These perceptions are not entirely unfounded. The cumulative effects of long-term consanguineous marriage practices impact disability rates to varying degrees (Khoury and Massad 1992; Hamamy 2012; Hamamy et al. 2005). On the other hand, the historically widespread lack of iodine availability across the region, which would have impacted prevalence of disability and other iodine deficiency-related conditions, is managed today through fortified foods and supplements (Scalenghe 2014, 4).

Better basic care and its impacts on survival, however, do not fully account for this health transition. Families position these empirical observations, along with the emergence of disability rights discussions in Jordan, in a broader narrative of social change. They consider them indicators of development, a process that involves material and spiritual progress (see Deeb 2006). Development operates through bodies, becoming visible through embodied states of health (and illness), but it ultimately requires changing social consciousness. This latter element of the process was repeatedly described to me in terms of society's need to develop proper *tow'iyya*, or awareness about disability. This moral-material development of awareness, while ultimately directed toward society, operates concretely through "the family" (*al-usra or al-'ā'ila*). Over the course of my research, the families, special education teachers, therapists, activists, and NGO workers I met, frequently told me that, "People here hide their children" (*yukhabūhūm*).[12] In describing his siblings' reaction to Amer's Down Syndrome, Abu Amer physically acted out the process of shutting a door and throwing away the key. This image of a locked door, with a disabled child hidden behind it, circulates among Jordanian locals, transplants, and expatriates alike. Families, professionals, and activists draw on culture (*thaqāfa*) to explain hiding as the product of ignorance (*jahl*), backwardness (*takhalluf*), and the power of shame (*'ayb*)[13] in Jordanian society and the Arab world, a community they imagine in terms of cultural and religious ties. They locate these powerful forces as belonging to the domains of tradition (*taqlīd*) and days past (*'abl*). The future, in contrast, holds potential for developing awareness and acceptance (*taqabbul*) of disability, both though the family and in society.

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[12] When I described my research to friends and acquaintances not directly connected to the project, they also reacted by articulating the same association between disability and hiding.

[13] This term is further contextualized and complicated in Chapter Two.

Disability histories

The word used by Abu Amer above to describe the family as disabled, *muʿāq*, is derived from the modern Arabic term for disability, *iʿāqa*. It comes from the root verb *āqa*, which means to hinder or prevent. Regional historians and scholars of Islam emphasize that no comparable term exists in the medieval or early modern archives.[14] The classical Arabic term *ʿāha*, or blight, most closely approximates the modern concept of impairment.[15] *ʿĀha*, according to medieval historian Kristina Richardson, conveys the sense of "a mark that spoils the presumed wholeness of a thing" (2012, 5). Richardson cautions, however, that "the category of blightedness or being marked encompasses more hybridity than the modern category of disability, and people of blights were characterized by physical deviance defined by debility, superability, and physiognomic undesirability" (2012, 5). Based on this description, *ʿāhāt* (pl.), clearly extended beyond the contemporary concepts of impairment and disability. They included "blindness, deafness and paraplegia; diseases like leprosy and halitosis; temporary ailments like ophthalmia and jaundice; extraordinary physical features like blue eyes, crossed eyes, flat noses, black skin, baldness, hunched backs, lisps and thin beards" (Richardson 2012, 6). While some *ʿāhāt* severely limited a person's status and degree of inclusion into social life, others were not considered disabling.

Mental and bodily difference nevertheless emerged as prominent aspects of identity during the Middle Ages and early modern periods, attracting considerable attention in the fields

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[14] For English-language sources with a comprehensive focus on disability in Islamic theology and jurisprudence, see Ghaly (2008, 2010) and Rispler-Chaim (2007).

[15] Mohammed Ghaly writes that, "in theological writings, the 'disabilities-plus group' was couched in the term *ahl al-balāʾ* (people of affliction) which was used to signify those people who went through difficulties in life, usually seen as a test (*ibtilāʾ*) for their faith and trust in God" (Ghaly 2016, 154). I did not encounter the term *ʿāhāt* in daily conversation, but I did once overhear a group of women discussing whether or not disability should be considered an *ibtilāʾ*. They associated *ibtilāʾ* with tragedy and thus reasoned that disability should not be included in this category.

of religion and law but also in everyday life. For example, Richardson observes, "a person with a noticeable physical difference often incorporated this attribute into his very name, suggesting the body's centrality in subject formation and its prominence in the social imagination" (Richardson 2012, 6). Sara Scalenghe, drawing from an extensive corpus of 16th-19th century sources, excavates the social dynamics and limitations experienced by those with *ʿāhāt*[16] and echoes Richardson's findings on the pervasiveness of difference. She writes, "Although there was no category for 'the disabled,' either conceptually or linguistically, people with impairments of the body and of the mind are everywhere in Arabic sources dating from Ottoman times" (Scalenghe 2014, 3).[17] Diversity of thought and experience, however, did not amount to radical undifferentiation or egalitarian social norms. Scalenghe notes that in the early modern period, "impairments of the mind were the most disabling in all spheres of life and were subject to the most severe legal restrictions" (2014, 164).

The etiologies of impairment that Scalenghe details provide tentative insights into how a condition like Down Syndrome might have been lived in earlier historical periods. "Early modern Arabs," she explains, "divided impairments of the mind into four broad groups: idiocy, melancholia, madness, and holy folly" (89). The potentially temporary nature of the latter three states, which were largely perceived as the products of humoral imbalance, distinguished them from "idiocy," or *ʿatāha*. This distinctive category "was the least fluid and ambiguous… It was viewed as a permanent state, and it was almost always congenital or acquired early in childhood" (2014, 89). The characterization of *ʿatāha* overlaps in striking ways with the contemporary

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[16] Scalenghe's sources include "biographical dictionaries, chronicles, travelogues, legal and medical texts, treatises on physiognomy, dream manuals, essays on specific subjects (on blindness, for example), works of belles-lettres, such as collections of jokes and anecdotes, and Arabic lexicons" (2014, 15).
[17] Both Richardson and Scalenghe voice concern about a widespread tendency to view the contemporary marginal status of disabled people in the Middle East as reflective of either historical continuity or Qur'anic mandate.

medical model of intellectual disability, which presents conditions like Down Syndrome as fixed in the body, immutable, and incurable.[18] Ultimately, however, significant archival gaps continue to limit insights into lived experiences of ʿatāha. Persons understood through this label figure marginally into the available sources on everyday life, and they are discussed primarily as legal and medical abstractions (Scalenghe 2014, 89). The political, legal, and medical transformations that occurred with the demise of the Ottoman Empire raise additional questions as to the region's disability histories. Future work tracing these 20th century disruptions and transitions may shed light on how these older social, medical, and legal systems merged with disability models imported by missionaries, colonial bureaucrats, and development organizations.[19]

From hiding to claiming disability

My interlocutors usually broached the topic of hiding with me by sharing first or secondhand accounts of discovering someone else hiding a child. They used these stories as foils for their own experiences and to position themselves in relation to my research. Benedicte Ingstad has written extensively on what she refers to as "the myth of the hidden disabled," a pervasive and top-down discourse that she links to early human rights and development initiatives (Ingstad 1995, 246). In an effort to promote the emerging global agenda of disability rights, advocates often highlighted the challenging and sometimes brutal conditions faced by disabled people and communities in the Global South. In so doing, they placed a mass emphasis on the barriers created by local "attitudes," which resulted in disabled people being hidden from society (Ingstad 1995, 246). Ingstad critiques this framing's focus on "attitudes" and beliefs,"

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[18] Scalenghe highlights the significant role played by Islamic jurists in shaping the extent to which these four categories became disabling. Scholars working across different time periods and geographic areas have detailed the repressive influence of legal institutions in the lives of intellectually disabled persons (Belt 2015; Carey 2003).
[19] Indeed, Scalenghe's next project will try to reconstruct this period of colonization and Mandate-era restructuring in terms of its impact on disability concepts and experiences (personal communication, 2016).

which can far too easily misrepresent or ignore the material constraints that shape local

economies of care and disability. During her long-term fieldwork in Botswana, family caretakers

emphasized the extreme difficulties that their resource-poor, rural settings presented. They felt

compelled to prioritize keeping disabled family members alive over considerations of their

flourishing and quality of life. Additionally, Ingstad's interlocutors did not always equate

domestic confinement with "hiding." Th accuracy of this description depended on the nature of

confinement practices involved and the kinds of social relations maintained or diminished in the

context of spatial restrictions.

I hesitate to equate the pervasive discussions about disability and hiding in Jordan to the

level of myth. In addition to numerous personal accounts, local media reports would emerge

from time to time that documented cases of particularly egregious neglect, abuse, or even the

murder of a disabled child or adult.[20] Such incidents, more often than not, involved various

practices of extreme home confinement and social deprivation. Yet even without this additional

layer of investigative materials, my interlocutors insisted that hiding was real, pervasive, and

crucial to my understanding of disability in Jordan. Hiding posed challenges for my fieldwork,

however, in terms of logistics and methodology, and especially with regard to sample bias.

Families hiding a child or adult would be hesitant to seek out the networks of advocacy and

services through which I met almost all of my interlocutors. In other words, the personal nature

of fieldwork almost guaranteed that I would meet only those families actively seeking services

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[20] One of the most (in)famous examples of this kind of media coverage came in the form of the 2012 exposé "Behind Walls of Silence (*Khalaf jidrān al-ṣamt*)" (BBC Arabic 2012). An undercover investigation of abuse occurring at a special education center located in west Amman, the film received widespread attention in Arabic and English media. Two cases that occurred during the latter part of my own fieldwork in 2015 also received extensive coverage, albeit more so in Arabic media and on social media. In the first case, a man threw his autistic son off the top of parking garage in western Amman and burned the body (Al Ghad 2015). In the second, authorities discovered an intellectual disabled woman in Irbid who had spent the majority of her life chained to the stairs of her family home (Malkawi 2015).

for their children, or those who had done so in the past. Given this constraint, I focus on how the families I did meet through such networks recognize and relate to hiding in their own lives.

What counts as hiding and why? Which practices fall on the acceptable end of the moral spectrum, and under what kinds of conditions do previously acceptable practices become problematic? Families confront these very same questions while navigating the changing social and therapeutic landscapes of disability in Amman. I received many warnings that research on disability would be extremely challenging, or even impossible, due to its "hidden" nature. The reality on the ground, however, was far more complex and dynamic. I arrived at a moment when many of the questions I sought to ask made immediate sense. This was especially the case for families I met through the al-Nur Society and other organizations like it. Circumstances have compelled these families, with all the brute force of lived experience, to evaluate seeming truths about kinship and personhood that are unsettled by disability. At the same time, they seek to bring their own moral commitments and truths to the larger world of disability ideas and practices that they encounter through local and global disability rights initiatives.

IV. The al-Nur Society: A meeting space

Mothers find organizations like the al-Nur Society through the efforts of family members, at the suggestion of a supportive nurse, or through the process of Googling and Facebooking Down Syndrome in Jordan. Like many of them, I also found the Society through Internet searches and social media. Having arrived unexpectedly in Jordan after funding restrictions upended my original project in southern Lebanon, I began fieldwork unfamiliar with the landscape of Amman and notably lacking in social connections. When Imm Zahra responded to my inquiry, a fortuitous and highly unusual outcome of online communication in Jordan, I jumped at the opportunity. We first met at an iconic Starbucks located in the affluent west

Amman neighborhood of Abdoun. In retrospect, I can only guess she chose this spot for my own benefit, assuming I would be more comfortable in a part of the city known for outrageous villas, cosmopolitan restaurants, and home to many embassy workers and expatriates. Imm Zahra brought with her a volunteer and longtime friend who had studied abroad in Europe and spoke fluent English. She was also fluent in English, however, having learned from coworkers in the Gulf during a former career in sales. We generally tried to speak Arabic together, in part because she enjoyed making fun of me, but we frequently conversed in English as well. At that first meeting, I explained that I wanted to spend meet families and learn about their lives. Imm Zahra seemed perfectly amenable to this prospect. I then waited patiently by the phone for a week before receiving a call from her asking where I was and why I had yet to come visit.

For many families, making the journey to the Society proves no small feat in a city lacking affordable, accessible transportation and suffering from extreme traffic congestion. Additionally, Amman is highly and tangibly stratified. Both scholars and residents divide the city into an affluent west and poorer, densely populated east (Ababsa 2013a; Hannoyer and Shami 1996; Potter et al. 2009). The mothers in my sample differ in terms of class, education, religiosity, age and number of children, ethnic identity and even citizenship status, allowing me to interact with an unusually diverse and dynamic cross-section of Jordanian society. This also meant that I could observe how class, capital, and family dynamics shape women's abilities to find and pursue services for their children. Throughout the dissertation, I utilize the phrase "residents of Amman" or the adjective Ammani (following Tobin 2016) to situate most of my participants, which gestures to the complexities of identity that play out in the capital today.[21]

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[21] The elusive and sensitive question of "who" counts as Jordanian – as vexing an issue for the ruling Hashemite family as for citizens and noncitizens of Jordan alike – remains an enduring legacy of American and European colonialism and the continued Israeli occupation of Palestine. Both historical and contemporary iterations of

Some of my interlocutors arrived in Amman decades ago, but they will never possess Jordanian citizenship. Others were very new to Jordan and hoped to resettle elsewhere as soon as possible, although it was unlikely they would secure the necessary papers to do so. Still others were born and raised as the daughters and sons of Jordanian fathers, the latter being the necessary precondition for citizenship in the Hashemite Kingdom, but some of them nevertheless identified as both coming from and belonging to other homelands. The urban bias of my research, however, means that I cannot speak to the realities and difficulties of life in the semi-urban, small-town, and rural parts of Jordan. I will say that my city-based interlocutors associated all of non-Amman – often described in terms of the countryside (*al-rīf*) – with more severe disability stigma and backwardness.

Staff at the Society, families, visitors, and patrons all subsume the goal of supporting the individual child with Down Syndrome under the broader goal of providing family support.[22] To speak of one without the other simply makes no sense. Societal change can only be achieved through families, although this responsibility ultimately rests more heavily with mothers. Time and time again, I listened to women urge each other to remember that "the mother is fundamental" (*al-imm hiyya al-assās*). One time, after hearing one of the early intervention specialists, Layla, mention this phrase yet again, I responded, "And what about the father?" Layla did not dismiss the father as an important actor, answering at first with, "yes, and the father." Men, however, deal with their own constraints, and women generally accept them as

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Jordanian and Palestinian identities, and their impacts on exclusionary practices of citizenship, occupy a position of significant importance in scholarship on the country (Brand 1995; Layne 1994; Shryock 1997). More recent work traces these enduring categories of concern as they intersect with forces of generational change, class, piety, neoliberalism, and gender (Adely 2012; Kaya 2010; MacDougall 2017; Tobin 2012).

[22] The Society focuses on children. Their limited direct service prevention, in the form of early intervention training, is geared toward children ages 0-9. In reality, they serve many individuals in their teens and even twenties and beyond, as best they can, expanding their programming and activities. Older individuals who age out of the available special education systems simply have nowhere else to go if they want life outside the family home.

significantly limiting. Layla continued, "But, he is at work, and he comes home at the end of the day tired. He doesn't always have time for this training." In both affective and effective terms, this is women's work. This gendering manifests spatially in many of the societies, where female staff and female family members are the status quo. The al-Nur Society, for example, is not sex segregated, nor is it a women's association, but only certain men can enter its spaces comfortably and without perceptibly changing the interactional dynamics.

Mothers claim a significant amount of agency for securing disability-related services, reproducing the more general gendered division of childcare that exists in Jordan. This gendered skew also reflects current labor trends, where the rate of women's participation in the formal labor sector hovers around 22%, as compared to 87% for men (The World Bank 2014). The 2016 overall unemployment rate of 14.6% (Department of Statistics [Jordan] 2016) surged to 18.2% by the first quarter of 2017 (Azzeh 2017). While male heads of household aspire to the role of breadwinner, many fail in their attempts and manage to do so inconsistently at best. During a conversation between three women very involved in the Society and quite comfortable with one another, the topic of husbands' participation in early intervention training arose. "He can't (*huwweh mā byi'dar*)," said Mona, referring to her husband. The other two women nodded in agreement. Mona gave me an explanation similar to the one Layla provided, pointing out that men are not home enough to perform the daily and repetitive labor of childcare. When they are at home, what's more, they tend to be exhausted from work or from trying to find it.[23] While not necessarily happy or satisfied with this arrangement, upending the normative gendered division

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[23] I rarely encountered essentialist arguments about men being *unfit* for childcare. Rather, women stressed the structural constraints placed upon men that affected their moods and temperament, making them particularly unsuited, especially to the detail-oriented exercises that early intervention activities require. I did, however, meet father who were far more involved in their children's life than their spouse. These men were welcomed for their efforts and presence.

of labor falls extremely low on most women's priority lists. They identify their most pressing concerns and challenges elsewhere.

Finding spaces: fieldwork

The days I spent at the Society included a number of possible activities: I showed up in the morning and drank coffee or tea with the staff; I observed early intervention training sessions with Hiba; I sat in the waiting room chatting with the employees and the family members (usually mothers) who arrived early with their children for appointments or lingered afterward; I occasionally attended family trainings or lectures on specific topics; and I appeared at local awareness-raising and social events. As time went on, staff assumed I would show up several days a week at the minimum, and my absences (usually time spent visiting other organizations or interviewing families privately) never went unnoticed. During my research, I formally interviewed 18 mothers of children with Down Syndrome at least once,[24] and my larger sample included an additional 50 mothers of children with Down Syndrome. My total sample of families was still larger, however, as I met and occasionally interviewed families whose children are intellectually disabled in other ways.

Anthropologists have become increasingly self-reflective and vocal about the ways that fieldwork and ethnography entail creation, omission, and reconstruction (Behar and Gordon 1996; Clifford and Marcus 1986; Ingold 2014), especially given the ongoing intensification of globalization and urbanization (Appadurai 1990, 1996; Marcus 1995). Even so, my fieldwork often felt acutely artificial in ways that were hard to articulate. This was due in part to the urban sprawl I navigated quite extensively, and it also has to do with the random and unpredictable nature of disability. Marginalized, socially limited disabled persons deeply enriched the Amman

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[24] In four of these cases, fathers were also present for a formal interview.

that I built through my field experience. Language skills, for instance, remain a source of struggle for all but the most adept of researchers conducting fieldwork outside their mother tongue. I was no exception to this reality. And yet by the end of fieldwork, I became more proficient at communicating with persons with Down Syndrome than most Ammanis, who often have little experience with or tolerance for speech impairments.

In my Amman, disability was everywhere. I toured special education and residential centers. I met special educators, therapists, and activists who brought me to their practices and organizations. I attended celebratory events and free medical screening days specifically marketed toward disabled persons and their families. Very little of this occurred systematically; I met families through other families, I joined Whatsapp groups, and I kept a close watch on mass Facebook event invitations, because invitations beget more invitations. Through the unusually independent, mobile, and unfettered life that I built for myself in Amman, I found disability everywhere I looked. Needless to say, this sensibility clashed strongly with my interlocutors' sensibility that disability was nowhere to be found. My mobility and rootlessness, however, also shaped my access and engagements in more complex ways.

I started my project with the intention of bypassing clinical spaces, and I initially planned my fieldwork by taking inspiration from a long tradition of Middle Eastern ethnography that is firmly anchored in domestic spaces (Lila Abu-Lughod 1986; Fernea 1965; Hoodfar 1997; Jansen 1987; Meneley 1995; Singerman and Hoodfar 1996). My second winter provided a logical point to transition from Society-based observations to formal interviews and house visits because life slows down during Jordan's winter months. This is particularly true for women whose children have compromised immune systems. Trying to navigate the city in cold temperatures and unpredictable weather, especially when relying on public transportation or taxis, usually results

in sickness. I first discussed my plan to transition to home visits with Hiba, one of the early

intervention specialists at the Society, and I recorded the following conversation in my

fieldnotes:

> Hiba immediately had a very strong reaction to this idea. Not of disapproval, per
> se, but almost of pity for me. She told me [visits] would probably be impossible,
> that mothers would not let me into their homes because of their situation, and
> because I am an American. They fear a media aspect, as well as what the
> neighbors might think seeing an American walk into their home. It's not like I
> haven't thought about this before, but it's a little concerning to hear her be so
> certain. I tried to counter this assessment with, "but they know me." Hiba flashed
> me a kind smile laced with gentle rebuke. "No, Christine. They don't."… She
> suggested that I consider interviewing women at the Society. "The Society is
> somewhere safe and legitimate for them and also somewhere they can be away
> from their families. And many of them have already poured their hearts out here,
> so it's a much more open space for them."

Hiba's predictions, for the most part, exaggerated the difficulty of the transition that I did in fact

make, although never quite as fully as I hoped.[25] The invitations that some mothers eventually

extended to me, while warm, gracious, and genuine, were hard won and involved a delicate

reading of cues and circumstantial constraints on my part. Hiba's cautionary words, however,

were both instructive and insightful. While my aloneness generated concern, if not pity, among

most of the people I met in Jordan, it also marked me as a difficult kind of stranger. How well

could anyone expect to know me? Especially since I lacked the social coordinates or shared

experiences that often helped to foster closeness among mothers.

Yet Hiba's concerns and suggestions were not just about me. They also spoke to the

ambivalence of domestic space for mothers of disabled children and for children themselves.

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[25] I did explore Hiba's suggestion of using the Society as a home base for conducting interviews. The Society's
home-like aspects, however, created their own challenges. During the one (and only) interview I held at the Society,
we were frequently interrupted, and after concluding, I received many queries about the content of our discussion
and my perception of how it went. I conducted the rest of my formal interviews either in women's homes, or I
accompanied them on errands and trips out of the house. In some cases, I visited women in their homes but their
domestic circumstances did not allow for formal interviewing. In these cases, I relied on observations, fieldnotes,
and occasionally more general audio recordings.

Home, Hiba implied, can be difficult for women to navigate, and my presence might further exacerbate a difficult situation. Many mothers build intense affective ties to the women and children they meet at the Society. For some, it is the only space in which they can "pour their hearts out." Notably, the Society utilizes an early intervention program (the Portage Program) originally designed for home-based visits, but they continue to offer sessions *at* the Society (Cameron 1997).[26] In part, this reflects the assumption that mothers will work independently to act as early intervention specialists for their own children. It also reflects an intentional commitment to creating a space outside the home where women can congregate and learn from each other.[27] Neither domestic nor completely removed from home and family, spaces like the al-Nur Society play increasingly important roles in the lives of Middle Eastern women, and they are capable of producing new kinds of intimacy and social distance (Deeb 2006; Ossman 2002).

V. Situating disability

My extremely unattached status, neither a wife nor a mother and far from my parents, puzzled many of the families I met. Kinship provides the intuitive and logical connection to disability in Jordan. Lacking this, my project and I remained perplexing.[28] Why was I interested in what most families considered an intimate issue? Imm Zahra described me as a volunteer from America (*mutaṭawwaʿ min Amerika*). When asked who I was and what I was doing in Jordan, I repeated this description verbatim, adding that I was a doctoral student studying "the relationship between disability and culture in Jordan." This usually made a good deal of sense. People would

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[26] The Portage Program is popular across Jordan, and most organizations offer home-based and non-home-based sessions.

[27] Landsman (1998) writes about the use of home-based early intervention programs in New York. Intended to keep infants comfortable in their 'natural environment,' she reported them as being extremely isolating for mothers (Landsman 1998, 89).

[28] This unattached status also generated genuine concern. Most of my interlocutors shared the belief that living far from kin, while an entertaining and appealing thought experiment, would prove a sad and dangerous reality.

nod approvingly and tell me that, "Culture is the problem." My methods for making sense of this problem, however, appeared quite strange. Confusion about how I could afford to come to Jordan and spend almost two years without a job understandably compounded this puzzle. Even for the significant number of adults I met who were in possession of Bachelor's and higher degrees, the "deep hanging out" that anthropologists claim as their inimitable research method remained quite suspect (a position shared, of course, by my own family).

The explanations forged to account for my interest in disability, unmotivated by the ties of kinship or a professional connection to special education, reveal how anthropologists occupy both global and local fields of knowledge and meaning. I became intelligible to many of my interlocutors through their belief that greater care and services are available for disabled people in the West (*al gharb*). My presence seemed to confirm this truth. Awareness and interest in disability must be significantly widespread and institutionalized in the United States, they reasoned, if I was traveling all the way to Jordan to study it comparatively. My presence then became another diagnostic marker of local backwardness. Many parents and teachers used my identity as a volunteer to lament the lack of any such spirit of volunteerism or civic responsibility in Jordan.

Societies in society

Members and beneficiaries of the al-Nur Society and others like it are very careful about the sorts of critiques they articulate or want to be associated with. For many families, the day-to-day goal of nurturing their children's development remains their top priority. Parents identify "society" and "government" as problems that infiltrate into their children's very bodies via the lack of available services. Very few families, however, actually express the desire to pursue a concrete agenda for political mobilization. They concentrate on the domains of family,

education, and rehabilitative therapies, rather than citizens' rights, state-centered resource

distribution, or legislative reform. What might appear to be political quietism, however, remains

an important and explicit condition of societies' right to survival.

For over 40 years, *jamaʿiyyāt* fell under the jurisdiction of Jordan's 1966 Law No. 33 on

Societies and Social Bodies. In the early 2000s, however, societies underwent an extensive

overhaul. The 2008 Law No. 51 on Societies,[29] which was subsequently amended in 2009 after

generating widespread criticism and negative press,[30] defines a society as:

> Any legal person composed of a group of persons no less than seven[31] and which
> is registered according to the provisions of this law to provide services or to
> undertake activities on a voluntary basis without aiming to derive or distribute
> profit, to realize any benefit for any of its members or for any specific person, or
> to achieve any political goals that enter into the scope of the work and activities of
> political parties in accordance with the legislation in force.[32] (Act 3)

Aspiring founders must apply for legal status through the Register of Societies, a monitoring

body created by the new law and housed in the Ministry of Social Development (MOSD).

Academic and popular presses often translate societies into the familiar categories of a non-

governmental organization (NGO) or civil society organization (CSO). While reasonable

approximations, the closeness of these terms obscures important details relevant to the

particulars of the Jordanian context.

First and foremost, the Registry can deny a society's application or dissolve an existing

society (and the grounds for denial remain unclear, as does the possibility for subsequently

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[29] This section uses the English translation provided by the International Center for Not-for-Profit Law (2016).

[30] Law 33 already granted the government extensive powers over societies' activities. Law 51 and its subsequent amendments, however, introduce new restrictions directly impacting foreign societies to a significantly greater degree.

[31] In 2016, the Ministry released a draft law that would have replaced Law 51 and called for increasing the mandatory number of founders to 50 persons. As of 2017, the status of the amendments remained unclear (International Center for Not-for-Profit Law 2017).

[32] Some organizations, however, remain exempted from this designation, including those regulated by laws pertaining to Islamic affairs and finances, minority religious organizations, and youth organizations (Act 3).

appealing such a decision). In 2015, for example, 41 societies were dissolved for "violations" (The Jordan Times 2015). Additionally, 70 other societies were placed under review and control of their daily and financial operations granted to temporary oversight commissions (Times 2015). Violations included not practicing stated work activities, failure to submit the legally required balance sheets for review, and/or the failure to establish headquarters at the appropriate address. Six societies were also under review for potentially receiving donations from foreign sources that, as per the 2008 law, require pre-approval. Societies cannot accept funds from "sources that violate public order or morals," and all foreign donations must be approved ahead of time (Article 8). Finally, society founders must possess Jordanian citizenship and no society can also be a member of another society (Article 24).

The many restrictions and stipulations placed on forming and operating societies point to the Jordanian state's attempts to control citizens and residents capacities to congregate, collaborate, and organize; all these activities emerge as potential threats. The timing of the new law is also noteworthy. Jordan's Muslim Brotherhood underwent significant structural and political changes during 2008, and the Muslim Brotherhood controls the wealthiest charity organization in Jordan, the Islamic Center Charity Society.[33] The state's increasing concerns and limitations on foreign organizations also potentially target international human rights groups, especially those that do not operate under the protection of memorandums of understanding (Human Rights Watch 2016). With minimal legal protections and an explicit prohibition against political activities, societies focus on serving their populations in ways that circumscribe critiques of the state.

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[33] See Clark (2004) for a detailed account of the ICCS in Jordan.

Political scientist Anne Marie Baylouny studies the *jamaʿiyya ʿāʾiliyya*, or family association, in both Jordan and Lebanon (2010).[34] She argues that these flourishing collectives actually facilitate and reinforce the withdrawal of citizens from formal politics and contribute to the further deliberalization of the Jordanian state.[35] At the time of her research, during the early 2000s, over two thirds of the 197 registered family associations had formed between the years of 1989 and 1999. This decade of growth speaks to the widespread effects wrought by IMF-driven structural readjustment policies that were implemented by the government to cope with economic decline and obtain some amount of debt relief. "For over one third of the population," writes Baylouny," kin solidarities have been reorganized, formalized, and registered as nongovernmental organizations in an attempt to cope with the removal of basic social provisioning by the state" (2006, 349). Their status as *jamaʿiyyāt* formally places family associations in the realm of civil society. Yet, their services are reserved for members, and members must be kin.[36] Notably, family associations lack "the classic component of a social movement, namely, its demand-making and state-centered character" (2006, 350). They focus instead on providing low or no interest loans and facilitating employment opportunities for members by providing the social connections necessary for doing so.

Family-based associations' abilities to create cross-class connections, through kinship ties, remain one of their major selling points. The fact that family groups have adopted and adapted this new hybrid format testifies to the flexibility and continuity of kinship-based politics

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[34] Following my interlocutors, I choose to translate *jamaʿiyya* as society. Both society and association, however, appear interchangeably in both popular and academic translations.

[35] To apply the framework of deliberalization might in fact overstate the extent and impact of the government's liberalizing overtures made during the late 1990s and early 2000s.

[36] Part of Baylouny's larger argument, in fact, is to show how different families and communities have learned to contract or expand their qualifications for kinship based on their position within Jordan's political economy. The latter is shaped by the Royal Family's long-standing strategy of cultivating loyalty from Jordan's powerful indigenous families through public sector employment and military leadership (Massad 2001; Shryock 1997).

in Jordan. The *jamaʿiyya ʿāʾiliyya* differs from a *jamaʿiyya* like the al-Nur Society in terms of its criteria for membership and mission statement, yet they also lack this state-centered character. Instead they direct their critical energies toward reforming issues described as social or cultural, such as the marriage of minors, women's low participation in the workforce, or promoting entrepreneurship. Given the enduring influence of personalistic patronage networks, described locally as *wāsṭa* (and translated into an array of terms, including favoritism, nepotism, connections, and corruption), considerable anxiety and paranoia can accompany civic initiatives, lest they draw the ire of someone powerful. These structural realities influence local disability activism, where conversations often remain vaguely critical of state mechanisms designed to support disabled persons (or the lack thereof). They become explicitly and intensely critical, however, of problems attributed to family, culture, and society.

Disability on global and local scales

If my interlocutors insisted on the superior quality of care provided to disabled people in the West, they puzzled over how this fit into a broader narrative of the West as both immoral and exploitative. Working in Jordan during the geopolitical era carved out by the post-9/11, pre-Trump, unending rhythms of the global War on Terror, many families either asked me to confirm or in fact insisted that the United States discriminated against Arabs and Muslims, especially those doubly marked by disability. In spring of 2014, I witnessed some of Jordan's most active disability rights activists and DPO leaders level this charge against a U.S. government liaison. The American official hoped to convene a roundtable discussion on Jordan's success in promoting disability rights (a premise vehemently objected to by all of the local experts in the room). Instead, he found himself on the defensive, denying that disability status affected visa processing. Draft executive orders on immigration issued at the beginning of the Trump

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administration, however, suggest that visa denial on the basis of disability may, in fact, become explicit policy, framed in terms of protecting taxpayers and protecting against "undesirable" immigrants (The Washington Post 2017).[37]

Learning with and from intellectually disabled people and their families, my fieldwork forced me to confront my own preconceived assumptions about Down Syndrome, my lack of familiarity with the neurodiversity movement, and the normative ideas about intelligence and capacity that shape my own perceptions of personhood. I often found myself on the receiving end of questions about U.S. disability rights legislation that I realized I knew very little about, accumulating a list of research topics about specific components of the Americans with Disabilities Act (ADA) and the Individuals with Disabilities in Education Act (IDEA). My own relative segregation from disabled people prior to my fieldwork, especially those with intellectual and developmental impairments, sharpened my critical perspective on "inclusion" and the belief that this has been realized successfully in countries like the United States. It also heightened my appreciation for the key role that state-market interactions play in shaping accessible and inclusive schools and workplaces, major topics of discussion and points of contention among families of disabled children in Jordan and around the world.

The modern concept of disability in the Arabic-speaking Middle East emerged as part of a broader proliferation of human rights and development initiatives that have taken root on regional and global levels. As a transnational movement, disability rights advocates and scholars grapple with a range of ontological, epistemological, and political problems. These can be

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[37] A Canadian case worth mentioning is that of a Costa Rican professor at York University who was denied permanent residency explicitly because his 13-year-old son with Down Syndrome would place an "excessive" burden on the Canadian healthcare system (McQuigee 2016). At the time of writing this dissertation, what's more, at least one "Muslim" ban attempt by the administration has failed, but a second, slightly more circumscribed ban is in effect.

glossed as the *what*, *who*, *where*, *when*, and *how* of disability. The vastly different political capacities, economic resources, and constructions of personhood that shape attempts to reimagine and improve the human condition complicate these interrelated questions. In Jordan, as in many other parts of the world outside North America and Western Europe, the United Nations (UN) and its capillary institutions serve as key conduits for disseminating disability rights discourses, legislative priorities, and strategies for adapting universally imagined protocols into local realities. The UN has increased its focus on disability over the past several decades, with the following declarations and initiatives standing out: The UN Declaration on the Rights of Mentally Retarded Persons (1971), the International Year of Disabled Persons (1981), and the International Decade of Disabled Persons (1983-1992). Additionally, 2003 marked the beginning of the Arab Decade of Disabled Persons, a designation decided on during the 2002 UN Economic and Social Commission for Western Asia (ESWA).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) – which was adopted in 2006, ratified in 2007, and entered into force in 2008 – is the world's most powerful international disability rights instrument. Jordan, along with 81 other countries, signed the convention on the opening day of March 30, 2007. The CRPD boasts the highest number of first day signatories in U.N. history. In this project, I approach the CRPD as a symbolic artifact of the international, institutional human rights culture that Jordan seeks to emulate in the drafting and passage of its own laws, such as the 2007 Law No. 31 On the Rights of Persons with Disabilities.[38] The CRPD does not actually define disability. Instead, the preamble "recognize[s] that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and

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[38] In 2017, Jordan passed an updated Law on the Rights of Persons with Disabilities.

effective participation in society on an equal basis with others" (United Nations 2006).[39] Rather

than compare these two texts (see Al-Azzeh 2012), I am more interested in following whether

and how local communities incorporate symbolic instruments like the CRPD as they attempt to

rework local structures for managing and making sense of bodily and mental difference.

Down Syndrome on global and local scales

Down Syndrome appears to offer a clear and generalizable inclusion/exclusion criteria:

the presence or absence of one of three possible chromosomal signatures and a consequent

spectrum of secondary characteristics and health complications (National Down Syndrome

Society). Yet even the very name of the condition reflects a specific history. Debates over

whether and why *mitlāzamat Down,* or simply *Down*, should replace the popular colloquial

description of *monghōlī* occurred throughout my fieldwork. Both terms, however, reflect deeper

historical relationships between Down Syndrome and medical research (Wright 2011).[40] The

prevalence of *monghōlī* in Jordan gestures to a largely unexcavated global history of Trisomy 21

and its migration via missionary, colonial, and development medical practices.

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[39] This distinction between impairment and disability reflects decades of scholarship and activism on the part of disabled persons, intellectuals, and activists. The disability-impairment distinction plays a central role in the social model of disability, whose origins can be traced to the "fundamental principles of disability" published by the British Union of the Physically Impaired Against Segregation ([1976] 1997). Decades of developing, revising, and debating the social model have followed. The disability-impairment distinction also lies at the heart of a substantial body of criticism across disciplinary boundaries (Corker 2001; Dewsbury et al. 2004; Goodley 2014; B. Hughes and Paterson 1997; Snyder and Mitchell 2000). The more humanistic roots of North American disability studies have somewhat offset the intensity of this debate in American academia (Davis 1995; Garland-Thomson 1997; Siebers 2010). Robert Edgerton's work on competence (1967) and Michael Angrosino's work on group homes (1998) provide examples of anthropological research on intellectual disability. Jani Klotz (2004) provides a comprehensive overview of Edgerton contributions to the study of intellectual disability, while Luckin (1986) and Gerber (1990) offer critical reflections on Edgerton's research trajectory and impact. Kasnitz and Shuttlesworth have criticized Anthropology's lack of engagement with disability and/or disability studies (1999), but there is a growing field of disability anthropology that synthesizes contributions across disciplines (Friedner 2015; Ginsburg and Rapp 2013; Hartblay 2017; Keating and Hadder 2010; Nakamura 2006, 2013).

[40] Down Syndrome, writes Richard Newton, "is not a medical condition but represents a common recognizable variation of the human form created through a random biological event. Nonetheless, as we will see, people with Down syndrome present with many common medical conditions and some that are more specific to the condition" (2015, 1). Nevertheless, it is widely perceived as a medical diagnosis in itself.

In 1866, John Langdon Down first described the condition of "mongoloid idiocy" based on his ethnological evaluation of residents at the Royal Earlswood Asylum for Idiots, where he served as superintendent after graduating from medical school in London.[41] Down was interested in contributing to *the* scientific debate of his time: the unity or diversity of the human species. He used cases of demonstrated "degeneration," as evidenced in the form of "mongoloid idiots," to argue that humans must ultimately be members of the same species since racial devolution was possible; if the case was otherwise, such deterioration could not occur. The inappropriateness of the many epithets derived from this early medical category, based as it was on the scientific racism of the 19th and 20th centuries, has become a focal point of both international and Jordanian awareness campaigns and initiatives organized by local organizations.[42]

Awareness that the international community no longer uses this term – albeit with a localized interpretation as to why[43] – speaks to the close engagement between Jordan's disability advocacy communities and transnational networks. It also reflects changing sensitivities to a term that connotes "ugly" or "stupid" and that families object to as a cruel and untrue representation of people with Down Syndrome. These shifting language norms remain somewhat tenuous, however. At least in some cases, when individuals became comfortable around me and adopted casual modes of conversation, they would revert back to using the term *monghōlī* but

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[41] The condition was clinically described by others before Down formally published and publicized his arguments.

[42] A statement published in the Lancet in 1961 by 19 prominent genetic scientists first raised the issue of changing the name (Rodríguez-Hernández and Montoya 2011). In 1965 the Mongolian delegation to the World Health Organization made a request that the term no longer be used, and henceforth it disappeared from WHO publications, setting a global precedent that paralleled national conversations (Howard-Jones 2012). The National Down Syndrome Society's preferred language guide also details the labels' further transition from Down's Syndrome to Down. John Langdon Down did not have Down Syndrome, rendering the "apostrophe 's' [that] connotes ownership or possession" inappropriate (National Down Syndrome Society).

[43] Most Jordanians did not explain this shift to me in terms of repudiating the original racism of the label, a history they may or may not be aware of. Rather, they described this impetus as a corrective to properly recognize national and ethnic identities. They described people with Down Syndrome as "looking Mongolian," but since they were obviously not from Mongolia, the epithet did not make sense. I also encountered a separate objection based on the recognition of *monghōlī* as a demeaning slur, although people did not consider the nature of this offensiveness to stem from racism, scientific or otherwise.

then correct themselves, sometimes even apologizing to *me*. These modifications reflect a recognition that the term is no longer seen as appropriate, but it also suggests that this knowledge has not yet become part of the widespread representational habitus.

These micro level negotiations serve as a reminder of the simultaneously transnational and local fields in which definitional politics unfold, as well as my own positionality in relation to them. The ways families and experts claim, question, and reject possible relationships between Down Syndrome and disability illuminate the particular stakes that different actors invest in disability and the disability rights movements. The reception of these categories reflects deeper histories concerning the nature and meanings of difference.

VI. Economies of care: disability, religion, and kinship

Throughout my research, I struggled to craft questions on the role that religion played in shaping intellectual disability in Jordan. Families rarely invoked Qur'anic verses or hadith (sayings of the Prophet) to engage in exegetical debates about disability, practices that have provided a wellspring of ethnographic research and theoretical innovation for anthropologists working with Muslim communities (Deeb 2006, 2015; Fadil and Fernando 2015; Hirschkind 2001; Mahmood 2005). Most members of disability rights and advocacy organizations in Jordan do not identify their work through explicitly religious idioms, aligning themselves firmly with principles and practices of the global human and disability rights movements. And neither mosques nor religious figures played major roles in helping families care for disabled children. My questions on this topic often elicited complaints about the perceived lacunae of such support.

My interlocutors nevertheless embraced a model of inclusion based on incorporation into a moral community, and religion plays a central role in how families and individuals imagine society. Many families ponder – sometimes seriously, but more often in jest – the possibility of

leaving Jordan to seek better services and opportunities for their children elsewhere. When Hiba asked Imm Rami if she had any family connections in the United States, the latter reacted strongly to the implications of the question. "My husband might consider [leaving Jordan], but my family is here! And it's too hard to be Muslim there. They don't have religion, and they don't raise their children properly." Hiba disagreed. "I have a friend raising her family in Britain, and all three daughters wear hijab." Imm Rami was not convinced. "It's easier to be Muslim in Britain," she proposed. Hiba then asked for my opinion on the matter. I granted that life could be challenging for Muslims in the United States, especially under the present political circumstances, but it depends which part of the country one lived in (my default answer to all questions about the United States). I pointed to Dearborn, Michigan as an example of this diversity of circumstances, explaining they would be more likely to walk down the street hearing Arabic and seeing women wearing hijab than not. "Religion is not in the hijab, Christine," replied Imm Rami. "Religion is in one's heart (*al dīn mish fīl hijāb. Al dīn fīl qalb*)."

While parents in Jordan discuss their children's right to state-funded social services and their desire to see subsidies for the private sector, things they imagine as fully accessible in "the West" (*al-gharb*), most do not desire the accompanying moral economy of personhood. The ways people enact hierarchical and interdependent relations between humans and God shape the shared and lived realities of disability in Jordan. There is, in other words, a spiritual economy of disability that shapes local disability worlds. I take this term from anthropologist Amira Mittermaier, who describes how young people in Cairo explain their motivation to do volunteer work as part of their duty to do good deeds for God, rather than a civic responsibility or form of activism (2014). Additionally, I draw on the work of Kathryn Burns, who defines a spiritual economy to express, "the inextricability of the material and the sacred, relying on a very old

sense of 'economy' as the managing of a house (Greek *oikos*) and pointing to the spiritual goals orienting such an activity" (Burns 1999, 3). This sense of economy aptly captures the equally moral and material dimensions of caring for one's kin. Care involves protecting and sustaining one's house (*bayt*) – a word that encompasses the structures, resources, and people connected through ties of kinship – as part of fulfilling one's duties to God.

Spiritual economies exist alongside and intertwine with other systems of value, however, and this is especially true in relation to family. An adult son who neglects the wellbeing of his aging parents will generate strong social sanction from those around him. A woman who fails to meet her mother-in-law's standards for cooking might generate more sympathy, but she will nevertheless be urged to adapt and fulfill her obligations in this acquired role. Parents who neglect their children generate disapproval and often outrage. This is decidedly the case when the child in question is perceived to be uniquely vulnerable and in need of extra care. Family members who fail to provide the kinds of care expected of them are considered morally compromised and may be described as bad Muslims. But this framing does not preclude recognizing problems as resulting from the pressures and conflicts wrought by circumstance.

Logics of delayed reciprocity animate relationships of obligation and care between kin, and the acute lack of alternative, non-kin structures for providing care labor perpetuates and maintains this system. As one mother explained to me while fretting over her eldest son's increasingly poor performance in school, "Parents here depend on their children for the future. I encourage my son to excel not just for his own personal growth, but also for the sake of my own wellbeing when I am older. I will depend on him." For parents of children with Down Syndrome, the progression of kinship-based relations of care, which are already fraught and prone to moral failure, becomes an even more complicated process. Children and adults with Down Syndrome

also care for their parents in various ways. In fact, parents often describe children with Down Syndrome as kinder and more emotionally perceptive than their children without Down Syndrome. Nevertheless, disability disrupts the normative economies of care that kinship futures rely on.

VII. Ambivalent Inheritance

To speak of kinship futures inevitably entails looking to the past. Kinship, and the various forms of inheritance transmitted through family lineage, stretch backward and forward in time Inheritance exists on multiple registers and speaks to the centrality of genealogy as identity, moral substance, and political power in Jordan and in the Middle East more broadly. It also gestures to the expansive reach of biogenetic knowledge and its entanglement in these historically deeper forms of genealogical reckoning. The geneticization of health and illness, family, and marriage play increasingly important roles in shaping Down Syndrome in Jordan. Inheritance nevertheless extends beyond and remains irreducible to genetics. This is why families can accept chromosome-based explanations of Down Syndrome but remain quietly unconvinced of their implications for family reputation. Inheritance represents a convergence of preparation for the future and remembrance of the past.

Nevertheless, inheritance remains a lesser topic within contemporary kinship studies, perhaps because it grates against present interests in the flexibility and creativity that can be marshaled to construct kin. Daniel Miller notes that many anthropologists and sociologists today analytically frame kinship as relationships built through practice. In choosing to do so, however, they end up avoiding ethnographic data that commonly "show an almost obsessive concern with kinship as formal and normative" (Miller 2007, 538). Even Marshall Sahlins notes this tension in his influential essay, "What Kinship Is, part one," where he famously proposes that kinship be

understood as "mutuality of being" (2011, 2). He acknowledges that, "people's freedom to revise their kin relationships… *does not mean that the relationships as such are under revision* – or otherwise without determinate properties and codes of conduct" (2011, 5, my emphasis). Miller draws this tension out more explicitly, suggesting that "flexibility and negotiation are a direct result of the struggle people have in trying to retain clear principles and formal expectations in kinship" (Miller 2007, 540).

The moral validity conveyed by marriage produces recognized genealogical descendants who are entitled to inheritance, assets, and their father's family name. Inheritance, in turn, encompasses the material and immaterial legacies that the present generation carries from the past and protects for the future. As families encounter Down Synome, many questions about *inheritance* emerge. First and foremost, parents and relatives frequently articulate concerns about whether Down Syndrome is *wirāthī* (inherited). Answers to this query – by professionals and laypeople alike – usually conscript biomedical objects like genes and chromosomes to explain how Down Syndrome develops and why. Biogenetics translate quite smoothly into local understandings of inheritance. Genealogical configurations of identity, power, and historical time, however, extend far beyond this new medium, both in Jordan and in the broader Arab Middle East (Samin 2015; Shryock 2013).

Families experiences with disability make them confront the ambivalence of kinship. Ambivalence, writes Michael Peletz, articulates the "simultaneous experience of powerful, contradictory emotions or attitudes towards a single phenomenon" (2001, 413). Peletz argues that to study kinship is to study experiences of ambivalence and violence. The data gathered by early ethnographers demonstrates as much, but they chose to mute the analytical significance of these darker forces given longstanding disciplinary investments in kinship as a tool for

maintaining solidarity, reciprocity, and structural cohesion. To some degree, a positive investment in social solidarity continues to animate kinship studies. Yet anthropologists increasingly grapple with modes of violence, exploitation, abandonment, and neglect that appear to be as equally central to the practices and politics of kinship (Biehl 2005; Garcia 2010; Weiss 1994; Weston 1991).

My own work asks how ambivalence and violence comingle with acts of care to variably transform the actors involved in such exchanges. Ambivalence, not to be confused with ambiguity, produces the affective and intersubjective realities of Down Syndrome in Jordan. The power of disability intrudes into families' lives with particular force. It can be destructive, but it can also be generative. In some cases, it ultimately transforms how individuals and families understand themselves and their communities. My interlocutors would often speak of people with Down Syndrome through what anthropologist Rayna Rapp has described as "double discourses," exceptional but average, normal but different, a blessing but a burden" (1999, 293). They are, in other words, an ambivalent inheritance.

VIII. Organization of the dissertation

The dissertation's structure reflects my argument that Down Syndrome changes over time and across space. I chart how individuals and families in Jordan age in relation to each other and under historical, political, and cultural conditions that enable and constrain the futures they imagine possible. Through their attempts to build and secure different kinds of kinship futures, families shape the current realities of disability in Jordan. Each chapter in the dissertation focuses on how these dynamics assemble during a significant moment in the life course: Birth and diagnosis (Chapter Two), early and middle childhood (Chapters Three and Four), and adolescence (Chapter Five). The concluding chapter considers life in terms of the inevitabilities

of aging and death. I discuss how nonsecular futures provide significant content for imagining Down Syndrome in the present (Chapter Six).

Chapter Two has two main aims. First, I offer readers a snapshot of the social and moral geographies that shape how families, and especially mothers, react to diagnoses of lifelong intellectual disability. Because the dissertation's temporal arc serves as part of my larger argument about the relationship between disability and futurity, birth and diagnosis provide a natural starting point. I approach diagnosis as a set of processes that generate different narratives for families and both reveal and expose them to various risks. Diagnosis generates intense anxieties about children's future marriage prospects, and in the aftermath of diagnosis, women often encounter anger and suspicion from other family members. Their experiences reveal how the local care economy relies on a kinship-based and gendered distribution of re/productive labor. This labor operates through evaluations of normality. Impairment and disability both illuminate and unsettle investments in the normal, and families adopt different strategies to protect themselves from risk.

In Chapter Three, I introduce the concept of a moral orientation to capture how mothers work to cultivate acceptance (*taqabbul*), which they contrast with the rejection (*rafaḍ*) of Down Syndrome that they describe as endemic to society. The idea of a moral orientation builds on Hayder Al-Mohammad's critique that the "anthropology of ethics" has remained focused on an individuated, ethical "self." By following how mothers work to produce and inhabit this moral orientation, I demonstrate different possible ways of *being-with* disability in Jordan (Al-Mohammad 2010, 426). The orientation of acceptance is neither straightforward nor uncontested, instead encompassing disputed paths to becoming a "good" mother.

Chapter Four turns to childhood, a stage of life that Jordanians widely equate with participation in systems of formal education. This chapter "zooms out" to explore how the concept of inclusive education has come to dominate discussions of childhood disability in Jordan, much to the frustration of parents, as well as some teachers and specialists. The disruptions that intellectual disability poses to parents' visions of their child's long-term welfare can affect their immediate choices about schooling and their assessments of education as an abstract value. Discussions about schooling, I suggest, index widespread anxieties about the difficulty of safeguarding children's wellbeing and economic security in the context of regional insecurity and global economic restructuring. Educational discourses, meanwhile, connect children to state and cosmopolitan visions of citizenship, development, and modernity in ways that often ignore complex realities and constraints of everyday life.

Chapter Five considers what happens as intellectually disabled children experience adolescence and puberty. Aging without achieving social standards for maturity, intellectually disabled adolescents experience form of "embodied asynchrony," a term I borrow from Allison Kafer (2013, 48). The ambiguity that certain intellectual impairments introduce generates explicit conversations about sexuality, bodily integrity, and what it means to be an full member of society. Intellectual impairments limit adolescents' capacities to meet the criteria for the successful performance of adult gender norms. Yet the stakes are not everywhere the same. While young women are policed and their bodies potentially surgically altered, intellectually disabled young men are far less likely to experience the same degree of invasive surveillance. For both young men and young women, however, adult personhood remains frustratingly out of reach.

The final chapter returns to the concept of kinship futures. I explore how parents and siblings wrestle with questions about the passage of time and confront anxieties when considering the inevitable: death. I highlight how nonsecular dimensions of relationality and accountability shape families' imaginations of the future and their perspectives on the burdens and literal blessings of caring for and being cared for by disabled kin. I conclude by gesturing to some of the other disability worlds present in Jordan, and I contemplate how these worlds will continue to expand while remaining grounded in local moral worlds and kinship futures.

Chapter 2. Risk

I. Diagnosing Down Syndrome

When Imm Sara and her sister brought six-month-old Sara into the Society for the first time, both women were already well versed in the clinical details of Down Syndrome. They confirmed with Hiba, the main early intervention specialist at the Society, that Sara was trisomy, meaning all of Sara's cells possess three copies of chromosome 21. They also listed many of the future health risks and developmental delays Sara might face. Born with a heart defect commonly found in children with Down Syndrome, Sara remained under the close supervision of doctors as they waited to see whether the infant would require open-heart surgery. During this first conversation, Imm Sara began articulating her husband's desire to know "whether or not there was any treatment." Hiba began to make a dramatic exclamation that practically drowned out the last words of Imm Sara's sentence. "Imm Sara! This is a syndrome (*mitlāzama*), as in, her whole life!" Staff and parents bristled when confronted with conflations between Down Syndrome and disease or sickness (*maraḍ*). They insisted instead on the distinctiveness of *mitlāzamat Down* as a mode of being in the world.

A baby's birth triggers social transitions and transformations for a host of actors connected to and through this new life. Spouses become parents, parents become grandparents, children become siblings, and so on. The unexpected diagnosis of a baby with Down Syndrome marks an additional set of transitions and transformations. Charles Rosenberg describes diagnosis as that which, "links the individual to the social system; it is necessarily a spectacle as

well as a bureaucratic event. Diagnosis remains a ritual of disclosure: a curtain is pulled aside, and uncertainty is replaced-for better or worse-by a structured narrative" (2002, 255). For families in Jordan, diagnosis has not yet achieved the formalization or predictability of ritual. Multiple possible narratives emerge, and they hang together tenuously –if at all. "It is significant," Rosenberg continues, "that most of us think of [diagnosis] as a discrete act taking place at a particular moment in time" (2002, 256). In reality, diagnosis unfolds as a "collective, cumulative, and contingent process" (2002, 256).

This chapter examines the collective, cumulative, and contingent *risks* – and the new possibilities – that a diagnosis of Down Syndrome reveals and creates for families in Jordan. Ulrich Beck (1992) and Anthony Giddens (1991) argue that a defining feature of modernity is the degree to which perceptions of risk dominate contemporary social, political, and economic life. The concept of risk evolved out of 17th century developments in theories of chance and probability (Hacking 1975, 1990). As God(s), fates, and tragedy ceded their explanatory authority to science and rationality, the notion of "chance" emerged, reconfiguring understandings and experiences of causality and human agency. Kaja Finkler explains, "a chance event was merely one whose causes were not known, but it was now deemed possible to calculate mathematically the probability of an event that involved human beings" (2003, 52). From mathematically produced projections of chance, one could then calculate risk. Today, the concept of risk holds enormous influence across the fields of public health, epidemiology, and clinical medicine, as well as in biopolitical governance more broadly (Foucault 1990, 2008). Ethnographers and historians are careful to point out, however, that different risks emerge as most meaningful for differently positioned social actors.

Diagnosis provides an ethnographic window into experiences and complexities of the

risks that converge at the nexus of disability, personhood, and what Finkler describes as the "medicalization of family and kinship" (Finkler 2003, 52, see also 2001). How diagnosis in Jordan enters into and disrupts networks and bonds of kinship, in turn prompts families to reflect on the stakes and risks of cultivating relatedness. The necessity and the costs of maintaining close social ties, especially among kin, are revealed through family members' attempts to come to terms with a child's diagnosis.[44] The intensity of this process ebbs and flows over different moments in a family's life cycle. Because this dissertation's overall temporal arc mirrors my broader arguments about disability and temporality, diagnosis provides a natural starting point. In cases of congenital disabilities, birth and diagnosis occur in close succession, if not simultaneously. In parts of the world where pregnancy and childbirth have become heavily biomedicalized, diagnosis may precede and alter the course of an impending birth. Given the limited use of prenatal screening and diagnostics in Jordan, however, the diagnosis of Down Syndrome continues to occur postnatally, and this adds another distinctive temporal dimension to the diagnostic process.

Diagnosis attaches itself to familial futures and pasts, portending various kinds of risks that affect family members unevenly and unequally. In tracing how the temporal and intersubjective threads of diagnosis weave family members together and split them apart, I focus on the experiences of mothers and their disabled children. The next section of this chapter, "neither sick nor normal," examines the importance of attempting to distinguish between sickness and disability for my interlocutors. Ultimately, however, Down Syndrome remains uncertainly positioned between these two domains, both in Jordan and elsewhere. In the section that follows, "marital prognostics," I consider some of the reasons why the diagnosis of a baby

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[44] In fact, as anthropologist Morgan Clarke observes, "closeness" (*qarābah*), [is] perhaps the nearest equivalent in Arabic to the English "kinship" (2007, 380).

with Down Syndrome generated marital conflicts for parents and also prompted extensive projections forward in time. Families worried about future marriages and whether disability would diminish the marital prospects of siblings and cousins, in addition to the more complex question of marriage for the child living "under diagnosis" (Martin 2009). The reasons for these prognostications intertwine in the fourth section, which focuses on "moral etiologies." Inspired by anthropologist Sherine Hamdy's work on political etiologies (2008; 2012), I use the concept of moral etiologies to examine how biogenetic and genealogical renderings of inheritance reinforce stigma against Down Syndrome and foster gendered distributions of blame and accountability. The final section turns to another kind of possible future, one currently materializing through the use of prenatal screening and diagnostics. Although still limited in application, the presence of these technologies has created morally fraught and previously unimagined capacities for knowing, and thus being able to change, kinship futures.

II. Neither sick nor normal

For many Jordanians, the label of Down Syndrome carries the moral authority of modern biomedical and therapeutic expertise, which they seek to harness in their attempts to rework the stigma of the commonly used moniker *monghōlī*. The latter remains a common way to describe people with Down Syndrome and has obvious and problematic racial connotations.[45] Down Syndrome's uneasy relationship with contemporary biomedicine, however, quickly becomes apparent to family members through their negative interactions with doctors, hospitals, and in their pursuit of healthcare more generally. Staff members at the Society make a point to ask new

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[45] *Monghōlī* is *also* connected to the medical history of Down Syndrome. Most Jordanians are not, however, familiar with *monghōlī's* origins as a now-discredited medical category (the same can be said of most Americans, for that matter). Jordanians link Down Syndrome and biomedicine together as indexes of a proper modern understanding of the condition. They contrast this with the stigma of *monghōlī*. See the Introduction for a fuller discussion of Down Syndrome and *monghōlī*.

mothers how they received their child's diagnosis.[46] When Hiba posed this question to Imm

Abud during her first visit, the latter reacted strongly to the prompt. Imm Abud described her

experience with doctors as awful. Rather than first discuss their son's Down Syndrome with her

and her husband, their doctor announced that Abud was *monghōlī* in front of both their extended

families, who had congregated to meet the new baby. "It should have been between us, in her

office," she exclaimed, the tone of her voice conveying dismay and still-raw emotion. Imm

Abud's husband was furious, and he initially wanted a divorce.[47] While the marriage ultimately

survived this turbulent moment, members of their extended and immediate family distanced

themselves from Imm Abud and her son. Even Imm Abud's own children could not understand

why their mother decided to "keep" their youngest brother.[48] "They stay away from him, and

they treat him like he's sick," she explained, "but *he's not sick* (*huwweh mish murīd*)!" Although

a few years had passed since the initial shock of Abud's diagnosis, relations with her family

remained strained. When Hiba asked for her husband's contact information, a standard procedure

of the intake interview, Imm Abud paused and suggested that she provide them with one of her

daughters' phone numbers instead.

Families who receive a diagnosis of Down Syndrome in the first days of their child's life

are better positioned, at least in theory, to secure earlier and more comprehensive health and

therapeutic interventions than those who find out months or even years later. Popular

representations of Down Syndrome in Jordan, as in the United States, place significant emphasis

on the cognitive impairments associated with the condition. For many individuals and their

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[46] The atmosphere surrounding these exchanges of information was usually conversational and open, and dialogues flowed in and out of more general discussions with other mothers and staff members.
[47] This additional detail led her and Hiba to a brief side conversation about why some men react this way. "*Mish insān!*" exclaimed Hiba (*he has no humanity*)*!*
[48] I was unsure what "keeping" versus "leaving" a child entailed. When I later asked Hiba, she explained that she thought not keeping a child meant "putting him in a residential center and acting like he's not part of the family."

families, however, health problems that include, "heart anomalies and conditions, hypothyroidism, leukemia, digestive ailments and celiac disease, [and] strong susceptibility to life-threatening pneumonia," emerge in daily life as the most consequential aspects of the Down Syndrome (Pohlman 2010, 54). These chronic bodily vulnerabilities foster an intimate dependence on and appreciation for medical technologies, the pursuit of which families frame as acts of love, care, and obligation.

Ethnographies of biomedicine have explored how global and local histories of inequality transform and rework medical practices (Street 2014; Wendland 2010). Medical anthropologists have effectively challenged biomedicine's singularizing assumption that bodies everywhere operate in fundamentally the same ways, tracing the historical and local circumstances that forge situated "local biologies" (Lock 1993, 1995, 2017; Lock and Nguyen 2010). They have also produced searing critiques of biomedicine as complicit in creating and reinforcing processes of social abandonment, inequality, racism, and political violence (Biehl 2005; Bridges 2011; Comaroff 1993; Farmer 2003; Hamdy 2012). Yet biomedicine can also provide opportunities. For example, it offers life-saving vaccinations against infectious diseases, although the pernicious effects of structural inequality increasingly undermine vaccination efforts (Barrett et al. 1998; Farmer 1999). Biomedical technologies can also offer life-changing solutions for previously intractable conditions like infertility (Bharadwaj 2016; Franklin and Ragoné 1998; Inhorn 2003; Inhorn and Birenbaum-Carmeli 2008). Some scholars have even suggested that, "medicine can also be empowering for the postcolonial indigenous subject," capable of wielding tools and measurements in efforts to make claims against a historically oppressive state (Meekosha and Soldatic 2011, 1393; c.f. Salmon 2007).

Like Imm Abud's, most families' earliest engagements with Down Syndrome come as a

complete surprise, described in terms of shock (*saḍma*), and they unfold through interactions

with biomedical actors and institutions.[49] Unofficial assessments or premonitions sometimes

precede a delayed formal diagnosis. In these cases, family members turn to Google, Facebook, or

even an older child's biology textbook, to search for information or confirmation. Doctors

approach diagnosis as a collective ritual, properly located within the extended family, or as a

private dialogue between patriarchal authority figures. Imm Abud criticized her doctor for

publicly revealing Abud's diagnosis, locating this news as rightfully belonging first and foremost

to husband and wife in their new roles as parents. The doctor clearly disagreed, choosing to

provide the details of their son's conditions to the larger kin group assembled at the hospital.

Conflicting interpretations about the proper disclosure of diagnosis, however, reveal

tensions beyond those of doctor-patient miscommunication. They gesture instead to broader

uncertainties in contemporary Jordan about how to fit impairment and disability into available

notions of health, normality, and difference. Veena Das and Rennu Addlakha, drawing on long-

term research in northern India, suggest that:

> A focus on kinship not as the extension of familial relations into community, but
> as the sphere in which the family has to confront ways of disciplining and
> containing contagion and stigma, yields startling revelations about disability and
> impairment as located not in (or only in) individual bodies, but rather as "off" the
> body of the individual and within a network of social and kin relationships. (2001,
> 512)

For families living in Amman, this description of impairment and disability as "'off' the body

made intuitive sense to me. The connective (Joseph 1993) and networked qualities of impairment

raise troubling questions about qualities of personhood, kinship, and social value in the face of

embodied difference. The anxiety and shock experienced during diagnosis merge with rapid

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[49] Approximately 97% of births in Jordan take place in either a clinic or hospital, a reflection of the country's almost total medicalization of childbirth (Department of Statistics [Jordan] and ICF International 2013).

attempts to manage and mitigate disability's feared consequences on collective family reputation. The marital troubles and mother blame experienced by Imm Abud fit into a widely observed response pattern that unfolds in the wake of diagnosing congenital disability in Jordan. Even individuals who align themselves against this reaction pattern identify concerns about marriage and heritability as serious obstacles they will inevitably confront among family and friends or, at the very least, in their wider community.

Care networks in Jordan rely on a gendered distribution of re/productive labor, which in turn takes shape through perceptions of normality. Impairment and disability illuminate and unsettle investments in being "normal," and families adopt different tactics to accommodate and protect the sanctity of their status as such. New framings and networks of disability advocacy, however, open up space for families to negotiate with the hegemony of normality. "The opposite of *ṭabīʿī*," Imm Zahra once argued, while sitting with a group of mothers, "is *maṣnūʿ* (manufactured), which makes no sense in relation to people!" Imm Zahra was playing with the semantic flexibility of the word *ṭabīʿī*, most closely associated with word for nature, *ṭabīʿa*. All humans are *ṭabīʿī*, she sought to imply, because God creates all life. Given the scope of this oneness, natural and normal blend together in meaning. Congenital disabilities occur for different (and sometimes unknowable) reasons, and they can cause serious hardship. To call Down Syndrome abnormal or unnatural (*mish ṭabīʿī*), however, marked one as guilty of a serious misrecognition; God doesn't make mistakes. Other interlocutors made similar arguments in claiming their children's radical equality before God. Their attempts to create spaces for belonging within their kinship networks, however, rely on hierarchical relationships of protection, guardianship, and vulnerability.

Evaluations of *normal* depend on an individual's capacities to fit within preexisting

family structures and roles. Certain impairments, and the assumptions able-bodied and able-

minded persons hold about their disabling effects, seriously threaten the abilities of persons with

Down Syndrome to "fit" at different points in time. The increasing medicalization of disability in

Jordan plays a complex role in these evaluations of normality and their disabling consequences.

Many of the social factors that contribute to the stigmatization of disability superficially align

with medical concepts, especially with regard to inheritance. The local beliefs and social

structures that define inheritance, however, rely on the importance of genealogy as a kind of

moral substance and the ultimate power of divine authority. These dimensions of inheritance

ultimately extend beyond and encompass the medical domain.[50] Parents seize on medical

knowledge as a new resource with the potential to challenge the nonmedical structures of power

and stigma that families encounter. Yet medical authority intersects with other modes of

patriarchal power and social inequality to imperil women and their children in special ways, as

the following example illustrates.

Damages: what does an extra chromosome do?

I met Reham at a free dental clinic hosted by the al-Nur Society. Clearly in her teens, she

was the oldest person with Down Syndrome in attendance at this particular event. Many of the

other families, whose children were much younger, watched Reham intensely, as though she

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[50] In Mariam Coker's research on stigma and mental illness in Egypt, respondents were not particularly concerned with the *labels* applied to different mental illnesses. They focused instead on whether the person's condition affected their ability to fulfill expected social roles. When shown a series of vignettes featuring persons exhibiting behaviors associated with various psychiatric disorders, "it was alcohol abuse, not the strange behaviors and words portrayed in the psychotic vignette, that elicited the greatest need for social distance" (Coker 2005, 925). Research participants used medicalized understandings of mental illness to contextualize and minimize the stigma of such conditions, which they recognized as potentially temporary and importantly amenable to treatment. Alcoholism, however – perceived as a moral failing against the teachings of Islam, contagious in its damage to social reputation, and associated with unpredictable violence – elicited more stigmatizing responses.

could offer them a glimpse into their own child's future. Reham was friendly, outgoing, and funny. She walked around the room with gusto, properly introducing herself to the many new acquaintances that filled the clinic. Her own mother and grandmother stayed somewhat more aloof, observing the scene at large and the rest of the parents in attendance. Reham began attending the Society after meeting several families at the clinic day, and I often chatted with her mother when she dropped Reham off in the morning or came to pick her up early in the afternoon. Eventually, I asked if she was willing to talk with me in greater depth, and she suggested we meet in a café at a nearby mall.

Imm Reham recalled the details of Reham's birth and younger years quite clearly; they seemed in some ways still fresh, despite the fact that Reham was approaching her 18th birthday. Imm Reham's husband worked in the pharmaceuticals industry, and they had moved around the Middle East for his work when Reham was younger. Imm Reham was well educated, well traveled, and had several close family members living in Europe, the United States, and the Arab Gulf. Although we began to talk about Reham's Down Syndrome in terms of the moment of diagnosis, Imm Reham shifted our conversation to earlier points in time.

> I saw people like [Reham] when I was younger, before I was married. You can tell from their eyes, more than anything else. But I didn't know anything *scientific* about them, that their name was *Down Syndrome*. I knew them like everyone knows them, as *monghōl*. When Reham was born, I didn't know anything was wrong for a month. But in the nursery at the hospital, I noticed her eyes. *She is different.*[51] After that, after a month, my husband told me that she has an extra chromosome. I also thought *'Oh it's better?! Maybe she will be a genius!'* He told me, "No, this extra chromosome, it damages. It doesn't make things better."

Imm Reham's husband eventually admitted to her that the doctors informed him of Reham's condition as soon as she was born.

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[51] Imm Reham code-switched throughout our conversation, turning to English to express particular words and phrases that I represent in her speech with italics.

Women consistently reported this experience of doctors bypassing them entirely and delivering diagnoses directly to their husbands. This selective communication did not endanger Imm Reham or her daughter, but the biased informational route often has grave implications for both mother and child. Strong models of normality and difference shape how families respond to diagnosis. In turn, their responses often reveal the primacy of agnatic ties and patriarchal bonds during moments of post-diagnosis shock. Imm Reham witnessed one such situation play out within her own extended kinship network. She explained:

> I have *a relative,* she gave birth to a girl with Down Syndrome. *One month before me.* Her daughter is practically the same age as Reham. *They are divorced! As soon as* the girl *was born,* when the mother returned home after the hospital, *the lock* on the door *was changed.* "*Go to your family,*" [her husband said]. *There are different reactions.* But no, my husband, he loves Reham very much, *and his family and my family.* Everyone.

Several months later, while visiting Imm Reham and Reham at their family home in a suburb of northwest Amman, we again spoke about Imm Reham's relative and her daughter with Down Syndrome.

> The daughter died. Very recently. She got sick, and they couldn't afford to take her to a hospital where she could get direct ICU care. She died on the hospital bed. The hospital refused to release the body to her mother. They insisted on waiting for her father, who had literally never seen her in his entire life. Eventually, his family showed up to claim the body and pay the expenses. They dealt with the burial, and the mother had no say.

Imm Reham shook her head in dismay. Reham and her relative's daughter experienced Down Syndrome in vastly different ways. Their "extra chromosome" intersected with larger structures of power and materialized through the contingent dynamics of kin relations, marital ties, and financial resources. Diagnosis and its consequences hinge, in part, on the relationship between parents as spouses. But these marital ties do not shape diagnostic trajectories alone. Families strive to distinguish between *maraḍ* and *mitlāzama* in order to create a space for *Down Syndrome*

apart from disease and beyond *monghōlī*. They nevertheless situate Down Syndrome in relation to the enduring primacy of kinship and its reproduction through marriage. The following section explores why diagnosis so deeply affects the marital ties families imagined as part of their futures, which in turn, significantly shaped how individuals and families relate to Down Syndrome in the present. I describe this intimate connection between diagnosis and future marriage through the concept of *marital prognostics*.

III. Marital prognostics

The points of tension and conflict that emerge in the previous narratives – sickness, normality, privacy, gendered blame, divorce – provide ethnographic specificity to the collective and structural forms of stigma that mark families and individuals in Amman's changing disability world. Families' negotiations of stigma cluster around one key term: ʿ*ayb* (shame, although I aim to complicate this translation). In Jordan, discourses around what and who counts as ʿ*ayb* circulate through everyday exchanges and in different social and relational contexts. Parents and older relatives chastise wayward children with "ʿ*ayb!*" – for failing to properly greet an older relative, stealing their siblings' toys, or running out in front of guests not properly clothed. In this delivery, ʿ*ayb* functions as a direct but relatively gentle form of admonishment akin to "that's rude!" ʿ*Ayb* can also draw attention to more serious social breaches, deployed to call out young men for hassling a woman on the street or uttered in response to the makeup-heavy, kissy-face selfie a friend's daughter posts on Facebook. This use of the term conveys a public statement akin to, "that's not right." I start with these deployments to situate ʿ*ayb* as a

well-established mode for articulating social criticism and calling attention to public[52] breaches of decorum and moral standards.

Yet ʿ*ayb* itself has also emerged as the object of widespread critique among my interlocutors. Families explicitly link the importance of *ʿayb* to practices they increasingly consider problematic, such as the stigmatization of disability. The term thus belongs to the zone of what Michael Herzfeld has described in terms of cultural intimacy, or "the recognition of those aspects of cultural identity that are considered a source of external embarrassment but which nevertheless provide insiders with their assurance of common sociality" (Herzfeld 1997, 3; Shryock 2004a, 2004b). By following how behaviors identified as *ʿayb* shape daily and changing interactions with Down Syndrome, the dangers that disabilities pose within families' local moral worlds emerge more clearly (Kleinman 1999). These dangers are complex and multifaceted, but families connect them to the marital problems and prognostications provoked by diagnosis. What, then, does *ʿayb* ultimately signify, and why is it considered problematic, both analytically and in social practice?

The anthropology of ʿayb

Accounting for the relationship between *ʿayb* and disability brings me to a field of anthropological work that has, over time, become the subject of intense and widespread criticism.[53] In its most direct translation, as shame, anthropologists have conventionally approached *ʿayb* as intimately bound up with the value, distinction, and perception of honor (*sharaf*). Anthropologists working in the Mediterranean region during in the middle of the 20th

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[52] I do not use the word public here in its classic Habermasian sense, but rather to convey the kinds of social space generated by the presence of non-intimates.
[53] Paul Dresch, describing his fieldwork in Yemen during the late 1980s, notes by that time that already, "honour had fallen under ban among Mediterraneanists" (2000, 110). My work on *ʿayb* both confirms his observation while problematizing why this must necessarily be the case.

century, influenced by prevailing theories of structural-functionalism,[54] argued that the existence

of an "honor-shame complex" provided evidence for the region's cultural unity (Abou-Zeid

1966; Campbell 1964; Pitt-Rivers 1954, 1966).[55] While individuals' engagements with the

concept of an honor-shame complex reflect the particularities of their fieldsites and theoretical

orientations, they shared some basic assumptions. To quote from the paradigmatic volume edited

by J.G. Peristiany, *Honor and Shame: The Values of Mediterranean Society*:

> Honor and shame are social evaluations and thus participate in of the nature of
> social sanctions, the more monolithic the jury, the more trenchant the judgment.
> Honor and shame are two poles of an evaluation. They are the reflection of the
> social personality in the mirror of social ideals… Honor is at the apex of the
> pyramid of temporal social values and it conditions their hierarchical order.
> *Cutting across all other social classifications it divides social beings into two
> fundamental categories, those endowed with honor and those deprived of it*."
> (Peristiany 1966, 9–10, my emphasis)

Several critiques have taken this early "Mediterranean" school of honor and shame to task.[56]

Michael Herzfeld (1980) argues that ethnographers paid far too little attention to the specific

linguistic terms and social context[s] that shaped indigenous terminologies of honor. Uni Wikkan

suggests that male anthropologists uncritically accepted men's descriptions of honor and shame

at face value while failing to give equal consideration to the ways that women shape and

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[54] Coombe (1990) notes that "the fundamental inadequacies of structural functionalism have not been remedied by subsequent explanations or interpretations of the honour/shame complex that adopt such divergent perspectives as materialism (Schneider 1971), economic determinism (Davis 1977), and structuralist symbolic analysis" (223).

[55] The easy elision between Mediterranean and Middle East obscures a considerably different set of geopolitical circumstances.

[56] Turning briefly to the study of shame outside the contested project of Mediterranean anthropology reveals strikingly parallel tensions and concerns that gesture to similar disjunctures between lived importance and academic discomfort. Fung, writing about childhood socialization in China, describes shame as "the quintessential sociomoral emotion" (Fung 1999, 181). She notes, however, that, "contemporary Western theorists tend to treat shame negatively and primitively as a problem to be solved or a disease to cure; shame is often associated with children, savages, and neurotics [Greighton 1990; Schneider 1977, 1987]" (Fung 1999, 182). The emphases in Chinese culture on "face, criticism, and evaluation," speak to the central importance of shame in developing personhood. Yet, Fung argues, relatively little attention has been directed to studying the processes through which shame becomes meaningfully embodied and incorporated into social interaction and structures of dominance because of a reticence on the part of scholars to engage a discredited term.

participate in their local moral systems (1984; see also Abu-Lughod 1985, 1986). A gendered

bias responsible for distorting the primacy of honor in the ethnographic literature resulted in the

relative neglect of shame as productive of its own complex moral terrain. "Could this be," asks

Wikkan, "why those who study honor and shame always insist that they are binary terms, and

always focus their discussion on honor, as if it were dominant" (1984, 635).[57]

In my own work, rather than approach honor-and-shame as elements of a fixed moral

code, I draw from more recent scholarship that approaches honor and/or shame as differently

situated and variably connected means for motivating actions and justifying reactions. In other

words, honor and/or shame are invoked as situated modes of practice connected to specific moral

projects. Anthropologist Morgan Clarke, for example, describes honor as the sense of "shared

responsibility for a group's common public standing… and the importance for that public

standing of sexual morality, a highly gendered domain" (2007, 380). He situates this shared

responsibility within the larger moral world of his interlocutors, where the importance of social

closeness deeply shapes people's sense of being in and negotiating the world around them. My

own ethnographic data show *'ayb* as a commonsense and effective way to articulate judgments

on proper socialization and moral legitimacy. It seems critical to note that when I prompted

interlocutors to explain the relationship between disability and *'ayb*, they found it completely

strange to describe *'ayb* in any terms other than *'ayb* itself. Describing a similar phenomenon

with regards to the role of *'ayb* in her own fieldsite, Wikkan suggests that, "shame is, to use a

distinction made by Geertz, an 'experience-near' concept… [people] do not, except fleetingly and

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[57] In an exchange between Wikkan and Kressel, the latter chastises Wikkan by cautioning her that, "an incomplete survey of terms regarding shame and honour in the cultural setting may distort the linguistic analysis and theoretical conclusions that follow" (Kressel and Wikkan 1988, 168). He follows this by wondering why Wikkan did not address other forms of the term "shame," concentrating only on '*ayb*. Wikkan's responded that her "whole analytical premise… is based on carefully contextualized data on occurrence and non-occurrence of the various terms in clearly identified groups," rather than relying on an Arabic dictionary as a meaningful key to social practice and value" (Kressel and Wikkan 1988, 170).

on occasion, recognize that there are any 'concepts' involved at all' [I976, 224]" (1984, 637).[58]

Yet my interlocutors did in fact clearly identify concepts and make connections between *ʿayb* and other aspects of their moral world. The following examples illustrate the kinds connections they did – and did not – make.

When I asked *why* families hid children with disabilities or *what* they were hiding from, the response connected *ʿayb* with culture; "this is our culture, a culture of *ʿayb* (*hadī hiyya thaqāfatnā, thaqāfat al-ʿayb*)." Despite the difficulty of describing what qualified something as *ʿayb*, families clearly link it to hiding children with Down Syndrome, both as the animating logic for this practice and as a judgment against it. In other words, some families feel that children with Down Syndrome cannot be presented to their larger kin and social networks, so they hide them. Other families, however, consider this very behavior and the thought processes enabling it as inappropriate and wrong. These linkages, in turn, provide an ethnographically grounded approach to tracing how *ʿayb* functions both as a designation of moral risk and a public form of moral censure, the exact targets of which can and do change over time. In the following discussion, Hana repeatedly connects *ʿayb* to the importance and risks involved in marriage. This connection, in turn, links back to the importance of collective reputation and the moral significance of genealogies addressed in the next section.

Being and feeling ʿayb

I first met Hana through her brother Jamil, who has Down Syndrome and attended a social event at the Society. Hana and Jamil were close; they lived with their parents in a northern

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[58] Many of the key terms also translated as honor – *ʿard, sharaf*, others – did not enter into the discursive field of my research. *Sharaf* appeared in local print sources to refer to a specific category of crimes – *jarīmat al-sharaf* (honor crime) – committed by the (usually) male relatives of a woman accused of endangering her family's reputation and honor. I frequently encountered idioms of honor, however, in the context of hospitality exchanges. "*Bitsharifna/ sharaftūna* (you honor/have honored us), a gracious host will proffer upon greeting, serving, and saying farewells to her guest.

suburb of Amman on a large family compound that included a small parcel of land, an abundance of fruit trees, and an enviable breeze. Hana had a Bachelor's degree in Arabic literature and taught English in a private high school. Sitting in a coffee shop on one of the busy streets surrounding the University of Jordan, I asked Hana to tell me more about her brother's diagnosis. Relatively young at the time of her brother's birth, Hana did not recall many details. "I remember that we knew Jamil was Down Syndrome from the hospital, from his birth.[59] It was a shock (ṣadma) in the beginning. I was young. I didn't really understand. But I remember my mother's face, my father's face…" She trailed off for a moment and then continued:

> Most of the people in my mother and father's families accept Jamil. [But] there are some people who said "no." They don't want to deal with him… The most important thing is that we treat him like he's a completely normal person, 100% (*shakhs tabī'ī mi'a bi mi'a*)… We didn't feel *haraj* (embarrassment).[60] People here feel *haraj* and *thaqāfat al 'ayb* – to have a Down son, *monghōlī*, that this is *'ayb*. Of course, this is a wrong understanding!

Hana identified both her mother and her father's families as distinct and important networks for measuring the effects of Jamīl's Down Syndrome, reflecting the roles of paternal and maternal kin in shaping families' perceptions of Down Syndrome.

In Hana's explanation, *'ayb* functions as both a feeling – "people here feel *haraj* and *thaqāfat al 'ayb*" – and as a quality inhering in people or things, "to have a Down son… this is *'ayb*." Possessing both affective and effective dimensions, *'ayb* encompasses how families feel

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[59] The National Down Syndrome Society and Global Down Syndrome Society have issued statements against the use of "Down's" as an adjective. However, I frequently encountered Down being used this way in local conversation. It's interesting to not that while issues surrounding person-first versus identity-based language are hotly debated across North American disability communities, I have rarely encountered Down Syndrome discussed in this conversations. Arabic grammar, however, allows for an easier adoption of Down Syndrome into identity-based language.

[60] *Haraj* was not a word I heard families invoke as frequently as *'ayb*. However, in local journalistic coverage of disability issues, the terms *haraj, khajal, 'ayb* – and less frequently *'ār* – appear to be used somewhat interchangeably (Al-Riahi 2017). Interestingly, *haraj* can also connote a sense of confinement or constraint, which aligned with a common set of images that people utilized to describe culture and tradition and burdensome, heavy, or consisting of walls.

about disability, and it motivates them to respond in certain ways. I asked Hana to explain where the idea that Down Syndrome is *'ayb* originated. "From society!" she exclaimed, as if this were the only possible answer. "From the customs and traditions. [People with Down Syndrome] look strange, so people can't think 'this is a normal person' (*shakhs 'ādī*)… People feel ashamed (*haraj wa khajal*)."[61] The significance of *'ayb* attests to the significance of marriageability in shaping one's status as an adult person and in a family's reputation and future security. When families talk about disability and *'ayb*, they speak to the importance of being deemed *normal*, a quality that gestures to moral and increasingly medicalized qualities.[62] The centrality of "normal" to the marriageability not only of individuals, but more importantly, of family collectives, reinforces and naturalizes gendered hierarchies of able-bodiedness and able-mindedness.[63]

Like many of my interlocutors, Hana turned to the social stakes of marriage to explain the content and consequences of *thaqāfat al-'ayb*. After describing the equation of disability with *'ayb* as a product of "society," she shared the following news segment to demonstrate her point:

> A month ago, I heard a story – if you can imagine – this girl was 3 years old and had Down Syndrome. Her father did not accept her (*ghayr mutaqabbal ilhā*), and he wanted to marry another woman to have normal children. Can you imagine?! We're in 2015, and there are people who still think like this. But there are also people, like you see at the Society, the families are happy and love their kids. But the majority of people don't accept… abnormal children (*ibnā' ghayr tabī'iyyīn*).

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[61] Here, *khajal* convey shame in the sense of disgrace; it can also signify shyness, timidity, and bashfulness; "Are you shy, Christine, (*intī khajlāna*)?" Female hosts would often tease me in their attempts to pile endless helpings of food on my plate, and in so doing to demonstrate the intimacy between guest and host. In that context, shame obtained the positive sense of embodying gendered ideals of modesty, deference, and appropriate conduct. Similarly, *'ayb* could also be used in constructive and positive ways, such as in the example of socializing children to adhere to norms of etiquette.

[62] In the context of disability and marriage, my interlocutors clearly posed the stakes of the issues at hand in terms of *'ayb*.

[63] I use this term and distinguish between these two dimensions of ableism, following Kafer (2013).

Existing marriages, children, and the hegemony of normality intertwine in Hana's example, and they hinge on perceptions of maternal responsibility, a point I will return to below. But what kind of children are normal children? I asked Hana for more clarification on the role of *'ayb* in generating this scenario. "I understand the word," I began, "but what does it *mean* here?" She thought about this and then offered the following explanation, concretely grounded in questions of future marital risk:

> [There is the] idea that when their children marry in the future, when people come to marry the girl – especially the girl – people will say "Ah… her brother is *monghōlī*. No no no. We don't want this. Maybe she'll give birth to a *monghōlī* baby. They think there is inheritance (*wirātha*). There isn't! But just a little while ago I saw a program on *Ro'ya* [a local TV channel] about Down Syndrome. They asked people in the street: "Would you marry a girl who had a brother with Down Syndrome?" Most people said no. They told them it's not inherited, and people said, "Maybe it's inherited. Maybe not" And some people said, "Stay away. Why bring problems (*laysh ajīb mashākil*)?"

Hana does not describe *'ayb* in terms of *'ayb*. In fact, she doesn't use the word at all. Instead she points to the persistent concerns about marriage and the potential for "bringing problems." Marriage exposes families to risk; disability – real or feared – intensifies these risks, which are embodied and social in nature. Normal children grow up and get married, and disability threatens this future for all children involved – or does it?

Note that the reporter clearly stopped to ask *men* on the street, as the question he posed was "would you marry a *girl* who had a brother with Down Syndrome?" Hana did not believe that Jamil's Down Syndrome affected her older and younger brothers' marital pursuits. In her own life however, she acknowledged that:

> When some people came to ask for my hand and found out I had a *monghōlī* brother, they distanced themselves… So then others suggested, "don't let Jamil enter [the room]; that way people can't see him." I said to them, "On the contrary, they will see him from day one. Anyone who wants to marry me needs to see him.

And anyone who doesn't like him… See you later! *Allah maʿak* (God be with you)!

Women spoke candidly about the risks that the presence of Down Syndrome posed to their own and others' marriageability.[64] Unlike in the past, however, new framings of disability have empowered women like Hana – with the support of her family – to judge the marital potential of a suitor and *his* family based on their attitudes toward a member with Down Syndrome. Hana was not the only young woman I met who dismissed encounters with prejudice as indicative of a suitor's ignorance and the sure sign of a poor match. Women's abilities to position themselves and make such claims, however, require some degree of social and cultural capital, in addition to familial support. The fact that perceptions of disability as *'ayb* can themselves be subject to critique, and in some instances by using the same terms (*'ayb* becomes *'ayb*) clarifies the work that *'ayb* does as a mode of moral exposure. Rather than accept disability itself as a form of exposure, families attempt to stigmatize disability stigma, exposing the moral weakness and backwardness of others.

IV. Moral etiologies

Biogenetic explanations for chromosomal disorders appear to make a good deal of sense in Jordan. The transmission of chromosomes follows pathways that overlap with the genealogies that families cite and use to trace their histories and origins. The biogenetic expression of Down Syndrome, however, which can only be described in terms of randomness and risk, does not seem to disrupt enduring concerns about its hereditary transmission and/or potentially contagious qualities. "Maybe it's inherited, maybe not." This ambiguity persists precisely due to the

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[64] Had I worked more with fathers and brothers, perhaps a different perspective would have emerged. Mothers and sisters, however, described the stigmatizing effects of disability as explicitly gendered and threatening the marriageability of women, rather than men.

entanglements of genealogy and morality. The alacrity with which chromosomes and genes have

been assimilated into local understandings of relatedness and genealogy suggests this preexisting

compatibility. So much so that anthropologist Marcia Inhorn has argued:

> Certainly in the Sunni Muslim world… pre-existing Islamic imperatives regarding 'pure' lineage, coupled with Islamic prohibitions against adoption, not only privilege but, in fact, mandate biological as opposed to social construction of families... biogenetic relatedness – glossed as *nasab*, or blood relations – is an absolute imperative. (2003, 120)

Morgan Clarke, in contrast, drawing on his fieldwork with Islamic theologians, jurists, and IVF

practitioners in Lebanon, arrives at a somewhat different conclusion. He writes that:

> The question remains as to whether *nasab* ('filiation') can indeed be seen as a gloss for biogenetic 'relatedness,' and classically at least the answer is no. *Nasab* is *legitimate* relatedness. All children born to a *married* couple are considered in Islamic law, both Sunni and Shiite, as the children of that couple. (Clarke 2008, 163 my emphasis)

Clarke's distinction points to the fact that a child born out of wedlock cannot claim *nasab*.

Irrespective of biological paternity, from an Islamic legal perspective the illegitimate child

cannot claim a place in their father's patriline.[65] Beyond legal distinctions, however concerns

about sexual morality, and belief in the role of marriage as necessary for preventing social crisis,

exist across different sectarian and religious communities.

> The values often glossed as 'honor and shame' in an anthropological literature that extends across the Mediterranean and throughout the Middle East are of enduring, if variable, importance. Public standing or 'reputation' (*sum'ah*) is tied to, among other things, sexual propriety, in particular the sexual continence of female relatives. (2008, 159)

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[65] The advent of paternity tests has raised bioethical quandaries across Muslim societies. See Shabana (2012) and Hasso (2010) for analyses of an infamous public paternity dispute that played out in the Egyptian media.

Even for communities that do not draw on *nasab*, children born out of wedlock may be denied recognition by their father's family and stigmatized by their mother's, as they embody evidence of moral indiscretion.

Inhorn and Clarke, along with many scholars who explore the role of new reproductive technologies (NRTs) in reshaping ideologies and practices of kinship, focus on these innovations in relation to the absence of desired children (Carsten 2004; M. Clarke 2009; Franklin and McKinnon 2001; Roberts 2012a; Strathern 1992). This latent pronatalism, however, leaves unconsidered the acts and processes intended to cut or deny ties of kinship, especially in cases of illness or impairment (Biehl 2005; Scheper-Hughes 1992; Weiss 1994). While illegitimacy, from a legal perspective, may entail a form of social death in Arab communities, marital legitimacy does not protect children or their mothers from the potential consequences of being labeled abnormal. Chromosomes aside, other substances, qualities, and dangers can be passed through family lineage.

Anthropologist Sherine Hamdy uses the concept of "political etiologies" to describe how patients in contemporary Egypt "make meaning out of illness and explain kidney disease in terms of the social, economic, and political ills afflicting Egypt as a whole" (2008, 554). The meanings that families in Jordan make out of disability lack the sharp biopolitical edge of Hamdy's Egyptian interlocutors, or those of families dealing with the fallout of Agent Orange after the Vietnam War (Gammeltoft 2014) and disasters like Chernobyl (Petryna 2003). The state, in particular, recedes from the meanings that families make out of congenital disability in Jordan. Yet these meanings nevertheless involve politics of the most intimate and enduring kind, potentially serving as moral indictments of family lineage. This is especially the case for congenital disabilities. An increasing focus on consanguineous marriage as a public health risk

has added yet another layer to the already fraught dynamics of marriage, lineage, and perceptions of moral culpability. These dynamics culminate in what I describe as moral etiologies, keeping in mind that the moral always involves different scales of power and politics. Moral etiologies unfold where scientific ambiguity and patriarchal authority can position women as agents of culpability. Women, in turn, draw on scientific ambiguity and spiritual certainty to challenge the legitimacy of existing moral etiologies.

Mothers as (clinical) risks

During an *eid* celebration at the Society during the summer of 2015, Imm Zayna stood chatting with a group of mothers while we waited for the sun to set. She looked around at her peers, her face pregnant with thought. "I suppose," she began, "that I'm the oldest mother in the room…" Her speech trailed off and she focused her sights on baby Zayna, who was fast asleep in her arms. Imm Zayna did not need to finish her thought, however, before being met by a chorus of "*tsks*." Imm Munir threw her arms out in front of her, "sister, the mother does not cause Down Syndrome (*ya ukhti, al-imm mā tasabbab Down*)!" Three or four other women seated around us nodded vigorously in agreement.

In fact, maternal age remains the only statistically significant correlation with increased risk for Down Syndrome. The majority of babies with Down Syndrome, however, are nevertheless born to women under the threshold risk of 40. This is because the under-40 population accounts for the majority of pregnant women. The presence and predominance of younger and first time mothers at the Society conformed to this distribution. In my own non-representative total sample of 68 women, I met only two mothers who gave birth to a child with Down Syndrome after the age of 40, and both of their pregnancies were unplanned. Older mothers who came into the Society were met with compassion, and occasionally, quieter

expressions of contempt. Peers expressed compassion for the challenges they were undoubtedly

facing and contempt for allowing a presumably unplanned pregnancy to occur. Equally as

unpalatable to most of my participants was the prospect of an older woman intentionally

pursuing pregnancy at an advanced age (although the local boundary for advanced maternal age

did not necessarily align with the medical boundary, set at 35 years).

Despite attempts to raise awareness that Down Syndrome is not genetically transmitted

from parent to child, women in particular encounter accusations of passing or somehow more

generally causing the condition.[66] The replication error causing Down Syndrome occurs as the

result of meiotic nondisjunction during Meiosis I or II. The reasons for this disjunction remain

poorly understood, despite the fact that Down Syndrome is the most common chromosomally-

based cause of intellectual disability (Antonarakis et al. 1992). In the most common form of

Down Syndrome, an additional copy of chromosome 21 exists in all cells of the body (resulting

in an overexpression of the genes located on this chromosome). While genetic in its makeup, the

condition is not hereditary.[67] This slipperiness extends across languages to Arabic, where the

term *wirāthī* can serve as a general translation for both terms.[68] Thus, Down Syndrome is *wirāthī*

but is not *wirāthī*.

I once mentioned the persistence of suspicions about inheritance to my friend Serene, and

she shook her head with an ironic laugh. Serene was a renowned special education expert and

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[66] Approximately 90% of meiotic disjunction errors are in fact of maternal origin (Christianson, Sherman, and Torfs 2004). The mechanisms and contributing factors to these errors remain poorly understood and do not appear to be hereditary (i.e. the risk of meiotic errors cannot be predicted before the actual errors occur). Researchers have suggested such varied contributors as genetic predisposition (James et al. 1999) and socioeconomic status (Hassold and Sherman 2000). Were local discussions of causality to reach this level of complexity – which admittedly they have not – then the skewed distribution of disjunction error to the maternal side would fit with concerning ease into the "mother is at fault" narrative.

[67] When discussing my research in the United States, I also frequently encounter the belief that Down Syndrome is inherited.

[68] I occasionally heard people make use of the adjective *jīniyya* in an attempt to avoid this confusion.

also a dedicated caretaker for her younger brother with Down Syndrome. When I asked whether she thought that emphasizing the non-hereditary mode of transmission responsible for Down Syndrome might disrupt local practices of stigma and blame, she shook her head in the negative. "Arabs blame the mother when a daughter is born. We all know who is responsible for that second X chromosome! And still they blame *her*!" Serene did not question that a considerable portion of the population would be familiar with biogenetic accounts of birth and development (they are, to varying degrees); rather, she pointed out an important disconnect. Biogenetic inheritance coexists with a second model. This model of transmission emphasizes the importance of the womb and operates in a context where men are better positioned to draw on patrilineal solidarity and patriarchal authority to blame women for unexpected birth outcomes.[69]

In the summer of 2015, during a brief return trip to Amman, I visited Imm Maha, whom I had met over two years prior on her very first visit to the Society with her daughter and husband. Imm Maha and her family had recently moved out of the basement level apartment they shared with several of her kin by marriage in one of eastern Amman's poorest and most infrastructurally distressed neighborhoods. While still located in the eastern part of the capital, their new second-floor apartment was located some 15 minutes away from their previous home. Her in-laws did not take kindly to their son and daughter-in-law's decision to relocate. The nuclear family of six, however, was preparing to welcome their seventh member and desperately needed more room to grow. During my visits to the former family compound, I was not able to talk with Imm Maha directly or privately. She was simply too busy preparing the day's next meal and taking care of her kin.

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[69] The majority of my research participants did not discuss the possibility that men might also be responsible for transmitting Down Syndrome. One mother did, however, express concern that her sons without Down Syndrome might also be able to "pass on" the condition to their own future children.

During those previous visits, Imm Maha's three sisters-in-law spoke for her and in the collective about their family's experiences with Maha, who was 5 at the time of my return. Basking in the possibilities for frank discussion that her new house allowed, Imm Maha spent at least 15 minutes telling me about how she suffered under her in-laws', and especially her mother-in-law's, authority for 16 years.

> You know Christine, the situation was so bad. I was under so much stress. The doctor told me that it was probably my mother-in-law who caused Maha to have Down Syndrome because she put me under so much stress. You know we don't have anything *wirāthī* (hereditary/genetic) in our family. My husband and I aren't related. I mean I'm from Iraq! He's Palestinian.

Imm Maha stressed the "distance" between her husband's and her own family origins; not only were they not related, they weren't even from the same country.[70] This statement reflects how, on the day-to-day level, genetics has become integrated into long-standing preoccupations with "marrying well." [71]

While the rules of basic Mendelian inheritance confirm an increased risk for autosomal, recessively inherited genetic conditions in consanguineous marriage, the vast majority of genetically inherited traits and illnesses are transmitted through far more complex mechanisms (even the classic example of eye color, in reality, does not conform to a simple inheritance pattern). Clinical research on consanguinity and chromosomal conditions like Down Syndrome, or sex-linked and more complex multifactorial conditions, has yet to establish evidence for any

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[70] In the Arab Middle East today, consanguineous marriages constitute between 20-50% of all marital unions, with nuptials between first cousins accounting for approximately one-third of all cases (Hamamy et al. 2005). In Jordan, consanguineous marriages account for 32% of all marriages, although this reported rate could benefit from updated study (Khoury and Massad 1992). The rate of marriages between parallel paternal first cousins (fathers are brothers), however, decreased significantly in marriages contracted after 1980 (Hamamy et al. 2005). Arab states, along with international development and health organizations, recognize the economic benefits of understanding the exact nature and extent of correlative and causal relationships between consanguineous marriage and genetic disorders, inherited conditions, and disabilities.

[71] A parallel discourse about the risks of consanguineous marriage also exists among Islamic scholars who note that "there are longstanding traditions within the Islamic corpus warning against such marriages" (Clarke 2007, 390).

direct inheritance patterns (El Mouzan et al. 2008). Complicating matters, historically extensive

practices of endogamous marriages may also affect locally expressed rates of illness and

disability at a level of population genetics that cannot be accounted for by the degree of

consanguinity between spouses (Bittles 2002). These subtle but significant complexities tend to

disappear from dominant representations of consanguinity in global public health and

epidemiology (Shaw and Raz 2015). Imm Maha nevertheless incorporated the basics of genetic

distance into her own moral etiology. The fact that she and her husband were not even from the

"same country" further testified to the degree of duress she experienced at the hands of her in-

laws. Once safely removed from their watch, she reworked the dominant paradigm of mother-

blame and placed moral culpability on the shoulders of her mother-in-law.

Alternative genealogies: "Alhamdulillah he is from God":

Men and women are not the only actors who play significant roles in moral etiologies. As

Jordanian families encounter and make sense of Down Syndrome, scientific moral authority,

geneticized risk, and culturalized blame intersect with powerful beliefs in the limits of

knowledge, the intentionality of God's creation, and the power of fate (*qadr*). Elizabeth Roberts

notes that, "the critical medical anthropology and STS default is still to leave deities to the side"

(Roberts 2016, 213). Even Margaret Lock's paradigm-shifting framework of local biologies

focuses on the dialectics of nature-culture relationships as defined in secular terms. This division

becomes fuzzier when God operates as an active agent in the creation and material formation of

life. For most of my interlocutors, God factors into diagnosis and determines the boundaries and

soundness of existing and emerging moral etiologies. By emphasizing uncertainty and chance as

chief causes of Down Syndrome, the certainty and completeness of God's wisdom enables

families to frame stigma as un-Islamic.[72] This indigenous mode of critique proves compelling

even when parallel accusations of scientific ignorance fail.

At the same *eid* celebration where Imm Zayna voiced concerns about her age, I spent

time chatting with Imm Khalil. Khalil, who had very recently become an older brother, attended

the Society almost every day. As I inquired about the new baby's health, I caught Imm Sami's

eye, and she came over to join us. Both women had fled the growing destruction of the Syrian

civil war with members of their immediate and extended families in tow. After they exchanged

greetings and congratulations about the new baby, Imm Sami turned to me. "Where are you

from?" she asked. I explained myself while wondering why she looked so familiar and whether

she was the mother of someone at the Society. After hearing a description of my project, Imm

Sami exclaimed, "Well do you want to come to talk me?!" I replied that I most certainly did. She

then clarified that she was in fact the mother of a young man with Down Syndrome whom I had

come to know quite well.

A few weeks later, I showed up in the working class neighborhood of Amman where

Sami and his family had made their temporary home in exile, along with many other Syrian

families. Sami waited dutifully on the street corner, tasked with signaling that I had arrived at the

correct building. When I spotted him, I sighed with relief that we had reached the right place. I

pointed to Sami and asking the driver to drop me off by my friend's son. He complied, shooting

a curious look my way but saying nothing. I wondered, in turn, whether this look was directed at

me or at Sami, or perhaps the combination of us together. I hopped out of the cab and Sami

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[72] While this could presumably slide into a framing of Down Syndrome as a "punishment" sent by God, I never encountered such a belief. While it was known that God might send trials and tribulations, the idea of disability as a "curse" was thought to mischaracterize God's relationship with human beings and His qualities of mercy and generosity. That being said, the existence of this idea, even if invoked as a foil against proper understanding, suggests that my interlocutors were aware of such a reading. For the most part, families explain the damaging stigma surrounding disability as a consequence of the cultural and political-economic importance of marriage and collective reputation, which facilitate un-Islamic attitudes toward disability.

guided me into their home, an unassuming apartment building sandwiched between a car repair center and a barbershop.

After preparing our Nescafe, Imm Sami and I settled in to our conversation. I asked Imm Sami about her pregnancy. Like many of her Jordanian counterparts, she recalled an intensely medicalized experience in Syria. Noting that she did not get pregnant until a few years after getting married, she nevertheless described the process as "very normal."

> When I was pregnant, in the 9th month, the doctors watched me very closely. There was a German doctor who was watching over me. There was nothing wrong at all. And every now and then they would show me the ultrasound and tell me that the child was normal and was moving and that there was nothing wrong.

As in the case of Imm Reham, who had only suspicions of Reham's difference until a month after her birth, Sami's doctors chose to selectively communicate his diagnosis solely to Imm Sami's husband. Neither of the men in question, however, reacted like Imm Abud's husband, who initially sought a divorce, or Reham's relative's father, who did in fact divorce his wife. Many of the men I met during my research did not publicly blame or actively seek retribution against their wives, regardless of their own private emotional responses.

Imm Sami's official exposure to her son's diagnosis came unexpectedly and unpleasantly at a hospital emergency room:

> They told Abu Sami that his son was born *monghōlī*. In colloquial Arabic we call it '*monghōlī*'. They don't use the words *Down* or *Down Syndrome*. Did you notice that? … At the beginning, they hid it from me. They told me that there was nothing wrong, but that he was just sick. They didn't tell me with what. Fifteen days later, he had jaundice. He was yellow! So, we went to the hospital, Abu Sami took me. He dropped us off in the emergency room. We were waiting for the doctor and then a second doctor came and said "Who is that, the *monghōlī* child?" I asked him what *monghōlī* meant and he told me it means that the child is disabled. And he apologized a lot, but I was very angry. I told him, "*Alhamdulillah*, He is from God."

In her response to encountering the diagnosis of *monghōlī*, Imm Sami removed her son from the realm of genetic alterity by locating him within the moral genealogy shared by all human beings; Sami was "from God," and that was something no legitimate doctor could dispute. Each time I visited Imm Sami at her home, however, she emphasized the impact of the gossip she endured about the etiology of Sami's Down Syndrome. "There was talk from our relatives that [it was because] I was old and that I got married to one of my relatives and because it took me a while to get pregnant." Returning to these memories on a later visit, Imm Sami added, "But even in America they don't know where Down Syndrome comes from." The fact that Down Syndrome exists in the United States, despite the absence of consanguineous marriage practices, carries symbolic value for many families. This is especially the case for individuals married to a relative, precisely because it challenges the widespread assumption that consanguinity somehow plays a role in their child's condition.

Many of my interlocutors are also aware that enormous gaps in scientific knowledge about Down Syndrome persist.[73] Families value scientific uncertainty for the space it gives them to make claims against existing moral etiologies of Down Syndrome (Whitmarsh et al. 2007). Imm Sami mentioned the positive influence of a family friend in this regard, who also happened to be a nurse.

> She told us that he came to us like this from God and that *Inshallah* we will have children who are better than him. So we accepted him, and Abu Sami accepted it. And even three years later, he told me that if I got pregnant it would be fine, and even if I didn't, it would be okay... Three years later, I got pregnant with Jawwad. I was afraid, but I prayed that God would give me a brother or sister for Sami. And then I gave birth to Jawwad. This convinced our relatives that the reason [Sami has Down Syndrome] was not because I was old or because my husband and I are related.

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[73] Down Syndrome remains one of the least funded genetic conditions that receive support from the NIH. In 2011, the NIH spent $20 million on Down Syndrome compared to $169 million on autism research, $29 million on fragile X syndrome, and $23 million on cerebral palsy (Diament 2012).

Not knowing *why* Sami was born with Down Syndrome enabled his mother to challenge her relatives' accusations. The arrival of their younger son, born without Down Syndrome, amplified the productive value of this uncertainty and inconsistency. At the conclusion of his wife's story, Abu Sami added his own thought, the final pronouncement on the matter: "It was from God."

As families attempt to forge new moral etiologies, science and religion do not emerge as conflicting domains of knowledge production. Science, in general, confirms the goodness and generosity of God; it is a gift and a tool for the benefit of humankind. Whether through the register of science or faith, human mediation inevitably imposes constraints on the benefits and limits of scientific knowledge. These limits are also morally prescriptive, expressed through the conviction that human beings cannot, and, more importantly, should not know everything. This stance has significant implications for how mothers engage with increasing opportunities for gaining knowledge about disability before it occurs.

V. Past perfect futures: New temporalities of diagnosis

Prenatal screening and diagnostics belong to the category of biomedical innovations initially referred to as new reproductive technologies, or NRTs. This label includes, among others things, ultrasonography, amniocentesis, in vitro fertilization, and preimplantation genetic diagnosis. No longer quite so new, although still dynamically evolving, NRTs are now more commonly referred to as Artificial Reproductive Technologies (ARTs). Feminist scholars, in particular, have documented the acutely gendered dimensions and consequences of these technologies, which operate primarily – though not solely – through female bodies (Inhorn 1994, 2003; Rapp 1999). Ayo Wahlberg and Tine Gammeltoft rightfully point out that while ARTs are most commonly framed as novel means for creating life, they are used just as much to select *against* bringing certain kinds of life into the world. Wahlberg and Gammeltoft employ the term

Selective Reproductive Technologies (2014), or SRTs, to call attention to these equal capacities for creation and termination.

Prenatal screening and diagnostic tests identify risk by analyzing fetal and maternal biomarkers. Practitioners and recipients of these tests code the results in different ways, as genetic, embodied, familial, and societal. For the mothers I met in my research, the risks that prenatal screening and diagnostics are capable of identifying paled in comparison to the moral, social, and epistemological risks posed by the technology itself. Women support and completely embrace robust medical monitoring to ensure the overall health of both mother and fetus. They are deeply concerned, however, by the specific kinds of knowledge that screening and diagnostics provide and the ethical dilemmas created in the process. Although the technologies in question remain relatively circumscribed in local practice, they serve as powerful catalysts for thinking through the stakes of maintaining family ties and the consequences of altering kinship futures.

While Beck argues that calculations and attempts to minimize risk have "colonized the future," the ways that women in Jordan discuss prenatal screening and diagnostics demonstrate how risks coexist and gain value in the service of differently imagined futures (Beck 1998, 12). These conversations usually focus on the *absence* of prenatal screening and diagnostics, which some women frame as a symptom of the healthcare system's underdevelopment, an anomaly in what is often otherwise considered one of the best systems in the region. The overwhelming majority of women who discussed this topic with me, however, expressed anxieties about the kinds of knowledge that prenatal screening and diagnostic technologies could bring into the world. They did not question the veracity or the reliability of the science. They doubted the wisdom of using it.

One day, while I talked with a few mothers sitting in the reception room at the Society, Imm Hamza arrived with her younger brother and her firstborn son, both of whom have Down Syndrome. Imm Hamza and her sisters took turns covering their transportation to various activities and doctors' appointments, as their own elderly mother was no longer capable of driving. Imm Hamza happened to arrive at a moment when two other mothers were comparing their shared experiences of not having received a prenatal diagnosis of Down Syndrome. Imm Hamza jumped in to the conversation with her own thoughts on the matter. "I was surprised that with all the advances of modern medicine, they didn't catch beforehand that Hamza was Down. But it's better that way," Imm Hamza continued. "What would I have done if I had known?" This past perfect contemplation of an already impossible future provides insights into the moral stakes of knowing – and doing – versus not knowing. Many mothers point to the intensity of postnatal diagnosis as one of the reasons they are capable of developing relationships and relating to each other, even while living in significantly different worlds of opportunity and constraint. Despite the absence of prenatal screening and diagnosis from their own experiences, the more distant accessibility and symbolic potency of these tools generates intense reflection among mothers of children with Down Syndrome.

Would you want to know?

Not long after World Down Syndrome Day 2015, Imm Zahra and I discussed our impressions of the festivities, which were coordinated by the Society in conjunction with various government ministries and a few corporate sponsors. During a conference on Down Syndrome and related medical issues held at a large public hospital in northern Amman, a younger woman stood up to ask the panel of health professionals a question. How was it possible, she wanted to know, that despite attending appointments consistently throughout her pregnancy, the doctors

never diagnosed her baby with Down Syndrome? I brought this moment up with Imm Zahra as we sat and debriefed. I was curious to hear her perspective on the woman's question. "It's impossible," said Imm Zahra. "Aside from it being expensive, we cannot have these tests here because abortion is *haram*."[74]

I countered this point, arguing that screening and diagnosis don't necessarily lead to abortion. They could be used to better prepare families for the medical, emotional, and financial demands that come with raising a disabled child. Imm Zahra brushed this aside as *hakī fādī* (just words, or useless talk, in its kindest translation):

> If a mother knows beforehand, even if she doesn't abort, she will be so sick with worry – What will her husband say? How will the children find out? What will the neighbors say? – that she will not take care of herself properly… In the US, it's not very important what people say, but here it is very *very* important. Through her anxiety, the mother may harm the fetus. Unless there is a danger to the mother, there shouldn't be any knowledge beforehand. This is something up to God. God creates what exists in this world.

She then turned to the other women present throughout the room and asked for their opinions. They all agreed; it was better not to know. One of them then turned to me. "What about you Christine? Would *you* want to know?" I sat and contemplated the question. Would I even have the option, I wondered, of not knowing?

The value of knowledge, as configured in the highly medicalized and individualized culture of American childbirth – or perhaps nuclearized might be a more accurate description – defines a woman's ethical agency as the pursuit of knowing everything she can. In her ethnography of amniocentesis in New York City, Rayna Rapp demonstrates that women who

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[74] In Islamic legal thought, abortion becomes definitively *haram* only after 120 days of pregnancy, when ensoulment occurs (Hessini 2007). Before 120 days, scholars contend that that abortion is "unconditionally permissible, permissible in case of having an excuse (*'udhr*), and generally reprehensible and forbidden [Wizaˆrat, vol. 2, p. 58]" (Ghaly 2008, 116; see also Rispler-Chaim 1999).

decide *not* to pursue amniocentesis or terminate pregnancy following a positive result were

subject to intense moral scrutiny (Rapp 1999). Genetic counselors, doctors, and nurses assessed

women's maternal fitness in ways that reflect the intersections of race, class, and gender in

metropolitan New York. Most of the women I worked with in Jordan, however, consider it

unethical to assume that one could know everything. They viewed *not* knowing as a kind of

protection against human weakness, a form of God's mercy. "I'm not sure," I responded to the

question.

As in the United States, pregnancy and childbirth in Jordan have become heavily

medicalized processes.[75] According to the most recent Population and Family Health Survey,

between 2007 and 2012, 99% of Jordanian women received prenatal care from a medical

professional and 78% of women made 7 or more prenatal care visits over the course of their

pregnancy (Department of Statistics [Jordan] and ICF International 2013). Almost all Jordanian

women during this period gave birth in a medical facility.[76] Yet the current reproductive

healthcare regimen makes minimal use of prenatal screening and diagnostics. Despite the

popularity of ultrasonography for the purpose of producing images, the technology rarely plays a

diagnostic role (Maffi 2013, 141). The prohibitive cost of certain equipment and the

corresponding laboratory tests certainly plays a role in this lack of services (Maffi 2013, 141).

Equally pressing, if not more so, are questions surrounding constructions of personhood, the

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[75] While the WHO's range for safe C-section rates falls between 5-15%, Jordan's stands at 28%, a level of excess comparable to the United State's own elevated rate of 32% (CDC 2015).
[76] Doctors attended 76% of these births, while midwives attended the remaining 24% (Department of Statistics [Jordan] and ICF International 2013, 110).

criminalization of abortion,[77] and deep attachments to kinship as a fundamental organizing principle of society.

Despite the medicalization of pregnancy and childbirth, fertility, conception, and childrearing remained fundamentally connective social processes in Jordan. Women identify the wishes, contributions, and resources of other kin, alongside God's will, as essential for both creating and raising children (see Roberts 2012). In asserting that it is better not to know, the nature of disability does not particularly enter into the equation for women like Imm Hamza and Imm Zahra. They understand, more than most, the challenges of raising a child in a deeply disabling society. But there are other factors at play, chief among them a desire to accept the authority of God and submit to His will. Submission, as a core aspect of adult moral personhood, involves an active struggle to cultivate moral continuity in the face of contradictory impulses and possibilities (Asad 1993; Das 1995; Mahmood 2001; see Deeb 2006 on commitment).

"It was my right to know":

Imm Maryam did not share the perspective of the women at the Society that it was better not to know. Unaffiliated with the al-Nur Society, Im Maryam nevertheless was familiar with many of the same families through the pages of Facebook and by running in overlapping social circles. I was introduced to Imm Maryam and her daughter, who was a toddler at the time, through a special education consultant who appeared with her on local TV shows where they sought to educate the public about Down Syndrome. When I visited her family at their home just

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[77] Jordan's restrictive stance on abortion is ostensibly based in religious law, or *sharia*. Yet the category of sharia often obscures the highly syncretic nature of postcolonial legal systems across the Middle East and North Africa. Historian Amira Sonbol, for example, describes Jordan's legal system as "a patchwork of *fiqh* (Islamic theological interpretations)… molded together with a dose of imported pre-World War I Western gender philosophy" (Sonbol 2003, 8). Current state policy has been slow to address or even acknowledge the heterogeneous corpus of opinions that exists among Islamic religious scholars on the issue of selective abortion. The diversity of regional laws on the issue can be understood, in part, as reflecting this lack of consensus.

outside the northern boundary of greater Amman, Imm Maryam candidly described the shock of her daughter's diagnosis to me; it was a narrative she had told many times before in different spaces and for different audiences. Four days after returning from the hospital, baby Maryam developed jaundice. Her older sister and one of her older brothers volunteered to take Maryam back to the hospital. When they arrived, she told me, "The doctor took one look at Maryam and said she was *monghōlī*."

Imm Maryam's children decided to keep this news from their mother until further tests could be run. They enlisted their father's help to make appointments for Maryam at other local hospitals. Imm Maryam learned what was going on when one of her sisters-in-law called to ask whether or not she was "going crazy" waiting to hear if her daughter was *monghōlī*.

> The world started spinning. I dropped the tray of food I was carrying. The first thing I did was go and read from the Quran to remember God (*dhakart Allah*). May came out of her room and said they were going to head out for another appointment about the jaundice. I said that they were all liars and they would do nothing of the sort. "She's MY daughter. I'll take her!" We went to four different hospitals, and they all said the same thing, "your daughter is *monghōlī*." At the last clinic, I was speaking with a young doctor in her twenties. "Please don't tell me Maryam is *monghōlī*," I said. The doctor responded that Maryam definitely was *monghōlī* and that she would probably die as a baby. If not, she said, Maryam would live to be 25 at most, with a mental age of 4. And death would be better.

Imm Maryam stopped and reflected on this memory with a sad smile. She struggled after receiving Maryam's diagnosis, crying, overwhelmed, and angry. "My husband was more accepting than I was," she recalled with a small laugh. "He would tell me, '*Alhamdulillah* [Thank God]. Some people have cerebral palsy, or autism!' *Alhamdulilllah*," she confirmed. I asked Im Maryam if she wished she had known about Maryam's Down Syndrome during her pregnancy. She thought about the question. "I'm not sure if I had found out beforehand, whether or not I would have kept my baby. But it was my right to know."

Imm Maryam was convinced that her doctor had realized Maryam's diagnosis but decided not to tell her. "It would have been my decision," she continued. "And I had a right to make it. I don't know. Maybe I would have aborted, or maybe I would have feared God. But it was my right to know. Maryam's birth was a cruel surprise; a mother is free [to make her own decisions] (*al-imm hiyya hurra*)." While her stance clearly differed from that of the women at the Society, that it was better not to know, Imm Maryam held many of the same key assumptions as her peers. The two alternatives she outlined were either aborting or "fearing God," the latter of which was clearly the moral choice for her. Yet it was the relationship to knowledge that she ultimately focused on. What continued to bother her most was her sense that she had not been given the chance to know and make her own choice. "A mother is free." Imm Maryam was a fierce advocate for her daughter. Maryam had transformed her world, bringing her new burdens and responsibilities, but also new opportunities. Imm Maryam was the first to admit that she was devastated by the "cruel surprise" of her daughter's diagnosis. She talked openly about the stigma she and her family encountered. This was stigma she had herself perpetuated before her own daughter was born with Down Syndrome. The process of caring for Maryam launched her mother into an unexpected – and initially undesired –project of moral becoming, to paraphrase Cheryl Mattingly (2014). And yet Imm Hamza's question about the uncertainties of this past perfect future remained; without the knowledge of Down Syndrome that Imm Maryam gained through lived experience, what would she have done if she had known?

Women do not view prenatal diagnostic technologies through a simplistic moral dichotomy of good and bad. Prenatal diagnosis figures as one node in a constellation of factors and moral hazards that animate the risks of relatedness. The new temporality introduced through prenatal diagnosis exposes the morally ambivalent and highly selective nature of their broader

kinship world. Kinship in Jordan unfolds as a high-stakes process of choosing and rejecting alliances; it is the ultimate selective technology.[78] Its critical importance for survival – especially through marriage – plays a significant role in creating the stigma that exists against disability in the first place. Women do not choose for their children to be born with Down Syndrome, but they do not want others to choose against them. They criticize a simplistic equation of disability with risk, pointing to the unknown and unknowable aspects of kinship futures. Many women sense the possibility – one overwhelmingly supported by the ethnographic record – that these technologies, if made widely available in Jordan, would create and distribute knowledge unequally. In so doing, they would create new dangers and dilemmas that, as women, wives, and mothers, they would be forced to navigate. As Imm Zahra put it, "God creates what exists in the world." In that certain truth mothers find powerful moral protection against the risks of choice.

VI. Children of Adam

"We are all children of Adam." I frequently encountered this refrain as my interlocutors shared their thoughts on the existence of disability in the world and the nature of human difference. This phrase speaks to a worldview that situates human relations in terms of both divine and genealogical networks of descent. These networks are capable of accommodating radical equality before God and vastly asymmetrical social hierarchies of power and authority. As families encounter and navigate the different temporalities of diagnosis, contemplating futures saturated by prenatal testing, they outline a series of morally ambiguous risks. While almost all my interlocutors articulate an explicit commitment to Islam, the demands and exigencies of family life create compelling, and sometimes antagonistic, moral imperatives. God is defined in terms of his mercy and compassion, family members generally less so.

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[78] Thanks to Andrew Shryock for providing this pithy description during a public lecture.

Common threads of experience connect the women (and sometimes men) who arrive at the Society. These include family hostility, social stigma, biomedical uncertainty, and emotional pain and resilience. Their experiences differ in significant ways as well, reflecting personal qualities and characteristics of women's relationships with spouses and kin, as well as structural factors of class, education, and social and financial capital. The birth of a child with Down Syndrome creates opportunities for new connections and alliances, some of them life-saving and life-altering. These connections unfold in the context of political and affective circumstances where social solidarity remains closely intertwined with bonds of kinship. This reality shapes disability alliances and activism in Jordan in ways that might appear frustratingly apolitical from the perspective of North American and European rights models. It would be a mistake, however, to underestimate the capacity of these kin-like groups to affect change on personal and political levels, since kinship itself provides the substance of both personhood and politics. Diagnosis is only a beginning, and a partial one at that. It unfolds within longer and broader familial trajectories stretching backward through genealogy and forwarded into kinship futures. The gendered labor involved in caring for a disabled child and the gendered ideologies of modernity that animate disability rights in Jordan position mothers as key agents of change and subjects of censure.

Chapter 3. Acceptance

I. Disability, modernity, and "good mothers"

Uncertainties about caring for disabled children provide a new domain for ongoing debates about the proper performance motherhood. This extension illuminates how gender and disability in Jordan remain inextricably linked and intersubjectively embodied through kinship roles and relationships. During disabled children's earliest years of life, mothers encounter intense scrutiny of their choices, their character, and the quality of their relationships with spouses and families. Many women experience constant and sometimes agonizing anxiety over the wellbeing and future status of their child. The intensity of this anxiety stems, at least in part, from a medicalized understanding that these formative early stages of life will "determine" a child with Down Syndrome's future degree of disability.[79] Women in Amman who seek out the currently expanding opportunities to understand, care, and advocate for a child with Down Syndrome find themselves engaging with kin and non-kin in unanticipated and unfamiliar ways. In doing so, they submit themselves and their families to exposure and scrutiny. These risks bring with them the potential for transformation, pain, and a host of unpredictable consequences. Mothers become activists and advocates, found community associations, form Facebook communities, and pursue new degrees. They also face marital problems, familial estrangement, and physical and mental health issues.

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[79] Most of my interlocutors understand disability through a highly medicalized paradigm, replicating diagnostic labels and measures of "severity" as inherent in bodies themselves rather than reflections of the interactions between impairments and social structures. However, they do also challenge the emerging medical hegemony over disability by drawing on a nonsecular framing of human difference and diversity.

In this chapter, I map the boundaries of an emerging moral orientation toward Down Syndrome: acceptance (*taqabbul*). Noting the tendency within anthropology to remain focused on an individuated, ethical "self," Hayder Al-Mohammad proposes paying closer attention instead to the ethical nature of *being-with* others (2010, 437). My introduction of acceptance as a moral orientation builds on Al-Mohammad's argument by delineating how mothers evaluate themselves and each other in their attempts to come to terms with their child's disability.[80] I use the concept of orientation to capture the multiple modes of *being-with* disability that mothers cultivate over time. Women in my research widely frame acceptance as one half of a binary that they contrast with rejection (*rafaḍ*). Acceptance requires various kinds of work: work on one's child, work on one's self, and the work of building care networks through relationships with family, teachers, health professionals, and extended kin. The orientation away from rejection and toward acceptance reveals the shifting and disputed practices involved in becoming a "good" mother in relation to a child deemed different. What acceptance involves in affective, practical, and imaginative terms, however, remains open to debate, even among women who appear to share common goals, beliefs, and parenting experiences.

The moral (re)orientation toward acceptance draws from languages of modernity and backwardness that have enjoyed currency among colonizers, nationalist reformers, Islamic reformers and revivalists, and techno-development specialists across the Middle East and North Africa (Abu-Lughod 1998; Adely 2012; Eickelman & Piscatori 1996; Osella & Soares 2009; Mitchell 1988, 2000, 2002; Salvatore 1997; Shryock 1997; Starrett 1998; Sukarieh 2012). Lara Deeb's pious *Shiʿi* interlocutors living in the marginalized suburbs of southern Beirut described

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[80] I do not place particular importance on distinguishing between ethics and morality. As both Fassin (2012) and Mattingly (2014) note, there is very little consistency in how these terms are deployed either within anthropological writing or in empirical reality.

their social world and its problems in terms of "things being *mutaqaddum* (progressed/advanced) versus *mutakhalluf* (backwards) [and] of how life was *'abl* (before) as opposed to *al-yawm* (today/now)" (2006, 16). The notion of *takhalluf* (backwardness) also resonated with the families who participated in my research. They described rejection as the vestige of a disavowed and morally inferior past, which nevertheless was extremely difficult to move beyond. In their own words, disability stigma reflected problems endemic to Arab culture (*thaqāfa*) and oppressive traditions (*taqālīd*).

The inability to progress beyond tradition indicates the persistence of society's *takhalluf* and results in the evident hostility toward disability. The broad concepts of culture and tradition that my interlocutors draw on become clear in the moral significance that families attribute to genealogical identity, which in turn informs the perceived benefits and risk posed by marriage. For families of intellectually disabled children, in particular, *takhalluf* acquires heightened significance. The term is also used as a clinical label for mental retardation, which is increasingly recognized as pejorative in its own right.[81] Parents play with and redeploy these semantic ambiguities in their critiques of disability stigma. "As Muslims," the mother of a five-year-old girl with Down Syndrome once told me, "we know God made this child. The *takhalluf* is ours, not hers."

In the next section, I explore the content and boundaries of rejection. As a mode of moral evaluation, rejection does not constitute a single or unitary object of critique, but it nevertheless remains the consistent foil for acceptance. I then turn to the question of acceptance, identifying two crucial kinds of work through which women cultivate this orientation. The first entails

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[81] Some parents and specialists considered the use of *takhalluf* in a clinical context, like the term "retardation," an inappropriate generalization. They instead invoked more differentiated languages of disability, impairment, delay, and tried to use specific diagnostic labels whenever possible.

mothers working on their children, particularly through training bodily habitus in the pursuit of normalization. The second entails mothers working on themselves, specifically by cultivating particular emotional states and forms of discipline. I briefly discuss the gendered dimensions of this work and the roles men play in cultivating acceptance, at least within the limits of my own observation. Finally, I analyze the relationships and collective identities that mothers forge through their common links to Down Syndrome, which they position uncertainly between a stigmatized, medicalized diagnosis and a core aspect of their child's identity. Throughout, I give close attention to how class, status, and social capital shape the ways that women relate to and judge each other as mothers.

II. Rejection

Women described the existence of maternal and familial rejection to me as evidence of society's "backwardness," the product of a culture that denies disabled persons – and children more generally – the rights and value afforded to them within Islamic and human rights frameworks. In making a distinction between Islam and human rights, I do not mean to imply that they are inherently separate domains. Rather, I gesture to the different kinds of subjects each of these moral projects envisions as the bearers of rights. For most of my interlocutors, basic assumptions about God, divine creation, and human weakness are groundwork for their engagement with liberal human rights discourses. The latter discourses seem perfectly legible and relevant. They diverge from the framework of rights expressed through Islam, however, in the desirability and feasibility they attribute to personal autonomy and freedom. Interlocutors blamed "culture" (*thaqāfa*) for marking disability as '*ayb* (as shameful or a form of moral exposure). The connections between culture, disability, and '*ayb* become clearer as women reflect on the risks involved in forging new marital ties, a necessary process for reproducing

families' moral genealogies. Mothers often draw on principles of rights and diversity, nested within the moral framework of Islam, to challenge the status quo.

Families' failure to accept and embrace disabled children, my interlocutors contend, enables and normalizes the failures of the wider society. This reasoning reflects the positioning of the family at the center of their shared politico-moral cosmology. While most mothers describe acceptance and rejection primarily through vocabularies of feelings and emotion, I use the concept of moral orientation to capture the affective, social, material, structural, and temporal dynamics of *being-with* disability. Rejection, by contrast, does not constitute a moral orientation but amounts instead to an immoral position. It is subject to critique and social sanction, although it is widely regarded as the norm. Rejection looms large in the public imaginary as an indictment of society's moral hypocrisy, underdevelopment, and weakened family bonds. It operates through exclusionary social structures that encompass children with intellectual disabilities and extend outward to encompass their families as well. Families may attempt to build their own exclusionary structures around a disabled child in an effort to protect the collective reputation of the family.

For example, when Imm Reham's niece Aisha secured a new job at a local restaurant, everyone was very proud of Aisha for taking on this new responsibility. But then, according to Imm Reham:

> Reham told her cousin, "I want to come and visit you!" Aisha responded, "Yes, okay! *But don't tell anyone you are my relative*." It was ringing in my ears. I cannot forget it, even now. Last week my husband suggested we go to visit Aisha. I told him, "You can go with the boys, but Reham and I will stay here." Look, Aisha's free [to do what she wants]… But I get angry. Aisha can say whatever she wants, and I can feel whatever I want.

Slights such as these, where family members deny or refuse to recognize their disabled kin as such, cause pain and anger,[82] especially given that kinship ties still structure much of the socializing and entertainment that provide life's more pleasurable moments. They also point to the subtle but rippling forms of isolation and marginalization that damage and diminish the social networks of individuals with Down Syndrome and their kin, especially mothers. Engagement parties, weddings, and funerals prove especially fraught terrain, but even a quotidian event, like visiting a restaurant, can become an experience of rejection. When one of Reham's other cousins got engaged, Imm Reham remarked with delight and astonishment that both she *and* Reham received invitations to the young woman's engagement party. This gesture touched Imm Reham, and even more so because the young woman in question was not their kin.

Mapping the social topography of rejection:

Rejection indexes the various fault lines that mark Amman's social topography. Women from "the Governorates" (*al-muhāfaẓāt*, which colloquially refers to all of the Governorates outside Amman) and from eastern Amman are described as most likely to reject a child with a disability. These women and families, in particular, thus require consistent intervention to mitigate rejection and promote acceptance. After one of my first visits to a Jabal Ahmar, a poorer neighborhood in east Amman,[83] Hiba, the early intervention coordinator at the al-Nur Society, was very curious to hear my impressions of the "other half" of the city. During this visit, I met a visually impaired young girl who was a neighbor of the family. She navigated around the space

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[82] Ethnographic research on disability around the world has documented families grappling with similar kinds of social isolation and stigma (Das and Addlakha 2001; Gammeltoft 2008; Landsman 1998). Disabled persons themselves write about these experiences at length in auto-ethnographic and personal accounts (Garland-Thomson 2014; Kafer 2013; Murphy 1987; O'Toole 2015). For an account that hits close to home, see the recent Anthrodendum blog post, "What I Wish I Knew about Anthropology and Disability: Notes toward a more enabling anthropology" (Friedner, Kasnitz, and Wool 2018).

[83] This particular neighborhood had originally been part of the Mohammad Amin informal Palestinian refugee camp.

of their small, narrow house largely by touch and managed quite well. The same strategy, however, could not help with her schoolwork. She was falling behind in class and would likely fail the school year. When I shared this story with Hiba, she became upset:

> They need to go to the Ministry (of Social Development)! The thing with people in places like Jabal Ahmar, is that they complain about how hard things are and how there's nothing for them. There is. Things are not as bad as they say. Blind children can go to school! Things are not that bad, Christine! … I once had a mom come in [to the Society]… Her seven-year-old was in *Pampers. Pampers*! At seven! How can this be? Why haven't you taught her? She said it was impossible! No, it's not.

At some point during Hiba's impassioned outburst, Kawthar walked into the room. "Kawthar, Hiba instructed her coworker, "Explain to Christine what families in East Amman are like." Kawthar turned to me. "They just want someone to find them a center where they can deposit their kids, and that's it." The stereotypes Hiba and Kawthar invoked were in fact at odds with their own variable experiences working with families from eastern and western Amman. Both women frequently analyzed, with considerable nuance, the unpredictable, heterogeneous effects of class and capital on families' acceptance and mothers' commitment to their children. The availability and utility of these stereotypes nevertheless speaks to the social politics involved in acceptance, which overlap and bleed into distinctions of class, ethnicity, education, and piety, inevitably in complicated ways.

Families living in East Amman face a significantly longer commute to the Society, which increases their likelihood of missing appointments or failing to show up for events. These outcomes only exacerbate the narrative common among staff and mothers from west Amman that poorer families are less dedicated to their children, and thus, less capable of undertaking the work that acceptance demands. Sarah Tobin argues that a powerful, self-consciously middle-class identity is emerging in Amman, which "is less about monthly income, and more about a set

of social and cultural practices that bring together this diverse society into a new kind of imagined community" (Tobin 2012, 100; Schwedler 2010). In her analysis of Jordan's relatively uneventful "Arab Spring," Tobin describes this the members of this middle class as:

> Articulat[ing] a kind of suburban consciousness. They have some level of post-high-school education; they are conversant in Western — particularly American — cultural references of leisure, including coffeeshops, malls and TV shows. Many Jordanians hone their English by watching "Friends" episodes with Arabic subtitles. They are a population who "want peace"… They are consumers of political information put forth on blogs, news and Internet sites, but are not otherwise politically engaged. Instead, they organize around certain places and times for consumption and around economic points for solidarity. (2012, 100)

Elsewhere, Tobin also discusses how many of these new patterns of consumption intertwine with activities and commodities associated with Islamic education, travel, business, and celebrations (Tobin 2016). These all point to the importance of a distinctly Muslim middle-class in Jordan, a phenomenon also explored in other contexts (Clark 2004; Fischer 2017; Maqsood 2017).

Some of my interlocutors live lives in no way approximate this description of middle-classness, while others most certainly do or aspire to. Those who fall into the categories of working-class or urban poor encounter these new possibilities, however, whether through siblings who marry well, colleagues at work, or on television – more commonly set to Turkish soap operas dubbed into Arabic than *Friends*. Tobin nevertheless captures the class dynamics and modes of calculative thinking employed by many parents, who approach disability advocacy as a social rather than a political project. Conspicuously consuming therapeutic and rehabilitative services, through what is quickly becoming a booming and lucrative industry, provides an avenue for mothers to visibly perform acceptance. These investments of capital allow families to make a collective statement, demonstrating that their children are loved and valued (see also Kaya 2010).

Parsing the moral politics of rejection:

Parents and specialists in Jordan recognize and make reference to government

inefficiency and a lack of adequate services as matters of stating the obvious. Yet, they are far

more likely to interpret other families' struggles – whether due to finances, lack of information,

insufficient bureaucratic savvy, or some combination thereof – as signs of backwardness and

personal weakness rather than as reflections of materially grounded disenfranchisement. This

analytic aligns quite strikingly with Omnia El Shakry's research on gendered politics in colonial

Egypt.

> Discussions on proper mothering, in both the metropole and the colony,
> intersected with philanthropic movements geared toward a pedagogy of the lower
> classes. [They worked to] reconstitute motherhood along middle-class lines of
> rational-economic and scientific-hygienic domesticity and child rearing, effacing
> and recasting class differences under the rubric of an 'ideal mother.' (1998, 127)

For mothers of disabled children in Amman, the rubric of acceptance and rejection works to

efface and recast class differences in terms of moral legitimacy. Yet, moral legitimacy ultimately

cannot be reduced solely to the politics of class. My interlocutors explicitly recognize that

"good" poor mothers existed, as well as "bad" wealthy mothers. In fact, women offer mixed

interpretations of how class and status shape the likelihood of a family rejecting a child with a

disability.

While attending a short seminar for undergraduate and Master's level students preparing

to work in the field of special education, the program's office director took particular interest in

my project as we chatted during a coffee break. "I know someone you *have* to talk to," he

exclaimed! "She's a special education teacher working in a resource room at a private school in

east Amman." Only a day later I received a call from Reem, who invited me to come to her

house, where she offered private lessons and speech therapy sessions to supplement her day job

in the school. Sitting in the salon of Reem's one-bedroom apartment, a multi-purpose space that functioned as a waiting room for children and their mothers, a salon to receive guests, and a play area for her own three children, Reem told me that the most difficult clients to work with are the affluent families from west Amman.

> I used to work at a center near the Palestinian Embassy [located between the 4th and 5th circles of west Amman's Zahran street]. They wouldn't even write this one child's name out because his family didn't want it known. He was listed on his chart as "S." These people are so "sophisticated," and they don't want anyone to know about the child! Here in east Amman, people are different. They're more open. They want to help and are more helpful.

Her interpretation, which diverged significantly from Hiba and Kawthar's representations of the differences between families in east and west Amman, points to the messy entanglements of class and morality in creating local disability worlds.

Rejection functions as a local category for differently positioned women to judge and be judged in their performances of motherhood. Rejection indexes backwardness. What exactly causes backwardness, and which attachments and practices are marked as backward, remain the subjects of contested and conflicting assessments. Families in west Amman are more likely to possess the financial capital necessary for pursuing the latest and highest quality services. This very privilege, according to Reem, also makes them more sensitive to the possibility that the disclosure of disability could damage their position in a high-stakes marriage market. Affluent families, according to Reem, are even more vulnerable to the pressures of stigma and inclined, for that reason, to hide a child and protect their reputation. Hiding certainly seems easier in the well built, spacious high rises of west Amman, where people are less likely to know their neighbors or interact with them. The wide, smooth streets in neighborhoods of west Amman usually lack pedestrians. Sidewalks hover at perilously high altitudes. Homeowners often plant palm trees directly in the middle of existing walkways, lest frustrated car owners attempt to

create easy overflow parking spaces. In east Amman, the cramped and deteriorated living conditions lead to the spillover of domestic life into the streets and onto the roofs. This closeness makes intimacy a more inevitable and matter-of-fact dimension of daily life, whether one desires it or not. Ultimately, however, the material realities of care – therapies, medicines, wheelchairs, hired labor – along with the various entertainment and leisure activities that determine quality of life, all require capital.

Families from Jordan and elsewhere, educators, specialists, and both local and foreign humanitarian and development workers all describe "hiding" as the epitome of a non-modern, shame-motivated response to disability. The family ashamed of disability hides their child. Parents often insist, "Everyone here rejects disability. Everyone hides." When pressed to account, then, for their *own* processes of rejecting rejection and embracing acceptance, parents generally provide a response that seem no less self-evident to them: "this is my child." Eventually, however, these succinct replies give way, revealing more complex unfinished narratives of cultivating acceptance through different kinds of labor.

III. Acceptance

Working on one's child: bodily norms

Early intervention and rehabilitation therapies operate through technologies of objectification that disassemble children's bodies into a discrete array of functions, delays, and risks. It is primarily mothers who, by engaging with specialists, learn to see their child through this medicalized gaze. They become (or fail to become) vigilantly attuned to the signs of muscular, visual, hearing, speech, and mobility impairments that serve as primary sites of therapeutic engagement. Most children with Down Syndrome experience physical delays stemming from generalized hypotonia, or poor muscle tone. Because muscular strength provides

the critical foundational base for so many early milestones – crawling, grasping, walking, and speaking – the provision of therapeutic services early in life can improve how children (and later, adults) move, communicate, and function independently.[84]

Through early intervention therapies, children's bodies and behaviors become the targets of formative and regulatory maternal labor. Scientific and technical goals for children's bodily and social development provide a framework that some mothers consider alienating and unforgiving, while others find it encouraging. These corrective programs assume children's bodies are endlessly malleable in their potential for growth and becoming. Thus, a child's failure to reach milestones indexes a mother's failures to "work with them." A somewhat paradoxical situation emerges whereby intervening and modifying the bodily and behavioral traits of one's child becomes the means to perform and realize "acceptance."[85] Mothers and the network of specialists and support workers who often become their friends and confidants grapple with this contradiction. On the one hand, they are expected to do everything in their power to mitigate their child's impairments. On the other hand, they are expected to embrace their child's impairments as part of their person and potentially unchangeable, regardless of how diligently they pursue therapeutic interventions. Tracing the ways that mothers evaluate and contest acceptance reveals the complexities of living with Down Syndrome and of Down Syndrome itself.

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[84] Whether early intervention services produce positive long-term benefits and to what degree remains the topic of considerable debate (Connolly et al. 1993; Lynch and Hanson 1993; Hines and Bennett 1996). There are methodological challenges involved in measuring the effectiveness of such programs (Majnemer 1998). Additionally, they rarely take accessibility and structural inequality into consideration. Regardless, staff, experts, and rights activists in Amman insist that early intervention is key to promoting typical development, if for no other reason than its ability to help parents emotionally connect to and invest in their child's growth and progress.
[85] The neurodiversity movement is in fact organized around critiquing this paradox and its underlying implications, which reflect a desperate desire to change rather than truly accept the possibility of differently wired brains/minds/selves (Cascio 2012, 2015; Hart 2014; Silberman 2015).

Coming to terms with physiological, developmental, and social risks created by the presence of an extra chromosome and a diagnosis of Down Syndrome, mothers share in their children's vulnerabilities. They feel they can no longer rely on general parenting advice, past experience, or their own intuitions once tasked with raising a child with disabilities. For some, the anxieties of raising one's first child with Down Syndrome intensifies this experience. One of the most active fathers at the Society stepped into the role of his son's main advocate because his wife was traumatized by their daughter's diagnosis. Once she gave birth to their second child – who did not have Down Syndrome – she became more capable and comfortable with participating in the Society. Nevertheless, her husband continues to serve as their eldest daughter's primary support system. Imm Reham, on the other hand, explained that, "because Reham was our first child, her normal was our normal." This statement alludes to the sense of contradiction expressed by some mothers who encounter disability activism in the later years of their parenting careers. The emergence of Down Syndrome, as an identity, expresses a form of difference that some iterations of rights discourses nevertheless seem intent on erasing. Are children with Down Syndrome "just like" other children? Many mothers would answer this question emphatically in the affirmative: Yes, they are just like other children. Yet they are also not like other children in important ways. Rayna Rapp also encountered this tension in her own fieldwork with parents participating in a Down Syndrome support group in New York, and she describes it in terms of a "doubled discourse of both difference and normalization" (1999, 294).

Down Syndrome, while arguably a biosocial label, nevertheless remains steeped in what disability studies scholar Simi Linton describes as the pathologization of difference that defines the medical model of disability (2006, 162). It also marks the presence of chronic and potentially urgent medical risks, including "heart anomalies, hypothyroidism, leukemia, digestive ailments

and celiac disease, [and] strong susceptibility to life-threatening pneumonia" (Pohlman 2010, 53). Given these bodily vulnerabilities, growth and development become formal, explicit tasks; they are conceptualized and objectified in training programs, checklists, and evaluations by experts. Milestones, in turn, are celebrated achievements rather than taken-for-granted products of time and nature. Mothers' concerns with shaping their children's bodies reflect particular orientations towards space and time. The emphasis they place on bodily normalization gestures to immediate and long-term goals of incorporating disabled children into the sphere of domestic labor and social roles anchored in kinship and hospitality. Specialists and therapists, on the other hand, often emphasize exercises and trainings whose benefits they couch in terms of cultivating children's abilities to enter non-domestic spaces and realize their right to be included in "society," most concretely meaning school and then the labor market.

Family members particularly focus their anxieties and disciplinary energies on children's mouths, given the mouth's importance for speech. Drooling and the protrusion of the tongue are considered problems of special significance; they are aesthetically unsettling. Staff and experienced mothers will constantly demonstrate tongue, mouth, and jaw exercises for new mothers, providing them with a variety of drills to practice at home. Hiba or Imm Zahra would scoop up whichever child happened to be nearby and coo them into acquiescence. They would demonstrate oil-based massage techniques meant to facilitate blood flow in the face and alleviate skin dryness by moving their fingers in gentle upward strokes around the neck and cheeks of the attentive or occasionally miserable child selected for the demonstration. In another popular drill, mothers are instructed to take a small piece of date (since any normal household in Jordan will have dates stored away) and place it in the corner of their child's mouth. To retrieve it, the child must extend and twist their tongue, exercising the muscles involved. A small chunk of carrot –

also beneficial and healthy – can be used to practice the same drill, moving the tongue from the upper right to the upper left corner of the mouth and back. For training children to be mindful of their appearance, the smallest drop of lemon juice is administered to the tip of the tongue as a gentle, bitter corrective.

These bodily exercises have myriad applications and objectives. Children with Down Syndrome struggle to build the muscle tone required for drinking, eating, and speech. They also struggle to inhabit social norms where bodily control is of the utmost importance. One day, Imm Haydar entered the Society, clearly excited. Imm Haydar's son was previously enrolled in early intervention programming at the Society, and she still liked to stop by and visit with the staff members she had grown close to. Speaking at lightning speed in the distinctive accent of her native Egypt, she began to share her story:

> Last week, we went to *Barshelona* (a chain fast food restaurant with branches all over Amman). The whole family went. This woman, she was staring at Haydar. Just staring. I knew it was about Haydar. So she approached me. "Down?" She asked. "Yes," I responded. "He's Down." The woman paused, and then burst out, "How can you get him to be so clean? My daughter, everything falls out of her mouth. She drools! The food… We can't take her out!"

She stopped for dramatic effect. "Can you imagine (*takhayyalī*)?!" Imm Haydar was shocked by this stranger's admission that she never took her daughter out to eat because of the awkwardness she felt about her daughter's chewing and drooling. Society staff considered Imm Haydar's own son extremely behind in terms of developmental and behavioral milestones. Despite their formal opposition to special education centers, they had urged her to enroll Haydar in a full-time program so he could receive more intensive attention and hopefully "catch up" to his peers. Thus, this stranger's recognition of Haydar as a "success," which by extension recognized his mother's and his entire family's willingness to work with and include him, became an even more salient achievement.

The social and symbolic importance of the mouth directs both maternal and expert gazes in concrete ways. Imm Farid, whose son is in his earlier thirties, understood the importance of working on Farid's speech even without the access to therapeutic knowledge or expertise accessible to younger mothers today.

> I would always try to work on his speech at home, to the extent I could, because there were no speech therapists… I would bring a mirror and teach him. I would ask, "Did you see how [to say this]?" And I would slowly enunciate the letters. I would tell him that he has to exercise always so that his muscles get stronger. *When you speak well, people will accept you*. Drool would run down from his mouth because his muscles are weak. *Alhamdulillah* he stopped drooling and he started to speak correctly, but it took a long time.

The attainment of proper speech stood out for Imm Farid as a shared achievement that required vigilant bodily training. Enabling her son to speak well would enable him to connect with others. The failure to control one's body in ways deemed acceptable, what's more, is justification for the imposition of control by others. Imm Farid's decision to train her son through practical, physical exercises and drills also gestures to pre-existing local sensibilities surrounding the cultivation of the body as necessary for social acceptance and moral standing within the community.

Historian Omnia El Shakry traces how, in colonial Egypt, *tarbiyya* (upbringing or education) and *adab*, "a complex of valued dispositions (intellectual, moral, and social), appropriate norms of behavior, comportment, and bodily habitus," served as vehicles for articulating visions of both modernity and proper gender roles (1998, 127; on *tarbiyya* see also: Cook 1994; Roald 1994). *Tarbiyya* and *adab* offered "resources indigenous to the Islamic discursive tradition that emphasized the proper pedagogy for children, cultivation of the body, and the moral education of the self as essential for the constitutions of a rightly guided Islamic community" (El Shakry 1998, 127–28). Bodily mastery plays a key role in elaborations of personhood, and indigenous paradigms of embodied, moral cultivation have long complemented

the "modernist disciplining of the body and rationalization of the household" associated with the contemporary nation-state (El Shakry 1998, 128). The mutual fashioning of mothers and children that I observed in my fieldwork is clearly not a new phenomenon. Regimes of therapy, child development, and behavioral training in Jordan both reinforce and extend pre-existing sensibilities about mother-child discipline and subjectivity (Kashani-Sabet 2006). Current rehabilitative therapies, combined with human and disability rights paradigms, identify disabled children as symbolically powerful conduits for creating broader social change. This identification in turn deepens the enmeshment between mothers and children.[86] While mothers work directly with and on their children through modes of early intervention therapy, acceptance also requires women to work on themselves. This work takes the form of emotional training and cultivation.

Working on oneself: Navigating fear

Through the teacher-student dynamic facilitated in early intervention sessions, along with various other formats for engagement – lectures, casual exchanges of information (and rumors and gossip), didactic sermons delivered by older mothers to younger counterparts – certain emotions emerge as critical sites for mothers to work on themselves and cultivate acceptance. One day, Imm Adnan came into the Society carrying her four-year-old son in her arms. She encountered a barrage of concerns, and then criticisms, from the older mothers who witnessed her entrance. "Sister, does Adnan not walk yet?" inquired one woman. Imm Adnan responded that Adnan could walk, but it was hard for him, and she was afraid (*khayfeh*) of him falling, getting sick, or getting somehow separated from her in transit. While her audience remained sympathetic to these anxieties, they ultimately urged her to get over them. As his mother, it was

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[86] For a slightly different take on the mother-child nexus, scholars critical of human rights and humanitarianism have noted that the conflation of women-and-children with innocence and victimhood serves to discipline those who violate ideals of political acquiescence (Babul 2015).

her responsibility to teach Adnan to rely on himself (ʿatamid ʿalā nafsu). Was she planning to carry him around forever? Looking uncertain and somewhat irritated, Im Adnan sighed and set Adnan on the floor, never taking her eyes off him for more than a second.

"The work of care," argues anthropologist Cheryl Mattingly, "demands the work of cultivating virtues" (2014, 5). Cultivating or suppressing specific emotional dispositions creates certain kinds of selves. In pursuing these different ideals of the self, mothers draw from and negotiate between different sources of moral authority, the visions of the "good life" they engender, and their implications for life with Down Syndrome. As they negotiate and disagree about what kinds of mothers they want and need to become, women connect these models of self both directly and indirectly to the broader circumstances of vulnerability and uncertainty that pervade life in Jordan. Anthropologists have explored how emotions are culturally constructed, linguistically shaped and mediated, and intimately linked to social and political contexts. Previous work explores these dimensions through analytical frameworks of folk medicines, embodiment, affliction, and suffering (Lutz and Abu-Lughod 1990; Lutz and White 1986; Robbins 2013; Rebhun 1994; Scheper-Hughes 1992).

Emotions offer a platform for performing and embodying different orientations toward disability. They also indicate how multiple and sometimes-conflicting moral frameworks inform women's attempts to inhabit the subject position of being a "good" mother. Fear *(khowf)* plays a central, if contested, role in how women conceptualize good mothering and how they experienced their sense of being-in-the-world. Many women actively seek to cultivate fear in themselves and their children. The belief that children with Down Syndrome do not exhibit appropriate levels of fear toward various sources of danger – strangers, cars, hot stoves, to name a few – looms large in the minds of concerned parents. Women link good mothering with the

positive quality of protectiveness, and fear possesses practical utility. Surviving in the urban metropolis of Amman, a city often described by inhabitants as difficult and exhausting (*mut'ib*), requires honing various kinds of fear and suspicion. Women need to guard against the possibility of being cheated, exploited, or violated, especially by strangers but also by friends and even family (MacDougall 2017). Fear, in different degrees of intensity, manifests in the quotidian practices that shape how women engage with each other and their environment. Operating with either too little or too much fear can cause problems.

The multifaceted dimensions of fear often emerged during early intervention sessions between Hiba and mother-child pairs. During one such winter session, Hiba commented to Imm Leen that her daughter demonstrated unusually fearful reactions to her surroundings. Especially disturbing to baby Leen was a long purple sash with jingly bells tied to the end that, if given even a gentle shake, would send her into fits of screaming and tears. Imm Leen looked thoughtfully at her infant daughter, wrapped in a bright pink snowsuit and bearing a striking resemblance to an oblong, fluffy marshmallow. With a pensive but deliberate tone she replied, "It's better she fear than not fear." Not long after this exchange, Hiba was working with toddler-aged Lujayn and her mother. Hiba wanted to see if Imm Lujayn had been practicing the various training drills and activities she assigned during the pair's previous appointment. As she proceeded through her checklist of inquiries, Hiba expanded her questions to ask more generally about Lujayn's daily activities and routine. Imm Lujayn began to blush, her youthful face framed by her black hijab and white underscarf. She occasionally shot nervous glances in my direction while I sat on the floor next to her, and she responded mostly in the negative to Hiba's questions.

Hiba: Do you let her play on the swings?
Imm Lujayn: I'm afraid (*anā khayfeh*)!

Hiba: Have you considered enrolling Lujayn in swim lessons? Swimming is very good for the muscles.

Imm Lujayn: I'm afraid (*anā khayfeh*)!

Hiba: Im Lujayn! Strengthen your heart (*bit'awi 'albek*). Children learn from each other. Lujayn is lonely.

Hiba then turned back to Lujayn and began testing another one of the skills on her agenda. Quietly, and speaking more to herself than to anyone else, Imm Lujayn responded to Hiba's prompt. "She's not lonely. Where she is, I am." Imm Lujayn did not believe her daughter might be lonely because she did not recognize Lujayn as lacking horizontal social ties to other children. Their vertical bond mattered more; no one would fear for Lujayn like her mother. Other mothers of young children articulate similar sentiments. They express anxieties about letting their children socialize with peers, let alone cultivate friendships beyond those with their siblings, cousins, and neighbors they know best.

Parents draw on a shared vocabulary of praise when describing people with Down Syndrome – "innocent," (*barā'*), "with white hearts" (*'andhum qalb abyaḍ)*, meaning pure and good, or "angels on earth" (*malā'ik 'alā al-arḍ*). While ostensibly positive, these characteristics nevertheless prove problematic. Having a white heart does not compare with the "strong heart" that Hiba urged Imm Lujayn to develop for herself and her daughter. Being a good mother means teaching one's child how to properly and successfully navigate moral dangers, an objective requiring both fear and strength. From an expert's perspective, excessive fearfulness suggests that a child is not getting enough stimulation, or perhaps it points to an insecure home life. This is one of the reasons Hiba mentioned Leen's anxious disposition and sensitivity to her surroundings. Yet many parents consider fearfulness, even in their youngest children, an apt instinct and one made even more critical when navigating the world with a disability. Mothers

often feel compelled to maintain constant vigilance and protect their morally innocent children from an immoral and threatening world, shielding their white hearts.[87]

Fear is seen as necessary, while its appropriateness and moral legitimacy depends on the subjects, circumstances, and motivations in question. One afternoon, Hiba and I walked to her car while discussing a common issue faced by many of the smaller organizations: namely, the length of their employees' workday (*duwwām*). Certain services receive much higher demand than others, ostensibly requiring specialists working in those areas to log longer hours (given the budgeting difficulties posed by the alternative of hiring more employees). The Society struggled to find a speech therapist who would commit to the extended hours they hoped to provide. Doing so would require staying alone in the building – located in a safe, middle class neighborhood – and locking up at the end of the day around 4 or 5pm. I asked Hiba why this issue had become so difficult to resolve, pointing out that the speech therapist could always start her *duwwām* earlier if she wanted to avoid rush hour (traffic being my own constant preoccupation and source of ire). She explained that I was missing the point. What was the objectionable in this scenario was being *alone* at the Society and responsible for closing (or opening).[88]

"We're afraid, Christine. There are so many stories about violence and rape now. Look – the laundry man who just entered the building to pick up a delivery is now pulling out in his van – see how he's looking at us? Maybe he'll come back tomorrow…" she trailed off. In this example, Hiba configured fear as an appropriate and necessary component of mature womanhood. Women need to be careful, manage the risks around them, and remain attuned to threats on their person or reputation. When taken to an extreme, however, fearful mothering

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[87] These qualities were also problematic for other reasons relating to aspects of personhood and specifically adulthood, issues I discuss in chapters Four and Five.
[88] Needless to say, someone had to take on these responsibilities at the Society.

acquires negative qualities. Fearing for oneself and one's children is reasonable. When fear

prevents a child from interacting with the world, however, it can become an impediment to

normal development. Precisely because mothers of children with Down Syndrome perceive their

children as particularly weak in cultivating a proper sense of fear, they disagree with the

suggestion that they are in turn being overly protective.

Thus, fear has emerged as highly problematic for educators and activists, who criticize

the "overprotective Arab mother" as a cultural problem and an impediment to progress for

people with disabilities. This particular tension reflects broader debates in Jordanian society over

what I have previously described as the risks of relatedness.[89] In her research with elite women

in a coastal city of Yemen, Anne Meneley discusses the centrality of fear to her interlocutors

experiences of wellness, pain, and suffering. Zabidi women recognize the existence of "a malady

called 'fright' (*fajaʿa*)," which women are susceptible to in the wake of experiencing an

emotional trauma or shock (*ṣadma*) (Meneley 2003, 21). Fright sickness reflects the ambiguities

and ironies of social closeness, whereby the people you care most deeply about become those

most capable of harming you. Tragedies, freak accidents, and violent encounters – a child falling

into a pot of boiling water, a fatal car crash involving family, the violent mugging of a loved one

– can all produce *fajaʿa*. When Meneley began her research in 1989, treatment came in the form

of a brief burn to the skin; the shock counterbalanced the fright and restored internal equilibrium.

It is not possible to avoid *fajaʿa*, which occurs as a byproduct of encounters with life's

unpredictable cruelties. Yet women who experience *fajaʿa* indiscriminately are described as

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[89] In her research on female friendships and ethical self-cultivation in Jordan, MacDougall writes that "to contemporary Jordanians, this closeness (*tarābuṭ ijtimāʿī*) is what distinguishes them as a culture, but it is also what is holding them back from progress" (MacDougall 2017, 18). In an astute analysis of a popular music video by the Jordanian band Jadal, she explains how young people think through the risks and burdens of maintaining close family-based social ties.

having a weak heart and are subject to moral rebuke. Meneley writes, "I myself was often criticized for having a 'weak heart' for my propensity to cry when others were crying, which was interpreted by the Zabidis as a dangerous and foolish oversensitivity to the concerns of those distant from me" (2003, 30).[90]

The moral politics of fear can change with time and circumstance. Returning to Yemen after a decade-long absence, Meneley discovered that *faja'a* is now increasingly subjected to new modes of reasoning. After a local woman had been the victim of a startling encounter with an unknown male, for example, Meneley asked whether the woman had sought out the prescribed burn to avert the effects of shock (*ṣadma*) that lead to fright. Her friend "sniffed, saying that they were too 'advanced' (*mutaqqaddam*) for the burning treatment, which smacks of *backwardness* to those who consider themselves modern" (Meneley 2003). Instead, the woman's family sent her to India to enjoy a restorative holiday. This perception of backwardness attests, on the one hand, to biomedicine's increasing hegemony over local experiences of embodied affliction. It also speaks to the increasing importance of piety in local politics of respectability.

Afflictions of fear become especially problematic when seen as symptomatic of one's lack of faith in God and inability to accept His will. In Jordan, this concern dovetails with the middle-class notion that good, pious mothers are tireless in their pursuit of programs for their children's development and enrichment. For mothers of disabled children, in particular, fear provides moral-emotional terrain for embodying and engendering contested notions of modernity, selfhood, and *being-with* disability. Unsympathetic and extremely critical assessments of women faced as regressively overprotective reveal intersections between gender

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[90] In Meneley's case, however, her sentimentality as an outsider actually proved endearing to the community of women she worked with. Positionality always shapes the production and reception of these norms, especially for ethnographies.

and disability while attesting to politics of cultivating a self that is both moral and modern, the precise boundaries of which shift over time but are nevertheless of enduring importance.

Working on oneself: Striving for submission

Both mothers and fathers invoked the term *ṣadma*, or shock, to describe their feelings upon receiving an unexpected diagnosis of Down Syndrome or other lifelong conditions. The vast majority of families and specialists consider *ṣadma* a completely natural response to a discovery of such magnitude. The danger of *ṣadma* lies in prolonging its symptoms: apathy, sorrow, crying, depression, and failing to complete one's responsibilities as a parent, spouse, and adult. Shock and fear (*khowf*) involve different qualities and temporalities. The importance of fear is linked to the realities of human – and especially feminine – weakness and vulnerability; women value fear for its role in facilitating survival skills and engendering properly feminine values of modesty, restraint, and deference.[91] Unlike fear, however, women stress the importance of overcoming *ṣadma.* They critique other mothers, and sometimes themselves in hindsight, for dwelling too long in a state of *ṣadma*. Sitting in Imm Maha's living room with her three sisters-in-law, I encountered yet another objection to *ṣadma*.

I met Imm Maha through the Society, although she did not attend very often, citing the difficulty of traveling from her home in eastern Amman. Born and raised in Iraq, her family has since scattered all over the world as refugees. Her parents lived in the American Midwest, a placed she referred to as "Chicago." She spoke often about her desire to visit them; she had not seen her mother in over 14 years. She and her husband met while at University in Baghdad. The couple and their young children sought refuge in Jordan after the U.S. invasion made life in Iraq

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[91] Fear, in this sense, connects to a different gloss of the word shame, or *'ayb*, as used my interlocutors. It closely resembles the way anthropologists have described *istahya*, *al haya'*, and *hasham*, which can be translated as shame but which also reflect a positively valued sense of modesty (Meneley 1995, 2003; Abu-Lughod 1986; Mahmood 2005).

too unbearable. Imm Maha could not lay claim to anything resembling "free" time at that point in her life. She was busy caring for her five children and extended family. She pushed back our first meeting repeatedly, as she explicitly wanted me to visit *after* her in-laws – who also lived with her – departed for a month-long trip to Egypt. Climbing the hill to her house for the first time, she informed me that even without them, my visit would nevertheless be full of family. Upon arrival I was introduced to Imm Maha's three sisters-in-law. They heard about my visit and were keen to ask me questions about Maha (on the assumption that I was studying special education and could provide an authoritative disability evaluation). We chatted about Maha's Down Syndrome in the course of getting to know one another. Her sisters-in-law provided most of the narration and interpretation of the diagnosis experience, leaving Imm Maha to prepare lunch. Not only did she have her own five children to feed, but also her relatives by marriage and their children. A steady stream of sons, daughters, nieces, and nephews began to straggle in from school and fill the narrow, nearly subterranean one bedroom apartment to maximum capacity.

When I asked how the family coped with the initial *ṣadma* of Maha's diagnosis, everyone within earshot issued a chorus of rebuttals. "No, no no! There was no *ṣadma*!" Alia exclaimed. Alia was Imm Maha's unmarried sister-in-law who lived in a small storage space located in the apartment's cellar. She appointed herself as Imm Maha's chief representative and my guide to the family's neighborhood.[92] From the kitchen, Imm Maha shouted over to us, in agreement with her sisters-in-law, "There was no shock, Christine (*mā kān fī ṣadma, Christine*)! Alia explained to me that *ṣadma* was not something a Muslim felt about the arrival of a child with a disability. "Everything is a gift from God. There was no shock because why would we be shocked by what

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[92] This appointment, I would later learn, did not sit well at all with Imm Maha.

God has given us?" *Ṣadma*, as Alia understood it, revealed a lack of faith in God's plan and the intention of His design.[93]

Alia then announced that before we started our lunch she would like me to meet Imm Omar, one of their neighbors. Imm Omar also had a disabled daughter, although her situation was quite different from Maha's. As Alia, Maha, and I walked through the narrow alleys of Jabal Ahmar, Alia provided me a unique oral map of the neighborhood. She pointed out various households and named different kinds of disabilities experienced by the residents inside (Down Syndrome, blindness, deafness, cerebral palsy, intellectual disability). In doing so, she conveyed an intimate knowledge of the various domestic states of wellbeing surrounding her. We arrived at the house of Imm Omar, who was slightly confused by my presence but graciously invited us inside nevertheless. Alia explained that I was visiting their family to learn more about Maha and about how Muslims understand disability. Alia herself introduced this specification. I never explicitly mentioned religion when describing my project, using the more general category of "culture" (*thaqāfa*), although almost every family I met was in fact Muslim. Imm Omar responded by showering me with several *masha'allahs*[94] and *habībtīs*,[95] inviting me to join the Qur'an study group that she and Alia both attended. She then went to bring Samira into the room.

Samira was the youngest of Imm Omar's seven children and her only daughter. She was both physically and intellectually disabled. Samira experienced extensive brain damage at birth (*ḍumūr al-'aql*, literally destruction of the mind). She neither walked nor talked, and her growth

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[93] In her discussion of *sadma* and the *faja'a* amongst elite Zabidi women, Meneley describes a similar dilemma. While the fright women felt from *sadma* revealed embodied ways of dealing with fear, injury, and loss, many women struggled to accept and move on from fright without conveying any sense of diminished faith in God's plan.

[94] An extremely common way to express praise, literally meaning "God willed it."

[95] A term of endearment used across different kinds of social relationships; it literally means "my dear one" or "my love." In this context, it conveys a sentiment of "sweet girl."

was significantly arrested. Alia explained to Imm Omar that I asked about her family's ṣadma on learning of Maha's Down Syndrome. Alia stressed the word ṣadma to Imm Omar and paused afterward, giving her friend a knowing look. She then connected this to a second idea that I had not actually expressed to Alia. "She has heard that people *here* interpret disability as a punishment from God."[96] Imm Omar responded with a start. "*Habībtī*! How could Samira be a punishment? She is my path to heaven. She is proof that God loves me. She is mine and of me. How could I reject her?" At this point in our conversation, Samira suddenly became extremely irritated, so Imm Omar rose to carry her daughter back into the house's interior (we remained in the salon space designated for receiving guests during our visit).

Alia turned to me in her friend's absence. "Imm Omar accepts her daughter's disability." Then she paused and thought about it. "No, she submits. This is the meaning of Islam, to submit. This is more than acceptance." In interpreting Imm Omar's conviction, Alia made a distinction between acceptance and submission, and she elaborated a particular orientation toward disability, one grounded in the imperative not merely to accept Samira's disability but to submit to God's will through it. Saba Mahmood uses research with female members of Egypt's Islamic Revival, or *daʿwa* movement, to critique conventional feminist scholarship for collapsing distinctions between agency and autonomy in pursuit of freedom. This leads, Mahmood argues, to a "profound inability… to envision valuable forms of human flourishing outside the bounds of a liberal progressive imaginary" (Mahmood 2005, 155). Alia initially described Im Omar's orientation toward her daughter as one of acceptance. Dissatisfied with its scope, however, she revised this initial description and instead invoked a paradigm of submission. This self-

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[96] Most of the families in my research described this belief to be backward and ignorant. Mothers cited ignorance of Islam, usually by referring vaguely to the dominance of "culture," as causing the local and regional stigma surrounding disability.

correction, I would suggest, is emblematic of how many families' commitments to their children fail to align with a disability rights agenda deeply invested in humanist principles of autonomy, equality, and independence. At the same time, submission should not be equated with fatalism, passivity, or the rejection of disability. "How could I reject her?" asked Imm Omar. Meneley also discusses this false equivalence when discussing why her Zabidi interlocutors would utter *alḥamdulillah* (praise God) upon the death of a child.

> These women contemplate the ironies of fate, eventually, if not easily, submitting to the will of God in a manner spoken about in terms of "patience' (*ṣabr*), encompassing both forbearance and endurance… This kind of submission to the will of God is a very active one, and is considered in Zabid to be an achievement worthy of social respect in this world and of reward in the afterlife… Passivity is not part of the way submission is perceived in Zabid. (Meneley 2003)

Meneley's interlocutors, like my own, struggle to recognize and accept God's will as the ultimate and intentional organizing force behind life's trials and challenges. They nevertheless attempt to align their own personal sense of agency as belonging to and within this divine agentive force.

Suad Joseph and Iris Jean-Klein have both written about gendered kinship dyads – those of brother-sister and mother-son – as critical for mutually elaborated forms of personhood and self in Lebanon and Palestine, respectively. Joseph's model of "connectivity" (1994) and Jean-Klein's of "cross-subjective self-enactment" (2000) analytically trace how forms of personhood take shape through broader structures of patriarchal and state power. Similarly, I would argue that kinship dyads, in contexts of disability, serve as key conduits through which individuals cultivate their relationships with God, which is part of their self-cultivation as moral subjects. Imm Iyad, a volunteer at the Society, explained to me that when the doctors' confirmed her son's Down Syndrome:

> I didn't depend on other people that they would lighten my burden. I worked on myself. I have conviction (*qanāʿa*). If someone has any problem or disaster, if he

himself from his heart is not accepting and convicted... *Alḥamdulillah* this is something from God. Everyone talks, but I have conviction. I worked on myself - *du'a* (prayer), closeness to God. I became closer to God. I felt that was a test and a lesson for me. I became closer to God, *alḥamdulillah*.

Imm Iyad stressed the active, ongoing, and varied kinds of work that adapting to Iyad's Down Syndrome required of her. Prayer, deciding to continue as a teacher (rather than leave her job as she initially intended), and becoming an active member of the Society all represented different avenues for this work. The labor, care, and moral stakes at hand were never just about Iyad. Rather, Imm Iyad brought these life events into her own relationship with God and her ongoing project of moral self-development. She became closer to God as a result of this work.

It would not be accurate, however, to present submission as a distinctively "Islamic" practice in *contrast* to the possibilities afforded by acceptance. Doing so would miss how "religious beliefs and timeless theological truths about God's purpose in creating human life gain new meanings when they are uttered in social and political-economic contexts that constrain, define, and enable possibilities of how that human life is lived" (Hamdy 2012, 247). For my interlocutors, basic assumptions about God, creation, and the nature of humanity frame their responses to diagnoses of disability and the work they undertake to create acceptance in themselves and others. Whether from a teacher at the Society, a mother who volunteers and spends time together there, or an activist with a higher degree from the United Kingdom, I constantly encountered the assertion that disability was ultimately God's will (*irādat Allah*).[97] This timeless truth frames how families assess and deploy acceptance in the context of their own familial and communal circumstances.

The distinctiveness of submission emerges as both a process and product of disengaging

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[97] This did not preclude robust discussions about developing public health and education projects to minimize rates of preventable disabilities (such as those caused by malnutrition, poor maternal health care, and consanguineous marriage).

with classed-based identity politics and practices of acceptance in favor of kin-oriented forms of normalization that are expressed through a distinctly Islamic idiom. The latter requires far fewer modes of consumption. Maha's family very rarely participates in Jordan's formal disability services sector, yet Maha's life is full of play, attention, and care from her parents, siblings, cousins, aunt and uncles, and grandparents. Maha's day-to-day routine involves more social interaction than many of the children I encountered at the Society, whose mothers dutifully showed up for weekly early intervention sessions and progress checks. When Imm Maha could manage to attend lessons or appointments, the specialists involved in her care marveled at Maha's clear ability to thrive, especially in terms of her speech development. At the same time, the potential for long-term negative effects from the lack of consistent early intervention services may cause greater challenges for Maha and her family in the future.[98]

IV. *Being-with* disability as a collective project

Processes and practices of state institutionalization that unfolded during the 19th and 20th centuries have intimately shaped the history of disability in many parts of the developed world. In most cases, powerful eugenics movements agitated and provided key support for institutionalization initiatives, reflecting the mutual interests and concerns of lawyers, doctors, politicians, and majority opinion (Asch 2001; Carey 2003; Carlson 2001; Phillips 2011). The Jordanian state, however, possesses neither the longevity nor financial capacities to facilitate large-scale institutionalization of children or adults with intellectual disabilities.[99] Intervention

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[98] When I returned to Amman a year later, Imm Maha had enrolled Maha at an UNRWA-run special education program near their new home instead of a regular kindergarten program. She explained that this was due primarily to Maha's continued difficulty with toilet training.
[99] The role of eugenic thinking in the Arab Middle East remains somewhat of a puzzle. The topic requires further historical investigation, as well as consideration of how local categories of race and ethnicity converge and depart from those favored by eugenics movements elsewhere in the world. Work on eugenics during the Ottoman Empire and early modern Turkey remain the exceptions to this gap (Alemdaroğlu 2005; Çağlı 2016; Salgirli 2011).

into families through Arab/Muslim women, however, has long provided a means for state and non-state institutions to remake embodied social relations in the Middle East, especially through the paradigms of public health and hygiene (Boddy 2007; Fahmy 1998; Maffi 2013; Najmabadi 1991).[100] I initially approached the al-Nur Society as an example of anthropologist Paul Rabinow's concept of biosociality. "If sociobiology is culture constructed on the basis of a metaphor of nature," Rabinow writes, "then in biosociality nature will be modeled on culture understood as practice. Nature will be known and remade through technique" (Rabinow 1996, 99). Rabinow documents biosociality at work by conducting ethnography in emerging communities forged between strangers who shared genetic conditions, or even predispositions to conditions. Genetic affinities and labels of risks create new kinds of social identities, ones that can be brought into existence only through the mapping of the human genome. An organization centered on Down Syndrome would seem to fit into this model.

The work of building community

The more time I spent at the Society, the less biosociality seemed capable of capturing the intimate and emotionally intense ways that participants became entangled in each other's lives. Members' often absent desire to organize politically around disability (or Down Syndrome specifically) and make claims on the state further muddled the application of a biosocial framework.[101] Problematizing biosociality's increasingly expansive reach as an analytical paradigm, Elizabeth Roberts argues that, "the concept should not be applied to every social grouping formed around a biological identity or disease status. Biosociality involves an

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[100] Similar dynamics exist in Israel. However, significantly higher rates of prenatal screening and diagnosis, selective reproduction, and the institutionalization of persons with disabilities have resulted in a different sociology of disability that merits its own discussion (Weiss 1994, 2004).
[101] Claire Beaudevin raises similar hesitations about applying the framework of biosociality in her analysis of the Oman Hereditary Blood Disorders Association (2013).

empirically traceable reimagining of the nature of the social and the biological in the face of new

biomedical and genetic knowledge or diagnostic technologies" (2008, 81). Noting the discernible

lack of patient or identity collectives surrounding infertility in Ecuador, Roberts suggests that

"the absence of biosocial collectives has to do with the devalued nature of citizenship in Ecuador

and the retraction of the social welfare sector of the state" (2008, 83).

   While collectives such as the al-Nur Society have become a visible part of the disability

advocacy landscape in Jordan, both the fragmented and hierarchical nature of citizenship and the

privatization of social service provision significantly shape the goals and identity politics of

many local organizations. Legally speaking, political disengagement remains an official

precondition of the organizations' right to exist. When speaking at public events, or when writing

for public audiences on Facebook, parents[102] – but very rarely specialists – use kinship-oriented

plurals to convey the nature of their alliances: "God bless *our* children, and protect them"; "The

Nur families have gathered for iftar." These invocations of relatedness reveal and reflect the

importance of kinship to the Society's goals, which are not centered on creating individual

subjects-with-disabilities empowered to make claims on the state. They focus instead on the

critical importance of compelling kin to recognize and value individuals with Down Syndrome

as family members, affording them all of the rights and privileges (and obligations) that this

recognition entails.

   Rather than reimagine the social, parents connect through Down Syndrome by drawing

on widely intelligible forms of kin roles and kin-like obligations. Doing so fosters feelings of

closeness, grounded in shared experience. In turn, these sentiments afford families the license to

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[102] Some parents (or other relatives) become known "personalities," organizing events, producing Youtube videos, and facilitating dialogues either on their personal Facebook pages or on public group pages. I distinguish these kinds of public figures from experts - medical doctors, psychologists, special educators, child development specialists, human rights advocates, and disability activists – who rarely invoke this possessive and kin-based language.

criticize, ask, intervene, compel, and of course, clash with each other. Often, tensions that

emerged between the Society members had to do with the very question of what it means to be

part of a collective that is ostensibly not defined in terms of kin. In her research with African

American families who have children with chronic and life-threatening illnesses in Los Angeles,

Cheryl Mattingly offers her own alternative to biosociality, writing that:

> Parents' ability to respond to the call or needs of their vulnerable children, and to
> create a social world in which their children can be better cared for, become
> primary moral projects… Furthermore, these are social moral projects that change
> shape over time, requiring the development of *communities of care*. (2014, 5)

This idea of a moral project geared toward building communities of care more closely captures

the family-like, intimate, and ethically charged engagements that unfold between Society

members.

"*That's the Problem with Arab Women!*"

Imm Fadi is a former employee in Jordan's booming tourism sector, and she lives in an

affluent neighborhood of western Amman with her husband and their 20-year-old son Fadi, the

youngest of three children. One day, while ostensibly at the Society to pick up Amer after youth

club, she lingered to chat with Imm Adil and her oldest daughter Lamia, who often accompanied

her mother and Adil to his training sessions. Imm Adil was frustrated with Adil's continued lack

of speech and what she perceived as a general failure to progress since beginning early

intervention classes and speech therapy. Drawing on her own experiences, Imm Fadi told Imm

Adil that when she needed a break from Fadi, she asked her husband to take over. "I get out of

the house and head to Mecca Mall, buy a coffee and a *croissant* from Cafe Paul, and sit and

watch the people go by. To clear my head, I mean. All mothers need alone time," she insisted. "And this is a problem with Arab women![103] They don't take care of themselves!"

Imm Adil nodded and laughed with a smile on her face but countered quite matter-of-factly that such a scenario would be impossible for her. "I have all my children to take care of! Plus, my husband would never accept this." Imm Fadi responded in an admonishing tone. "You must marry someone who has confidence in you! There has to be confidence between you two!" Im Adnan objected to the implications of this statement for her own marriage. "There is confidence (*thiqa*)! But his mentality (*'aqlu*) is simply different," she shrugged. "He didn't even want Lamia to attend university because it is coed!" These easy transitions between discussions of child development, marital relations, and self-care offer just one example of how Down Syndrome takes shape neither as a discrete category nor a specific sociopolitical identity. It participates in and is shaped by ongoing conversations about what it means to be a modern woman and a good mother.

Not in front of other people!

During World Down Syndrome Day 2015, a conflict emerged that offers insights into the fraught and messy interpersonal relationships fostered by al-Nur Society and other collectives like it. While brief, this moment reveals the complex interplay of intimacy and estrangement that emerges between women linked through their children with Down Syndrome. Whenever I attended conferences on disability in Jordan, the question-and-answer sessions, usually described as "dialogue sessions" (*jalsāt hiwāriyya*), proved raucous affairs. They culminated in frustrated

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[103] I was unclear how Im Fadi positioned herself in relation to this statement. As a member of Jordan's Circassian minority, she may have been subtly referencing the cultural distinctions between Arabs and Circassians that members of the latter community often mentioned to me. The Circassian families I met tended to attribute to their Arab friends and neighbors more orthodox religious commitments and social conservatism, which they often describes as constraining.

parents screaming, sometimes at the speakers, sometimes at each other, and other times at everyone, or no one in particular. Imm Hana, an active volunteer in the society, served as an unofficial moderator for one such event. During a transition between panels of speakers, she began a public rebuke of sorts, which she directed toward the dwindling crowd that remained to attend the day's final session. Imm Hana rhetorically asked the audience members why people with Down Syndrome continued to face so many obstacles and forms of social exclusion. Then she provided her own answer: "It's because families don't have commitment." She continued by making a distinction that speaks to the tension between a biosocial identity of Down Syndrome, as imagined in a liberal enactment of citizenship-based disability rights, and the kinship-oriented realities of Down Syndrome in Jordan. "You only advocate for your *own* children and not for the rights of children with Down Syndrome."

At one point during this soliloquy, which vacillated between an impassioned rallying cry and an uncomfortable invective, Imm Munir called out from the crowd and began to argue with Imm Hana. She challenged the latter's narrative of unmotivated families. Imm Hana then shot back that Imm Munir had missed the most recent meetings at the Society and was therefore not in place to comment on families' relative lack of commitment. "Your problem is that you don't follow up on anything!" This entire exchange unfolded in front of the assembly room. Imm Munir fell silent at Imm Hana's accusation. After a few minutes, she got up and exited the room, her eldest daughter Shuruq trailing behind her and staring at the floor. Very shortly after, a few other women also exited the room. Feeling awkward about the general atmosphere and exhausted from trying to follow the multiple back-and-forth conversations happening simultaneously, I decided to follow them.

Outside, I found Imm Munir visibly agitated, gesticulating widely with the red sleeves of her *jilbāb* angrily flapping through the air. Imm Iyad, who also happened to be standing outside taking a break, joined the commotion. "I couldn't attend that meeting because Munir was in the hospital! In the hospital! He gets sick all the time! I had to be with him, and this puts limits on my time!" Imm Munir shouted. One of Imm Munir's friends, trying to soothe and justify her indignation at the same time, reminded Imm Munir that she "should not show our internal divisions to these people," meaning other audience members. Imm Iyad agreed, reinforcing this point. "These discussions shouldn't occur in front of people (ʿadam al-nās), *yā* Imm Munir!" After each counterpoint, Imm Munir repeated somewhat tangentially and with great emotion that she couldn't attend most things because Munir was always in and out of the hospital.

In many ways, this scenario played out like a family conflict. Imm Iyad and the other women surrounding Imm Munir admonished her for engaging in a public argument and offering strangers fodder for gossip (*kilām al-nās*; lit. people's talk). These kinds of rebukes are classically associated with fears that family members articulate to one another out of concern for their individual and collective reputations. Imm Hana criticized families for continuing to advocate for their children *as such*, rather than advocating for their children as children-with-Down-Syndrome. The social, among this community, is still comprised of kinship-based relationships and identities, above and beyond other biomedical or biosocial categories. Imm Iyad's agitation reflects continuing uncertainties about the demands that women can make on each other as advocates, especially in light of the very real demands of childcare they constantly face and the grinding exhaustion that accompanies their attempts to be good mothers. During a brief return visit to Amman in 2016 I learned that Imm Munir no longer brought Munir to the

society. Judging from a Facebook post, I surmised that she has since enrolled Munir in a full-time, private special education center.

Starting from somewhere:

At one point in my fieldwork, an American NGO worker contacted the Society with the hopes of coordinating a workshop in a rural village located between Amman and Kerak. I initially assumed Imm Zahra would be eager to accept, but she expressed major reservations. What was the point, she asked me, if families themselves were not willing to do the work necessary to improve their children's lives? I was not so certain, offering a response that amounted to something along the lines of, "You have to start somewhere… Don't you?" Imm Zahra disagreed. The fact that this invitation came from an American volunteer (Who was she and who did she work with?) rather than a parent did not bode well. She located the seeds of change in the family and with individuals in the context of their family roles. You do not have to start from *somewhere*; you have to start somewhere specific – with the family, and especially the mother.

How then, I wondered, did Imm Zahra account for this internal spark? This question was one in a series of chicken-and-egg problems that families, teachers, and advocates involved in Jordan's disability worlds debate at length. How does cultural change occur? What are the main units in this process? How does it spread? The first time I met Imm Zahra, she told me about the traumatic experience of receiving Zahra's diagnosis. The doctors' insisted that Zahra would likely die. Zahra experienced ongoing heart complications during her early childhood. And, Imm Zahra experienced overwhelming anxiety in trying to figure the kind of child that Zahra, with Down Syndrome, would become (a very funny and very stubborn child, as it turned out). I asked Imm Zahra *why* she decided to fight her doctors, family, and friends and commit herself to

creating change, although perhaps what I really wanted to know was in fact *how* she did this. She responded matter-of-factly, "Because I believed in the rights of my child. God gives us chances. Why would I take them away from her?"

Imm Zahra's response in no way minimized her commitment to Zahra, but she anchored this commitment in a third relationship, her relationship with God. Her recognition of God's sovereignty and Zahra's rights compelled her to action. Amira Mittermaier describes a similar positionality among youth volunteers in urban Cairo who do not describe their work through the paradigm civic engagement. Instead, they "embed volunteering (*tatawwuʿ*) within a spiritual economy that disrupts the affective underpinnings of altruism … [and] evades compassion" (2014, 519). Within this spiritual economy, volunteers' relationships with and duty to God emerge as paramount. They ground their engagement with social inequality in a commitment to doing good deeds for God – and the desire to gain rewards. Imm Zahra's activism and tireless efforts to mobilize those around her originate – in part – from an understanding that she owes something to God. If she did not advocate for Zahra, she would be guilty of taking something away that she does not have the right to take – chances. Kinship and religion are both part of the social in Jordan, and it is through these domains, in the form of collectives that draw from both, that families are creating new disability worlds.

V. Acceptance?

Parents orient themselves towards their disabled child in ways that are flexible, dynamic, and changed over time. They involve situated and contextually forged relationships of distinction and difference, the social markers that constitute moral personhood (Kittay 2005). Imm Zahra is, in many ways, a paragon of acceptance. She works constantly not only to advocate from the familiar platforms of human and disability rights but also to promote commitments viewed as

radical by many who know her. Disability and Down Syndrome remain new, unsettled terms, and they are only just beginning to provide substance for alliances, coalition building, and more basic forms of comprehensive care. Imm Zahra, however, often challenges fellow parents and advocates to think of Down Syndrome not as a disability at all, framing it instead as a learning delay that becomes disabling through the lack of adequate support systems in place. This claim is often met with scorn and concern by professionals in the special education sector but also by other parents. "Imm Zahra does not accept that Zahra has a disability," Imm Fadi opined one afternoon while we sat together in the Society's reception room and chatted about recent goings-on in her life. "Moms come for hope, and they need hope, but we have to be honest, too."

Yet, one day, Imm Zahra offered a more nuanced glimpse into her own orientation toward her daughter and how life has changed after having a child with Down Syndrome.

> I love Zahra, and my role as a mother is to try and help her to the best of her ability. But I'm exhausted. The challenges will not end. I can never let her walk behind me. I worry about her burning herself. About her spilling something. About her being alone.

Imm Zahra described herself as exhausted (*taʿbaneh*), and she cannot envision a future free from this exhaustion because Zahra will always have Down Syndrome. Mattingly writes that, "In the face of the suffering and challenges of their children, parents often find themselves propelled in a quest to imagine a new sort of life for themselves or to become different kinds of persons. They are propelled into a new, often unexpected and unwanted project of becoming" (2014, 5). The meaning of *taʿbaneh* is closer to that of illness or being worn down than a mere lack of energy or sleepiness; it connotes a state of damaged wellbeing. Given her anemia, low blood pressure, constant toothaches, and reliance on chewing ice cubes and coffee beans, Imm Zahra's body revealed the toll of this ongoing project of becoming in ways that were impossible to hide.

This chapter has examined how new practices and attitudes toward childhood disability

have a variety of consequences for women as mothers, wives, and caregivers. Rather than focus only on moral subjectivity or on the identity politics that frame women's experiences as mothers of children with disabilities, I show how these are interrelated by using the concept of moral orientation. The orientation toward acceptance captures some of the shifting and changing ways that women inhabit – or attempt to inhabit – the subject position of a "good" mother. The figure of the good mother coalesces around forms of access, consumption, and engagement heavily mediated by class and social capital. A gendered cultural politics informs the construction of acceptance as the modern orientation toward disability. Acceptance is most clearly and explicitly performed through the visible consumption of therapeutic services, although these are recuperated back into the frameworks of family and piety.

Nadia has both intellectual and physical disabilities, and she can no longer walk. The first time I visited Nadia and her mother at their home in East Amman, she took one look at me and put her head down, covering her face with her hands. Her brother informed me that Nadia would respond to my presence like this; it was a tic she had picked up over the years, although they were not certain from where. He gently admonished his sister, saying, "'*ayb ya māmā*.[104] Several hours of my visit had passed before Nadia would cease to shield her face from my eyes. While Nadia did own a wheelchair, she was dependent on her mother, her brothers, or her father to carry her up and down the stairs of their second floor apartment. Nadia's father lived with his second wife and their three sons in a different part of Amman. He visited Nadia frequently, however, because Imm Nadia and Nadia live on the floor above several of his kin. Imm Nadia did not find this arrangement agreeable, but she had no means to create an alternative situation for herself. No longer capable of lifting her daughter, Imm Nadia would show up at social and

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[104] '*Ayb* in this case functioned as a gentle form of chastisement that roughly translates to "this is incorrect/impolite"; children in Jordan are often addressed as *māmā* or *bābā*.

charitable events ostensibly being held for her daughter – summer parties, special performances, Ramadan *iftars* – alone. The first time I met Nadia was at a support group for mothers of intellectually disabled adults living in East Amman. While almost all of the other intellectually disabled adults attended a daily crafts workshop, Nadia stayed at home. The community organization's building was wheelchair-accessible to a limited degree, but the workshop space was not.

As we sat discussing their difficult situation, Imm Nadia stressed to me that she did not want Nadia to live a secluded life. "There are people who are embarrassed by their children and hide them in the house. I'm not embarrassed. Whenever people come to visit, Nadia is always present. She greets people, she eats with them, and she sits with them!" When Nadia aged out of the day program she attended as a teenager, both she and her mother became increasingly restricted to their home. Nadia traveled only so far as the roof deck hovering over her relatives living on the floor below, and her mother rarely went much farther. Imm Nadia insisted that she was not, nor had she ever been, embarrassed by her daughter. She accepted Nadia as she was. Yet they lived their lives largely confined indoors, unable to participate in or consume the services and activities available within an emerging disability world that remained quite literally out of their reach. Acceptance in the absence of accessibility, under the wider circumstances of vulnerability that constrained Nadia and her mother, left them both stranded.

Chapter 4. Inclusion

I. The right of every child

The previous chapters focus on the earliest phases of a child's life, tracing how family

members and kinship networks shape moral frameworks of diagnosis and practices of early

childhood development, bringing disability into being in the process. Childhood constitutes a

specific life stage, involving embodied, social, and cultural expectations that vary across time

and space (Stephens 1995). As babies age into childhood, non-domestic spaces and non-kin

relations gain importance in their lives. Jordanians today widely equate childhood with

participation in formal education. When interacting with children, adults and teenagers will often

ask, "and in what grade are you?" as the natural follow-up to "how old are you?" Across class

lines, people accept and enthusiastically pursue education as desirable and necessary, though as

anthropologist Fida Adely has shown, their reasons for doing so remain diverse and complex

(2004, 2012). Education has also become a focal point for Jordan's disability rights activists and

policy makers, where the concept of inclusion (*damaj*) dominates local and national organizing

efforts. An expansive network of development organizations and both local and transnational

NGOs promote inclusive education as the key to building an inclusive Jordanian society. In fact,

during my fieldwork I rarely encountered a distinction between inclusion and inclusive

education. Both were described as *damaj*.[105]

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[105] An alternate translation relies on the term *shāmil* as an adjective for inclusive, but *damaj*, in its noun form, remained far more common, at least in my fieldwork.

During the spring of 2014, I attended an event held as part of an advocacy campaign promoting inclusive education across Jordan. During this time, I was living with Dunia, an older woman active in Jordan's advocacy and volunteer communities. A car accident almost three decades prior left Dunia paralyzed from the waist down at the end of her late twenties. In the aftermath of the crash, her then newly-established business career ended and her young marriage dissolved. The months I spent with Dunia gave me perspective on the realities of living as a physically disabled woman in Jordan. We often passed the time watching Indian soap operas dubbed into Arabic – her favorite followed a family raising an autistic child and fighting societal stigma – or American movies. The plot lines of Forrest Gump and the Dark Knight became jumping off points for discussions about political freedom, censorship, or the rise of religious extremism. Dunia completed an online Master's degree in special education, as well as a certification course in early education. Her mobility impairments, health issues, and perhaps most significantly, her age, limited Dunia's ability to find paid work, but she was regularly invited to various events in and around central Jordan.

This particular event was held at a public school in the city of Madaba. It was one stop in a series of talks organized by the al-Nur Society across several of Jordan's governorates. The day's program involved lectures addressing inclusive education from the vantage points of human rights, citizenship, and pedagogy. A group of mostly-female volunteers from a local charity also coordinated art activities, face painting, and games to entertain the young children in attendance. As Dunia and I approached the school's only entrance, she groaned. A series of uneven, cement steps stood between us and the door. Ultimately, with the help of three young men recruited to lift Dunia and her chair over the lip of each edge, she made it into the building. This happened regularly when Dunia left the house, and she had developed a steely disposition to

manage such indignities. We entered the auditorium, which was filled mostly with women and included several mothers I had met at other events and workshops, as well as teachers and staff from a well-known special education center located on the outskirts of town. A group of men lingered by the door, looking somewhat uncertain as to the permissibility of their presence. "Of course you can come in," exclaimed one of the organizers. Sensing their hesitancy, she ushered them out of the doorway and into empty rows of chairs.

The president of the local disability advocacy group spoke first. She began her welcome speech by asserting that, "inclusive education serves all children. It is their right and is guaranteed by the constitution." I couldn't help but look at Dunia, who had struggled to even make it through the door of the school. Her face was impassive. This was not the only time I attended an inaccessible event promoting inclusive education. Over a year later, while participating in various events held in celebration of World Down Syndrome day, I attended a series of talks held at a government building in downtown Amman. While functional ramps had been installed at the main entrance, the stage in the conference hall lacked the same accommodations. The physically impaired speaker scheduled to open the conference leaned on his cane while surveying the stairs up to the podium. He looked at me and shrugged. "It's always like this."

II. Access and inclusion

What does it mean to advocate for inclusion in the glaring absence of accessible infrastructure? What can the inclusive education's dominance on the agendas of formal activist, governmental, and nongovernmental institutions tell us about the "performance of human rights"

(Slyomovics 2005) in Jordan?[106] Writing about accessibility in Petrozavodsk, Russia, Cassandra Hartblay describes a popular meme that circulated among her interlocutors – adults with mobility and speech impairments – over the course of her fieldwork. The meme featured various examples of nameless, placeless, inaccessible wheelchair ramps marked as distinctly Russian by architectural styles and Cyrillic signage. Hartblay also provides her own images, one of a ramp impossibly transected by a handrail, and a second with a crumbling lip and awkward position in relation to the door, to provide further illustration. The presence of these structures raises the obvious question: "What is accessible design if it doesn't provide access to anything for the intended user" (Hartblay 2017, 2)? Access, writes Hartblay, refers simultaneously to "a global discourse, a design practice with specific local implications, and a normative concept that people with disabilities use to describe the nexus of public infrastructure, mobility, and social participation in their daily lives" (2017, 2). Inclusive education also refers to a global discourse and a normative concept. Inclusive schools, where they successfully operate, both draw on and create different kinds of accessibilities (Friedner and Osborne 2015). In my own fieldwork, families understand inclusiveness as a quality and an abstract standard. It cannot be guaranteed or even observed through material, spatial, and technological interventions, which ultimately both rely on and reproduce the underlying social politics of design. Inclusiveness remains elusive. Both supporters and critics in Jordan frame inclusion as a fundamentally moral and problematically immaterial ideology.

In 2014, Jordan's Higher Council for the Affairs of People with Disabilities (HCD) launched a campaign entitled "My Place is Among You" (*Makāni Baynkūm*). The multimedia initiative included press releases in local papers, advertisements on radio programs and TV

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[106] Although I take this phrase from Slyomovics, my own use seeks to convey a slightly more sarcastic and theatrical use of the term.

series, posters, and the production of at least one large banner – hung on the overpass between west Amman's Shmeisani and 3rd circles. A promotional video shot for the campaign and uploaded to the Ammancity Youtube channel opens with the ringing of a school bell, while the camera follows young students filing into their classrooms. The picture then cuts to a female student sitting in class and fending off another girl's attempts to grab her hearing aid. "Cut it out (*khalās*)," she cries. A third classmate intervenes, wagging her finger to chastise their disrespectful peer. In the next frame, a young boy struggles after someone knocks his walking aids out of reach during the rush to lunch. A classmate hurries over, smiles, and hands the assistive devices back to him. The voiceover intervenes: "Take care of your peers with disabilities. It reflects on your morals and compassion. Their place is among you." The two disabled students featured in the story then assert in unison, "My place is among you (*makānī baynkūm*)!"

The description underneath the video describes the goal of the *Makānī Baynkūm* campaign as, "promoting community awareness on the importance of the right of inclusive education" (Ammancitytube 2014). This emphasis on awareness aligns with the analytical framework I have described in previous chapters, whereby families, educators, and activists in Jordan agree that cultural ignorance and societal backwardness cause the intense stigma and marginalization of disabled people and their families. Rights activists, transnational organizations like the United Nations, specialists educated in western institutions, and some advocates vocally champion inclusive education as critical for developing Jordan's families and Jordanian society. Yet many parents and teachers, including some who fought – and paid dearly – for their children to pursue inclusive educational opportunities, view these claims warily. This chapter attempts to work through this wariness. I place the arguments marshaled for and against

inclusive education in the context of broader debates about education in Jordan, which link schooling to contested ideologies of progress, modernity, and development (Adely 2009; see Luykx 1999 for a similar ethnographic study in Bolivia).

The ethnography in this chapter traces how parents, teachers, experts, and activists deploy inclusive education to make broader claims about schooling, education, identity, and society. It does not feature the experiences of disabled children in either inclusive schools or special education centers. The sobering reality that so few disabled children in Jordan actually access schooling of any kind influenced my decision not to conduct fieldwork in an educational setting. World Bank estimates place the enrollment rate for school-aged disabled children in the Middle East and North Africa at approximately 5% (cited in Peters 2009). More recent figures, based on Jordan's 2015 census, suggest the situation is slightly less terrible: approximately 21% of disabled children are enrolled in educational programming of *any* kind (Madhar 2017; Al-Nimri 2017). The disparity between disabled and nondisabled children's schooling in Jordan is quite shocking, given that the country's overall gross primary school enrollment rate is approximately 98%.[107]

Consistent access to educational institutions remains exceptional for most intellectually disabled children in Jordan. I use the term institution intentionally here, as separate special education centers remain the primary schooling option available to disabled children in Jordan. Both for-profit centers (*marākez, s. markez*) and non-profit foundations and charities (*mu'assasāt and jamaʿiyyāt*) fall under the domain of the Ministry of Social Development rather than the Ministry of Education, a jurisdictional gap that can cause problems for students and families

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[107] Gross primary refers to the total enrollment in a specific level of education, regardless of age, expressed as a percentage of the official school-age population corresponding to the same level of education in a given school-year (FHI360 2014). Two percent of Jordanian youth do not complete primary school (FHI360 2014).

(Alodat, Almakanin, and Zumberg 2014).[108] In this fractured system, most families experiment

with different possible educational trajectories. Over time, they mix enrollment at private or

public centers with attempts at mainstream schooling, and most also experience periods when

their school-aged disabled children receive no formal educational programming whatsoever.

These inconsistencies of access and exposure, needless to say, disrupt children's learning

processes and compound existing learning difficulties. A pernicious cycle emerges in which the

myriad structural barriers to education reinforce the pervasive stereotype that intellectually

disabled children "can't learn."

    Many advocates of inclusive education describe parents who do not support inclusive

education as in denial and lacking a progressive, modern stance on disability rights. They draw

on the discourses of social critique I have outlined in previous chapters and redeploy them to

label critics of inclusive education as guilty of the "backwardness," attributed to culture (*thaqāfa*)

and ignorance (*jahl*)*.* The ethnographic moments that follow, however, demonstrate the

multidimensional and situated qualities of parents' skepticism toward or rejection of inclusive

education paradigms. Parents who decline to support or pursue inclusive education do not

believe their children are any less deserving of education, friendship, and growth outside the

home than nondisabled children are. Quite the opposite, in fact, is true. Many parents end up

drawing a distinction, however, between education and schooling. They consider education

necessary for advancement in today's world and for personal development. They also articulate

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[108] According to Al-Khatib and Al-Khatib (2008), as of 2007 the Ministry of Social Development supervised 69 centers that provided educational services for approximately 2,700 students classified as having mild to severe intellectual disabilities (Directorate of Disability Affairs, 2007). They estimated that this number accounted for "5% of the target population" in Jordan based on an international prevalence rate of 2% (2008, 111). The authors do not, however, conclude that the other 95% of children with intellectual disabilities are necessarily out of school. Rather, they argue, at least some portion of this population remains "hidden" in mainstream education by a lack of diagnosis (2008, 111). This issue tends not to be relevant in case of children with Down Syndrome, who display phenotypic features that often mark them as "intellectually disabled" regardless of the degree to which their own personal learning challenges fall on a spectrum of disability.

serious doubts about whether any schools in Jordan could actually provide a quality education for their children. This is especially the case given the precarity steadily encroaching on daily life and eroding possibilities for stability, let alone upward mobility.[109] Parents describe schools as spaces of violence, risk, and neglect, and they wonder what kinds of parents would choose to ignore these realities for the sake of ideals.

Dominant rights discourses in Jordan present education as a universal and abstract path to liberal enlightenment (Abu-Rabia-Queder 2008). They depict inclusivity as a straightforward process and moral good, and they rely on a nationalist-developmentalist framework that positions schools as critical partners for promoting citizen identities and developing civic commitments. Parents, in turn, view education as critical for individual and familial survival. Inclusive schooling, from their perspective, will not necessarily guarantee effective education, thus diminishing its value. Parents are well are that inclusion, in the holistic vision presented by advocates - requires changes far deeper than the spatial and material configurations in Jordan's schools. How can they expect teachers and students – strangers – to create inclusive environments when they cannot even count on their own families to do so? The ongoing privatization of education in Jordan only exacerbates parents' skepticism and adds another layer of complexity to everyday practices of inclusion in the context of neoliberal capitalism.

In the following sections, I provide a brief overview of inclusive education philosophy and scholarship to contextualize the ideas that families in Jordan encountered through formal disability right channels. I then situate these ideas in relation to more critical voices of

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[109] My interlocutors pointed to multiple factors in articulating this sense of precarity, among them regional instability, the Syrian civil war, unemployment, rising costs of living, and the recent devastating Israeli offensive against Gaza (Operation Protective Edge). The latest refugee crisis has placed immense burdens on Jordan's school system. During the time of my fieldwork (2013-2015), many schools ran double shifts or far exceeded their stated classroom capacities in an attempt to provide Syrian children with education.

researchers conducting work on disability in the Global South, and I situate their arguments in relation to anthropological and area studies perspectives on education and schools. I then turn to a collection of ethnographic moments that provide different examples of how and why parents deftly critique an abstract ideal of "inclusion" while also continuing to reject and fight the existing discrimination against their children.

III. Inclusive education: An overview

What does inclusive education look like, and who is it for? "The term has become most closely associated with the global movement to educate all students with disabilities in general education classrooms" (Barton 1997, 45). More broadly, however, "the basic premise… is that schools are about belonging, nurturing, and educating all children and youth, regardless of their differences in culture, gender, language, ability, class, and ethnicity" (Artiles and Kozleski 2007, 357). A truly inclusive educational system would render redundant the very qualifier of "inclusive" and eliminate the special education industry. Inclusive education theorists share this fundamental commitment to the elimination of special education.

> It is not primarily a question of the quality or adequacy of what is offered in a special school. Even a superbly well organized special school offering the highest quality curriculum and educational input to its children has no right to exist if that same education can be provided in a mainstream school. [Dessent (1987:97)], quoted in Barton (1997, 235).

Despite the clarity and consistency of this position, critiques have emerged regarding the (geo)politics of theorizing inclusive education from the standpoint of universalizing ideals rather than the concrete historical and social contexts that shape systems of schooling and ideologies of education. Inclusive education, Slee acknowledges, actually entails a fundamental "oxymoron."

> Schools were never really meant for everyone… As an historical artifact, schools were established for a minority of privileged students… The relatively recent

advent of mass compulsory schooling merely elaborated the processes of social stratification and exclusion through a range of dividing practices in the school (Slee 2001, 172; See also Khan 2012).

The institution of inclusive education ultimately aspires to radically transform schools and rewrite their very purpose.

While Slee recognizes schools as an "historical artifact," he nevertheless writes with this artifact squarely located in the United Kingdom. The contributors to a special issue of *Childhood* entitled "Education, childhood and disability in countries of the South– Re-positioning the debates," [110] problematize the clear hegemony of first-world assumptions that dominates scholarship on inclusive education. They vocalize a shared concern with "the naïve transfer of toolkits and indexes, developed by Northern-based academics, funded by international organizations, who have little experience of realities of schools" beyond the industrialized democratic nations that comprise the Global North (Singal and Muthukrishna 2014, 298). Editors Nidhi Singal and Nithi Muthukrishna, point to the strikingly consistent representations of "disabled children's childhood and education in the global South" through reductionist paradigms of neglect, oppression, and abuse (2014, 293). These paradigms, they note, call for "the liberalization and emancipation of people with disabilities in the South on the basis of the 'enlightened', 'civilizing' work of Northern scholars and agencies" (2014, 293). In keeping with my observations on the work that inclusion does in Jordan, I would add to Singal and Muthukrishna's description only that local elites play a significant role as mediators of such discourses.

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[110] Regarding their choice of terminology, Singal and Mutukrishna write that, "Over the years 'North/South' has become shorthand for highlighting the complex set of inequalities and dependencies between countries divided not by geographical boundaries, but by fundamental economic inequality. Significantly, most countries of the South also share the legacy of having been conquered or controlled by modern imperial powers, resulting in a continued legacy of dependency, poverty and exploitation… the core of the North comprises countries which were the imperial powers and now continue to be the major centers of global capitalism" (2014, 294)

Anthropologists of education have pursued wide-ranging engagements with inclusion, raising questions of power and privilege in and between classrooms and non-school spaces. In fact, disability and special education remain less central in the (American) anthropology of education than issues of race, ethnicity, language, and class (for exceptions see McDermott and Varenne 1995; Mehan, Hertweck, and Meihls 1986; Rogers 2002; Smardon 2008). In the anthropology of education, inclusion operates more commonly as an analytic than as a subject of investigation in and of itself. Studies of inclusion in the field of education, however, frequently do focus on disability, special, and inclusive education. They also emphasize the use of "ethnographic case studies" and "ethnographic methods," although they mobilize the term somewhat differently. Ethnographic, in this deployment, reflects an emphasis on intensive qualitative fieldwork within school settings more so than gesturing to an analytical relationship between fieldwork and theorizing. In other words, inclusion itself does not emerge as an ethnographic focus but is instead defined at the outset and then measured through qualitative participant observation and interviewing.

If educational studies and anthropology arguably marshal ethnography in distinct ways, studies of schooling in the Arab world tend to fall into one of two additional camps: broad policy evaluation and/or quantitative analyses, with "number toting often reinforcing a sense of 'deficit'" (Mazawi and Sultana 2010, 5). Throughout the region, reformers at different historical moments and of various ideological convictions have seized upon education and schooling as critical means for pursuing their contested visions of modernization and development, especially in relation to reshaping gender norms and relations between women and men (Najmabadi 1998; Shakry 1998). Despite the abstract preoccupation with education, observes Fida Adely, and especially in relation to gender and development, "surprisingly little of the scholarship in the

region has paid attention to schools as important institutions in the lives of girls and/or the meaning of education for young women *and* their families" (2012, 14). Ethnographic research on education in the region continues to expand, however, and is guided by a focus on analyzing the relationships between schooling, the state, and religious revitalization movements (Eickelman 1992; Hefner and Zaman 2007; Herrera and Torres 2006; Starrett 1998; see Adely and Starrett 2011 for a comprehensive overview).

Adely's 2012 monograph, *Gendered Paradoxes: Educating Jordanian Women in Nation, Faith, and Progress* (2012), draws on fieldwork conducted primarily at a girl's high school in northern Jordan. Her research explores how schools provide a critical space for young women, their teachers, and their families to negotiate the meanings and purpose of education. Education in Jordan plays an increasingly powerful role in defining the parameters of successful Jordanian womanhood. While schools provide students and teachers quotidian spaces to interact and negotiate divergent constructions of Jordanian identity and gendered morality, education also represents "an idea, a discursive project of global development" (Adely 2012, 15). Adely addresses, in passing, the various forms of inequality reproduced through differential access to private versus public schooling, as well as the tiered educational system that assigns lower performing students to a vocational track after 10th grade. Yet as my own research in Jordan shows, some students fail even to reach the high school level (a point she also notes). Those with unaddressed learning disabilities and perceptible intellectual disabilities, whether formally diagnosed or informally recognized, encounter structural barriers that prevent them from accessing the Jordanian educational system at all, let alone successfully graduating.

Like education more generally, inclusive education intersects with discursive projects of human and disability rights, and ultimately the practices and ideologies of subjectivity and

citizenship that these projects encompass. The Jordanian constitution guarantees the right to free

public education from grades 1-12, while Law No. 33 on the Welfare of Disabled Persons,

passed in 1993, introduced specific legislation guaranteeing Jordanians with disabilities the right

to education. Law No. 31 on the Rights of Persons with Disabilities, informed by Jordan's

participation in the United Nations Convention on the Rights of Persons with Disabilities

(CRPD), later replaced the 1993 Law.[111] In its 2007-2015 National Strategy for Persons with

Disabilities, the Higher Council for the Affairs of Persons with Disabilities (HCD)[112] repeatedly

cites a commitment to inclusive education as one of the key strategies for promoting the rights of

persons with disabilities. The document, in fact, dedicates a significant portion of text

exclusively to the topic of inclusive education (Al-Azzeh 2012, 149). This commitment aligns

with Article 24 of the CRPD, which states that, "Parties shall ensure an inclusive education

system at all levels" (2007). Inclusive education, according to the CRPD, means that, "Persons

with disabilities are not excluded from the general education system on the basis of disability,

and that children with disabilities are not excluded from free and compulsory primary education,

or from secondary education, on the basis of disability" (2007).

Though families unanimously denounce the barriers to schooling, lack of education, and

illiteracy that disproportionately affect disabled children and adults in Jordan,[113] they

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[111] Jordan signed the CRPD on March 30, 2007 and ratified the convention in the following year. While the passage of Law 31 and the ratification of the CRPD occurred almost simultaneously, Jordan was also involved in many stages of drafting and negotiating CRPD content between 2002-2006, presumably shaping the drafting of the domestic law (Al Azzeh 2012, 18).

[112] The HCD was created in 2007 after the passage of Law No. 31 on the Rights of Persons with Disabilities. It oversees and coordinates relevant policies and programs affecting persons with disabilities and ensures the implementation of Law 31 to the fullest extent. In practice, most of my interlocutors believed it functions most concretely to provide financial support to families who could not afford quality special education and therapeutic programs and to offset resource room tuitions in mainstream schooling programs. While the HCD was charged with overseeing the implementation of Law 31, its actual powers to compel various ministries to action remained unclear at the time of my fieldwork, limiting its ability to effect change on either policy or practical levels.

[113] The literacy rate among youth and young adult populations in Jordan currently reaches 99% (FHI 360 2014). Among disabled youth (older than 15 years of age) illiteracy rates currently stand at 33% (Mahbuba 2016).

nevertheless remain ambivalent about the promises and assumptions embedded in available framings of inclusive education. My interlocutors often invoke the description *hiber 'alā wara'*, or ink on paper, to describe legal and policy instruments like Law 31 and the UNCRPD, if they are even aware of their existence. This evocative turn of phrase highlights the perceived gap between formal performances of the state's commitment to rights, which usually result in yet more ink on paper – reports, documents, agreements, initiatives – and the realities of daily injustice, inequality, and sheer infrastructural lack. Inclusive education still belongs to the deceptions and empty promises of ink and paper. According to most parents, it is class and capital that most decisively shape their children's access to formal education, but even financial resources fail to guarantee full inclusion.

IV. Paying for inclusion: The commodification of education

Over my two years of fieldwork I was able to attend events held in honor of World Down Syndrome Day (always held on March 21st to honor three copies of chromosome 21). The celebrations, which coincide with "Mother's Day" in the Middle East, offer families an opportunity to congregate in one space and interact with the representatives of the formal political and legal institutions that, on paper, affect persons with Down Syndrome. The conference portions of the day usually involve informational presentations, some sort of cultural performance featuring persons with Down Syndrome, and a social portion with entertainment activities and free lunches for all participants. Toward the end of one presentation on *damaj* (inclusion) by an expert from the Higher Council for Disabilities, a conversation between two audience members seated a few rows behind me reached the tone of an argument and caused a good amount of distraction for those within earshot. One of the disputants, a middle-aged man, grew so frustrated that he jumped up from his seat and made a dramatic exit from the auditorium,

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yelling loudly and speaking more rapidly than I could understand. I turned to the other participant in this exchange, Imm Fadi, whom I knew from the al-Nur Society, and I asked her what made this man so upset.

She told me that his son had Down Syndrome, and he had grown increasingly frustrated by the HCD representative's talk because it was completely divorced from reality on the ground *(al-arḍ al-wāqiʿ)*. He could not afford to pay private school fees for his son, so he felt that listening to a presentation on inclusion was useless, because "private school is the only way to access any sort of inclusive program." Then she shrugged. "Hey, we paid for *damaj* and it still didn't help." Imm Fadi and her husband worked for a private-sector tourism company and are now retired. They have three children, and 20-year-old Fadi is their youngest. Fadi experiences many health complications, some of which are a result of his Down Syndrome. Imm Fadi has struggled to figure out how she can best serve and advocate for her son. I had previously interviewed Imm Fadi, and much of our conversation centered on her preoccupations with the different educational systems Fadi participated in during his childhood and adolescence.

> [Fadi] went to a preschool. At the first one, people started to figure out he was Down, and they started to hide him. I told them "No. My son will not be hidden. I want people to take him and accept him." They told me they couldn't do this, so I took him to another nursery, and they accepted him directly.

Returning to the previous chapter's theme of moral orientation, Imm Fadi accepted her son, and the work of acceptance required her to relocate Fadi to a preschool that would not hide him. This work also entailed the expenditure of significant capital.

> [Then] he went to Amman Superior (a private school). It's known that they take 1 or 2% [students with] disabilities and integrate them. He stayed there for a year or two. But he didn't benefit. They just go into the class and go home. There was no training or learning *(tadrīb aw taʿlīm)*. There was no *ihtimām* (care, attention). After that he went to al-Shams Academy (another private school)… He spent 3

years in KG, and it was the same problem… They didn't know how to work with disabilities.

Imm Fadi sent her son to two different private schools to include him in regular schooling and avoid the special education system. In Jordan, while families often find public schools to be wholly unwelcoming, private schools often demonstrate more willingness to work with families – as long as they are willing to pay.

> He stayed with them until he was ten, and he would go to the resource room and take Arabic and math. And they had activities for sports, arts. But there wasn't follow-up. There was no *shadow teacher*.[114] There was a resource room with one teacher and maybe 10 students, 12 students.

Resource rooms represent Jordan's current approach to inclusion.[115] The majority of the parents and specialists I spoke with perceive them quite negatively, and for a variety of reasons supported by existing research on this semi-inclusive approach. Resource rooms offer suffer from a lack of coordination and cooperation between the resource room teacher and the general education teacher, in addition to student crowding in the resource room and inadequate teacher training[116] (Al-Khatib 2007; Amr 2011). Resource rooms, moreover, do not comply with the definition of inclusive education that Jordan adopted in its Law on the Rights of Persons with Disabilities or the definition of inclusive education provided by the CRPD (Alodat, Almakanin, and Zumberg 2014, 224).

When Fadi began resisting his school day schedule, his mother decided that her options

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[114] Italics represent Imm Fadi's use of this term in English.

[115] As of 2007 there were 511 resource rooms in public schools, serving a total of 12,300 children in grades two through six (Al-Khatib and Al-Khatib 2008, 109). While students with intellectual disabilities may be included in these rooms, they are not categorized as such. In the absence of in-school diagnostic/evaluation procedures, school staff members classify students more broadly as having "learning disabilities." I also occasionally met children with intellectual disabilities who attended *only* the resource room classes at a mainstream school via individual arrangements with school administrators and resource room teachers.

[116] These topics have received consistent attention in unpublished Arabic language dissertation and master's theses by students at Jordanians universities, many under the supervision of Dr. Jamal Al-Khatib. Other unpublished Arabic language reports are housed in the Ministry of Education.

were running out.

> He didn't want to go inside. He didn't want to go with the routine, to return to class. So, they contacted me over the phone and told me they were trying to get him inside, but they couldn't... And there was more than one complaint. So, I thought about it, and I decided, okay, let me look for a center (*markez),* a center for disabilities *markez khās li-l-iʿāqāt)…* And of course, I didn't want to pick a place where I'd have to fear for him, a place that wasn't organized or [where] the environment wasn't appropriate for him (*makān mish murratib aw biʿa mish munāsaba li-lu*). So, I found a center, and it was very put together. The teachers were very educated and understanding. And they accepted him.

Imm Fadi valued her son's education. She never assumed that Fadi's Down Syndrome negated or compromised his *right* to education. She sought different ways to realize this right, enrolling him in some of Amman's most prestigious private schools, most of which have begun experimenting with the same resource room model that the Ministry of Education is slowly implementing in public schools. In his early childhood, when Fadi's preschool teachers tried to sequester him from the other children, his mother objected, insisting that, "my son will not be hidden (*ibnī mā bitkhabbā*)." However, the quest for a school that could provide Fadi with the care (*ihtimām*) he deserved led her farther away from the mainstream.

I would like to return to the angry father sitting next to Imm Fadi who stormed out of the World Down Syndrome Day conference. From the perspective of many parents I spoke with, discourses on inclusion that refuse to engage with the broader structural realities shaping the education sector in Jordan feel infuriatingly divorced from reality. More expansive capitalist forces of inclusion and exclusion already mark schooling in Jordan as a contradictory commodity for purchase rather than a universal right. During the question-and-answer session, this much was pointed out to the HCD representative by frustrated parents who chose to stay and speak their minds. An older woman, flanked by her adult daughter with Down Syndrome and her husband, stood up and reiterated that regardless of what the law might claim, only private

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schools actually accept disabled children. While she spoke, the man sitting in front of me nodded vigorously in agreement, rubbing his fingers together to make the sign for cash. Eventually, the question-and-answer session devolved into parents shouting: "Where? Where can we put our children?! Tell us which school will take them, and we're *there*."

Amidst this collective outburst of anger, Imm Yusuf stood up and dramatically announced, "Give me a classroom, and I will teach them!" A round of applause followed her declaration. In private, however, Imm Yusuf explained that she was no longer certain inclusive education could work in Jordan, at least under the present circumstances.

> Look, at first, I wanted inclusion. I want my son to be included (*anā bidī ibnī yindamaj*), but, there have to be specific preparations for it to happen. There has to be early intervention (*al-tadakhul al-mubakkir*), and at 5 or 6 years old there should be a class for... for… *Down*. They have Down Syndrome (*humeh Down*). *Khalās*! Accept that they have Down Syndrome (*kunī mutaqabbaleh humeh Down*)! They have Down Syndrome. Afterwards, I would integrate him, even if it meant him entering school a year or two late. The important thing is that my son would have to be ready to handle it (*al-muhimm huwweh ibnī byakūn muhay'a*)."

For parents like Imm Yusuf, inclusion makes them uneasy in its liberal appeal to sameness. As she concisely put it, "accept that they have Down Syndrome." Many of my interlocutors made a distinction similar to that between equality and equity. By emphasizing his Down Syndrome, Imm Yusuf insisted that for Yusuf to succeed, he would need a system that recognizes and honors his specific needs, rather than broadly asserting he should be in a classroom with other children because he is just like every other child.

Imm Yusuf stressed the utmost importance of Yusuf's learning to read and write. Attaining these skills ultimately mattered more, from her perspective, than the kind of environment he learned them in.

> I know a mother who put her daughter into an inclusive school. After a year we ran into each other and the mother was crying. Her daughter didn't benefit at all

(*mā istafadat ay shī*). I told her, "You wronged your daughter (*intī ẓalamtīha*). The teacher can't specialize in her! She has a whole class to look after." If I'm just like, "I want my son included!" maybe I'm not doing him justice.

Here Imm Yusuf describes education as a set of skills that her friend's daughter failed to acquire in an inclusive classroom that could not meet her needs. The young girl's happiness, her social experience in the classroom, or the positive impact of her presence on nondisabled peers were not recognized as other potential benefits of her education. Like many parents, Imm Yusuf approached education first and foremost as an investment in developing concrete and ideally, marketable skills. They define the relative success or failure of their child's schooling, whether in an inclusive or special program, in very concrete and functional terms. This perspective extends to nondisabled children as well, who are encouraged to study fields that will ultimately "matter" in terms of financial security and social capital. Possessing certain kinds of knowledge and skills deeply impact what kind of person a child can or cannot become.

V. "She cannot be educated": Debating educational futures

Schooling and education levels are increasingly important components of personhood and status in Jordan. With education widely available and directly connected, in popular imagination, to prospects for employment, upward mobility, and social stability, educational failures have practical, economic, and moral consequences. Descriptions and evaluations of intellectual disability in Jordan pivot around three main diagnostic categories: mild (*basīṭa*), moderate (*muttawasaṭa*), and severe (*shadīda*). While some families encounter these classifications upon bringing their children in for evaluations at diagnosis centers run by the Ministry of Health, others receive them from teachers and special education teachers who employ a variety of methods to flag students as either eligible for resource room services or incapable of being included within mainstream classrooms (Al-Natour, AlKhamra, and Al-Smadi 2008). The social

impact of these categories extends far beyond the classroom. They affect how families and teachers evaluate a child's potential for learning and families' willingness to pursue particular educational paths. These medico-educational categories, and the work they do in building or constricting a child's imagined futures, emerged quite clearly in an encounter I observed between Reem, who works in a resource room at private school in northern Amman, and the parents of one of her students, Tamara.

In addition to teaching, Reem offers supplementary lessons for students with disabilities in her home. Families find Reem largely through word of mouth. She provides academic support, speech therapy, behavioral therapy, and occupational therapy to students of all ages, some of whom are enrolled in schools or centers, while others primarily stay at home. Her degrees are in special education, which she earned from a private university.[117] While Reem worked with students, I would chat with their mothers on the classic, low-rise couches lining the walls of the living room. We sipped coffee, or perhaps juice, and nibbled at the chocolate wafer cookies provided by Reem or her daughter Samira at the arrival of each new client. Reem brought me along to appointments with some of her clients and even arranged visits with families whose children she knew from previous posts on my behalf. On one such visit, we went to speak with Abu and Imm Tamara, who live quite close to Reem's own neighborhood (*jabal*)[118] in greater east Amman. While I introduced myself, Tamara zoomed around their apartment, excited to have guests, and her baby brother cried while his parents passed him back and forth, trying to soothe him.

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[117] Jordan's public universities, particularly the University of Jordan in Amman and Jordan University of Science and Technology in Irbid, are considered to be the country's most prestigious and academically sound institutions.
[118] Many neighborhoods in east Amman are names for the *jabal*, or hill, on which they sit.

Tamara's parents spent the first two years of her life searching for a diagnosis of their daughter, who they initially thought might have Down Syndrome. Tamara, they eventually discovered, was born with a non-inherited chromosomal condition usually caused by a partial deletion that develops in utero. This partial deletion can result in mild to moderate intellectual impairment, delays in speech and language skill, phenotypic facial features sometimes resembling those of Down Syndrome, lifelong problems with sleeping, and certain behavioral issues. Tamara was enrolled in the third grade, and she spent most of her day in the resource room, returning to the main class occasionally. As in Fadi's case, Tamara's parents experimented with different types of educational programing, but they perceived the effects of her time spent in a special education center as extremely negative. They wanted her to remain in a "regular" school supplemented by a resource room and additional lessons. Tamara's parents were keen to gather as much information as they could from Reem, and they reacted to her authority with a mixture of respect for her specialist qualifications and confusion about Reem's prognostications.

Speaking as much to me as to Imm and Abu Tamara, Reem explained that, "people with mild mental disabilities are able to reach the 6th or 7th grade (*al ʿiāqa aqliyya basīta wasal lī-l-ṣaf al-sādis, wasal lī-l-ṣaf al-sābi*)." Her father reacted with surprise to the precision of this boundary. "She wont be able to complete her studies?" he asked. Reem responded in the negative. "Her mental abilities are less than a normal child's. Tamara can learn a vocation, and she can be trained, but she cannot be educated *(qābila al-tadrīb, bas ghayr qābila al-taʿlīm)*." This distinction between training and education points to the hierarchies of knowledge increasingly perceived as valuable in Jordan. These hierarchies are embedded in the general education system and profoundly impact students' post-educational trajectories. In her own fieldwork, Adely observed that the accessibility and value Jordanians accord to formal education

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produces particularly difficult counter effects. "Not being educated or not doing well in school can now be considered a deficit and is often tied to implicit assumptions about a girl's behavior and respectability," (2012, 130).

This link between educational achievement and moral status comes out clearly in relation to female students assigned to the "vocational studies" track after 10th grade. One of Adely's interlocutors asserted to her that, "smarter students have better morals and better behavior. It's as if the students who are not smart enough are not smart enough to make the right moral judgments" (2012, 133). Longstanding concerns about moral intelligence and accountability, especially in relation to the successful performance of gendered norms and standards of sexual propriety, shape perceptions of intellectually disabled children and adults as potentially threatening to their family's reputation. Formal education and the class-based respectability politics fostered by educational inequality add yet another layer of complexity to the lives of intellectually disabled children, whose feared "inability to learn" matters more now than ever before.

Tamara's parents negotiated with Reem about the inevitability of the limits that these diagnostic labels imposed on their daughter's future. In doing so, they conveyed the importance of education to their construction of Tamara's personhood.

> Im Tamara: Academically, what grade will she reach?
>
> Reem: Academically?
>
> Im Tamara: What level will she reach and still be able to learn new information?
>
> Reem: Not everything in depth… She might reach the fourth grade.
>
> Im Tamara: You mean she might reach multiplication?
>
> Reem: She will learn multiplication. I worked with a student with Down syndrome, and he doesn't speak. I finished multiplication and division with him, even though he can't speak. He knew how to write in Arabic and English.

Im Tamara: What level will she reach in English?

Reem: She will learn the letters and some words, and she will be able to memorize them. She has a good memory for vocabulary.

Tamara's parents focus on highly specific, objectified tasks relating to mathematics and language learning, but they also resist Reem's equally specific and objectified responses (which diminish Tamara's learning over the course of the conversation from "sixth or seventh grade" to fourth grade). Reem offers numerous examples of her experience working with other students "like Tamara" who have achieved various levels of educational proficiency.

The vast diversity of impairments Reem invoked and the spectrum of possible educational outcomes she connected them to undermined her own claims about what Tamara's disabilities might allow in her future. When Reem mentioned that she once met a student with Down Syndrome who went on to study at the University of Jordan, Abu Tamara exclaimed "*Masha'allah*!" while his wife responded, her voice rising, "ʿ*Anjadd* (really)?" Reem confirmed, and then she continued, "I have another girl with an intellectual disability… [who] studied and became a hairdresser. Three years after, she came by with her mom in her own car!" Imm Tamara was captivated by the possibilities. "But Reem, I want to ask you – Don't those children have slow learning development?" Reem nodded. "There are students with Down Syndrome that I finished a 6th grade curriculum with," Reem added. Imm Tamara then pushed Reem to address the apparent contradiction between the labels applied to these individuals and their own lived experiences. "Good. So, how are those students different from Tamara?" Reem had no satisfactory answer.[119]

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[119] I suspect that much of the prognostic capacity Reem invested in these diagnostic labels came from her own experiences and training background. Other Jordanian special educators reading this exchange might object to Reem's framing, while disability rights advocates most certainly would. As in the United States, approaches to special education in Jordan are diverse, and more conventional approaches in the field continue to rely on and

Tamara's parents thought about her future in terms of education, but while Imm Tamara articulated hopes of her daughter conforming as much as possible to a traditional educational trajectory of "academic" learning, her husband was concerned that constructing her life on such terms left little space for Tamara to "have her own future," as he put it. Abu Tamara embraced the idea of vocational training because it could provide Tamara with a "future" based in skills and services, like hairdressing, even if those skills and services were stigmatized as lesser forms of knowledge. "When will we know if she is capable of learning?" he asked Reem, as though his talkative and energetic daughter did not already embody several years of different kinds of learning. While Reem and Imm Tamara went back and forth about which grades she might complete in her future years of academic schooling, Abu Tamara pushed back against his wife. "You hope she will be educated," he began, "but if she isn't very academic, what do you think she will become?"

Abu Tamara became increasingly emotional as they continued to talk about the future. He grew more vocal in contesting the relative importance of an "academic future."

> Abu Tamara: We know that our daughter will not become a doctor. But we accept her, *Alhamdulillah*… We want her to be independent. And if she succeeds academically, we'll thank God. But if that doesn't work out, she can learn a vocation. My daughter is a blessing… We are accepting. She is from God. *Alhamdulillah*.

Abu Tamara challenges the increasing equation of social value with labor market performance. By situating Tamara as both beloved and a blessing, a description I discuss more fully in Chapter Five, Abu Tamara invests his daughter spiritual, moral, and social value. Adely opened her ethnography with a vignette in which one of the local high school teachers, Miss Suheil,

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reproduce medical models of disability. Additionally, perceptions of intelligence and ability in Jordan are connected to the rise and global proliferation of standardized testing and IQ measurements.

criticized her female teenage students – and their families – for "'the bias Jordanians have against 'working with their hands… We all want our children to be doctors and engineers'" (2012, 7). Abu Tamara also criticizes this increasingly hegemonic discourse of "becoming a doctor." Instead, her articulates a position that requires a moral orientation. "We *accept* her."

VI. Costs and benefits: Thinking toward the future

Reem and Tamara's parents dealt largely in prognostications, imagining what stretched before the nine-year-old in terms of the potential future paths that would develop throughout her childhood. Reham, however, is a teenager, and she fits uneasily within the available categories of child, adolescent, and woman. Shifting societal expectations of education, employment, and marriage are reshaping Jordanian constructions of womanhood. Reham's experience as a teenager with Down Syndrome highlights the powerful norms of femininity that rely on the performance of various abilities. When Reham and her mother showed up for a free dental screening hosted by the Society, I noticed her immediately. The bubbly, outgoing teenager was thrilled to be out and about, meeting new people and mingling. As Reham socialized and formally greeted all of the families and staff crammed into the crowded event, her mother held back and surveyed the scene.

Reham and her family live in an upper class suburb in west Amman, and Reham, her parents firstborn, has two younger brothers. When I asked Imm Reham about her experiences pursuing inclusive education, in which Reham had been enrolled for most of her life, she offered an ambivalent reflection on what inclusion had given her daughter.

> You feel in the schools, the time she spends in the class with the rest of the
> normal girls (*al bināt normal*), it's *useless*. I feel that they are on one side, and
> Reham is on her side… The schools Reham went to take the fees for her class
> plus 50% extra because of the help. So we were paying around 2000 JD per year.
> It was better, but she also wasn't benefitting (*mā kānat tistafīd*) when she was in

the [integrated] class… I mean, she doesn't have friends. You feel that most people who know her, *they feel sorry for her, not taking her as a friend*. They have sympathy for her (*'ātif 'alayha*); it's not that they really like her. Maybe I don't want her to have Down Syndrome friends. I don't know. I don't know... We have Reham, but we still can't accept the presence of Down Syndrome in different forms. We still have resistance to it. I don't know.[120]

Imm Reham wonders if it is her *lack* of acceptance led her to pursue inclusive education for Reham, a laborious process that entailed navigating the schooling systems of the many different Arab countries she and her family had lived in, traveling for her husband's work in the pharmaceutical sector. This thread of acceptance runs throughout the different family narratives I recorded during fieldwork. Imm Reham's particular use of acceptance here – as a way to problematize her resistance to cultivating Reham's relationship with peers who have Down Syndrome – highlights the sometimes contradictory work acceptance does in parsing out the politics of difference, sameness, and identity.

With her daughter in the throes of adolescence, Imm Reham was uncertain of the costs and benefits of having kept Reham in an inclusive classroom. Reham would soon age out of all available programming. Her mother worried about Reham's lack of friends and her nondisabled classmates' unwillingness to treat her as a peer and see her as a person (*ka-shakhs*) rather than as someone to "have sympathy for." Additionally, Imm Reham spoke at great length about the fact that despite Reham's literacy, intelligence, and sociable nature, she has little to no chance of finding a job. Although Law 31 instituted minimum quotas for hiring disabled persons in the private and public sectors, the regulatory and enforcement mechanisms of this stipulation remain unclear, and older legislation not yet repealed actually contradicts the spirit of the quota. The Medical Committees Statute No. 58/1977, for example, contains a list of prohibited conditions

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[120] Im Reham switched between English and Arabic whenever we spoke. English words here appear in italics.

that disqualifies an individual from seeking employment in the public sector, and this list

effectively excludes persons living with a wide array of impairments and disabilities (Al-Azzeh

2012).

Imm Reham reflected on the inevitable passage of time and her family's transition to the

next foreseeable stages of life:

> [My] other two will grow up, get married.[121] I always tell my husband "what
> about you start a business so Reham and I can work there? Even a supermarket!
> Let's do something." I don't know if people employ them [persons with
> disabilities], but I think we're probably the best option to find her a job. You want
> an atmosphere that you trust.

Imm Reham thought about Reham's education in terms of employability, and she was not alone

in doing so. This framing of education is consistent with a neoliberal operationalization of

education for individual economic betterment and national development, embracing the

assumption that education will lead to higher rates of participation in the workforce. For the

families of intellectually disabled individuals, the question then becomes what kind of education

– not as a path to enlightenment or self-knowledge but as a path to economic security – will

satisfy this goal. Imm Reham's focus on finding a way to include Reham within the labor

market, however, is also predicated on her assumption that Reham will never become a wife or

mother. "At the end, we will be three."

The World Bank and other development agencies refer to Jordan as a development

"paradox," because the widespread and successful inclusion of Jordanian girls and women into

all levels of the education sector has failed to affect their persistently low rates of (formal)

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[121] Adely (2012) has shown how education has become, to some extent, a prestige commodity in the Jordanian marriage market, influencing attitudes towards the importance and value of education. The question of marriage for people with Down Syndrome is something I address in the next chapter.

participation in wage labor. Adely's work, on the one hand, calls into question the assumptions about wage labor and empowerment that justify this framing as paradoxical. Many of the educated, working women she spoke with appreciated the opportunities that careers afforded them. They nevertheless regretted the toll on their relationships, the exhausting "double shift" required to work while maintaining a home, and they encounter uncomfortable challenges in their workplace interactions. Adely clearly demonstrates how young Jordanian women – and their families – objectify and value education on their own terms, using educational achievement as cultural capital to enable conventional and collective investments in marital arrangements.

Being "educated" in Jordan today can increase a woman's appeal and offer more leverage in negotiating the terms of the marriage contract, a development that Adely's female interlocutors enthusiastically supported. Employment, however, provoked more ambivalence among the teenagers she spoke with. This was in large part because they observed their own teachers and female relatives struggling to balance the demands of work with the demands of being a wife, mother, and well groomed, attractive, adult woman. Reham's mother, however, did not anticipate that her daughter would be able to meet many of the standards that define adult womanhood in Jordan, especially marriage and motherhood.[122] Employment, in Imm Reham's mind, offered an alternative way for Reham to experience adulthood, albeit in an "atmosphere you can trust." Several of the parents and siblings I spoke with emphasized that trust is often lacking from interactions with people who are not kin or close friends, and that it is hard to find in social worlds beyond the home.

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[122] What Reham envisioned for herself is another matter entirely. Like most of her peers, she wanted to things happening all around her: marriage and children. I discuss this clash of desires and aspirations more fully in the following chapter.

VII. Inclusion into what?

Simply put, inclusive education, as envisioned by education and disability rights activists, does not exist in Jordan. Inclusive education requires investing financial and human resources in restructuring classrooms, schools, and teacher development. Thus far, these resources have been marshaled most successfully in Jordan's private education sector and by schools that self-consciously orient themselves toward global (and European, British, and American) curricula and testing standards. Resource rooms, furthermore, do not actually create an inclusive classroom experience, and as Giancreco rightly points out, "many practices have been labeled as 'inclusion' which are not inclusive in nature. This has led to misplaced criticism about inclusion, when in fact what was being criticized often was either: (a) not inclusive, (b) a partial implementation effort, or (c) poor quality efforts" (1997, 194). Yet many families and teachers offer critiques of inclusion that cannot be fully accounted for by acknowledging widespread failures to operationalize and properly implement inclusive design. Rather, their concerns have to do with broader uncertainties about the purpose and value of education, hierarchies of knowledge and skill determined by the labor market and economies of prestige, and the widespread knowledge that even the best education cannot guarantee individual financial stability. Family and kin networks remain critical to securing these goals.

Lana, a special education teacher, articulated this most clearly in her conversation with Imm Eisa, at a summer party we all attended in a new cultural center boasting a much-coveted playground and semi-green space. Lana asked Imm Eisa if she planned to find an inclusive school program for Eisa once he reached kindergarten age. Imm Eisa conveyed considerable anxiety about the possibility of finding an inclusive program that would meet her standards. Lana nodded in solidarity. To demonstrate why she did not think Imm Eisa's aversion to inclusive

education was at all problematic, she asked the following set of questions:

> Lana: Do you hide Eisa from your family?
>
> Im Eisa: No of course not!
>
> Lana: Everyone knows [that he has Down Syndrome]?
>
> Im Eisa: Everyone knows.
>
> Lana: Do you take him places with you or leave him at home *(fil bayt)*?
>
> Im Eisa: We take him everywhere.
>
> Lana: Isn't this *damaj* (inclusion)? Why do we have to have educational *damaj*? Why is that the standard for what *damaj* means?

Lana and Imm Eisa oriented themselves toward their own project of inclusion. *Al bayt*, in Jordan

and across the Middle East, functions as a simultaneously educational, social, and political

institution that competes with alternative domains for the production of identity and allegiances.

The claim that "inclusion is an aspiration for a democratic education" (Slee 2001, 168) will not

necessarily prove compelling for communities whose members' well-being and social networks

remain kinship-based in significant ways and even into the highest levels of politics, rule, and

welfare. Nor will it resonate in a decidedly undemocratic state like Jordan, which is unlikely to

experience strong pressures for democratization any time soon, given the country's strategic

importance to ongoing anti-terror operations and the increasingly anti-refugee policies of most

European and North American countries.

Mothers from diverse social backgrounds express a shared, patterned representation of

the meaningful social coordinates in their lives. "The *bayt* is fundamental," asserted Imm Iyad,

the mother of a 4-year-old with Down Syndrome, while discussing everyday frustrations with a

group of women in the reception room at the *jama'iyya*. "Without the family, the individual

rights will not be realized." The importance of the *bayt*, which can refer to the physical domestic

structure of a housing unit, smaller neo- and patrilocal settlements, and larger kinship groupings, does not merely reflect the continuing emotional and symbolic resonances of home and family (Vom Bruck 1997). The importance of the *bayt*, while part of the region's deep cultural history, also reflects its adaptive function as Jordanians attempt to cope with and mitigate the wide-ranging effects of structural adjustment policies aimed at liberalization (Baylouny 2006, 349).

Individuals and nuclear families in Jordan turn to kinship networks for protection, support, and access to capital in formal and novel ways as state-provided or subsidized goods and social services are absorbed into a prohibitively expensive private sector, or disappear entirely. Sociocentric understandings of which spaces matter and how social change occurs are deeply informed by these experiences of kinship, vulnerability, and political economy, which are shaped by their own historical dynamics. Ammani residents across class and geographic divides embrace this perspective. While attending a mothers' support group linked to an organization operating out of one of Amman's poorest, most vulnerable eastern neighborhoods, I listened as women discussed how social change could occur in the context of disability rights. An older mother, pondering the question, volunteered the following directive: "First yourself, then the *bayt*, then the neighbors, then the society."

None of my interlocutors disputed the importance of education. The relationship between education and schooling, however, remained open to debate. Schools are not abstract universals but particular institutions, grounded in time and space and subject to constraints that, in Jordan, have becoming increasingly severe. The *bayt* serves as the ideal center of social life and inclusion, but it is nevertheless rife with tensions and contradictions of its own. An unanticipated diagnosis of Down Syndrome or other congenital conditions can potentially disrupt a family's home life in profound ways. Most families would experience a child's subsequent exclusion

from education on the basis of their disability not as logistical inconvenience but as deeply

wrong. Ultimately, however, families are less concerned with the type of institution their

children attend than with the feasibility of enrolling them in a place that is safe and beneficial, or

which, at they very least, will not expose them to harm.

Intellectually disabled children can and do fit with relative ease into the category of

childhood. Ongoing debates over the kind and quality of education they will receive attest to this

alignment. As mothers of young children with Down Syndrome constantly tell each other, all

children differ in terms of their development. Some walk early, while others continue to crawl

for months. Some are exceedingly amiable while others are crabby and cry all the time. Some

children show an aptitude for academic learning, others struggle with basic reading, writing, and

math. Children with Down Syndrome fit on this general spectrum of ability and growth, and

parents and specialists work to remind each other of this diversity, irrespective of disability

labels. The transition out of childhood, however, is fraught by comparison, and the possibilities

are harder both to envision and realize.

Chapter 5. Adulthood

I. Disjunctures

"Christine," Nahida called out to me, one eyebrow raised at my tardy arrival to the summer *ifṭār* celebration. "Did you come here alone?" Equally intrigued and aghast, she then asked me, "*Where* is your family?!" I laughed at her evident bewilderment and explained that my family was far away in America, and yes, I was alone. She then leaned in closer and whispered conspiratorially, "lucky you (*niyyālik*)!" Nahida has Down Syndrome, and she was 18 at the time of this exchange. Opinionated and outspoken, she has battled serious and sometimes life-threatening health problems on more than one occasion. Nahida's mother dotes on her only daughter, sandwiched between older and younger brothers. Wherever Nahida is, one can almost always find her mother stationed within shouting distance. Occasionally, Nahida and her mother were subjects of gossipy criticism, usually having to do with Nahida's outfit choices. A volunteer once whispered to a staff member: "Why is she dressed like that! Look at her chest!" Nahida did not wear hijab, nor was this expected of her, although some of her female peers with Down Syndrome do in fact cover their hair and dress more modestly. The comment about Nahida's chest, however, and concern about the inappropriateness of her dress for her body, gesture to enduring sources of tension during my research.

Families struggled to reconcile intellectually disabled people's irrefutable signs of physical development with their perceived inability to meet widely shared standards for social maturity. Personhood in Jordan is assessed according to how one demonstrates possession of

'aql, "a complex concept, fundamental in most Muslim cultures, from Morocco to Afghanistan, that can be glossed as reason or social sense" (Abu-Lughod 1986, 90). Individuals demonstrate 'aql by embracing highly regulated and normative models of gendered embodiment, and these models present problems for persons labeled as intellectually disabled. "The absence [of *'aql*]," writes Meneley, "is associated with children and the insane" (Meneley 2000, 65). To lack or possess diminished *'aql* does not result in a denial of personhood. It does, however, seriously circumscribe the kind of person one can be become.

While intellectual disability is usually translated as *iʿāqa 'aqliyya*, I occasionally encountered an alternative description of *iʿāqa thihiniyya* (mental disability). When I asked a who was active in disability outreach about the difference between these two phrases, she responded vaguely that they were essentially the same, but the latter "sounded nicer." On another occasion, when speaking with a university professor of mathematics who is also the father of a toddler with Down Syndrome, I described my research as a study of *iʿāqa 'aqliyya* and culture. He nearly recoiled from the term, responding quite gruffly, "*iʿāqa 'aqliyya*? Is that what we're calling Down Syndrome now? Why can't we just call it a learning or developmental delay (*ta'akhur tʿalīmī aw namawī*)?" These reactions could be interpreted as a father's refusal to accept his son's Down Syndrome or perhaps even dismissed as semantics. Instead, I would propose that they reflect the significance of *'aql* to adult personhood in Jordan. Adulthood requires the performance of highly differentiated gendered identities and expressions of heteronormative desire that ideally – and usually – culminate in marriage. Marriage, in Jordan, is a highly elaborated, closely regulated, social and religious institution accompanied by clearly defined conditions and terms. While some parents of intellectually disabled children attempt to

create ways for them to achieve adulthood, others deem impairments of 'aql as incompatible with adulthood, a stance that creates intense, intractable difficulties with the passage of time.

Young people and adults with Down Syndrome are far from silent about their own hopes and desires. They consistently inform their family members, friends, teachers, and specialists that they want the same things as their siblings, cousins, and the actors on their favorite television series: companionship, romance, and love. Fully absorbed in their local cultural milieu, they imagine typical adult futures for themselves, usually articulated as a desire to get married. Their attempts to enact these futures, in turn, prompt extensive conversations and debates among their guardians and caretakers; these are the conversations I was able to observe most closely throughout my research. Even the parents of younger children who are years away from the onset of puberty will sometimes fixate on its eventual arrival, attesting to the significance of this transitional moment. But exactly is the nature and trajectory of the transition that puberty initiates, and what roles does *'aql* play in marking the passage from one life phase to the next?

II. Life stages and embodied asynchrony

'Aql not only shapes notions of proper masculinity and femininity across Arab and Muslim societies; it expresses an indigenous theory of human development. Lila Abu-Lughod writes that from the perspective of her Egyptian interlocutors, "only the insane and the dim-witted do not develop 'aql *over time*; like children, they have no social sense" (Abu-Lughod 1986, 91, my emphasis added; see also Crivello 2008, 47). Both Abu-Lughod and Meneley examine the imbrications of gender, personhood, and power by examining how different actors attempt to claim or are denied *'aql* (see Peletz for similar research on *akal* in Malaysia). Neither researcher, however, clarifies how "insanity" or "dim-wittedness" fits into the local etiologies of

mental difference that might exist in the communities they worked with,[123] although Abu-Lughod's distinction between insane and dim-witted implicitly suggests some degree of differentiation.[124] Additionally, neither scholar fully explores to modes of temporality expressed through this developmental model.

Youth and adolescence:

The category of "youth," or *shabāb*, plays a significant role in Middle Eastern politics and popular culture. Historians of the region have documented the importance of youth in early nationalist and postcolonial movements seeking to achieve independence and modernity (El Shakry 2011; Jacob 2013; Meijer 2000). Anthropologists, in turn, have examined how the contemporary Middle East's demographic "youth bulge" marks young people as key agents of development – and security threats – from the perspectives of both state institutions and non-governmental organizations (Herrera and Bayat 2010; Swedenburg 2007; Simonsen 2005; Sukarieh 2012). Another robust vein of ethnographic research explores the implications of revivalist religious movements for pious youth subjectivity (Atia 2013; Deeb and Harb 2013; Masquelier 2005; Schielke 2008). More recently, the term has acquired particular salience across disciplines, as well as in the popular media, due to the role of youth activists in sparking and sustaining the Arab Spring movements and their aftermath (Singerman 2013).

Adolescence, or *murāhaqa*, conveys a more narrowly medicalized meaning than *shabāb*. It usually refers to the onset of puberty (*bulūgh*) and, specifically for young women, menarche. These bodily changes acquire varying social and symbolic significance across Middle Eastern and Muslim communities, affecting how young women and men dress, interact, and relate to

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[123] In her discussion of fright illness (*faja'a*), Meneley makes a clear distinction between *majnūn* and *faja'a*, but she does not interrogate the intricacies of the former as meticulously as she does with the latter (2003).
[124] This distinction actually aligns with Scalenghe's research on categories of intellectual impairment in Ottoman times (2014), when idiocy (*'ataha*) and insanity (*majnūn*) were considered distinct categories of mental difference.

both elder and younger generations (Clarke 2007; Pearl Kaya 2010; Meneley 1995). Historian

Omnia El Shakry offers a comprehensive picture of "the adolescent" (*al murāhiq*) in 20th

century Egypt, which emerged "as a social scientific category of analysis, demarcating the

psychological literature from the more popular writings of the mainstream press that addressed

"youth" (*shabāb*)" (El Shakry 2011, 592). The core preoccupations in this psychologized model

were the energies, powers, and dangerous sexual desires inherent in the adolescent. Although the

sexually frustrated adolescent subject usually took the shape of a disaffected and unstable young

man, the adolescent female also garnered concern, especially in her propensity to violate norms

of heterosexual desire. "Adolescence," writes El Shakry, "emerged as a distinctive stage of life,

with its own unique psychological contours of subjective experience, in need of self-monitoring

and management by experts" (2011, 595). Much like the political promise and unpredictably of

shabāb, adolescents posed risks and possessed potential. The discipline of psychology, however,

framed their inherent volatility as the product of inner turmoil, and of sexual desire in particular.

In doing so, they abstracted youth from the social and political realities shaping their worlds.[125]

Childhood

Neither experiences nor conceptual genealogies of childhood in the Middle East have

received attention equal to those of youth and adolescence (see Fernea 1995 for an exception) .

In ethnographic accounts, children are often defined by their lack of *'aql*. Carolyn Sargent and

Nancy Scheper-Hughes criticize anthropologists for treating childhood "as a transitional life

stage devoid of any meaning or value… perceived as a permanent state of becoming rather than

as a legitimate state of being-in-the-world" (1999, 13). It seems important to distinguish between

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[125] El Shakry's work helps contextualize and denaturalize the givenness of *shabāb* and *murāhaqa* in a regional context, although scholarship focused on the Levant during this period would further clarify how these ideas circulated and took root beyond Egypt

cases where this representation occurs as the result of an ethnographer's assumptions, and those in which it emerges through participant observation, although cases of the latter kind certainly require adequate analysis. The description that Scheper-Hughes and Sargent offer as the sine qua non of sloppy scholarship resonates considerably with some of the attitudes toward children that I witnessed among my own interlocutors.

While adored, spoiled, and subjected to endless Facebook-bound photo shoots, children in Jordan are generally seen as small humans in training, subjects-in-formation who can neither be held accountable for their actions nor, accordingly, taken *too* seriously.[126] Amira Mittermaier, for example, describes the doubts that emerged among her research participants when a girl of three received a dream foreshadowing the death of the community's religious leader. The validity of a dream portending the future was not at issue, but the identity of the dream recipient raised concerns. "According to all schools of Islamic law," Mittermaier writes, "a child of that age lacks reason (*'aql*), and according to many Egyptians I know, children should not always be believed because they tend to make up things" (2012, 248). Children's lack of *'aql* marks them as limited. Childrearing (*tarbiyya*), essentially involves training children to develop and properly embody the qualities and capacities of *'aql*.

Embodied Asynchrony

Intellectual impairments unsettle normative expectations about the progression and alignment of *'aql*, embodiment, and maturity. To think through the nature of these unsettlements, I draw on Alison Kafer's concept of embodied asynchrony, which she elaborates by analyzing controversy surrounding what has become known as "the Ashley Treatment." Born with static

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[126] Geoffrey Hughes reports similar observations on the constriction of childhood, based not only on his ethnographic fieldwork but also on considerable time spent as a schoolteacher in rural Jordan (personal communication, 2018). I am thankful to him for providing feedback on this chapter and drawing out some of these points.

encephalopathy, Ashley X experienced severe, lifelong impairments of her brain and body. In 2004, at the request of her parents, surgeons at the Seattle Children's Hospital performed a "hysterectomy, a bilateral mastectomy, and an appendectomy" on then-7-year-old Ashley (Kafer 2013, 49). Two years of a high-dose estrogen regimen followed this series of operations, which the hospital performed without seeking the ethics review mandated by both state law and hospital policy in cases involving the sterilization of a minor. Ashley X's parents and doctors justified these invasive procedures as means to ensure Ashley's quality life. By severely arresting her growth, they argued, Ashley would be spared the pains and discomfort of puberty. By keeping her body the size of a small child, Ashley's parents would never be forced to seek care for her outside the comfort and safety of their own home. Her parents describe Ashley and others like her who received similar procedures, as "pillow angels."

Ashley X's story demonstrates how normative modes of temporality underwrite ableism and justify intervention into disabled bodies and minds. Ashley became a "monstrous figure" and demanded intervention because, as Kafer writes, her "body was growing apart from her mind… As a result, she was embodied asynchrony" (2013, 48). Particularly egregious in Ashley's case, Kafer contends, was the undeniable femaleness of her body:

> The Treatment did not improve her cognitive or physical functioning nor was it intended to do so. Yet it is undoubtedly a curative response to disability. Ashley had to be cured of her asynchrony, at least to the fullest extent possible. She also had to be freed of the specter of her future body, the full-sized, large- breasted, menstruating and fertile body to come. (2013, 57)

While very few of the individuals I met in Jordan experienced impairments as extensive as Ashley's, embodied asynchrony aptly captures the disjuncture that caretakers and other nondisabled people perceive as central to intellectual disability. The dimensions and dynamics of embodied asynchrony are formed in the shared and interlinked life courses that family members

create in their struggles to care for one another. The significance of communal and kin

orientations, however, by no means obviates the importance of the individual. Rather, individuals

achieve full adult personhood by fulfilling their obligations in the vertical and horizontal

relationships that shape their own relational sense of self (Joseph 1999). Suad Joseph's concept

of patriarchal connectivity captures these relational dynamics of self, kinship, and power. "By

connectivity," she writes, "I mean relationships in which a person's boundaries are relatively

fluid so that persons feel a part of significant others (Joseph 1993, 452). Where the ideal of

connectivity prevails over that of an autonomous self, "maturity is signaled in part by the

successful enactment of a myriad of connective relationships" (1993, 452). Intellectually

disabled young men and women struggle to establish the connective relationships defining

maturity. In fact, they struggle even to keep those relationships open as future possibilities.

The stakes of embodied asynchrony are evident in emerging debates about the

sterilization of women and girls with disabilities (*isti'sāl/izālat al-raḥam*). While the issue of

sterilization, in particular, is new in Jordan, these conversations represent a new iteration of

longstanding communal and legal anxieties about the sexual and reproductive lives of persons

deemed "not normal" in the MENA region (Scalenghe 2014). They also echo facets of disability

histories around the world (Block 2007; Carey 2003, 2010; Phillips 2011; Stern 2015). Such

commonalities attest to the significance of sexuality and reproduction in constructions of

disability, as well in ableist justifications for intervening into the lives of disabled persons across

time and space. The experiences of mothers with intellectually disabled sons demonstrate how

disability shapes and disrupts local constructions of masculinity, creating constraints and

circumstances different from those encountered by disabled women. Young men with intellectual

disabilities rarely face the same degree of bodily intervention as their female counterparts. For

both young men and women, however, perceptions of *'aql* determine the kinds of adults they might become. For nondisabled peers, the onset of puberty marks a transition into adolescence, a phase they experience as "betwixt and between" on their certain path to adulthood (Turner 1969). By contrast, disabled young men and women do not experience the same kind of transitional adolescence. Instead, they become further entrenched in embodied asynchrony.[127]

III. "She will stay a child her whole life"

Lina did not look as old as her 25 years, nor did she visibly present as disabled. I wondered if I had misunderstood her younger sister Huda, who urged me to contact her mother upon learning about my research. "I have *two* sisters with intellectual disabilities," Huda exclaimed when, almost four months earlier, we met at a private training session on special education. I attended class one evening at the invitation of Ibrahim, a well-known counselor and special education lecturer who freelanced as a consultant and trainer. His almost all-female audience during this training consisted of Bachelor's and *Diplom*[128] students studying special education in universities around greater Amman. Once they successfully completed the course, students would receive a certificate of participation. They hoped this piece of paper would bolster their resumes on the job market, where they sought work in the special education sector or, less commonly, in the resource rooms offered by schools experimenting with semi-inclusive

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[127] Writing on the stigmatization of chronic pain in the United States, anthropologist Jean Jackson describes chronic pain sufferers as liminal subjects who disrupt the mind-body Cartesian dualism that grounds U.S. biomedical culture, as well as moral codes that rely on a clear distinction between sickness and health (2005). In using the description of liminal, Jackson writes that she seeks to combine both Victor Turner's conceptualization of liminality as "betwixt and between" (1969), as well as Mary Douglas's work on dirt and pollution as "matter out of place" (Douglas 1966). In many ways, Jackson's description of chronic pain as confounding categories resonates with my observations on intellectual disability, but I am not convinced that liminality aptly captures the sense of positionality of young people with Down Syndrome and other intellectual disabilities. The disjuncture and sense of impossibility conveyed by Kafer's concept of embodied asynchrony seems to better account for this stuckness.

[128] The Jordanian equivalent of an Associate's degree.

education programming. At the end of that session, I took Huda's contact information and promised to be in touch.

Traveling via a small coaster bus, I departed from the Raghdan bus hub that connects Amman's urban core to its ever-expanding peripheries and the other governorates. Huda and her mother were waiting in their car, idling in front of a nondescript furniture store on the route between Amman and Zarqa. As we pulled into their home's secluded driveway, framed by a trellis covered in grape vines, Imm Lina half-joked that she hoped none of her neighbors saw us; they would be curious about such an unusual visitor and expect introductions. Huda's younger sister Samar waited for us inside the salon with Hala', their youngest sister; Lina was the eldest. I did not meet Imm Lina's husband, who worked long hours as a truck driver, or her son. Hala' joined us for the first hour of my visit, playing animatedly with an empty water bottle. She giggled at the sensation of ribbed plastic against her skin and the crackle it emitted when she applied pressure to the materials with her hands. Hala' acquired pervasive developmental and physical impairments shortly after birth, and she could neither walk nor talk. Imm Lina described her youngest daughter's condition as *ḍumūr ʿaqlī*, literally atrophy of the *ʿaql*.[129] When Hala' grew tired of this entertainment, Huda pushed her sister's wheelchair back into the domestic interior of the house to lay her down for a nap.

At different points throughout her life, Lina had been diagnosed with developmental delay (*taʾakhur al-namū*), a moderate intellectual disability (*iʿāqa ʿaqliyya mutawassaṭa*), and eventually a psychological condition that her mother simply described as "like schizophrenia" (*hāla nafsiyya zayy al-infisām*). Mental illness compounded her intellectual impairments and led

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[129] This was not the first time I encountered a medicalized use of *ʿaql* rather than brain (*damāgh, mukh*).

to Lina's classification as severely disabled.[130] Lina was thrilled to entertain guests and sat by my side for the entirety of my visit. Earlier that day I left my glasses in the taxi ride to the bus station, so I had resigned myself to wearing sunglasses in the dimly lit salon for the entirety of my visit, while apologizing profusely for this awkward arrangement. Being extremely near-sighted, I cannot see without strong prescription lenses. Whether to ease my embarrassment, or perhaps because she liked my style, Lina ran to get her own sunglasses and donned them in solidarity.

I was not accustomed to conducting interviews with multiple family members at the same time, preferring to speak with mothers and sisters separately and alone. I adopted this approach to mitigate the potential complications that arise when asking questions about experiences and emotions that family members may not be keen to share with one another. While some women tried to ensure that a maximum number of family members would be present for my visits (in which case I often chose not to record due to sheer acoustic constraints), others intentionally arranged my visits for times when their children and spouses would not be home. Imm Lina's daughters did not leave her side for the entirety of my stay, attesting to both the gendered and collective dynamics of their family's experiences with Lina and Hala'. I asked whether I could record our conversation, and Imm Lina replied matter-of-factly: "It's no problem." She downplayed my assurances of confidentiality, reasoning that they had experience with reporters, so I was not a big deal. At first not fully understanding this remark, I nodded and proceeded to ask Imm Lina if she thought her community was accepting of disability.

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[130] In describing this progression of Lina's diagnoses, Im Lina used the categories recognized by the Ministries of Health and Social Development, and the Higher Council for Disabilities, which distinguish between mild (*basīta*), moderate (*mutawassaṭa*), and severe (*shadīda*). These categories reflect a medicalized approach to disability and have been strongly criticized by activists and scholars who advocate for an approach to disability based on the social model.

> There's more acceptance (*taqabbul*) now. A long time ago, people would hide them (*khabbūhum*) and stay in denial and not speak about them. And maybe, in cases of marriage, when people would come to ask for a girl's hand, her father and her grandmother – the father's mother[131] – would tell her not to say anything. Even my own mother… would ask, "Does everyone who enters your house have to see [Hala']?" And I would tell her that Hala' is part of our life, and people need to know that she is present.

This reply touches on familiar themes of acceptance, hiding, and the importance of marriage networks in shaping family members' engagements with disability. Unlike many other parents I met, however, Imm Lina articulated a more optimistic perspective, describing the present as a significant improvement rather than a period of as-yet unrealized potential for progress.

In this initial response, Imm Lina focused on her experiences with Hala'. Lina's impairments were not immediately visible, unlike those of her youngest sister. Lina also moved independently and possessed a greater capacity for verbal communication than Hala'. Nevertheless, it was Lina who generated a greater degree of concern for her family. Her mother explained:

> Lina had her period for four months. And it was four months of torture. From the first day until the last day she would scream that she was sick and that there was blood and that she was going to die. She was too disgusted to stay in the bathroom. She would keep throwing water [on herself, in the bathroom] so that she wouldn't see any blood.

Frustrated, Imm Lina sought out further advice that would thrust her family into the center of a controversy they had not anticipated and did not fully understand. She first returned to the diagnosis center.

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[131] Im Lina specifically identified the father's mother, the paternal grandmother, as important here. The quality of the relationship between a wife and her mother-in-law is a frequent topic of conversation among women and a constant plot device for soap operas, literature, and songs across the Arab world. Given the historically widespread tradition of patrilocal residence, young wives enter their husband's extended family unit at lower levels of household hierarchy. Only with time, children, and age do they accrue status and authority (Altorki 1986; Fernea 1995; Moghadam 2003).

The doctor told me that there were cases where they perform hysterectomies (*fī ḥālāt byi'staṣalū al raḥam*), and he asked me what my opinion was on the matter. I told him that in my opinion it was not necessary for her to keep her uterus. She has a mental disability, and I am not going to let her get married.

Imm Lina described Lina's "health" as her primary concern. The employee at the center told her that she needed to speak with an OBGYN for advice on this issue, so she next sought out the expertise of one such specialist.

Will it affect her in any way?" I asked. [The doctor] told me no. She asked me whether I would prefer to take it [the uterus] out with surgery or whether I would prefer to remove it through suction. I told her I didn't know. I told her that people would be concerned with her virginity (*al- ʿuzuriyya*), so people might talk, but [the doctor] should do what she saw best for Lina's health. I mean it didn't make a difference to me whether she remained a virgin or not.

Imm Lina's explanation reveals how marriage, sex, and collective family reputation mutually shape the composition of able-bodied womanhood in Jordan. Imm Lina separated fertility and sexuality from her understanding of Lina's "health," because her daughter would never get married. Lina's fertility thus became emblematic of her embodied asynchrony.[132] The parents of Ashley X articulated a similar logic. They justified dramatic intervention into their daughter's disabled female body based on their imaginings of possible and impossible futures. Virginity, in Jordan, plays an important role in ideal constructions of femininity (Mahadeen 2013).[133] The fact that it "didn't make a difference" whether this surgery penetrated Lina's hymen reveals how her

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[132] An interesting parallel example is found in Amal Hassan Fadlalla's work with Hadendowa Sudanese women. Fadlalla writes that "women… who experienced multiple reproductive traumas, are seen as women whose fertility has gone awry and are thus perceived as more threatening to the collective well-being than are infertile women" (Fadlalla 2007, 7). While Fadlalla's focus on reproductive trauma does not directly apply to my research, Lina's family considered her disability itself a reproductive trauma. Intellectual disability inherently marked her fertility as something "gone awry," matter out of place.

[133]Mahadeen provides two common sayings in this regard. The first "compares women to soda cans that, once opened, cannot be closed again and cannot regain their original value. Another compares women to delicate glass which also cannot be repaired after it is broken" (2013, 81).

exclusion from the category of "marriageable" directly affects her possibilities for embodying female subjectivity.[134]

Imm Lina did not arrive at the decision to pursue her daughter's hysterectomy alone. Although her husband figured minimally in our conversation, he would have needed to provide verifiable consent before any hospital would be willing to perform such a procedure. Imm Lina also sought the advice of medical experts, none of whom tried to dissuade her from the operation. She did, however, encounter dissenting voices that challenged this normalizing, medicalizing framework, as well as her own assumptions about the moral legitimacy of the operation.

> So what happened next? After the operation, people started fighting with us about the issue of motherhood (*qaḍiyyat al-imūma*). "It's her right to be a mother (*ḥaqqha bitkūn imm*)." Lina is fundamentally a child! In the Center, they request that we delay the age of marriage and do not marry girls too young.[135] Then they go back, even with this mentality, and say that it is a girl's right to be a mother. But [Lina] is a child, and she will stay a child for her whole life. They are not very logical!

The issue of child marriage is the subject of rights and awareness campaigns across the Middle East, funded by local, regional, global, and state initiatives (Sweis 2011).[136] Imm Lina drew on the liberal discourse of children's rights to subvert the liberal discourse of disability rights. By

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[134] Virginity encompasses broader values of feminine propriety and respectability and is not dependent solely on the status of the hymen. In fact, Islamist sexual education courses have begun to explicitly promote awareness of this lack of equivalence to rectify the "backward" emphasis on gathering proof of a woman's virginity on the night that an engaged couple consummates their marriage (see G. F. Hughes 2017).

[135] I'm not sure what "center" Im Lina was referring to, but it could have been any number of local or international NGOs or governmental organizations that sponsor awareness campaigns about the harms of marriage for young girls and relatively recent changes to the legal age of marriage (formally set at 18, but possible as young as 16 with permission from a judge).

[136] Jordan has witnessed a significant rise in average ages of marriage: 24 for women and 29 for men (Ajaka 2014). There are at least two socioeconomic factors contributing to this trend in Jordan. First, the importance of education, for both boys and girls, is seen as an economic necessity and a prestige item in terms of making a "good" marriage (Adely 2012). Additionally, the groom is responsible for the wedding expenses, the bridewealth (*mahr*), and any other items agreed upon in the marriage contract. In the current economic climate young men often have to save for years to afford their wedding license and the expensive social rituals that surround the affair (Hughes 2015).

squarely situating her daughter as a child, Imm Lina invoked a status that entails unassailable

rights to protection. Having located her daughter in a phase of perpetual childhood, Imm Lina

then sought the medical technologies necessary to intervene and alter her daughter's body so it

would align with this designation. The temporal dynamics of this framing, moreover, illuminate

the imbrications of disability and futurity that shape her reasoning. There are many women in

Jordan who do not marry.[137] Yet it was the impossibility of Lina's marital future as a disabled

girl-woman that made her body problematic in ways that a nondisabled, unmarried woman

would not experience.

   "Do you know Safiya?" Imm Lina asked me rather abruptly. I was surprised by the

question; I had met Safiya, who is a well-known and fiercely outspoken disability rights activist.

She is especially keen to address more taboo topics relating to family, gender, and sexuality. I

answered Imm Lina's question in the affirmative. "I hate this woman," Imm Lina responded,

unexpectedly switching to English for dramatic emphasis. Then, returning to Arabic, she began

to explain, initially addressing Safiya as though she were standing in the room with us:

> You have no right to judge me if you haven't lived my circumstances! Okay,
> Safiya, she has a physical disability. But her intellectual capacities are there
> (*qudrāthā 'aqliyya mowjūdeh*). Everything is easier. You can manage yourself.
> Even me, as a normal person (*banī ādam ṭabī'ī*), if I started to have problems with
> my intellectual capacities, everything would change – including my own family's
> acceptance of me! (*ḥaṭa taqabbul ahlī wa usratī*).

Imm Lina's distinction here points to the significant differences attributed to impairments of *'aql*

versus those of body. People with minds recognized as damaged or incomplete experience

impairment and disability differently than those whose minds are not, something emphasized by

feminist scholars who work on issues of significant intellectual impairment (Carlson and Kittay

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[137] In fact, anxiety about a crisis of marriage and looming epidemic of "spinsterhood" are common in local and regional discourse (Adely 2016; Hasso 2010; Hughes 2015).

2010; Kafer 2013). At the same time, I also met individuals with physical, sensory, and mobility impairments who frequently remarked that their families, and especially strangers, treated them as though they had problems processing information and ideas, rather than problems walking, hearing, or seeing, a conflation that reflects the deeply embodied dimensions of *'aql*.

Imm Lina and Safiya spoke about Lina's hysterectomy, although I was unclear exactly how they connected and whether Safiya had sought out Imm Lina or vice versa. Regardless, their conversation did not go well. Safiya did not support Imm Lina's desire to pursue operation. "She told me that I didn't do the hysterectomy [so Lina] could be more comfortable. She told me I did it so that when her father or her brother sleeps with her, she won't get pregnant." Imm Lina's rage became evident in retelling this story. Safiya's accusation that Imm Lina was complicit in aiding and abetting incestuous sexual abuse did not prove an effective strategy for dissuading the latter from sterilizing her daughter. Safiya linked the hysterectomy to Lina's family in a relationship marked by inherent violation. On the one hand, available data overwhelmingly suggests that disabled women everywhere experience higher rates of sexual abuse and violence that those without disabilities, and this is certainly the case in the United States (Harrell and Rand 2010). Yet I also encountered a highly classed discourse surrounding incest in Jordan,[138] with certain elite Jordanians describing sexual abuse as an inevitable consequence of the collective sleeping arrangements that prevail in more "traditional" and lower class communities. They also imply that poverty and religious conservatism foster toxic sexual repression and ultimately deviance. There exists a discourse of incest accusation that reflects broader politics of class and kinship practices. I cannot assess the validity of this discourse or its relationship to the actual prevalence of incest.

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[138] Other anthropologists working in Jordan have also encountered this narrative among elites (Adely 2017, personal communication).

In responding to Safiya's accusations, Imm Lina pointed out that she sought guidance from diagnostic and medical professionals. Technically, "the Ministry of Health and the Ministry of Social Development suggested it!" Safiya redirected her critique in light of this point, telling Imm Lina that the Center suggested the operation for the same reason, "so that when her advisor at the live-in center sleeps with her, she won't get pregnant." Imm Lina responded indignantly: her daughter had never slept in a residential institution, and she vowed she would never let this happen. By locating the threat of sexual harm in both the family home and the state run institutions, Safiya implicated both spheres as guilty in their failure to protect disabled women and enabling violations against them. Her arguments with Imm Lina portray disabled women as overwhelmingly vulnerable to abuse, whether committed by family members or by agents of the state (or actors in the private sector). In my own conversation with Safiya, we also discussed issues of puberty, menarche, and sterilization. She described families as unwilling to work with their daughters in skills of self-care relating to menstruation. "I think they do not even see their daughters as women," Safiya told me. She was, I believe, correct in this assessment. Some families see their daughters as undeniably female, but womanhood becomes anomalous, and even threatening, in the presence of certain intellectual impairments.

Despite their conflict, Imm Lina was not oblivious to Safiya's general commitment to the issues of disability rights. "Maybe," she hypothesized, "it's just that she cares so much about the rights of disabled people. Kind of like a cat that eats its children because it worries about them… If this is how you want to protect them, it is not the proper way!" Contrasting Safiya's misguided attempts by likening them to a mother destroying her offspring, Imm Lina justified her own maternal efforts as protection for her daughter. She did not consider the hysterectomy as bodily harm but rather construed it as an act of preservation, an act of care performed properly.

Safiya told me that they were going to teach me [to take care of Lina]. So I told her okay, lets assume that they teach me. But if I get sick? Safiya told me that they would teach her sisters. But her sisters are at the age when they should be getting married. Should I prevent them from getting married? She told me no, it was fine for them to get married. Okay. But if I die and her sisters get married, or, if I get sick?

Menstruation involves symbolic and practical dimensions that play out in different ways for differently abled female bodies. Proper dealings with bodily fluids of all kinds – blood, semen, urine, vomit – are critically important for maintaining social and religious norms in Jordan. Both men and women are provided clear and explicit instructions regarding the maintenance of the body in general, and especially in relation to prayer and the successful completion of *wuduʿ*, a state of physical and spiritual purity necessary for prayer. On another level, however, bodily fluids are intimate, sticky, pungent materials that become especially unpleasant to encounter outside the domains and activities to which they are assigned (Al-Mohammad 2007). In explaining her decision to pursue the operation, Imm Lina stressed Lina's inability to understand blood and her inability to clean herself. A menstruating woman possesses the capacity to bear children and the capacity to threaten ritual space; she is also bleeding. Imm Lina's concerns were focused on quotidian, material dimensions of providing care. "Who will change her?" she asked rhetorically, dramatically suggesting Lina's father and brother only to highlight the inappropriateness and impossibility of such a scenario.

Vastly unequal power dynamics separate Imm Lina and Lina's doctors from Lina herself, who presumably had very little say in the decision to remove her uterus and was most likely not consulted at all. Having flagged these issues, I would like to consider how Imm Lina configured the hysterectomy as an act of care. Anthropologist Angela Garcia, discussing the relationship between a mother and daughter sharing in the struggles of heroin addiction, writes:

> For Eugenia and Bernadette, the arts of care included small gestures meant to ease pain.... They may have wounded as much as they healed. Nevertheless, they were oriented toward relieving the pain of the other and, as such, they were moral acts, embedded in the everyday context of shared vulnerability and difficult life circumstances. (2014, 56)

Eugenia and Bernadette are by no means perfect analogies for Imm Lina and her daughter, yet they can be used to illuminate Imm Lina's position. The sight of menstrual blood distressed Lina, and her mother sought to ease her pain. Imm Lina emphasized her discussions with the doctor about whether the surgery would affect Lina's health to demonstrate that she was not trying to harm her. Imm Lina considered Lina a child, discounting any marital, and therefore sexual or reproductive future or identity for her daughter. Safiya, by contrast, insisted upon Lina's status as a woman who would be made infinitely more vulnerable to harm by what the hysterectomy could theoretically enable – nonconsensual sex with no risk of pregnancy.

Imm Lina and Safiya's boundaries of care and harm are based on how they understand Lina as a person – child or adult, girl or woman – in relation to her intellectual and physical capacities. In doing so, they inscribe both gender and disability on Lina's body. Im Lina worried about a future in which she would no longer be able to care for Lina, or for Hala'. This responsibility would then fall to their sisters, or so she hoped. In a local political economy that configures care as a precarious resource dependent on the availability of female kin, Safiya's designation of the family as a threat to be neutralized and overcome simply did not fit with pervasive everyday moral sensibilities. Rather, women like Imm Lina construct and make sense of disability in relation to kinship futures. While Imm Lina's solution, like Ashley X's parents, was to "cure" Lina of her embodied asynchrony, some parents challenged the inevitability of such a disjuncture.

IV. "Don't treat them like children":

The connection between intellectual disability and embodied asynchrony manifests itself in different ways and to varying degrees. Not all families experience the onset of puberty as a traumatic rupture. Imm Rana, for example, normalized her daughter Rana's experience with menstruation. She did so precisely by foregrounding the capacity of a 17-year-old with Down Syndrome to provide self-care. "It was fine. *Alhamdulillah* it just went smoothly. [Rana] learned how to take care of it and take care of herself. It was normal." Imm Rana did not frame menstruation as inherently problematic. In stressing Rana's ability to "take care of it" and "take care of herself," however, she implicitly acknowledged the social and material challenges that menstruation poses for proper care of one's own body. It was clearly important that her daughter demonstrate the ability to meet those challenges in a socially acceptable way. If Rana had a harder time "taking care of it," would her mother have perhaps resorted to more extreme measures? Imm Rana did mention hysterectomy as something that some families pursued once their daughters reach menarche, and she made no explicit judgments about this choice.

Importantly, Imm Rana did not view Rana as a "child," incorporating her more squarely into the realm of adolescence. She recognized and felt conflicted about Rana's romantic teenage longings, which she recognized as such, as well as those she witnessed in her daughter's peers. While visiting Imm Rana and Rana at their home in an upscale neighborhood in northwest Amman, Imm Rana admitted that:

> I don't like how [people] joke with them, like they don't take them seriously… A while ago – she loves watching Turkish soap operas, you know, and some of them are very open. She turned to her father and asked him, "When will I be able to fall in love? When I'm 18?" Can you imagine!? Dear God, ask me that, not your father! But she really means it! {Laughs} At least she was asking first… But they are really thinking about this stuff. They want this. Don't treat them like children, because they don't see themselves that way.

This was not the first time that Imm Rana and I discussed the trials of adolescence. Yet, Rana was not fully incorporated into the role of an adolescent, given that her mother could not accept the conventional future her daughter desired as a viability possibility. Many months earlier Imm Rana told me about a conversation she had with Rana that left her feeling troubled.

> Rana told me, "When I get married, I want to have 6 kids." I told her, "Six?! Who's going to take care of those?!" We have a housemaid, so she told me "Don't worry, I will bring two housemaids!" I told her, "You should take care of yourself first!" … They're normal feelings for people their age. Of course, when her friends are getting engaged she's going to say, "When is it my turn?" But my view is that at the end, it will be me, my husband, and Rana.

Imm Lina interpreted Lina's period as matter out of time, given that her daughter would "always be a child." Imm Rana acknowledged Rana's transition from child to teenager, framing her feelings as "normal for someone her age." She actively criticized nondisabled adults for infantilizing her daughter.[139] Yet this transition marked Rana as capable of bearing a child who would require care beyond what her mother believed she was capable of offering, and thus the transition would never be complete. Imm Rana's anxieties about her daughter's sexual maturity influence Rana's life in immediate ways. She expressed intense fear that Rana's disabilities would render her uniquely vulnerable to abuse or exploitation, a worry expressed by many families and one also shared by families of nondisabled young women. Sitting in the kitchen while Imm Rana prepared lunch, with Rana in the next room watching a Turkish soap opera, Imm Rana explained that the close physical proximity of various programs in Amman factored crucially into where they enrolled Rana. "Abu Rana is against any option where Rana would be on a bus… Where she could end up the first or last one on a bus, because of abuse. We're afraid

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[139] Rana, unlike Lina, had attended a mainstream school her entire life. While she struggled with the academic subjects, she could pick up on social cues and engage in conversation with relative ease. In other words, these two young women experienced significantly different impairments and disabilities.

for her." Vulnerability, understood as physical fragility or moral weakness, is not imputed solely

to disabled women, but the existence of disability heightened this already gendered quality.

Imm Maryam envisioned a different future for her daughter Maryam. In explaining this

future, she also demonstrates how gender and disability intersect on a spectrum of vulnerability.

We sat and talked about Maryam with Imm Maryam's older daughter, Amina. Given their 10-

year age gap, Amina often played the role of second mother to her six-year-old sister. Imm

Maryam made it clear to me that she fully supported the right of people with Down Syndrome to

marry. "I hope that I can marry Maryam to someone without Down Syndrome, so he can take

care of her. A woman with Down Syndrome can give birth to a healthy baby,[140] and then that

baby can take care of her later in life."[141] Imm Maryam maintained a possible future for Maryam

that conforms to normative, traditional gender roles – Maryam as wife and mother – while

allowing her to envision a radically more independent existence for Maryam as an adult capable

of creating her own family. This projected future would also secure Imm Maryam's own future

status as being cared for, rather than continuing to care for Maryam. Needless to say, Imm

Maryam strongly opposed the permissibility of performing hysterectomies on disabled women.

When we broached this subject, however, Imm Maryam concentrated less on what a

hysterectomy would mean for Maryam's marriageability and fertility; instead she based her

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[140] While many women with Down Syndrome are infertile or experience significantly impaired fertility, some women can get pregnant. The babies of women with Down Syndrome who carry to term have an increased likelihood of being born with Down Syndrome or other congenital and physical disabilities, but some women with Down Syndrome give birth to babies without any complications or congenital conditions (Bovicelli et al. 1982; Sheridan et al. 1989). Men with Down Syndrome are usually infertile (Pradhan et al. 2006).
[141] While patrilocal, post-marital residence patterns remain prevalent in Amman, they are increasingly being modified by a confluence of factors: rural-to-urban migration, nuclear families adopting neolocal practices apart from either side of the family, out-migration, and personal preference. Over the course of my time in the field, two families I knew relocated away from neighborhoods where the husband's extended kin resided; in one case the family sought to move closer to the wife's mother and care for her, and in the other case, the family simply wanted to put distance between the nuclear family and the paternal relatives (parents and sisters).

objections on broader themes of bodily integrity, God, and creation.[142] "[Hysterectomy] is

haram, forbidden in Islam" (she exclaimed. "God made her with a uterus (*Allah kḫala'hā maʿa*

al raḥam). Who am I to take that from her?" She had initially been shocked to discover that other

women were willing to consider the procedure for their daughters. "Mothers say they're afraid of

their [disabled] daughter getting pregnant. Why would she be in a position where she'd be

capable of getting pregnant? Do you let her wander the streets?!" Imm Maryam extended this

argument to non-disabled women to demonstrate the fallacy of their logic. "People fear their

daughters – healthy daughters – having relationships and getting pregnant. But do they talk about

taking out *their* wombs?!"

Imm Maryam's objections were not intended to trivialize the fear of illicit relationships.

At one point during our conversation Amina asked me if it was true that girls in America could

go out as they pleased. She expressed jealous approval when I granted that in general, unmarried

young women had more autonomy in their daily movements than was common for many of their

Jordanian peers. As Amina listed off her daily routine to draw attention to the lack of

unchaperoned time that would allow for her to "go wherever she wanted," Imm Maryam

protested her daughter's implicit criticism. "I fear for you," she exclaimed. "I have to," turning

first to Amina, then to me, and throwing her hands up in the air when neither of us verbally

reinforced the legitimacy of this stance. Imm Maryam did not distinguish between Amina and

Maryam in terms of needing to protect them from the threat of bodily assault or assault on their

reputations. She treated her daughters as both valuable and vulnerable in their gendered

identities, which she preserved through maintaining their possible marital futures.

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[142] It's worth pointing out, however, that unlike the other individuals discussed in this chapter, Maryam was only
four. She and her mother had yet to confront the immediate, messy materiality of puberty and bodily hygiene.

V. Harm and protection: Islam and the moral legitimacy of sterilization

Both supporters and critics of hysterectomies for intellectually disabled women invoked

Islam to legitimize their stances as morally sound. Jordan's Department of *Iftā'* (plural of fatwa,

or legally nonbinding expert religious opinion) issued a formal position on this issue in 2014 at

the request of local disability advocates. After collecting testimonies from medical, child

development, and human rights experts, the Department's official decision-making council

issued a formal fatwa against the permissibility of hysterectomy for disabled women and girls.

The reasoning they provide, which is accessible via the department's online website, outlines a

particular conception of the right to bodily integrity, premised not on the construction of an

inviolably sovereign subject-in-body but rather on submission to the sovereignty of God over all

bodies.

Decision no.194, 2/2014 is titled "Forbidding removal of the wombs of girls with

disabilities and society's obligations toward them (*hurmat izālat arḥām al-fatayāt dhuwwāt al-*

iʿāqa wa masu'liyya al-mujtamaʿ tijāhun)." The text reads as follows:

> It is not permissible to undertake the removal of a [body] part made by God
> *except in cases of illness that can be cured by this procedure* (my emphasis
> added). As for those with an intellectual disability or illness, we do not see this
> type of operation as permissible, as it infringes on God's creation, poses health
> risks through the surgery, and has the negative effect of enabling abuse and
> causing harm and damage to these girls. It is the duty of parents and guardians to
> protect their daughters with intellectual disabilities and to spare them what may
> harm them, just as it is society's duty to offer them protection from exploitation
> and enact the necessary [legislative] measures to ensure this. It is the right of the
> weak to their protection (*fa haqq al- ḍa'īf siānathu*).[143] (Department of *Iftā'* 2014)

This reasoning is consistent with previous statements on the matter. In an online query submitted

to the research council in 2009, for example, a mother wrote:

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[143] It's interesting to note that the word chosen for protection, *ṣiāna*, conveys sentiments of chastity and virtue (Hans
Wehr 2001). *Maysūn* is a popular name for women.

I have a daughter who is 13 years old and she has a mental illness (*hiyya murīḍa 'aqliyya*) and she has a complete lack of self-control (*lā tusaytar 'alā nafsha*), even with using the bathroom. Please provide me with a *fatwa* in the matter of removing her womb, since she is completely unable to control herself.
(Department of *Iftā'* 2009)

The scholar(s) who responded to this woman's inquiry also denied the permissibility of removing the girl's uterus. They provided the same justification, verbatim, as that of the formal decision reached in 2014. Additionally, they recommended that this woman "[seek out] the help of charitable and social services that specialize in these matters."

The 2014 fatwa identifies four interrelated reasons why the hysterectomy procedure is incompatible with Islamic ethics: 1) It infringes on God's creation; 2) the risks of the surgery outweigh the benefits; 3) it has the negative effect of enabling abuse and causing harm and damage; 4) it denies women and girls with intellectual disabilities their right to protection. The first two claims, that the hysterectomy infringes on God's creation and creates greater harms than benefits also emerge as salient issues in Sherine Hamdy's research on bioethics and organ transplantation in Egypt (2008; 2012). The families Hamdy worked with were overwhelmingly opposed to kidney transplantations from live donors, despite a ruling from state religious scholars that deemed the operation morally permissible. Many of Hamdy's interlocutors instead cited a dissenting opinion issued by the popular Islamic scholar Shaykh Shaʿrawi, who argued, "you cannot donate a kidney, since it is not yours to give" (2012, 3). Imm Maryam articulated a similar sentiment in denying her right to take away Maryam's uterus, which was something given to her by God.[144]

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[144] Muslim religious scholars, in general, see sterilization as "challeng[ing] the wisdom of God in creating reproductive organs in man and woman" (Rispler-Chaim 1999, 137). Certain procedures become permissible, however, when they offer life-saving treatment for an illness, such as uterine cancer.

Hamdy writes about speaking with a famous surgeon who gave up his practice after reaching the conclusion that transplantation was not morally sound. He did so by carefully considering the "legal-ethical principle in Islam: *la darar wa la dirar* [no harm can be inflicted or tolerated]" (2012, 144). In light of Egypt's destructive transplant market, which preys upon the bodies of the poor, the surgeon eventually decided that the harms transplantation inflicts on society outweighs the good achieved through individual operations.[145] Depending on how the scale and scope of the problem are defined," Hamdy argues, "different risk-benefit analyses will inform ethical decisions" (2012, 147). Viewing the problem of transplantation on a social scale, rather than that of a patient's life, the value of individual good act transforms as part of a larger, unethical process.

Imm Lina, Safiya, and the fatwas described in this chapter all make claims to an ethics of protection and a desire to mitigate harm, but they define the scale of the problem differently. For Imm Lina, her daughter and the rest of her family need protection from the problems created by Lina's embodied asynchrony. "Who will care for her?" Imm Lina repeated constantly when retelling the story of Lina's operation. Both Safiya and the fatwa position women with intellectual disabilities as subjects who have a right to care, but that very right in turn creates their need for protection. Pregnancy, or maintaining the ability to become pregnant, preserves the capacity of a woman's body to provide testimony that her assigned protectors have failed. Members of the *fatwa* department are broadly sympathetic to the challenges of providing care, urging the mother of the 13-year-old who submitted her online inquiry to seek social services that could support her. They were more concerned, however, with the ramifications of altering the female body in ways not intended by God and what the consequences of such alterations

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[145] The surgeon was aware of the religious council's official position on transplantation, but he pointed to their alignment with the Mubarak regime to call into question their capacity to issue sound and just rulings.

might bring. Their different lines of reasoning also converge on unstated assumptions about male

sexuality, immorality, and aggression.

The fatwa also reveals divergences between the concerns of Jordanian scholars of Islam

and those of biomedical doctors. Data from 2012 indicate that approximately 64 hysterectomies

were performed on disabled women and girls, although the exact number remains unclear, as

registered cases likely only reflected various procedures with proper medical validation (Al

Azzeh 2012, 121). Several online news outlets have covered this issue over the past 15 years,

and publications often include testimony from named medical authorities expressing their

support for the procedure. From the perspective of two doctors interviewed from the Islamic

Hospital[146] and Al Bashir hospital,[147] sterilizing disabled women and girls amounted to "a mercy

for their families" (Shadid 2009). In a different online news article, an OBGYN from Al Bashir,

"defended the compassion of the operation and argued that, 'the girl is not fit to become a

mother, and she will not marry… The family fears that there will be problems with her, like she

will be raped and have a disabled child, and how could she care for him?'" (Amman Net 2007).

Note that in the doctor's argument, while the possibility of rape emerges as a problem, equally

(or perhaps more) concerning is the prospect of this hypothetical victim of rape giving birth to a

disabled child."

When I mentioned this argument to Tasnim, who studied special education at a private

Islamic university, she shook her head in frustration. "Hysterectomy is forbidden in Islam.

People with some disabilities, like Down Syndrome, they can get married! Plus, it's not about

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[146] The Islamic Hospital is a large, private non-profit hospital located in downtown Amman. The Islamic Center Charity Society, Jordan's largest Islamic social institution and the charitable branch of the Muslim Brotherhood, runs the hospital. Janine Clark (2004) has written extensively on the class politics and implications of the Islamic Hospital and the controversy that its private status has generated.

[147] Al Bashir Hospital is a large, public hospital located in the Ashrafieh neighborhood of eastern Amman.

rape, these arguments, they just fear [she made the gesture of a pregnant belly]. And then there's

a baby with no father and a mother who can't take care of it." Local conversations about sex

between unmarried individuals, especially in instances of rape, unfold in the context of abiding

concerns over children born out of wedlock who remain the responsibility of their maternal kin

alone. These concerns are compounded by the dangers an unmarried pregnant woman might face

from her own family members if left in such a situation.[148]

Biomedical and religious authorities configure the boundaries of the body in significantly

different ways. Biomedicine, in Jordan, combines modern technologies of surveillance,

penetration, and control with a distinctly de-individualized construction of the body in alignment

with Joseph's model of connective selves. Doctors often define the boundaries of women's

bodies in relation to their kin. They discuss removal of the uterus neither solely nor even

primarily as something that will benefit (or harm) the woman in question, but rather as a "mercy"

for her family. In contrast, Imm Maryam and the fatwa both emphasize individualized bodily

integrity in terms of a wholeness that, while in no way synonymous with bodily or sexual

autonomy, nevertheless cannot be threatened or compromised to satisfy the wishes of kin.

Hamdy notes that in Egypt, tales, myths, and urban legends – as well as stark realities –

surrounding kidney theft have "[become] a stand-in for allegations of exploitation and

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[148] An illegitimate child is not, in Islamic legal law, formally considered kin; they cannot claim *nasab* (relations of filiation; see Clarke 2009). As such, the father cannot be legally compelled to support the child, and the child will have no right to inheritance. These restrictions are particularly salient in Jordan. Like many other postcolonial countries, Jordan has a dual legal system that treats marriage, divorce, and inheritance laws under the banner of "personal status laws." Amira Sonbol describes this system as "a patchwork of *fiqh* (Islamic theological) interpretations from various Muslim schools of law, particularly the Hanafi and Maliki, molded together with a dose of imported pre-World War I Western gender philosophy" (Sonbol 2003, 8). Christian marriages take place in the Church and follow Christian religious law (which often makes divorce far more difficult to pursue, especially for women, when compared to their Muslim peers). Inheritance law in Jordan, however, is treated as personal status law. Additionally, while tribal courts of justice were outlawed in 1976, these mechanisms for dispute resolution remain popular means to avoid or influence formal (i.e. state-run) legal institutions and frameworks (Alon 2007; Layne 1994; Massad 2001; Oweidi 1982; Shryock 1997; Watkins 2014).

vulnerability" (2012, 14). Sterilization in Jordan, while not an issue that has reached the level of

public myth, reveals widespread fears about the exploitation of vulnerable women by their

families and other more powerful figures tasked with providing them care. These fears directly

inform the majority position crafted by religious scholars, as well as the views of many

concerned families and activists who condemn the practice. The fatwa describes the

hysterectomy as potentially "enabling abuse." Although it does not provide any more detail,

Safiya's own accusations more bluntly articulated why this might be the case.[149]

The various relationships that supporters and detractors make about women,

hysterectomy, and vulnerability ultimately amount to ableist fears about disabled women's

sexuality, which become especially acute in the case of intellectually disabled women. These

fears is by no means unique to Jordan, however. Pamela Block, for example, examines a 1994

Philadelphia court case that ruled in favor of one Dorothy Wasiek's motion to sterilize her

"severely retarded" daughter, Cindy. After a seven-year legal battle, the court granted Dorothy's

request to perform a hysterectomy on Cindy, who could not take contraceptive pills because they

interfered with her anti-seizure medications. Since oral contraceptives were not an option,

Dorothy "decided that sterilization would be the best way to protect her daughter" (Block 2000,

247). But protect her from what, exactly? Dorothy grounded her arguments for sterilizing her

daughter entirely on the premise of protecting her from the threat of rape. In reality, writes

Block, "the central theme in this story was not Cindy Wasiek's safety, but rather how to allay her

mother's fears. Cindy Wasiek's entire life was structured on her mother's fear of her being raped

and becoming pregnant" (2000, 247, my emphasis). These fears did not stem from a specific or

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[149] Hughes (2017) has noted a similar convergence in Islamist and liberal representations of Muslim men's sexuality as threatening in his work with Jordan's Islamic Chastity Society.

personal threat, but rather from Cindy's intertwined conditions of being female, intellectually disabled, and fertile.

For intellectually disabled children, the embodied aspects of their impairments often pale in comparison to the attention given to the nature and extent of their cognitive differences. When intellectually disabled young people begin adolescence, however, their embodied capacities – primarily for sex and reproduction – can overdetermine their actual experiences of intellectual impairment. This overwhelming embodiment of intellectual disabilities becomes clearer in comparing the experiences of young women with those of young men.

VI. "A boy grows up": Male trajectories

Intellectually disabled young men face different constraints than do their female peers. While they also encounter intense surveillance by family members, caregivers, and teachers, they are far less likely to find themselves the targets of invasive bodily modifications. They enjoy a greater degree of individualized bodily autonomy than their female counterparts, which rings true for gendered experience in Jordan more generally. Because of patrilocal residence practices, a man's departure from his childhood home does not hold as great a symbolic significance for their transition to adulthood as that of woman's. In fact, the common expectation is that they will not leave home.[150] Many mothers continue to care for their adult sons, although they anticipate the introduction of younger and more active domestic laborers in the form of adult sons' wives.[151] The presumed inability of intellectually disabled young men to fulfill the roles of

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[150] Thanks to Susan MacDougall for pointing this out to me.
[151] This pattern obviously does not apply to all families. In some cases this is due to the financial impossibility of realizing this patrilocal residence pattern. In other cases, couples may simply want to establish a nuclear residency or be forced to live apart from extended kin due to work requirements, although this is less common in Jordan. Half of the country's population lives in the small region known as the Amman-Ruseifa-Zarqa area, which accounts for "91% of the capitalization of Jordanian companies (8.6 billion dinars out of a total of 9.4 billion in 2010), it is home to more than half of Jordan's businesses, and the seat of government and justice" (Ababsa 2013b).

husband and provider, however, severely curtails their transition beyond the status of a dependent.[152] Like intellectually disabled young women, they navigate two disjunctures simultaneously, uncertainly positioned within both their kinship networks and gender identities. Families struggle to answer a persistent, two-sided question: "What type of daughter/son is my child, and what type of man/woman can they become?"

Young people with intellectual disabilities destabilize both the performance and reception of local gender norms. Many families recognize that intellectually disabled young adults possess bodily and emotional needs and desires like anyone else. They question, however, the degree to which their children can successfully inhabit increasingly adult bodies in accordance with strong norms of adult behavior. Described as both cultural and religious in nature, these expectations place significant emphasis on modesty and propriety between men and women. A gendered interplay of autonomy and constraint is especially clear in the discourses of older women, who often speak quite candidly about the desires and sexual habits of young men. Parents and teachers negatively discuss young women's desires, and they usually do so in euphemistic terms of finding a boyfriend or husband. More explicit accounts of female sexual desire and activity are rare.[153]

For young men, however, this talk assumes a franker tone. Marcia Inhorn, drawing on her research with infertile couples in Lebanon and Egypt, writes that "in the Muslim world… masturbation connotes illicit sexuality, and is deemed by some men to be the cause of their own

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[152] Adeline Masquelier writes that young Mawri men in Dogondoutchi, Niger "are feminized by their inability to forge an assertive and productive masculinity through proper marriage. They have not yet moved away from the domain of female authority" (2005, 60). While to some degree this description holds true for intellectually disabled young men in Jordan, infantilization and feminization are not necessarily coterminous. In other words, remaining at home does contribute to the infantilization of intellectually disabled young men, and they do experience feminization through their association with the need for continued protection and care. But the families and specialists involved in the lives of intellectually disabled boys and young men are also very concerned with teaching them to demonstrate normative markers of masculine gender identity.

[153] My own status as an unmarried would have also played a role in marking this topic as inappropriate.

male infertility" (Inhorn 2007, 39). Many of Inhorn's male interlocutors explicitly implicated women, and especially their mothers, as contributing factors in the tormented relationships they developed with masturbation. For example, Inhorn describes a conversation with one man struggling with infertility who asserts:

> Arabs don't have a reasonable attitude toward sex. The problem is, the mothers are always telling their children, especially in the Muslim community, 'This is no good. *Haida haram*! [i.e. this is sinful].' Just to think about sexual matters is wrong… So, in cases where I would have an erection as a teenager, I wouldn't know what to do, because I wasn't taught. (2007, 44)

In my own research, while some mothers did express a belief that masturbation was *haram*, others drew on medical or biological arguments to frame masturbation as something natural, albeit subject to strict regulations.

During a mother's support group in east Amman, for instance, one mother asked how she could prevent her son from masturbating. The special education professor brought in to lecture on the topic of adolescence (*al-murāhaqa*) launched smoothly into an explanation that masturbation was completely natural and probably practiced by all male teenagers. Their responsibility as mothers, the professor continued, was to teach their sons where masturbation was acceptable and what to do afterwards– that is, how to properly wash one's body and deal with soiled clothes. She then added that too much free time could increase the frequency of a boy's masturbatory practices. If one's son masturbated excessively, the first question to ask oneself should be, "Why does he have all this free time in his room alone?!" I attended discussions in more than one group setting where expert speakers themselves introduced the topic, emphasizing the practice as natural and normal (*ṭabīʿī*), not inherently problematic. Although this framing did not convince everyone, the matter-of-factness with which women

much older than myself would easily segue into talk of masturbation suggests a certain quality of mundane pervasiveness.[154]

Imm Farid supported and advocated for her youngest son at a time when almost no medical or educational services were available to him and public discussions of disability rights were rare. Sitting in the courtyard outside their home, enjoying a long snack of juice, coffee, and melon before family lunch, I asked Imm Farid about her views on hysterectomy for girls with Down Syndrome. Completely reversing Imm Maryam's denunciation of hysterectomy as *haram*, Imm Farid considered surgery the best course of action.

> I support it, and so does Islam. If my daughter had Down Syndrome, I would have to remove her uterus. It's better for her, and it's better for her mother. If she got her period it would be such a challenge. Let her be comfortable (*khalīha tirtāḥ*).[155] And girls have sexual desires more than boys; that has been proven, scientifically. With a boy, you need to look out for him 24 hours a day, so imagine how much harder is it to look after a girl? You need to be even more on guard.

Her position regarding boys, however, was quite different.

> When there is a boy, I am against the idea of a mother going to a doctor for medicine to lower his sexual desires. Because it of course affects him... So it's wrong that the mother of a son who has Down Syndrome then causes him to suffer from another condition. It is wrong that a mother with a boy with Down syndrome should have to have even more problems. It is his right to live his life.

Imm Farid did not invoke the principle of *la darar wa la dirar* (no harm can be inflicted or tolerated) that Hamdy discusses in her work. Nevertheless, she drew on logic closely resembling this principle and reasoned herself to a conclusion opposed to that of the scholars who issued the fatwa. The removal of the uterus, she argued, did not constitute harm. In fact, from her

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[154] Indeed, Inhorn acknowledges a wide variety of positions on masturbation in Islamic thought, including practical arguments that view masturbation as preferable to illegitimate sex and as biologically beneficial (Inhorn 2007; see also Khuri 2001).

[155] This instrumental, largely negative view of menstruation was something I encountered throughout my research. When gauging opinions about hysterectomy among friends unconnected to my project, many described a period as oppressive and completely useless if one did not plan to or could not have children

perspective, it introduced benefits for both mother and daughter (the primary benefit being not having to deal with menstruation). Administering libido-reducing medicine, however, would introduce additional harm by negatively affecting the overall health of a boy/son– and note she did not use the word man (*rajil*). Consequently, she could not sanction such an intervention.

Imm Farid assumed that mothers and daughters share the burdens of menstruation and thus would share the benefits of its cessation. In this utilitarian framework, menstruation becomes an embodied but also disposable nuisance in the absence of a marital future, nature made strange through circumstance. Regarding males, however, a different situation emerges because, Imm Farid explained, "a boy grows up. I mean, it is no problem, teach him to go to the bathroom. That's his right to get his sexual desires out of his body. Watch out for him. Teach him go into the bathroom, to wash and clean himself; this is normal. But he cannot do it in front of people!" Describing masturbation as something easily contained and managed by the individual male subject, Imm Farid's stance reflects her broader assumptions about male and female bodies, sexuality, and subjectivity, as well as the potential shifting sensitivity of these topics. While discussions about sons registered both self- and other-oriented expressions of heteronormative desire, similar discussions about daughters emphasized other-oriented expressions of heteronormative desire and were far less physical in nature. The vulnerability that parents impute to disability, and the sexuality associated with adolescence, shapes how young men and women inhabit their gendered identities. These identities change over time and become clearest in relation to an adult status largely denied to them.

VII. Gendering vulnerability and aggression

Imm Fadi is a retired tourism sector employee who lives in an affluent suburb of west Amman with her husband and Fadi, the youngest of her three children. She described to me the

onset of Fadi's puberty as a dramatic rupture that ultimately affected her whole family's

wellbeing. She recalled that when he was young:

> We didn't feel like we had a disabled child at home, because we treated him like a
> normal child. And from birth to 15 years, everything was normal… [Then] he
> turned 15. Of course in the Arab World, you know that matters of the body and
> sexuality, to be frank… It's not that it's forbidden to talk about it. There's started
> to be more discussion about it. But, it's not honest, and it's not enough. And a
> mother, of a disabled son, can expect that at adolescence there will be hormonal
> changes.

Imm Fadi followed this introduction with an abrupt change of topic. "One day he went to al-

Markez [a very expensive and exclusive special education center located in west Amman], and

he refused to get off the bus." I later realized that this particular memory stood out for Im Fadi as

a turning point. It marked the onset of behavioral and affective changes in her son – anger, tics,

and aggressive outbursts – that she connected to one particular issue. "The main problem we

have is the bathroom. The masturbation influences his mind. We don't forbid him from entering

the bathroom, but when he starts, our routine changes, and then there's conflict." The bathroom

became a metonym for the disruptiveness of puberty.[156]

    Fadi's family eventually turned to medicine to control his behavior, both "the bathroom"

and the physical outbursts Imm Fadi described as increasingly common. The introduction of

pharmaceuticals into his daily routine, however, caused further problems. Fadi began having

seizures, which his doctors sought to control through even more medication. This escalating

cycle of medications and side effects unfolded exactly as Imm Farid feared it would, with drugs

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[156] Michael Gill (2015) criticizes the trope of the threatening, excessively masturbatory intellectually disabled
person, which reflects an ableist refusal to acknowledge people with intellectual disabilities as sexual beings, let
alone as having rights to sexual expression. I find Gill's analysis somewhat problematic in its depiction of the
sexuality and sexual activities of nondisabled persons as somehow outside the realm of power and unrestrained by
disciplinary measures. That being said, the implications of this trope certainly should be kept in mind during the
mother-centric narratives I discuss.

creating new problems and causing additional harm.[157] On the one hand, Imm Fadi depicted her

son's masturbation as excessive, but she also tied this excess to vulnerability. She wondered

aloud whether Fadi had learned to masturbate at the special education center she sent him to.

Imm Farid and Imm Fadi both describe intellectually disabled men as especially

vulnerable. At one point Imm Farid recalled a memory from many years ago when she brought

Farid on the bus with her to visit family in Aqaba. Upon boarding, Imm Farid had to deal with

the reactions of fellow passengers, who initially tried to physically shield their children from

looking at or interacting with her son. "I would tell them that he's not aggressive (*huwweh mish

'udwānī*!), that he loves other people, that he loves music. He's not aggressive!" At the mention

of aggressiveness, her daughter-in-law Jumana, who had joined our lunch date since she lived in

the same family compound, jumped into the conversation:

> Jumana: There is a girl named Aziza who sexually harassed Farid, but Farid
> understands that there are body parts where it is not allowed for others to put their
> hands on. He was very polite with her, and he came to tell us what happened.
>
> IF: Aziza came and held his hand, and he would tell her that this is not allowed…
> *Haram, haram*! I told him to hit her. He told me that he couldn't do that because
> it's not right. {She chuckled}. I told him to not let anyone come close to his pants
> or to his underwear. I told him to punch anyone that gets close to him there.
>
> Jumana: It is good that he is aware. They try to take advantage of him
> (*yistagalūhu*), but he is very careful.
>
> IF: When Farid walks, he walks like this [imitates someone with their arms tightly
> at their sides and their gaze lowered] and says excuse me so that he can pass. His
> siblings take care of him and teach him.

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[157] Farid was not the only young man with Down Syndrome I met who was on pharmaceutical regimes to control obsessive compulsive behaviors and psychological problems. When I returned in 2016, a new arrival to the young adult program had several doctors in his family who prescribed him multiple medications to control his tics and outbursts. They were, one staff member told me, "destroying his brain."

I smiled at this description because it so accurately captured Farid's bodily habitus. He was extraordinarily conscientious while navigating the mostly female space of the Society, always careful to employ exaggeratedly deferential physical gestures exactly as his mother conveyed.

Farid's mother and sister-in-law described Aziza as predatory and Farid as vulnerable. Aziza, who was the same age as Farid, frequently articulated her desire to find a boyfriend, much to the concern of her family. Once, at an event very early on in my fieldwork, a volunteer coordinator who knew Aziza well from the special education center she had attended for years, asked me to monitor her and another young man with Down Syndrome. She wanted to "keep them from flirting." I was caught off guard by this request and wrote in my fieldnotes about how uncomfortable I felt being tasked with policing the social interactions of two individuals older than myself. I watched Aziza and the young man in question, Hassan, happily and perhaps flirtatiously chat with each other; they made sure to stay a chair's distance apart the entire time. I also witnessed Aziza actively express her own concerns about maintaining local moral standards. When she attended events where music and dancing occurred, she did not partake and once chastised her friend Lara, only five years her junior, for shaking her hips too suggestively.

According to his family, Farid felt that Aziza crossed a boundary when she tried to hold his hand. "He came to tell us what happened," in Jumana's words. But this boundary was tied to an internalized understanding of his body as completely off limits. Farid's family entertained the possibility of him experiencing natural sexual desires, but only so long as they remained self-directed. These desires ceased to be acceptable once they involved another partner. When Imm Farid described her son's tight and restricting body language in the presence of women, she expressed this as a positive evaluation; this was how men should act, although many do not. In local constructions of masculinity, aggression can be potentially positive but in excess becomes

reframed as backward and un-Islamic (Hughes 2017). The stereotype that people with intellectual disabilities are inherently more aggressive than those without also contributed to many families' anxieties about how their children will be perceived. Imm Farid criticized Aziza for being sexually aggressive and less capable of controlling her sexual desires while praising Farid for his lack of aggression and visible demonstration of modesty and obedience. While seemingly an inversion of gender norms, these characterizations actually draw from and reinforce normative depictions of feminine sexuality as exceedingly dangerous, and women as less naturally capable of self-control (Abu-Lughod 1986; Mernissi 1975).

Imm Farid was not the only mother who contrasted her son with Down Syndrome to a dominant yet morally flawed ideal of (hyper) able-bodied masculinity. Imm Sami lives in a working-class neighborhood of Amman where many Syrians displaced by the war have found housing. She spoke highly of 18-year old Sami's moral character.

> He is not aggressive, nor does he get upset easily or cry. He was very sweet, and he still is. Even if he were to stay at home for the entire day, he doesn't go outside the house. I keep telling him to go outside and play, and he doesn't respond. I keep telling him until he goes. He loves silence and to sit at home, and he loves organizing the house, and watching TV and writing…. The neighbors' children play with him, but they don't accept him. They want him to be aggressive like them, but he doesn't like to be like that.

Both Sami's mother and father praised his lack of aggression and emphasized his conscious decision to "not to be like that." Later on, Imm Sami, continuing to reflect on Sami's good qualities added that, "We've taught him what is *haram*, what is ʿ*ayb*, what should not happen. We've taught him not to harass girls. Even his teachers in Syria stopped letting him greet them by handshake when he turned 10 years old, and until now he doesn't greet [women with his hand]." His father chimed in with a smile, "he just dances." Imm Sami concurred; "Yes he dances, but he doesn't greet [women]!"

Sami was clearly invested in this ideal of modesty. On a previous outing I sat behind him and another teenage boy – placed into the special education system due to severe learning disabilities – while riding a bus on a spring outing. Sami's companion turned around to first stare at me. Then he began to ask me questions about myself. Sami followed suit, turning around to observe our interaction. Once his seatmate had both my and Sami's attention, he leaned over to Sami and whispered something in his ears, presumably a comment of the sort teenage boys whisper to each other when in the presence of young women. Sami looked at me and then looked back at his friend and exclaimed *haram*! He sat down and stared straight ahead for the remainder of the car ride, ignoring his seatmate's requests to rejoin the conversation or at least engage him in sidebar chatting.

From the minute he got home from his job as a car mechanic, a thankfully translatable skill that allowed his family to survive under precarious circumstances,[158] Abu Sami sat with us and actively contributed when he heard a question that piqued his interests. He shared his wife's concerns about their son's vulnerability. Sami had previously secured employment at a popular local restaurant chain, but eventually his parents grew uncomfortable because they felt his bosses were exploiting him. They also worried about the influence other employees might wield over their son. Abu Sami elaborated vaguely. "He might not always realize things. For example, if someone told him, 'Let's go and get something,' he might go with that person. Those are the worries that we and others have for them; that someone will take advantage of him." Imm Sami confirmed this general fear of exploitation. "When he was in a restaurant, for example… We always told him not to take anything from anyone, even water. He brought his water from home. Even the restaurant manager asked us why we sent him with water, and I told him so that no one

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[158] The vast majority of Syrian refugees live outside of the designated refugee camps of Zaatari, Azraq, and Emirates Jordanian (UNHCR 2018).

will take advantage of him or harass him." Sami's parents feared his inability to manage the relationships of hospitality and reciprocity that form the core of Jordanian social life, protection and isolation emerging in equal parts.

Unlike Imm Farid, however, Imm Sami did not view masturbation as something normal. While talking about Sami's commitment to piety, prayer, and his refusal to shake women's hands, she commented, "Everything just needs its own warning. Even if they want…" She paused and got quiet. "Other things… you know what I mean," her voice dropping a bit lower.

> So that they don't make it a habit, we tell him that it is *haram*. One of the mothers told me that she was jealous of me because I was able to make my son understand that… We worry about him, but we watch him closely.

While Imm Farid acknowledged her son's sexual desires but sought to keep them self-directed, Im Sami sought to suppress her son's urges entirely. Neither woman, however, embraced the possibility that her son might eventually get married.

VIII: Marriage matters

Many families refuse to consider the question of marriage, while others invest a great deal of imaginative and practical labor in maintaining this vision of a possible future. Family members support or oppose marriage with a variety of arguments. Some families see in marriage a vision of their child's future security, happiness, and companionship. Many of those opposed offer materialist arguments against marriage, pointing to the expenses and work that maintaining a household economy requires. Other arguments focus on the intellectual and emotional requirements that a *shar'ī* (meaning both religiously legitimate and legal) marriage entails. Still

others use the issue to critique a local "obsession" with marriage and to point out that moral personhood in a properly Islamic society should not hinge on marital status.[159]

Imm Farid and Imm Sami voiced similar objections to the desirability and feasibility of marrying their sons. Abu Sami, however, openly disagreed with his wife. When we began to talk about the "future," Sami's parents oriented themselves differently in time and space. For Imm Sami, the future marked a space of painful uncertainty, linked to their status as refugees in a country that they felt was difficult and inhospitable. After prefacing her statement by declaring that her faith in God was greater than her fear of the future, Imm Sami went on to describe the impossibility of returning to Syria, the toll that living in a state of *ghorba* (homesickness) took on their wellbeing, and the strain of facing the endless hardships living of in Jordan. Abu Sami, at this point in the conversation, asked his son to leave the room for a few moments. He then turned to me and said, "When you say future, are you asking if he will one day get married?" Without pausing to hear if this was in fact what I imagined, he continued, "I hope that I can marry him to a girl like him. But people tell me it is impossible." He trailed off. Imm Sami then interjected, disagreeing with her husband, and they began to argue:

> Imm Sami: No, I am against this. I am the first one to oppose this.
>
> Abu Sami: Why?! What is the reason?
>
> Imm Sami: So that he will not have a child like himself. Who will take care of him? Am I right? I am 60 years old and I take care of him. If he gets married to another girl like him, there will be two people that need to be taken care of.

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[159] Whether parents would ever raise this critique with regards to a single adult child without a disability remains questionable. Marriage remains a key component of the transition to adulthood in Jordanian society, although trends and ideas about marriage are in fact changing (Adely 2016). For example, Jordanians are well aware that "westerners" tend to marry later. Many of the women and men I knew either connected this trend to the perceived moral deterioration of western society, approved of it as practical and necessary to succeed in today's economy, or combined a paradoxical mix of both assessments. They recognized that similar trends had taken root in their own society, and these trends were subject to extensive debate (Hughes 2015).

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Abu Sami: That doesn't have to be the case. He doesn't have to have children. But just so that he can learn to be responsible and have a life. Like other countries, where they try to have them depend on themselves and they have real work. When he sees his brother get married, he will ask why not him? And he will get sad and frustrated (*biṭḥizni nafsu wa bitdayi'*). When he watches TV and sees two people in love, he watches them closely. He gets happy and laughs.

Imm Sami: Yes, of course he has feelings and affections. He's human! (*ilu 'awātif wa andhu mishā'ir. Huwweh insān!*)

Abu Rami: I hope that he will get married, even if they don't do anything, just so that they can be two people together, so that they will be a family and have a house.

Imm Sami articulated two major concerns. Echoing the doctors who support hysterectomy operations, she brought up the issue of Sami having a child "like himself," a child he and his wife would not be able to care for. Aside from the question of children, however, a marriage "to another girl like him" would mean more work for Im Sami. Daughters-in-law are both expected and valued for their contributions to their mother-in-law's home and personal wellbeing. Im Sami did not believe that a daughter-in-law with Down Syndrome could fulfill this role. To the contrary, Imm Sami would be the one required to prolong and expand her role as a caregiver in her old age.

Imm Farid echoed these concerns when I asked her whether or not people with Down Syndrome in Jordan got married. She responded:

If I wanted to marry [Farid], I would have to meet the girl's parents and their financial situation would have to be very good. Because they [people with Down syndrome] have expenses for medicine and food... I am not able to take care of another like my son; it would be impossible. But if her [financial] situation was very good, and they take him for a month, and then I take him for a month, then… maybe.

Imm Farid described the responsibility of caring for two adults with Down Syndrome as impossible (*mustaḥīl*). She did not foreground Down Syndrome itself but emphasized her material objections: food, medicine, expenses, and the implicit emotional and physical burdens

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that care work entails. Like Imm Rami, she anticipated that Farid marrying would culminate in the addition of another resident to her household, one for whom she would be expected to accept primary caregiving responsibilities and costs. That was a prospect she could not agree to. Imm Farid connected the limits of her domestic economy and issues of household governance to the larger political economy of caregiving in Jordan:

> We don't need any problems… I would consider it ignorance (*jahl*) for us to marry them. Why? Why is it so important? Leave him alone. Let him be. Once, when these doctors from Switzerland came, they told us to let them get married. "It's his life," they said. You all provide him everything, but here it isn't like that! Why would I marry him? To carry his burdens on top of my own (*'ibā'u fowq 'ibā'ī*)? Should I ask his siblings [to help]? If the government helped a little and gave him a salary, I would get him married. But to make the whole thing my burden – it's impossible.

Families and experts often deployed accusations of ignorance (*jahl*) to critique local practices of shaming and stigmatizing disability. In this case, however, Imm Farid obliquely accused the Swiss doctors, authoritative and prestigious figures, of being ignorant. Their thoughtless promotion of marriage for people with Down Syndrome irrespective of local context and constraints marked them as the backward ones. She also pointed out the enduring connections between Farid and his siblings. The idea that siblings remain responsible for each other's care is by no means novel or unreasonable (Joseph 19993). Parents understand, however, the precariousness of this sibling-dependent care, especially given the difficulties of making ends meet in contemporary Amman. They know they cannot rely completely on the generosity of their other children, as much as they hoped for it.

Despite changes in betrothal practices and the criteria that make for a "good" match, marriage in Jordan continues to operate as a fundamentally communal process conceived in terms of collective wellbeing. That the decision to marry should ever lie solely in the hands of individuals remains cultural anathema among both Muslims and Christians in Jordan (Adely

2016). At the same time, the particular arguments parents marshaled for or against the marriage of their disabled children – and the anxieties these arguments indexed – reveal how sexual morality and constructions of disability are intimately intertwined. While in constant conversation with globally circulating rights discourses and productions (such as the UNCRPD), these constructions remain grounded in a local world where marriage is deeply connected to moral personhood, kinship politics, and resource distribution.

IX. Unresolved conflicts

For families who invest a great deal of time, energy and passion into advocating for their children's rights to education, employment, and (more fundamentally) for respect and dignity, ambiguous adolescence and stalled adulthood present painful contradictions. One day, Farid returned home from the Society rather smitten with a female volunteer he had met. He went to his mother and showed her the girl's picture on Facebook. She responded, as she had before in similar situations, first by pretending not to understand his desires and then by redirecting them.

> He started to ask me my opinion of her. I looked at her and asked him, "Who is that?" I understand what he wants, but I pretend that I don't understand. He told me, "This one! I am asking you what you think of her." I told him, "I don't like her at all. She is very arrogant." I told him that I didn't like her at all, and that she was not pretty. He disagreed… I changed the subject so that he would forget and talk about something else. But there was a period when he would talk about it a lot.

The inability to get married raises frustrating and unresolvable questions for people with intellectual impairments as they age. After one of many such conversations, Farid, visibly upset, asked his mother, "Am I sick? Is that why I can't get married?"

These struggles are by no means unique to people with intellectual disabilities in the Middle East. Reflecting on the life of her younger brother with Down Syndrome, feminist philosopher Sophia Isako Wong (2002) writes that, "nobody quite knows how to deal with the

idea of an individual with Down syndrome being sexually active, let alone having her own

family" (107). Elaborating on this point, she continues:

> In this society, mentally retarded adults are caught in a double bind. They are pervasively treated like perpetual children misplaced into sexually mature bodies who should be carefully monitored and prevented from expressing themselves. Institutional structures as well as social norms restrain their sexual impulses. If a retarded person acts on her impulses, for example hugging a person she finds attractive, she's punished by her parents or social worker for "inappropriately showing affection" and further restrained. If she learns to suppress her impulses and doesn't show them, she's considered asexual and therefore isn't provided with opportunities to develop romantic companionship. (2002, 108)

Given how strongly my interlocutors emphasized that Jordanian/Arab cultural values dictated

families' attitudes toward disability, they might be surprised by the degree to which the society

in question, Wong's hometown of Alberta, Canada, captures many of the tensions at play in their

own lives.

Chapter 6. Conclusion

Families in Jordan imagine the future in terms of relationships between kin, and Down Syndrome emerges through these relationships. Imagined and feared futures loop back to shape the present in myriad ways, and in so doing, they shape Down Syndrome itself. The lineal relationships between parents – mothers in particular – and their children are usually central to these issues. With the passing of time, however, siblings become increasingly vital actors and sustainers of kinship futures. How do families imagine relationships yet to come and the roles they will play? Families cannot avoid, nor can they completely articulate, these futures, but they acknowledge the inevitability of death with a mixture of aspirational acceptance and practical concerns. Questions about care haunt the future, forcing family members to distinguish between what they can and should expect from their family members, especially as they contemplate generational transitions and transformations. To understand how the presence of death shapes these relationships of care and futurity, one must consider notions of morality and personhood in Jordan, both of which are informed by shared notions of religious truth and commitment, albeit to varying degrees. The pivotal concepts that hold together these elaborate dynamics – namely, ambivalent inheritance and kinship futures – are in turn situated in relation to larger disability worlds. My interlocutors and I interacted as fellow inhabitants of these worlds, not as total strangers, and many of the people I worked with most closely understood my research as one moral project among many others, and they incorporated me into projects of their own. These worlds continue to shift and expand into new territories, but they also face ongoing challenges in the form of local and regional circumstances that undermine their security.

I. Maintaining moral accountability: ʿajr and hisāb

Imm Tariq lives in an upper-middle class neighborhood of west Amman. She left her native Iraq over 20 years prior to my meeting her. Her family members live scattered across the globe, in Europe, Canada, and the United States and keep in touch primarily through a giant family WhatsApp group. Ten-year-old Tariq, the youngest of Imm Tariq's three sons, has Down Syndrome. As we sat drinking coffee in the salon of their family home, Imm Tariq and I discussed various facets of life – the superiority of Iraqi cuisine, the *ṣadma* she experienced on learning of Tariq's Down Syndrome, and her dream of one day opening a nature-based therapy program for intellectually disabled children and adults. She lamented Amman's sprawling urban landscape, which she described as a negative influence on one's psychological health and wellbeing. Imm Tariq described her son as a person like every other human being: (*huwweh insān)*.

> He doesn't understand that anything is different about him. He's a human being, and we have to treat him as such! And that he has a right to live his own life. Right? This is important. Religious experts tell you, "Take care of him. Watch out for him. He will take you to heaven… I once asked a religious woman (*daʿiyya*) about this… She told me that he is a path to God, a path to heaven (*tarīq li-l-janna)*.

The idea that a disabled child creates a path to heaven – and I use the word child to signify a kin relationship rather than an age or category – emerged repeatedly throughout my research. Recall that Imm Samira, introduced in Chapter Two, responded quite strongly when her friend Alia mentioned some Muslims might understand disability as a curse. "*Habībtī*!" she replied. "How could Samira be a punishment? She is my path to heaven. She is proof that God loves me. She is mine and of me."

What does it mean to be a path to heaven? How is this path created, and for whom? I asked Imm Tariq as much.

This phrase means that – look, a disabled person doesn't come to just *any* family. That's not how it works. This is a test from God. He's telling you, "This person needs care. This person has needs. Are you going to provide for him?"... It's like with normal children! Normal children are also a trust from God (*amānah*). It's the same thing… This sends you to heaven. That is the meaning.

Like in Hamdy's discussion of the body and ethics of organ donation (Hamdy 2008, 2009, 2012), Imm Tariq identified children as a trust (*amānah*) from God. While children are "of" their parents, to take from Imm Samira's words, they ultimately come *from* God. This godliness intensifies in the case of disabled children, whose needs increase the rewards (*ʿajr*) gained through the good deed of providing care.[160] Amira Mittermaier encountered a similar sentiment among young people participating in community service initiatives in Egypt, who frequently reminded each other "the poor don't need us; we need the poor. They're our gate to paradise" (2014, 524). This logic does not fit within a humanitarian or even a humanist justification for the work they undertake; it concerns matters of life – and death – beyond the human.

Many of the volunteers in Mittermaier's research, like many parents entrusted with providing care and raising a disabled child, understand themselves as fulfilling a *duty* to provide for others in order to maintain their relationship with God. Yet the provision and continuing need for care does not fully account for what makes intellectually disabled persons unique and particularly valuable within this spiritual economy. As Imm Tariq's explanation above makes

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[160] In his typological study of benefit granting in Islam, Kazuo Ohtsuka (1988) notes that while *thawāb* definitively refers to rewards granted in the afterlife, *ʿajr* ostensibly covers both rewards in this life or the afterlife (142-132). In everyday conversation, however, my interlocutors primarily used the term *ʿajr*, rather than *thawāb*, but they explicitly connected *ʿajr* to entering heaven. I have not encountered distinctions between *ʿajr* and *thawab* in ethnographic research, with anthropologists appearing to define both as "reward" (Atia 2013; Deeb 2006; Schielke 2009). I once asked my friend Rania to explain the difference between *hasanāt* and *ajr* to me. After laughing and exclaiming that this was an odd question, I explained that I often heard people discuss both, and I wondered whether they were the same thing. Rania answered definitely in the negative. She did, however, equate *ajr* and *thawāb* as things you need to enter heaven. *Hasanāt*, by contrast, were good deeds that could help you at heaven's door, but they were not as important as mandatory requirements like fasting. Fasting gives you *ajr*. Donating to a good cause gives you hasanat. After providing this distinction she paused, "maybe I should check the Internet, just to be sure." Her Internet search, however, was inconclusive, and we moved on to other topics.

clear, all children are blessings from God, and caring for any child increases one's ʿajr. So the difference at hand is not one of kind but one of degree. It is nevertheless significant. This is because many family members and professionals believe that intellectually disabled persons do not hold accounts with God (mā yuhāsibū). In other words, they do not, nor will they ever, need to worry about committing sins and accruing ʿajr – they are already guaranteed a spot in heaven. The embodiment of ʿaql, which is central to assessments and performances of adult personhood in Jordan, plays a role in how people with Down Syndrome embody this non-accountability.

While investing intellectual disability with a particular kind of value, this framing nevertheless comes at a cost. The non-accountability that makes intellectually disabled persons valuable also makes them vulnerable. Not having an account means that family members and caretakers in turn became even more accountable, justifying the close surveillance and restrictions they impose on intellectually disabled kin, especially as they age out of childhood. The more valuable one becomes in defining closeness to God, the more risk one poses to reputation and individual accounts of kin. ʿAjr and hisāb provide insights into aspects of personhood and agency that emerge through hierarchical, nonsecular relationships where matters concerning the afterlife shape everyday, interactional aspects of disability. But the inevitability of death intrudes into families' everyday realities in other ways as well. To reiterate, families do not necessarily describe the economies of care that shape their futures in terms of Islam, but caring well for family makes one a good Muslim. The moral economy of care in Jordan possesses spiritual dimensions, but it is equally thought of in terms of the fragile exchanges and debts between kin.

II. Fraught transitions: continuing care

Parents and siblings fear for the future in terms of questions of care that loom in the distance. Hana's mother occasionally became distressed when thinking about the future, asking her daughter, "'If I die, and your father dies, what will happen with Jamil?" Hana usually responded by trying to problematize the nature of the question itself. "We don't know. Maybe I will die first! It's not always the older generation that dies first," she added somewhat ominously to me. "Of course, I fear the future, for everything in my life. We can't think too much about the future because it makes life hard." One dimension of Hana's critique speaks to the moral implications of fearing the future. As a good Muslim, Hana tried to remind her mother and herself that that the future belongs to God. But Hana's avoidance of her mother's plea also reflects how young people in Jordan today cannot rely on the normative trajectories imagined through kinship futures. Across the Middle East, displacement, war, and poverty continue to disrupt and demolish family and generational cycles, and "it's not always the older generation that dies first." Perhaps more importantly to Hana, her mother's fears center on Jamil. Hana, in turn, re-centers these fears to acknowledge her concerns about her own life. As a young woman living in her parents' home, Hana also has to wonder about what will happen to her after her parents die.

Like Hana's mother, Imm Fadi spoke openly about how she feared for her youngest son's future. Fadi's turbulent transition to adolescence exacerbated his mother's concerns about providing for him in the future and who, besides her, would be capable of doing so. On the one hand, she worried about Fadi's safety and happiness, and she dreaded the possibility that he would eventually live in some sort of residential center. On the other hand, she expressed equal

concern about asking any of her children to commit to caring for Fadi after she passed. In describing these anxieties, Imm Fadi situated herself within a transnational disability community.

> Now I'm thinking about his future… it's not just us thinking about the future. I opened Youtube and I saw that many families - even in Britain - have fears about the future of their children with Down Syndrome. In Britain, some families… marry their children with Down Syndrome. But, even with marriage, they need supervision from the mother and father… In Britain [people with Down Syndrome] are educated, and they can work, but they still need a mother or father supervising their routine... So the mothers [there] suffer, and we mothers suffer too.

Turning to the Internet to conduct her own research, Imm Fadi noted that futures everywhere seem fraught with tension. Even in Britain, where marriage, education, and work are possible (unlike, she sought to imply, in Jordan), questions of guardianship, care, and supervision endure, and they are linked to the burdens of mothers.

Sibling relationships in the Middle East have been used to theorize gender, patriarchy, and power (Joseph 1994; Joseph and Slyomovics 2011; Kaya 2010; Moallem 2005), kinship and statecraft (Jean-Klein; Peteet 2010), complexities of artificial reproductive technologies (Clarke 2007), and theories and practices of kinship more broadly, especially through practices of milk kinship (Al-Torki 1987, Guindi 2012; Holy 1989; Clarke 2007). Less attention, however, has been given to the practical forms of care and accountability that link siblings across time, especially in caring both for aging parents and for each other after parents die. As she considered her children's possibly connected futures, Imm Fadi felt deeply troubled by her options. "For me," she said, "as long as I'm alive, my son will stay with me. I will care for him at home. After that... I tell his siblings - this is your choice. At that time, you do what's appropriate… They shouldn't carry guilt." Imm Fadi paused for a second, digesting the weight of the words that hung in the air. "But *Insha'allah* no. *Insha'allah*. We'll leave it to God. We'll leave it to time."

Although Imm Fadi tried to reconcile herself to the idea of leaving this choice to her other children, the implications for Fadi's future proved too unsettling.

III. Disability worlds

The moral, temporal, and social dimensions of intellectual disability in Jordan are manifest in how families encounter and negotiate Down Syndrome and other intellectual disabilities. The passage of time and nonsecular dimensions of temporality play key roles in shaping the meanings and experiences of disability in Jordan, which emerge through interlinked life paths shared by kin. I have used the notion of *kinship futures* to capture the collective and evolving nature of these dynamics. Disability, I argue, must be placed in the broadest possible context to be understood in its local iterations, while locality in no way implies isolation from the global and transnational circuits of ideas, alliances, and activism that the very word "disability" entails. Devlieger et al. introduce the notion of "disability cosmology" to capture, "the largest possible perspective on the making of disability worlds," or the worlds "generated by experiences of disability" (Devlieger, van Hove, and Renders 2006, 77).[161] Disability worlds can be multiple and contradictory, and they exist inside of, apart from, and enmeshed within non-disabled worlds. This was true of my fieldwork, and I'd like to conclude by thinking through the implications of this complicated process of enmeshment.

A different world

During Ramadan, many of Jordan's philanthropic and charitable organizations coordinate *ifṭārs* for people in need. I attended one such *ifṭār* in the city of Madaba, which was sponsored by

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[161] Faye Ginsburg and Rayna Rapp titled their 2013 annual review piece "Disability Worlds," but they do not contextualize the use of their term as an analytic. "Inspired by the local and worldwide disability rights movements," they write, we are increasingly convinced of the global importance of bringing disability perspectives to every domain of human life, recognizing the commonalities as well as differences among them" (2013, 62).

a national organization that focuses on addressing hunger in Jordan. To coordinate the event, they worked in conjunction with a local women's society, providing basic meals and toys for the families in need who attended. My former landlord, Dunia, invited me to join her. She had convinced the father of a young autistic woman she met many years prior to send his daughter and her caregiver to attend the event, to give them a chance to get out of the house and celebrate. Dima was in her early twenties. She was non-verbal, quite tall, and extremely thin. She showed up with a water bottle in her hand, shaking it and observing the flows of water and light quite contently while wandering around the room. Her caregiver, Linda, sat in a chair while looking bored. They had arrived far too early and were the only two people in the gymnasium that doubled as a dinner hall.

I went over to talk with Linda about her work and her life with Dima. Linda was originally from a small village near Irbid, and she had completed a B.A. in education. She rolled back the sleeves of her long black abaya and became more animated as she talked. She eventually secured a job in the special education sector, and at one point she worked in a center that served autistic children on the very northern edge of Amman. When the center announced they had a client looking for a full-time caregiver for his adult daughter, she jumped at the post. The salary was over double what friends made in the private special education sector. With her significant raise and bi-weekly trips back to her family in Irbid, Linda was extremely happy with her job. When she left to visit family, Dima's father would come and take care of her. She described him as a good man who loved his daughter. But after the death of his first wife, he remarried, and Dima became an unwanted figure in the new marital home. "He's not ashamed of her, or anything like that. When they host gatherings in the family *diwan* (meeting hall), he lets her wander around and stay by his side. But I've never met the second wife…" I asked Linda if

Dima had any friends. She gave me an incredulous look. "She knew her mother; she knows her father; she knows me; and she knows the gatekeeper (*ḥāris*). That's it."

As I sat contemplating the dynamics of death, (re)marriage, and care that shaped Dima's lonely life, other families began to arrive. For almost the entirety of my fieldwork, I worked in disability-centered spaces or met families in their homes. I rarely encountered firsthand the intense stigma and ostracism that families spoke about. This particular occasion, however, provided me with another perspective. People stared at Dima. Young girls stared and whispered. Mothers shot concerned glances her way and held their children closer. One woman, after watching Dima for a few moments, got up and relocated her whole family to a table farther away from where we sat. Much to her chagrin, Dima followed them, although this was only because they had relocated by the window, and Dima enjoyed the rays of sunshine. I walked over to join her, and she grabbed my hand without looking at me. We then walked back to Linda.

At this point, Dunia arrived and joined us at our table. This officially made us the oddest table in the room – a woman in a wheelchair, an autistic woman shaking a water bottle continuously (stimming), and a clearly foreign guest. Dunia informed me that while the *ifṭār* was open to anyone in need, almost every family in attendance was raising at least one disabled child. Scanning the room and watching everyone stare back at us, she added, "If these families actually live with some sort of disability, and treat Dima like this, imagine what the families who have no experience with disability are like." Then Dunia did something unexpected. She shouted out, "Hey everyone, this is Dima. She likes to move around a lot. This is something from God (*shī min Allah*). Everyone has their own issues. You can talk to her. You can call her name. She'll respond. She understands." Dunia's announcement amounted to a watershed moment of sorts. Her tactic was not necessarily in Dima's best interest. Dima dislikes loud noises, for one thing.

Dunia was correct, however, to insist that our audience recognize Dima's capacities for response and communication, although she responds and communicates on her own terms and in ways that the other children and adults present might not have found familiar.

Recognizing these issues, Dunia's speech nevertheless moved Dima from the category of a threatening person to the category of a vulnerable person, and people began to engage with her. Eventually, more families arrived with members who embodied various kinds of disabilities. Dima, already made a less exceptional through Dunia's intervention, became an even more mundane figure. The sun set, the food boxes were distributed, and everyone turned their attention to breaking the fast. It struck me, however, that this *ifṭār* lacked the sense of conviviality I had experienced elsewhere, such as during iftars held at the Society. The event's somewhat fractured organization may have played a role in this. Regardless, each of the tables in the room ultimately felt like an island. Families did not engage each other through shared experiences of disability in the ways I frequently observed elsewhere. Needing a break from the post-dinner chaos of children receiving gifts and beginning to ride their sugar highs, I walked outside. There I ran into Inas, chain smoking and chatting with her friend Iyad and his brother. Both Inas and Iyad were physically disabled wheelchair users. They were part of the volunteer team that organized the meal. They asked me the usual questions about who I was and what I was doing in Jordan. "Let me tell you," Inas started, "Jordan is the worst country in the world *and* in the Middle East to have a disability in. There's no money and no infrastructure." Almost simultaneously, we all glanced at the giant gaps between the curb and the parking lot, one of the many elements of the center's completely inaccessible design. Inas invited me to visit her at work, and after some further chatting, we made our way back inside.

Cosmologies and cosmopolitanisms

Dima's story differs from most of the individuals I met through my research. In large part, this is due to the absence of her family, and especially her mother. Dima is the only child her mother gave birth to before falling ill and ultimately succumbing to cancer. Her father now lives with his second wife and their children. Essentially, Dima no longer belonged to a collective kinship future. Devlieger et al. propose the notion of cosmology to push studies of disability beyond an overwhelming focus on culture and identity and to recognize the greater stakes of disability as a form of being-in-the-world and disability as generative of worlds. But what really is a world? And is each person, or each experience of disability a world unto itself? The concept of cosmology, reflecting a desire to take the "broadest perspective possible," allows us to see how disability generates and has the capacity to dramatically remake relationships. It is through these relationships that worlds are built or become imperiled. Most of the participants in my project understand themselves as connected and connecting through disability, and they struggle to wield this connectivity to nurture their collective needs and individual trajectories. The dissertation tracks the relationships – and moral risks – that families of disabled children create, as well as those they attempt to challenge. Over time, the relationships change, as do the risks. Down Syndrome itself is also changing and will continue to do so. This dynamism reflects evolving practices of care and expanding opportunities for persons with Down Syndrome to determine the meaning of the label applied to them. These capacities, in turn, open doors into other disability worlds.

Almost all the families I met in Amman cultivated connections with disability communities both in person and online. In fact, most parents, and definitely all of the organizations I encountered, use and follow social media accounts more diligently than I do.

Social media facilitate engagements on a global scale, although these ultimately maintain clear, distinctly local goals and effects. **"Down Syndrome Without Limits"** (*mitlāzamat Down blā hūdūd*), for example is a public, Arabic language Facebook group with over 13,000 members, approximately .01% of whom I know personally. "We Have Down Syndrome, Our Lives Have Meaning" (*mitlāzamat Down maʿānā, ḥayātnā lahā maʿnā*) is an Arabic Language Facebook Community Page with 32,455 likes and 32, 287 followers. "Love Syndrome" (*mitlāzamat al-ḥubb*), also a community page listed under the subcategory of "public figure," features one young man in particular. Most of these communities are run by the family members of people with Down Syndrome – mothers, fathers, and siblings – who seek allies, friends, and connections, in the more instrumental sense of the words.

These pages prominently feature images. On some accounts, especially in the case of group or personal pages associated with schools, special centers, or individual family members, almost all of the photographs will feature actual members of the communities. Other popular images include stock photos or photos of individuals with Down Syndrome who have achieved some sort of pop culture status. These photos frequently have inspirational quotes pasted over them. One popular recurring meme features a smiling, nameless child with Down Syndrome, usually the same blonde boy or a brunette with pigtails, whose face is bordered by Arabic text in various fonts. The text has variations of the phrase, "you are beautiful but the eyes of your society are ugly." In other cases, images or posts include biographical details about the specific person featured. For example, when Frank Stephens testified in front of Congress in the fall of 2017 to advocate for increasing the NIH budget allotted to Down Syndrome (which is disproportionately limited given the prevalence of the condition), his face suddenly appeared all

over my newsfeed. His speech was translated into Arabic, with subtitles provided underneath the actual C-Span video or in a separate text on the side.

Images do not always dominate online accounts. Some pages widely distribute information – primarily medical or rehabilitative in nature – about Down Syndrome. Others serve as message boards, with parents looking for advice on good schools, methods for discipline, or child-rearing techniques. Members will also share conflicts and awkward moments with society, as in the case of one woman from North Africa who described entering the post office and having to respond to an employee's queries about what was "wrong" with her daughter. Thumbs up, hearts, and angry faces follow in torrents, and comment threads can climb to hundreds of messages long. Facebook walls and Instagram feeds enable connections between Arabic speakers living around the world and under extremely different circumstances, from Occupation in Palestine and revolution in Egypt to extreme wealth in the United Arab Emirates. They also enable connections with English-speakers around the world, and it is here that many of my interlocutors find their most provocative comparative material. If Down Syndrome everywhere consists of the same chromosomal signature, why do people with Down Syndrome live such different lives? How is it possible that a person with Down Syndrome in Switzerland can go to school, have a job, and get married, while in Jordan they are often consigned to severe disability and early death? These reality gaps create both hope and anger, speaking to the aspirations, inequalities, and immobilities that shape the production of cosmopolitan imaginaries and practices of identification (Appadurai 1996; Schielke 2012).

Online connections allow me to continue communicating with interlocutors and observe evident shifts that nevertheless remain mysterious from afar. Friendships end, careers change, families move, crises occur, and achievements are celebrated. The use of social media across the

Middle East attests to shifting domains of public and private, although the online worlds I encountered remain structured by the same moral standards that exist offline as well. The increasing public-ness of piety intertwines with the emergent public-ness of disability, giving a distinctly religious tone to many of the interactions and depictions that occur online. Individuals and group pages post fatwas pertaining to intellectual disability and ask members for their opinions. One topic of persistent concern: fatwas relating to marriage for persons with Down Syndrome. This has been accompanied by a small, but nevertheless significant, increase in shared posts featuring young Arab couples with Down Syndrome getting engaged or married.

Moral projects and (kinship) futures yet to come

Throughout the dissertation I describe my interlocutors as both actors and targets of various moral projects. They largely saw me as an ally in such projects, although their contributions to my work have far surpassed any help or utility my presence might provide for them. Nevertheless, in thinking through the simultaneously global and particularly local dimensions of connectivity generated through disability, I often return to an early encounter in my fieldwork. The Society hosted a free dental clinic, and it gave me a chance to meet long-term members, as well as many newcomers drawn by the much-needed services. The dentist providing the free services, Lama, fled Syria at the start of the war. She first made her way to Beirut and then decided to settle in Amman. She asked what brought me to same city, and I began to describe my project. Lama became progressively more enthusiastic as I explained the details of my research. "We are all human," she exclaimed, aptly summing up the core premise of the discipline of Anthropology. She then connected this statement to the goodness of God, whom she began to praise at some length. Imm Zahra, standing beside me, began to chuckle. "Christine is one of the least religious people you'll ever meet." The dentist, however, disagreed.

"Religion is in good works. God put us on the planet to be good to each other. *We* need each other. *He* doesn't need us! But we need each other to understand each other and live with one another; this is being religious (*hayy maʿnā al dīn*)." Lama had no problem incorporating me into her own moral project, making my presence perfectly legible on her terms.

The children and adults with Down Syndrome I met during my research created worlds in and around themselves, but for these worlds to flourish they require commitment from and connections to kin. The possibilities of their worlds ultimately depend on their incorporation into kinship futures, and in cases of family conflict, they remain supremely vulnerable. Down Syndrome in Jordan will continue to unfold at the nexus of global ideas and local practices, on Facebook walls and in conference halls. Demographic pressures and worsening economic conditions will continue to have transformative, unpredictable effects on families, communities, and political dynamics in Jordan. As persons with Down Syndrome live longer and healthier lives, they will challenge families, neighbors, and society to engage in new debates over what defines normal and who gets to decide. In turn, broader shifts in marriage practices, economic mobility, residence patterns, religious engagement, and legal structures will shape and reshape what it means to be disabled and what kinds of impairments become disabling in Jordanian society. But not everything will change. The future will remain unknown. It belongs to God, and it depends on family. These truths, as they have already done, will continue to motivate family members to fight for their children, challenge the status quo, and elaborate new kinship futures.

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