

When the state does not care:

Disability rights in a context of multi-layered crises, instability and disablism

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Abstract

Although the UNCRPD is the guarantor for the rights of persons with disabilities, it is critiqued for conceptualizations of individualized rights, in stable contexts where rights are state-protected. We investigate how disability rights can be advanced in unstable and crisis-affected contexts in the Global South. We use the case of Lebanon, which has experienced multilayered crises, has not ratified the UNCRPD, and has outdated policies based on charity-medical models of disability. We argue that, in a disablist and unstable state, any progress made is threatened by the absence of institutionalization of rights, and interrogate the limitations of the UNCRPD. Through a critical policy review and interviews with self-advocates and disability activists, we suggest a new model of action for disability rights affirmation by strengthening community governance, initiatives, and networks; solidarity and joint actions between disability and wider civil society groups; international advocacy; and the political identity of the disability movement.

Keywords

Lebanon; disability movement; human rights; disablism; UNCRPD

<a> INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) proposes to be the key guarantor for the rights of people with disabilities worldwide. However, it is critiqued for its conceptualizations of individualized legal rights, in assumedly stable contexts where rights

are state protected (Meekosha, 2011, Lang et al., 2011, Meekosha and Soldatic, 2011). It is unclear how disability rights can be advanced in unstable and crisis-affected contexts in the Global South, especially non-signatory states.

Lebanon presents an interesting case for such a context. A small country of the Middle East with Oriental and Western influences, the country has a tumultuous history of war and humanitarian crises, and constant instability at political, security and economic levels. It has witnessed a 15-year civil war (1975-1990), multiple Israeli bombardments and aggressions, a full-fledged war against Israel in July 2006, and two protracted refugee crises (Palestinian refugee crisis in 1948 and 1967, and the Syrian refugee crisis in 2011). In the past two years alone, Lebanon has witnessed multi-layered crises which have deeply affected the lives of all its residents. First, an unprecedented economic and financial crisis, ranked by the World Bank as being among the three worst crises in the world since the mid-19th century, with a rising inflation rate and a massive depreciation of the local currency (The World Bank, 2021). Second, political and civil unrest, after the Lebanon Uprising of October 2019 (“*thawra*” or revolution in Arabic), where thousands gathered in the streets to protest the dire living conditions and called upon governmental action. Third, the Covid-19 pandemic, which hit Lebanon a few months later, and where the initial governmental response to the pandemic was qualified as inadequate (Gebara, 2020), with excessively strict lockdowns imposed that further exacerbated the economic downfall of the country (ILO & FAFO, 2020). Lastly, on August 4th, 2020, a massive explosion that hit the heart of Beirut, due to a fire in a warehouse where 2750 tons of ammonium nitrate had been unsafely stored at the Port of Beirut due to governmental neglect (Geha, 2021). This resulted in a humanitarian disaster and was described as one of the most powerful non-nuclear explosions in history.

These conflicts and disasters in Lebanon have historically exacerbated the dire situation of people with disabilities in Lebanon, with the destruction of rehabilitation institutions and increasing numbers of war injuries and war-afflicted impairments (Kabbara, 2012, Kingston, 2013). It is estimated that 10-15% of the population in Lebanon have a disability (Combaz, 2018), and more than 102,149 individuals are holders of the disability card (Abdallah, 2017). People with disabilities in Lebanon face a systemic lack of access to and provision of services, rights, and resources. More than 80% are unemployed, and less than 1% access public education (Combaz, 2018). Healthcare services lack accessibility and affordability (Baroud, 2017). The Beirut

explosion also created “new disabilities” with approximately 800 people developing a chronic impairment due to injury, and these people have not received from the government any kind of compensation, free access to healthcare and needed surgeries, or work allowance due to loss of livelihoods after the explosion (Hammoud, 2021, Ghsain, 2021).

The state has also failed to ratify the UNCRPD, making Lebanon one of the remaining 12 non-signatory states in the world. The main assumptions in common human rights discourses, which are also insinuated in the UNCRPD, is that 1) policies are state-led, disability rights are state-protected, and state capacity is assumed; 2) the context offers a certain level of stability to sustain policies and practices that promote disability rights and 3) systems and policies to further disability rights seem to be independent of language, culture, religion, and ethnicity (Meekosha, 2011, Lang et al., 2011, Akerkar et al., 2016, Akerkar, 2007, Akerkar and Devavaram, 2015). In contrast, Lebanon presents a complex context of instability, multi-layered crises, a segmented sectarian-based political system coupled with disablist¹ governance (Khawam, 2020), in a non-signatory state of the Global South. The aim of this chapter is to explore how disability rights can be advanced in such a context, with a focus on the following research questions:

1. What are the contextual and political obstacles and challenges to disability policy formulation in Lebanon and how do they hinder/limit disability rights activation?
2. Which actors, dynamics, mechanisms, and strategies influence the policy discourse in Lebanon towards disability rights activation?
3. How has the disability rights movement navigated through the Lebanese context to further the human rights of people with disabilities?
4. What learning can be gained for disability rights mobilisation from the Lebanese case?

Learning from the Lebanon context can be relevant not only in non-signatory states and/or conflict settings, but also in many international contexts where disability rights remain poorly enacted, and where the implementation of the UNCRPD continues to be lacking, due to limited state capacity,

¹ While the authors acknowledge that the terms ‘disablism’ and ‘ableism’ can sometimes be used interchangeably, they are highlighting the discriminatory and oppressive nature of the absence of adequate enforced policies, hence the use of the term ‘disablism’.

insufficient accountability measures and/or rampant discrimination (Aldersey and Turnbull, 2011, United Nations Department of Economic and Social Affairs, 2019).

<a> METHODOLOGY

Methods used include a critical review of the Lebanese disability policy context in academic and grey literature, and transcript analysis from interviews with seven disability activists in Lebanon, including four self-advocates², carried out between October 2020 and May 2021. Each self-advocate holds either a founding and/or leadership role in an organisation of people with disabilities (OPD) in Lebanon. The other activists (who are not self-advocates) are parents of young people with intellectual disabilities. These interviews were part of a doctoral research project on job readiness among youth with intellectual disabilities in Lebanon³, and aimed at developing a better understanding of disability rights and the disability policy context in Lebanon. Analysis in this chapter will explore tensions, power relations and dynamics in the disability policy process in Lebanon and explore who are the makers and users of the disability policy discourse.

The research methodology used is qualitative and is based on political activist ethnography, which focuses on “producing knowledge that can be mobilized by civil society activists and members of social movements”(Bisaillon, 2012, p.608), and where the researcher’s aim is to expand their knowledge “to grasp how a ruling régime works with a view to transforming it” (Smith, 1990, p.629). G.K. (author) is a researcher, disability activist and a disability service user (having a daughter with a disability) based in Beirut, Lebanon. Through this research project, she explores the disability rights movement in Lebanon across history and throughout the current crises, while acknowledging her own role in the disability movement⁴ and personally experiencing the crises while residing in Lebanon. S.A. (co-author) is an academic based in Oxford, UK and an advocate for human rights and disability rights in the Global South. She is also involved with the disability

² All four self-advocates identified as being disability activists (confirmed through the interviews). Two had a physical disability, one had a visual disability and one had an intellectual disability.

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⁴ G.K. holds leadership positions within two disability advocacy networks: Steering Committee Member of the Disability Hub, located at Centre for Lebanese Studies since September 2019 & Board Member of the Lebanese Down Syndrome Association since August 2018

rights movement in Lebanon⁵. The co-authors provide an insider-outsider perspective to the issue of disability rights in Lebanon.

The conceptual framework for analysis is based on the policy-as-discourse theory, coupled with human rights and development studies perspectives. Policy-as-discourse perceives social problems (and hence policy problems) not just as a matter of whether a specific policy has been advanced or opposed, but as socially constructed through the policy discourse of the various interest groups and actors involved (Bacchi, 2000, Shaw, 2010). The focus of policy analysis hence is not in the ‘problems’, but in the ‘problematizations’, namely how policy problems are identified, analysed and solutions are addressed (Kriztman, 1988 as cited in (Bacchi, 2000, p.48). This framework is relevant to be used in analysing the Lebanese context where, given the lack of disability policy (or lack of its implementation), it is pertinent to explore the problematization of disability discourse in policy and political discourses,

<a> LEBANON’S APPROACH TO GOVERNANCE AND SOCIAL POLICY

Before addressing disability policy and advancement of disability rights, it is important to provide some background on public governance and social policy in Lebanon. The country’s social geography is complex and diverse and represents the most concentrated mix of ethnic and religious groups in the Arab Region (Jawad, 2002). 26% of the residents are estimated to be non-Lebanese (data extrapolated from UNHCR, 2020). There are 18 constitutionally recognized ethnoreligious subgroups known as ‘sects’, belonging to these three religions, with the most prominent being Sunni Muslims, Shi’a Muslims, Maronites Christians, Orthodox Christians and Druze (Jawad, 2002). Although the state is by definition secular, its constitution (set out in 1926) is confessional (i.e. related to confessions of faith or sectarian religious subgroups): it ensures equal representation of each of the 18 religious subgroups into public functions, hence laying the foundations for a sectarian power-sharing political system (Geha, 2021, Nagle and Clancy, 2019). Although often presented as being the key to preserve peace and reduce tensions between confessional

⁵ SA is the founder member of the Disability Hub, located at the Centre for Lebanese Studies, Beirut and is involved with the Hub’s campaigns on disability rights in Lebanon.

communities (Nagle and Clancy, 2019), the power-sharing system failed to prevent a civil war in Lebanon, which expanded between 1975 and 1990, and further created or sustained sectarian-based political parties. This led to the ‘sectarianization’ of society after the civil war, which was where “key belligerents—for example, state elites, proxy actors, and militia groups on the ground—manipulated and constructed ethnoreligious identities, typically through acts of extreme violence, to cleave society along communal lines in pursuit of strategic self-interest.” (Nagle and Clancy, 2019 p.2).

This sectarianization reflected itself in all forms of state governance, including social policy and functioning. The public welfare sector is relatively weak, and relies essentially on non-governmental actors - partly funded by the government - to provide essential services and care for groups considered vulnerable, such as people with disabilities, older people and orphans (Jawad, 2002). Many of these organizations are sectarian-based, and since the government has not enforced any strict system to monitor their work, they dominate public and informal channels of service provision, giving them power and privilege over the groups they are serving. Many of their practices can be discriminatory based on political and/or sectarian partisan affiliation, and can further exacerbate social inequalities (Cammett, 2015).

In addition to the confessional political system, the Lebanese state is characterized by weak structures to support legal frameworks and policy reform. This is essentially due to the centralization of power, outdated bureaucratic mechanisms, inefficiencies in administration, and overall mismanagement (Haase, 2018). Its political economy is more that of a liberal laissez-faire system headed by what Jawad calls “a politically impotent bourgeoisie” (Jawad, 2002, p.321). This political elite has been described as “resilient” (Geha, 2019 p.66) and has been able to sustain its power through multiple forms of corruption (Adwan, 2004). Clientelism, a widespread form of corruption in Lebanon locally known as “wasta”, is manifested through appointment of key public functions by each political leader to selected individuals within their own constituency, for political and financial personal gains (Nagle and Clancy, 2019).

<a> DISABILITY POLICY IN LEBANON: ANALYSIS OF LEGAL FRAMEWORKS, CHALLENGES, AND OBSTACLES

In the backdrop of this macro-economic and political context, we take a closer look into disability policy in Lebanon.

** Law 220/2000 for the Rights of Persons with Disabilities in Lebanon**

The unique piece of legislature directly related to the rights of people with disabilities in Lebanon is Law 220, issued in 2000 (Law 220/2000, 2000). The passing of law 220 was a significant achievement towards the advancement of disability rights in Lebanon in the post-war era, as it established the precedents for the rights of people with disabilities with regards to healthcare and rehabilitation services, education, employment, political participation, housing, and transportation. It also allowed for the issuance of a national Disability Card, which is the only documentation providing entitlement to a list of disability benefits.

Despite this achievement, the impact of the law 220 on improving the lives of people with disabilities remains severely lacking due to many flaws in its content and its implementation. First, it was issued before the declaration of the UNCRPD, which makes it outdated and does not pave the way for the implementation of the CRPD, as some tenets are not aligned and might even seem contradictory with what the CRPD calls for (Baroud, 2013). Second, the law does not use the social model of disability, and instead adopts a medical perspective on disability. This is clearly shown in how the law defines disability in Article 2, as a reduced capacity (or incapacity) to perform life activities and participate in social life, mainly due to the impairment or lack of functional ability (Law 220/2000, 2000). This definition hence fails to address the environmental, structural, and attitudinal barriers that could shape the disability experience, and is not aligned with the classifications of disability in the International Classification of Functioning, Disability and Health (ICF)(World Health Organization, 2001) or the International Classification of Diseases 11th revision (ICD-11)(World Health Organization, 2021). In consequence, given that this definition was used to set the eligibility criteria to the Disability Card, the benefits provided through the card also adopt a medical and charity viewpoint and do not look at the holistic needs of people with disabilities with regards to inclusion and participation. Finally, Law 220 does not recognize the right to participate in public and political life; does not strictly promote inclusive education; fails to provide enforcement measures for employment quotas and support to make the labour market inclusive for people with disabilities; and does not present effective legal remedies for victims of

discrimination (especially in the workplace). This is why the law can be described as fuelling “cruel optimism” (Berlant, 2007)p.33), since it represented a series of incomplete promises which could not be materialized.

** Disability policy implementation and monitoring, between histories of political disablism and clientelist governance**

In addition to issues with the content of Law 220 and its relevance to the current context, there are problems with its implementation, enforcement, and monitoring. Twenty years after the passing of law 220, barely any implementing decrees have been issued, and the government failed to sustain policy reform and to ratify the UNCRPD which would safeguard these rights. There is no real recognition from the state of the contribution of people with disabilities in Lebanon, and it continues to perpetuate a medical model of service-delivery buttressed with charity discourse. As an example in relation to employment, Lakkis (2019), one of the self advocates contends:

Today we see many violations happening against the rights of people with disabilities, one of which is denying them the right to access jobs. Many cases have been recorded of organizations either refusing to hire people with disabilities or granting those jobs for which they are overqualified. By the law 220, this is illegal. Yet again this law on so many accounts is not enforced nor respected (UNDP Lebanon, 2019 [online]).

Many factors are attributed to this failure, and include 1) the lack of political will to invest in rights-based discourses, as opposed to the usual client-based service provision feeding a political clientelism mentality; 2) the lack of public funding investment in disability policy reform and 3) sectarian factionalism reflected in social policy (as described above), which opposes principals of universal rights and creates nepotism in access to services and care.

During the Lebanon Civil War, militia and sectarian groups had set up medical and rehabilitation centres to support the injured and the newly disabled (Kabbara, 2012). These centres were the predecessors of numerous current non-governmental care institutions, which flourished through post-war funding, and have gained hegemony by being strongly politically affiliated to the political elite (Kingston, 2013). These sectarian-politically entrenched care institutions reinforce the charity

discourse, perpetuating the image of people with disabilities as “passive service recipients”. They rely financially and administratively on their political counterparts, allowing political leaders to consistently use disability as a “political card” to showcase their “service to communities” and win electoral votes, while ironically doing nothing within their legislative or executive functions and political power at the state level to advance the rights of people with disabilities in Lebanon (Kingston, 2013). This clientelist approach was explained by one self-advocate:

We are calling for collective action [to further disability rights], and they [government politicians] try to “shut you up” with individual favours.

Sectarian factionalism also infiltrated the functioning of the National Council for Disabled Persons (NCDP), which is a national committee joining together representatives from the Ministry of Social Affairs (MOSA), Organisations of People with Disabilities (OPDs) and rehabilitation institutions to advance disability affairs. Its structure, roles and responsibilities are defined by Law 220. Although bringing together at the same table these various groups with often opposing views was an accomplishment, the power influence was clearly unbalanced, with the care institutions having excessively high political leverage upon the MOSA (Kingston, 2013). And although the NCDP managed to successfully establish the Disability Card program, OPDs felt that it was not doing enough to advance civil rights of people with disabilities.

I submitted my resignation from it [the committee]. The committee considered that it was not its role to monitor whether people with disabilities were able to vote (self-advocate).

Sectarian and political affiliations soon became one of the criteria for election and/or appointment within the committee, which led to the dysfunction of the committee, thus reflecting the same fate as many of the current public sector institutions in the Lebanese sectarian power-sharing state. The transparency of the council was also questioned by the same self-advocate:

This committee is dependent of the MOSA – so dependent on the minister. It should be an independent committee, not affiliated to MOSA. How can its role be about transparency and accountability?

Overall, rights of people with disabilities in Lebanon have been constantly pushed aside, deprioritized and/or neglected, in a persistent disablism from the state across the past decades

(Khawam, 2020). How have disability rights been advanced in the context described above? How did the disability rights movement navigate in this context?

<a> THE DISABILITY RIGHTS MOVEMENT IN LEBANON

 The birth of the disability rights movement in Lebanon

The Lebanon Civil War (1975-1990) coincided with the emergence of the global disability movement to reject the medical model of disability and to fight against barriers to inclusion. And while the war in Lebanon increased the need for immediate assistance to people with disabilities through care and rehabilitation institutions, it was also the birth (in the 1980's) of initial forms of self-organizing for groups of people with disabilities, inspired by this global movement. Triggered by the socio-economic exclusion of people with disabilities, OPDs started to dissociate from the traditional charities or service-oriented institutions and militia groups, and to mobilize towards rights-based activism. They also had an active prominent role in leading anti-war and anti-violence protests during the Civil War, which were defining moments in making people with disabilities visible and heard in Lebanon (Kabbara, 2012).

In the post-war era, community-based initiatives were launched by parents' groups and self-advocacy groups to push against exclusionary residential care and institutionalization provided by the prevailing care institutions, towards inclusive schools and community-based day care centers (Kingston, 2013). The nascent movement was also determined to position itself within the national policy arena and invested in persistent and often disruptive protests to demand that rights of people with disabilities are respected in Lebanon's reconstruction and reforms. 'We moved from being a marginalized group that has to be "looked after" to a political force to be reckoned with.' (Kabbara, interviewed by Kingston, 2013, p.199). OPDs were also key players in the drafting and adoption of Law 220/2000, which was one of the first real victories of the disability movement in Lebanon (Kingston, 2013).

 A constant battle against institutionalization and sectarianism

The core of advocacy work from activists and OPDs is to shift the disability discourse from service provision and rehabilitation towards rights-based action, from segregation and institutionalization towards inclusion and community-based care and independent living. This opposes the mission of many service-based care institutions in Lebanon, which are financially supported by the Ministry of Social Affairs to continue providing institutionalized care, with no real accountability, quality standards and supervision of their work (Kingston, 2013). Some of the care institutions are also accused of perpetuating the charity model to gather more funds.

We have seen this. Some institutions “destroy the personality” of the beneficiaries just by having them live in segregated places, and a lot of time because their staff lack competence due to limited resources (self-advocate)

In addition to opposing the sectarian-based rehabilitation institutions which foster political clientelism, the disability movement has also increasingly shaped its non-sectarian political identity. After the civil war and the reinstalment of what was said to be democratic elections, some OPDs strongly advocated for the right to vote and created watchdog committees during the Lebanese parliamentary and municipal elections to monitor the accessibility of voting polls (data from interview with three self-advocates). The shift in identity politics was evident through the discourse during and after the popular uprising of October 2019, the momentum of the revolution allowing the OPDs to take a secular political stance and join in the slogans “Killoun yaa’ni killoun” (“All of them” in Arabic), signifying their opposition to the entire ruling class and their sectarian politics (Ayoub, 2019).

** The disability rights movement across multi-layered crises**

The consecutive crises in Lebanon continuously shifted national priorities and pushed disability rights further behind in the country’s political agenda. One self-advocate said:

We were always being told “now is not your time”.

But every new crisis was also seen as an opportunity by the OPDs to put pressure on governmental leaders and to advocate for the inclusion of people with disabilities in crisis response strategies, such as by: advocating for accessible and inclusive reconstruction of damaged public buildings and schools after the July 2006 war and after the Beirut Explosion (Wehbi, 2012, Ghsain, 2021),

active participation in the Revolution of October 2019 demanding rights for all (Ayoub, 2019; Khawam, 2022), opposing austerity and ensuring social protection throughout the current financial crisis (Lebanese Organizations of People with Disabilities, 2020), prioritizing the vaccination of people with disabilities in the Covid-19 pandemic (Disability Hub Lebanon, 2021), and advocating for the rights and rehabilitation of the victims injured and/or new disabled by the Beirut August 4 blast (Ghsain, 2021).

** Complex internal dynamics, leadership and representation**

It is crucial to state here, that despite all progress made, there was never “one” unified disability movement in Lebanon. In reality, the disability movement, as presented in this chapter, is the result of actions from several groups and clusters of advocacy work, with often diverging paths and strategies. Despite continuous initiatives to join efforts and raise united demands, the movement has typically witnessed power struggles and in-house quarrelling over leadership and funding across the years, which has been generally detrimental to the advancement of disability rights.

We are not yet a coalition. Maybe we need a new generation in modern thinking, suggests one activist, highlighting the necessary shift in mentality towards better cooperation.

There is also an observed hierarchy within the disability movement, where issues of people with physical disabilities seem to be at the centre of disability activism, while the cause of people with other types of disability such as intellectual disabilities, is relatively marginalized or even absent from the policy discourse (Khawam, 2020). A self-advocate reflects:

People who are deaf and people who have an intellectual disability – I felt that they were the most marginalized [within the movement], maybe because they are the less “vocal”, there are communication barriers, and in many cases the parents speak on their behalf.

More generally, though, as argued in the next section and despite complex internal and external dynamics, the vibrant disability movement in Lebanon has continued to push for human rights and dignity for people with disabilities, across the various multi-faceted crises the country has been going through, in a form of hopeful resistance (Khawam, 2020).

<a> DISABILITY RIGHTS ACTIVATION IN A DISABLIST STATE: BARGAINING WITH THE STATE OR BY-PASSING IT?

Lebanon can be compared to what Deets calls a “passive-aggressive state”, where overall inefficiency in the power-sharing structure leads to resistance to policy reform, as power-holders use veto to maintain the status-quo and to preserve their power (Deets, 2006). Political governance through non-state institutions is a strategy used by those in power in this context (Deets, 2006), as can be seen by the heavy sectarianism and politicization of disability-focused non-governmental organizations and institutions in Lebanon which perpetuate the sectarian divide (Kingston, 2013). However, this has also pushed for alternative forms of functioning and mobilization, away from the sectarian status-quo promoted by the political elite. (Nagle, 2018). Non-sectarian social movements in Lebanon have detached themselves from sectarian identities either through hegemonic compliance, constructive engagement or active resistance to the system (Nagle, 2018). This is also applicable to the disability movement: while very few actors of the movement have complied with the current state-of-affairs, the movement has essentially responded either by 1) engaging with the state – what we present here as a form of bargaining, mediated by international actors; or by 2) actively resisting the disablist governance of the state and developing alternative modes of mobilization which by-pass the state altogether. The following section will describe these two mechanisms of action.

 By-passing the state: community governance, networks and cross-movement solidarity

In response to the inefficient and passively disablist state (Khawam, 2020), the disability rights movement actors have recourse to what Deets identifies as ‘communal governance’ (Deets, 2015), illustrating how “significant functional communal autonomy can be achieved in the absence of coherent institutions designed to support it” in the Lebanese public policy context (Deets, 2015, p.330). Examples of communal governance can be seen through OPDs in Lebanon investing in community-based development projects that would aim to “mimic” or model the principles and rights called for in these policies.

Even after the law 220 was passed, we realized there were still a long way for it to be applied. This is where we shifted our strategy towards creating models or prototypes for

inclusion. We chose as a priority working on employment, education, political rights, and the promotion of an accessible and inclusive environment, says the leader of one of the prominent OPDs.

The aims of these projects or models were not only to influence public opinion by increasing awareness on the rights of people with disabilities and reducing stigma, but also to build enough empirical evidence to increase pressure upon the state and policymakers towards the implementation of law 220 and, later on, the ratification of the UNCRPD. This also meant introducing or contextualizing new models of inclusive development, such as the promotion of community-based rehabilitation (CBR) in several areas in Lebanon in the 1990's, and the creation of inclusive education prototypes in some schools in Lebanon. It can be said that the movement's actions has, in many instances, replaced the state; and compensated for the state's inaction by building community grassroot models of inclusion. The movement was the driver for change, instead of change being state-led. Although these projects did not have "legal authority" and were not reflective of the official policy discourse which favoured institutionalization, they were developed with the aim to influence or ignite policy reform. (Deets, 2015, p.334).

Another element of communal autonomy is reflected through networks, which are individuals, groups or entities tied together in a form of relational identity (Deets, 2015). Networks act as 'organic and informal social systems' (Jones et al 1997, p 313) and highlight shifts in policy governance discourses involving various actors (Deets, 2015). In the context of Lebanon, the interactions between OPDs, civil society organizations, schools and private sector institutions towards inclusion of people with disabilities, can be understood as representations of communal network governance.

We worked on protocols and signed agreements [with the private sector] – this helped increased employment for people with disabilities”, suggested a prominent self-advocate, illustrating how these networks helped promote inclusive employment as an example.

Cross-movement solidarity (i.e. joining efforts with other civil society and human rights movements) is another community-based strategy used by the disability movement, which was reinforced through grassroot partnerships built during the October 2019 Uprising and successive street protests. We now explore the engagement of disability rights actors with international actors in the next section.

 Bargaining with the state: international organizations as mediators of policy reform

Given the significant gaps left by the Lebanese state in responding to basic needs, international aid agencies and NGOs have historically been key players in Lebanon's humanitarian and development plans, filling gaps left by the government across various sectors, from education to health to agriculture and industry.

While international aid actors largely overlooked disability issues until 2016-2017 (Combaz, 2018), two recent examples showcase the increased recent involvement of international agencies such as United Nations organizations, in promoting the rights of people with disabilities in Lebanon. These include: 1) joint action between the International Labor Organization (ILO), UNICEF and OPDs towards the development of a comprehensive national rights-based social protection system, and 2) a proposal with UNICEF and ILO towards the design of a National Disability Allowance (ILO & UNICEF, 2021). These initiatives invite for a "constructive dialogue with the government" (Lebanese Organizations of Persons with Disabilities, 2020, p.1), and hence highlight the role played by UN agencies in initiating, mediating, or catalysing policy dialogues, and supporting the government technically and financially in policy reform. However, disability activists have different views and opinions about this role. On one hand, some disability activists perceived the UN agencies' leverage on the government as positive and strategic:

They have influence to talk to the government. The government might listen to them, instead of listening to the OPDs.' said one self-advocate. Another self-advocate added:

I am happy with the work that the ILO and the UNICEF and what they are doing. Things might take time to change, but I do believe that we are moving towards change. [...] It is ok if things at least only get fixed on paper. Even if the policy is not implemented. At least this would be a first step forward.

On the other hand, other disability activists seemed more cautious of this role:

The UN agencies won't make the government angry; they are diplomatic with the government. The UN agencies will not contradict the government. They can be supportive of OPDs, but you can't depend on them. They can influence the government – but it is not the same "dose" as OPDs. They bring technical support to governments but is the government ready to implement? said a self-advocate. Another self-advocate contended:

I see them [international organisations] as double-faced. They support us, but they also work with the government. They are our allies, but at the end they are diplomatic with the government.

Activists also highlighted some power unbalances where UN agencies might overuse their power:

[...] at the end, they [UN agencies] will do what they decide, it is like as if we [OPDs] are working for them.'

International NGOs (INGOs) are other actors that may come into play with a bargaining role, as they coordinate directly with local state actors such primary healthcare and social development centres. They are perceived by the activists as having a positive role in service provision; however they are led by their own agendas and funding streams:

INGOs are less abided by the government [than UN agencies], but they are also tied by their funding. And once a project ends, they leave you all alone' contended one self-advocate and head of an OPD. "The INGOs are good, but this also varies with their individual agendas." said another self-advocate.

However, one critique was presented to the INGOs: activists felt that they do not do enough towards promoting inclusion, since they still support, fund, or collaborate with rehabilitation and care institutions.

<a> TOWARDS DISABILITY POLICY REFORM IN LEBANON: FRAMING DISABILITY IN THE HUMAN RIGHTS DISCOURSE

What change is to be sought out? Which reform is needed now? Is there a need for a new law, or rather a need to update the current law 220? Activists have various views on this question:

[Law 220] is an obsolete law now. It is not consistent with the UNCRPD nor the SDGs. It is very old now, we either need a new law, or to re-write law 220 and change it in a radical way. We need a new disability assessment in Lebanon, regarding classification, etc. and relating the right to the need in terms of allowances and entitlements" said one self-

advocate. *Law 220 now is of no use, even if it includes a quota, the country has changed a lot.* said another self-advocate.

Some activists also contend that the ratification of the UNCRPD would not be enough. The answer to these questions requires situating the disability rights movement in Lebanon within the global human rights discourse, using the policy-as-discourse theory.

** Problematizing disability rights in the human rights discourse in Lebanon**

The UNCRPD is a concrete proposal for the affirmation of universal human rights of persons with disabilities, and was fought for by global disability movements, given that the earlier human rights laws, namely the Universal Declaration of Human Rights Declaration (1948) and the International Covenants on civil and political rights; and social, economic and cultural rights (1966) had failed to deliver against the discriminations of people with disabilities and the affirmations of their dignities in societies (Kanter, 2014). We find that the Lebanese disability movement also has had to navigate through similar tensions between the universality of human rights and the particularity of the disability rights in their interactions with fellow human beings and civil society groups. Examples are shown through the movement's participation in the Lebanese revolution of 2019 and anti-war campaigns (between 1995 and 2000) which were about affirming the human rights and the rule of law for all Lebanese people. Disability activists position themselves as both human rights and disability activists in such wider societal interactions:

I am a disability and human rights activist. This is how I present myself to people who do not know me', says a leading self-advocate.

In relation to the 2019 uprising, a self-advocate contends:

I was part of the revolution movement. I did not feel that we needed a separate "revolution" for those with disabilities. I felt [...] we should be part of the bigger movement of the revolution.

Yet the disability activist also feels that more should have been done during the 2019 uprising by other civil society organisations in recognising disability rights while demanding universal human rights for all with better cross-movement solidarity. The politics of the Lebanese disability

movement also provide a good critique of some of the assumptions underlying human rights and the UNCRPD that we have identified in our introductory section, namely that rights are state protected and are independent of cultures. These underlying assumptions are modelled on the notion of abstract individual rights, separated from the social context lived by people with disabilities and mediated through the intersubjective relations within a society (Akerkar and Devavaram, 2015, Akerkar et al., 2016). The earlier discussion on engagements with communities by the OPDs in Lebanon is based on an understanding that it is important to engage with the intersubjective social worlds of people with disabilities in order to further their individual rights. Community initiatives by OPDs have included home and community actions, awareness raising within families and local communities to confront the barriers to the participation of people with disabilities and to realise their abstract individual rights. By-passing the state, OPDs have adopted the incremental strategy of promoting disability rights at local levels (Kingston, 2013).

Similarly, the recognition from the disability movement in Lebanon that it cannot depend upon the state to further the rights of people with disabilities, defines the movement's politics and approaches to the UNCRPD. While acknowledging the importance of the UNCRPD in furthering human rights of people with disabilities, disability activists also highlight that its mere ratification will not lead to substantive changes in the policies and practices needed to make the Lebanese society more inclusive. This partly comes from their experience in relation to the implementation of the law 220 which has remained mainly on paper, and partly from their evaluation of the 'rule of law' and the 'political class' in Lebanon. A disability activist contends:

We need to ratify the UNCRPD. But even if we do ratify the UNCRPD, as long as we are in a country which does not respect human rights and does not have accountability, nothing will change. And this is what we need to work on now, to have a strong state with the rule of law.

For yet another disability activist:

UNCRPD will not be enough. It is because our political class do not care.

These narratives highlight the awareness among disability movement actors that the affirmation of disability rights via affirmation of their human rights through the UNCRPD is contingent upon

their recognition as full citizens via social contract by a neutral (non-sectarian and non-clientelist) state that does not exist in Lebanon.

Given these reflections, how should the relation between the UNCRPD, human rights and disability rights movement be conceptualized in Lebanon? We propose here the use of Rancière's conception of human rights to formulate this relation. Rancière (2004, pp 302) contends 'the Rights of Man are the rights of those who have not the rights that they have and have the rights that they have not' (Rancière, 2004). That is, to the extent that the excluded act as though they have human rights (by mobilizing them), they can be said to have those rights that they still do not have. Hence, the value of mobilising the UNCRPD and its human rights claims by the Lebanese disability movement, a disenfranchised group, lies in questioning the existing social hierarchy and making normative and substantive claims to the equality of people with disabilities with their fellow country residents, as if they have those equality rights (Akerkar, 2020). More generally, the Lebanese context shows that the disability movement bridges the space between universal human rights and particular disability rights; individualist human rights and the intersubjective lived lives of people with disability through their political actions of affirming the equality claims of people with disabilities in all social realms.

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<a> CONCLUSION: A NEW MODEL OF ACTION

In conclusion, Lebanon presents a rich and complex case of government failure to reinforce disability rights policies and to enact human rights for all citizens. Where most states are assumed to be patrons of human rights and protectors of citizen rights, Lebanon has witnessed alternative forms of community-based actions and activism to compensate for (and sometimes resist) governmental malfunction. The disability movement has either bargained with the state by engaging third party external mediators, or by-passed the state and created alternative networks for disability rights activation. Several lessons on disability policy and human rights can be drawn from the Lebanon context.

First, disability policies and international conventions such as the UNCRPD present significant limitations in contexts where the rule of law is lacking, and systems for protection, implementation and monitoring of social policies are weak, fragmented, and/or dysfunctional. Disability policy

reform (through amendments to national laws and policies and ratification of the UNCRPD) is a necessary step but not the main venue through which the lives and well-being of people with disabilities are improved or protected. “*We cannot wait for the state*” is a common reflection among all disability rights actors in Lebanon, acknowledging the imminent and sustained need to take matters ‘in their own hands’, and build parallel community-based mechanisms to ameliorate the living situation of people with disabilities.

Second, solidarity is key in shaping the disability discourse and is a true (re)affirmation of universal human rights in such contexts. Various forms of communal solidarity have been historically observed in Lebanon and strengthened after the revolution of October 2019 and the Beirut explosion, in what Geha presents as community-driven resistance (Geha, 2021). “Constructive resistance occurs when people begin to build the society and polity that they desire independently from the structures that govern their live” (Sørensen, 2016 as cited in (Geha, 2021, p.13). Solidarity involves co-joint actions in communities, but disability activists also talked about solidarity across civil rights movements. Cross-movement solidarity solidifies the disability rights discourse in human rights advocacy, positioning the rights of people with disabilities on an equal basis with others, and was identified by one self-advocate as “*the only way forward now*”.

Third, the role that can be played by third party actors, such as the international community, UN agencies and international organizations is highly significant, given the power and level of influence these actors present. Their role needs to be further explored and strengthened beyond diplomatic programming and more towards strategically shaping the national disability rights discourse.

Finally, and most importantly, where disablism is state-induced and politically driven, disability rights activation cannot but be a *political* endeavour. According to Shakespeare & Watson (2001), disability politics is first and foremost about establishing disability as a political issue, a matter of political power and oppression, revolving around the identity of a minority group, disabled by society (Shakespeare and Watson, 2001). The disability movement in Lebanon has historically shaped its political identity and gradually re-enforced its anti-sectarian stance. Strengthening this identity using a rights-based approach and fostering proactive citizenship (Helou, 2021) are important steps towards political change and policy reform (Memari and Hafizi, 2015).

The narratives in this chapter have illustrated a new model for action towards policy change, relevant not just in non-signatory states and/or unstable contexts, but also in countries where the UNCRPD implementation continues to be lacking or where accountability measures are insufficient (Aldersey and Turnbull, 2011). The model calls for building evidence for policy development and advocacy through an incremental bottom-up approach, from grassroots interventions to international actors in the disability rights arena. The political mainstreaming of disability rights in human rights battles is an imperative to shaping the policy discourse and to pave the way for structures and systems to protect the rights of all citizens alike. This is not only a call for political and human rights activists, but also for activist scholars, academic and community researchers to join efforts and further expand knowledge and evidence-for-policy research on the role of non-state actors and alternative modes of action in disability rights enactment and practices.

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