

development

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By

Umm Adnan, [ii](#) like many women I met during my research on Down Syndrome and kinship in Jordan, was extremely protective of her son Adnan. The youngest of four, Adnan was constantly battling sickness. His health issues, in conjunction with Down Syndrome, marked the toddler as especially vulnerable, and Umm Adnan reacted by cultivating her own brand of fierce maternal surveillance. On one occasion, I watched her enter a community organization that served as a hub for my research while carrying Adnan in her arms. The other women sitting in the reception room – some accompanying their own children to lessons or appointments of various kinds and others fulfilling administrative and organizational roles – reacted to this sight with concern. Could Adnan not yet walk? Adnan could walk, his mother averred, but it was difficult for them both. She feared him becoming fatigued, falling behind, or getting separated from her. Carrying him was easier – and safer. Her audience responded with compassion but also criticism; they urged her to think of her son's

long-term wellbeing. Adnan would only develop skills and independence by using his own two legs.

Umm Adnan and her audience were focused on a more intimate and fleshy kind of development than what David Mosse describes as “big-D development” (2013, 228). The latter dominates the ruling Hashemite family’s vocabulary of governance, as well as that of the cosmopolitan elite; it also informs the humanitarian and civil society organizations that work with government ministries and hybrid public-private partnerships to form a robust “political economy of acronyms” (Moore 2005; see also Sukarieh 2016).

Inextricable from the class and (post)colonial politics of the region, the notion that societies can and must develop resonated strongly with my interlocutors and informed the disability legislation and rights campaigns gaining traction across Jordan. In this piece, I situate the hegemonic narrative of “big-D” development alongside tarbiyya, a long-standing model of human growth and change that has its roots in Islamic traditions of learning. These frameworks overlapped and intertwined, contributing to what I call embodied development. I use this term to highlight how existing regimes and practices of development intersected in the lives and bodies of children with Down Syndrome, positioning

them at the nexus of national, personal, and family projects.

Big-D development and tarbiyya possess distinct genealogies and extend toward different horizons, yet they converge in placing the highest value on education. The Ministry of Education's official title as the steward of both tarbiyya and taʿlīm (education) gestures to this convergence. Tarbiyya encompasses "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). Transmitted through formal educational channels and quotidian life lessons, tarbiyya attests to a widely shared sensibility among my interlocutors that human beings can and must develop – socially, morally, and spiritually – with the careful guidance of elders and mentors. The role of education is equally critical for facilitating "big-D development." This is precisely why, according to the World Bank, Jordan presents a "gender paradox"; women's ever-increasing participation in formal education has not created the expected outcomes: parallel entry into the formal labor market and decreased fertility rates (Adely 2012; see also Abu-Lughod, Adely, and Hasso 2009).

These close links between education and development shaped my interlocutors' everyday engagements with childhood disability. Through early intervention and rehabilitative therapies, the embodied development of disabled children became the target of formative and regulatory maternal labor, and mothers became the targets of social and educational development programs. Some women found these technical frameworks empowering and readily intuitive, while for others they proved alienating and opaque. I watched as mothers negotiated between the undeniable presence of additional chromosomal material and the plasticity of its implications. They urged each other to remember that a child with Down Syndrome was "like any other child" (zayy ayy ?ifl t?n?). Yet they also urged each other to recognize how Down Syndrome could impact the course and scope of embodied development, demanding the pursuit of new approaches, resources, and tools. Children's growth and maturation transformed into explicit tasks, materialized through programs, checklists, and evaluations by experts. These new practices reconfigured various milestones – of walking, speech, and dexterity – as celebrated achievements rather than taken-for-granted products of time and nature. And in turn, they generated new practices for objectifying and cultivating embodied development in disabled

children.

Conducting ethnographic research on Down Syndrome in the capital city of Amman^[iii] led me to varied spaces and communities. I met political activists, professors, philanthropists, special education teachers, therapists, and of course families. I attended support meetings, conferences, public events honoring international days of acknowledgment (usually designated by the United Nations), and I visited women and families for meals and gatherings. Most of my interlocutors lived in west and east Amman. They were mothers to babies, toddlers, and preteens with Down Syndrome, although some had children in their early twenties to mid-thirties. I use the word child here to emphasize the importance of family roles and relationships in their ongoing elaboration of Down Syndrome (mitlzman Down, or simply Down), which remains an unevenly recognizable diagnostic and biosocial identity. Working to foster embodied development, family members – usually mothers and female kin – entered into relationships of collaboration and discipline with specialists and with each other. They forged networks for communicating and connecting. They shared tips, videos, and websites offering techniques of embodied development, which ranged from the best oils for persistently dry skin, to drills that

utilized small chunks of healthy vegetables to strengthen tongue muscles, to the pros and cons of bouncy swings.

The booming fields of speech, occupational, and rehabilitative therapies offered frameworks for materializing diagnoses of disability, delay, and chronic conditions, at least for families who could access them. Not exactly medical, but certainly medical-adjacent, these regimes merged with long-standing approaches to embodied development rather than replacing or creating them de novo. An older woman described how, long before speech therapy was established, she drew on her observational skills and a household mirror to achieve what she understood as a maternal duty—developing her son’s ability to “speak well.” Despite their shared success, she nevertheless lamented the absence of established services during his childhood. As I have pursued a disability-centered anthropology, tarbiyya has helped me think through the social and gendered dimensions involved in the cultivation of embodied development. Mothers pursued low-tech, accessible forms of therapy and training while anticipating their children’s struggles to inhabit social norms that placed immense emphasis on bodily control. One mother recalled a stranger accosting her while on a family outing at a local restaurant to confirm that

her son was Down. The stranger wanted to know how they developed her son's skills for proper eating (a standard requiring one to perform both muscular operations and rules of etiquette successfully). She would not take her own daughter, who had Down Syndrome, out to restaurants because she made too much of a mess.

Early childhood development initiatives invested embodied development with endless possibilities for growth and becoming, as well as more uniform expectations for success and what this looked like. When children failed to meet expectations, mothers struggled. Why, wondered one woman, did her friend's son start to communicate with speech while her own son preferred to gesture and rely on body language? Was she doing enough for him? Was his Down Syndrome different? The paradoxes of embodied development multiplied. A child with Down Syndrome was "like any other child" but also different; children with Down Syndrome shared something important in common yet also differed from each other, as all children do. Down Syndrome – in its fleshy and lived implications – emerged and receded from the frame at various points in time, and in various ways. As mothers and allies worked to create more accessible lives for children with Down Syndrome, they used and

adapted the resources available to them. Ideologies of “big-D” development and philosophies of tarbiyya shared certain synergies with each other and with newer therapeutic frameworks. Generative while also deeply normative, these models identified disabled children as important actors/objects in their respective projects. They left women like Umm Adnan and their children navigating the stubbornness and malleability of bodyminds to confront the contingent roles that Down Syndrome might play in shaping their becoming.

Notes

[\[i\]](#) *This formula literally translates to “mother of + name of child.” While in principle parents take on the name of their first-born son, in practice they may be referred to by the name of any of their children. I use this naming practice, with pseudonyms, to mirror how my interlocutors commonly referred to each other using the parental title with the name of an individual’s child with Down Syndrome.*

[\[ii\]](#) *Most research in the MENA region takes place today in capital cities (Deeb and Winegar 2014). While population demographics play a part in this trend, it has nevertheless resulted in notable urban skew over the past few decades. In my*

own interlocutors' social mapping, the Governorates beyond Amman were described as far more hostile to disability, as well as inadequately connected to the resources that remain largely concentrated in the capital.

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as change over time.

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