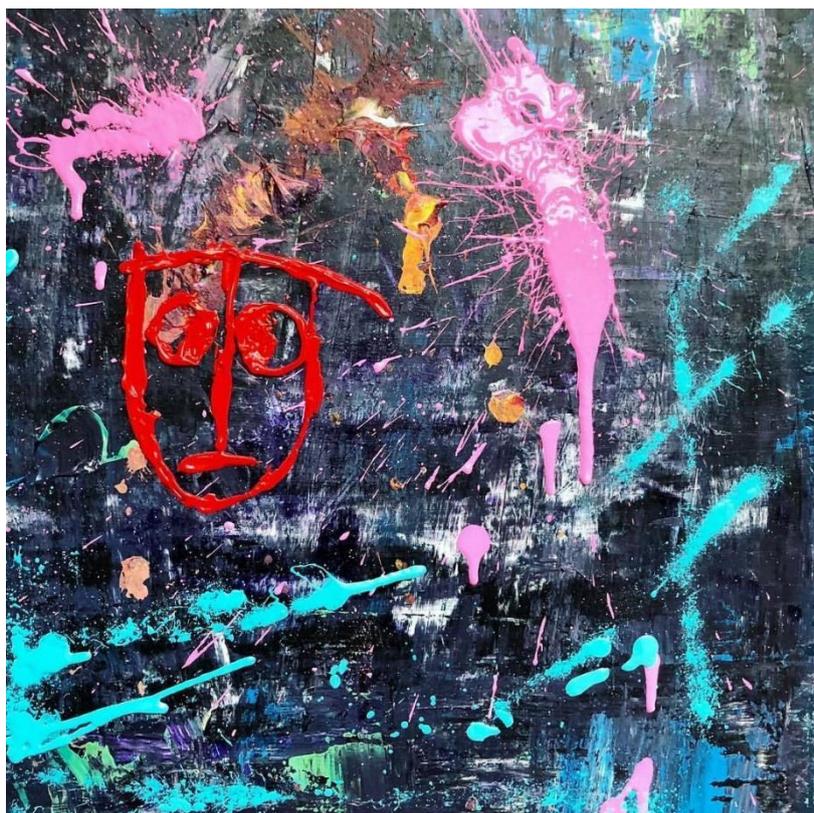


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**“What About Us?”:
The Unheard Voices of the Lebanese Revolution**

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Art by Sevy Marie Eicher, a 16-year-old non-verbal artist with Down Syndrome. Source: Instagram @sevymaryart

With a yellow ribbon in her hair and a slightly oversized backpack on her shoulders, she looks at me and waves goodbye. She then turns away, with a smile of excitement, as she walks up the stairs of her school. First day of school after months of lockdown. Some people thought she would never be able to learn, some thought she would never belong in a school, and there she is, with her reading books, drawing pads, and math activities, proud to start a new year. My daughter is one of thousands of children with intellectual or learning disabilities in Lebanon.¹ Her school, a small private special education institution in Greater Beirut, has struggled to survive throughout the country's multiple crises over the past year: a pandemic, a national socio-economic crisis, and a massive blast that shook its capital, destructing lives and infrastructure. With no support and recognition from governmental entities, the school, like so many other special education and inclusive education institutions in Lebanon, is left alone to fight its battles. As I watch my daughter go to school, I cling onto this semblance of normalcy in our current precarious and chaotic realities, while feeling the deep solitude of a lonesome fight against an uncertain and treacherous future. What will Lebanon do for you, my little one? What rights will you indulge in? What social protection will you benefit from? What platforms will there be for your participation? How valued will your contribution to society be? Who will be shouting your worth?

In the absence of a state that cares, children, youth, and persons with disabilities, as well as parents and organizations in Lebanon are alone to lead the fight for equal opportunities in education, employment,

¹ In this article, the terms "intellectual disability" and "learning disability" will be used interchangeably, though the author acknowledges the existent differences in definition and classification in the literature.

social participation, and inclusion. The disability rights agenda has been historically advanced in Lebanon, not by the government, but thanks to the efforts and actions of communities and civil society. However, any progress made risks to remain unstable and un-sustained in the absence of national governance and translation into effective policies and laws.

In October 2019, a movement started in Lebanon – the people's uprising, finally speaking up against governmental incompetence and corruption, and the state's sustained inability to provide basic rights to its citizens, residents, and communities. The *thawra* (revolution) was born and continues to exist, in diverse forms and slogans, amid controversies, criticism, and doubts of its existential importance, suspicions of hidden agendas and manipulations, and critique of its effectiveness. While many still question the revolution, no one can deny the burst it ignited in people's lives. A disruption to the system, a glitch to everyday functioning, a flicker of hope that the corrupt and "resilient" governance system (Geha, 2019) might somehow be perturbed. That civil rights may one day be respected. That change may one day see the light.

The revolutionary heroes and disability representation. الثوار الابطال

And at the forefront of the battle lines, the revolutionary heroes. These anonymous fighters, persevering against unjustified law enforcement, violent riot police, and live ammunition trying to silence them, carry the torch of human rights, raise their voices, scream to unwilling ears the civil rights and liberties they are entitled to. The disability community was proudly represented by some of its heroes too.

Many long-time disability activists, such as members of the Lebanese Union of People with Physical Disability and others, are once again roaming the streets, proving their existence, calling for their rights. People have also shown solidarity with fellow protesters with a disability. Everyone recalls the hopeful story of the young man from Tripoli, cleaning the streets after the protests, who got offered a prosthetic leg. Everyone has seen the video of the hearing-impaired young man, singing to his peers, the slogans of the *thawra* (revolution) using sign language. Many have posted selfies in solidarity with the two young men who each lost eyesight due to unnecessary violence by riot police. الثورة بعيونكن. "We will resist" is what they are saying.

Loud voices shall not die.² "الصوت العالي ما يموت، والثورة بوسط بيروت"

The revolutionaries restlessly chant "Loud voices shall not die." What about the unheard voices? What about the whisperers, the silent, the silenced, and the forgotten? What about the estimated 5000 children and youth with intellectual or learning disability³ in Lebanon? They have been almost absent from the *thawra* battlefields, aside from timid efforts from some local organizations, and a musical play performed in Martyrs' Square by a group of performers with special needs (Hamadi 2019). The question here is a

² A popular slogan shouted during the Lebanese protests in January 2020.

³ In this article, the terms "intellectual disability" and "learning disability" will be used interchangeably, though the author acknowledges the existent differences in definition and classification in the literature.

rhetorical one. We are not talking about a mere physical absence on the revolution streets, but about an absence in discourse. In other words, why hasn't their cause been heard? Why hasn't it been loudly emphasized, together with the numerous other social issues that have been raised and are still restlessly being raised by the revolution?

The cause. القضية

I have come up close and personal with the daily struggles for inclusion and participation faced by people with disabilities in Lebanon, being the parent of a delightful and beautifully mischievous little girl with Down Syndrome. I am also a leadership member of two disability-focused organizations in Lebanon and a current PhD researcher in disability studies. Presenting the following state-of-affairs stems both from a reading of the various realities and political discourses, as well as from a personal struggle.

Research reports in Lebanon show multiple structural inequities for people with disabilities, and persons with intellectual disabilities are particularly the most discriminated against and marginalized in sectors such as education and employment (Combaz 2018). Lebanon has not yet embraced a model of inclusive education, which leaves children with learning disabilities with limited options in education. They can either enrol in public education that would fail to provide an appropriate environment for their learning needs or enrol in a few select inclusive or specialized private schools and pay expensive discriminatory fees. Only 1% of children with disabilities in Lebanon are enrolled in public education (Combaz 2018). Some non-governmental organizations (NGOs) offer informal or semi-formal forms of education to remedy this gap; however, resources and quality remain sub-par.

It is estimated that about 80% of persons with disabilities in Lebanon are not or have never been employed (Combaz 2018) and the percentage becomes significantly higher for persons with intellectual disability. The state has failed to promote inclusive workplaces, to ensure equal employment opportunities, and to protect individuals in the workplace against discrimination. The Lebanese Law 220/2000 for the rights of people with disabilities abolishes discriminatory recruitment in the workplace, instructs a 3% quota, and imposes financial penalties for non-adherence, but its enforcement remains severely lacking. Some organic and scarce non-governmental initiatives currently explore various models for skills training and inclusive employment. The endeavours achieved by businesses such as Agonist Coffeeshop, the first coffee shop in Lebanon to employ almost exclusively persons with learning disabilities, are commendable. However, this is not enough. We need to push this further in a sense where equitable and inclusive education and employment for all becomes the norm, and not a social media sensation or a tokenistic manipulation.

Passive disablism

Thomas (2010) defines disablism as "a social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorized as 'impaired' by those deemed 'normal'" (p.37). I would like to argue that the past and current inaction from the state constitutes a form of passive disablism. This can be reflected in how the government views disability: law 220/2000 is the

only current piece of legislature that tackles the rights of people with disability in Lebanon. However, it adopts an outdated medical model of disability, and hence does not recognize the social and environmental determinants that shape the disability experience, failing to look at disability from an ecological perspective. Also, often, a charity language is used by policymakers and politicians when discussing disability. “We are doing good for you because we are the good ones” is what they insinuate – not because this is your right. Not because this is everybody’s right. There have also been negative representations of disabled people in the media.

Law 220, as presented within the current context, represents only what Runswick-Cole & Goodley (2015) call “a cluster of promises” (p.168): equal employment, inclusive education, free healthcare, to only name a few – which are unfortunately only reflected through ink on paper. Every now and then, officials make statements about supporting the needs of people with disabilities, without any official commitment from the government to implement its clauses or to issue reinforcing decrees. Lebanon has also not yet ratified the UN Convention on the Rights of People with Disability, which sets a legal framework to ensure that human rights and fundamental freedoms of persons of all abilities are met. The past and present narratives have continuously presented a “cruel optimism” (Berlant 2011), where people with disability are made to believe that change will happen, only to be faced with frustrations and disappointments.

Disability and the socio-economic crisis

For the readers who are unfamiliar with the current Lebanese socio-economic and political crisis, here is a snapshot of the current situation and its effects on disability rights in Lebanon, along with some prognostic scenarios.

While the crooked crows in power bicker and fight for their last piece of the dying worm, the country’s economy swirls down a vertiginous decrescendo and is near an eminent crash. The worm wiggles helplessly to save its life, and so do the 100 or so organizations working with persons with disability in Lebanon, facing the threat of closure at the end of every month. This has been worsened by the Beirut explosion, as some organizations have now suffered additional costs for reconstruction and recovery. These organizations serve approximately 12,000 persons with disability, providing services that range from healthcare, to education, to protection, to employment. They have been doing what the government should have been doing. And now, these same organizations are not able to do it anymore because of the government not doing what it should. The Ministry of Social Affairs who contracted these organizations to provide services for the disabled, has not released the due funds for more than a year now. This has caused these organizations to take emergency measures to persist in their work such as lay-offs, downsizing, and intermittent closures, which ultimately affect beneficiaries, and some centres have been forced to shut down.

The current politico-economic crisis exacerbated by the pandemic is affecting all sectors and all segments of society in Lebanon, and even neighbouring countries. Everyone is exposed, but not everyone is affected equally. The impacts of the crisis are differentially distributed, and as expected, the most marginalized individuals are the ones who suffer the most, as observed among disability focused organizations. And, with the current crisis and an expected International Monetary Fund (IMF) bailout,

what would this mean for the disability community? How would this affect the basic needs and quality of life for people with intellectual disability?

Without going into an in-depth economic analysis and a discussion on capitalism and neoliberalism, the quick answer would be obvious, as often happens whenever the IMF intervenes: austerity. The financial crisis and subsequent austerity measures will not only affect individuals with intellectual disabilities, but also their families, caregivers, and other support networks they depend on. If the sole providers for individuals with ID have significant reductions in their income, or lose their job, or cannot access their money at the bank, not only will their lives be negatively affected, but also, the lives of the persons with disability who depend on them, hence increasing the precarity of living for those already in significantly precarious lives.

“Nothing changes if nothing changes”

Following these concerning scenarios, what can be done to ensure that the dignity and rights of people with disabilities, including those with an intellectual disability, are not dismissed or deliberately neglected within the chaos of the current crisis? As hope and promise fade, as would the late Chris Cornell solemnly sing, what change should be sought out, what glimpse of breakthrough should be pursued, for the safeguarding of humanity and equity for all?

Nothing changes if nothing changes. Any major social change inherently implies a change of dynamics, a shift of paradigm, a schism in the business-as-usual. A nudge, a kick in the system, that would ignite another change, either consequently, exponentially, through a ripple-effect or through diffusion. I believe in the power of small changes, the magic of new beginnings, the drivers of movement, the igniters of transformation. Some may argue that pushing this agenda, in an already scarce work environment, and unemployment rates increasing every week, is ludicrous if not absurd. I would like to argue the opposite, and believe that now, more than ever, is the time to talk about this. I cite here some reasons and suggestions for change.

First, I refuse the narrative of oppression and victimization and believe in the agency of persons with all disabilities. In fact, most actions of structured or consequential discrimination in history, have led to the rise of resistance movements among the disability community. Historically, especially during the Roman times, having a disabled body was a perceived normality. It is only towards the Middle Ages, with the scientific progress, the development of contemporary medicine, and the introduction of medical and scientific models to explain the observed, that disability was labelled, categorized, and compartmentalized as a difference to the norm (Braddock and Parish 2011). It is with this labelling that came increased discrimination, but this also fostered a consequential sense of identity, which was then the starting niche of advocacy and self-advocacy movements (Braddock and Parish 2011). This re-activism has also reflected itself in reactions to structural or policy decisions, such as the Disabled People Against Cuts movement in Britain, and the global People First, “Nothing about Us without Us” movements (Braddock and Parish 2011). Public debates need to challenge traditional misconceptions and stereotypes on individuals with learning disabilities as lacking competence, articulation, and agency to express their needs. Over the past decades, increased focus has been given on the strengths,

capabilities, self-determination (Shogren et al. 2006), active role (Levitt 2017), and the decision-making capacities of people with intellectual disability, especially with regards to employment (Timmons et al. 2011; Bush and Tassé 2017). Research has shown that most adults with intellectual disabilities seek economic independence and self-sufficiency through employment (Migliore et al. 2007; Nord et al. 2013), and successful models of supported employment are now the norm in several countries in the world, with positive outcomes for the individuals and the community.

Second, I believe in the power of solidarity, of “common bonds” (Bates et al. 2017). Now, more than ever, we have witnessed both random and organized acts of solidarity across the entire Lebanese territory. More than ever, and once again, people living in Lebanon have shown to be an army of determined ants, a buzzing beehive working together, irrespective of gender, race, nationality, and socio-economic status, to assist each other and fill in the innumerable gaps unsatisfied by the government. Now, more than ever, people are sensitized to social issues, are attentive to the suffering of others, are sharing their grievances, and are initiating support. It would be strategic now, more than ever, to raise the flag of human rights and direct attention towards the needs of individuals with disabilities, especially those with intellectual disabilities. It would be the timeliest to influence public opinion in how it views and reacts to disability, and initiate conversations and concrete actions with regards to inclusion. These “common bonds,” although fragile in nature, have shown to often be the lifeboats for individuals with learning disabilities, that have helped them sustain themselves in contexts of precarity (Bates et al. 2017). Now is also the time for cross-movement solidarity, into convergent demands and targeted actions (Zajak, Janson, Pleyers, & Lenz, 2020).

Third, I believe in organizations, civil society and independent actors. I believe that NGOs, and specifically international NGOs and United Nations entities who are not directly influenced by the economic crisis because of their external sources of funding, can have a crucial role in the advancement of disability issues within the crisis. Local organizations in Lebanon, including self-advocacy groups, may often feel limited by their own operational and organizational capacities, and may not succeed in organizing themselves towards systemic social change. I hence believe in the contribution of international organizations, social enterprises as well as private sector actors in assisting local organizations and self-advocates, in alleviating some of these limitations and in creating partnerships for change. Now is the time for socially invested corporate social responsibility initiatives; now is the time for programmatic change for international organizations and a shift in technical objectives towards current urgent community needs, a redirection of funds towards socio-economic development, with disability rights and concerns at the forefront of decision-making, so that no one is left behind. Persons with intellectual disabilities could form independent advisory groups or be included in executive boards or expert panels to inform discussions and decisions, as they would know best what is the most relevant to them.

These public and private organizations, including academic institutions, can also support in the generation of data, through relevant research and assessments – the lack of sufficient relevant and reliable data on disability in Lebanon, which would guide policy and practice, being at the core of the problem.

Fourth, I believe in systemic change. And this entails changes at the policy level. And we will always continue to push policymakers, decision makers and people who hold a position of power, to ratify the

UN Convention on the Rights of Persons with Disabilities, review, update, change and implement the content of law 220 accordingly. With every change of government, and despite general public opposition and mistrust, it becomes a strategic time to advocate for policy change and pushing the disability agenda onto any new government's table, and positioning the disability cause as a priority portfolio.

These constitute just a mere selection of micro-, meso- and macro-system changes which could be provoked to strive for dignity and equity for people with disabilities in Lebanon, especially those with learning disabilities.

Hope as a political statement

Amid multiple crises, collective trauma, and despair, I would like to present hope as a political statement. Away from current sterile and empty discourses praising the "resilience" of the people living in Lebanon, and away from the usual manipulative speeches from political parties inciting naïve and blind optimism from their followers, I am suggesting a reconceptualization of hope as a socially constructed form of popular resistance. Hage (2003, as mentioned in Kleist & Jansen, 2016, p.382), defines "societal hope" as "collective visions of 'meaningful life and dignified social life' within a given society." In the face of consistent abuse of power and political incompetence from the state, hope within a stance of dignified resistance from the disability community is a strong statement in itself. This also differentiates itself from the current shallow mediatization and romanticizing of persons with disabilities as "those with a strong will" (ذوي الإرادة الصلبة), and paternalizing representation of children and youth with intellectual disabilities as "angels on earth." Persons with disabilities are citizens, and they have rights that should be met. Period. A radical shift in discourse is long overdue.

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