

***‘INCLUSIVE FOR WHOM?’: THE EXPERIENCES OF
SYRIAN REFUGEE CHILDREN WITH
DISABILITIES AND THEIR FAMILIES IN
ACCESSING EDUCATION IN LEBANON***

**by
Giada Costantini**

**A thesis submitted to the University of Birmingham for a degree of
DOCTOR OF PHILOSOPHY**

Department of Education and Social Justice
School of Education
College of Social Sciences
University of Birmingham
May 2024

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

*To the Syrian children and their parents, without
whom this work would have never been possible.
And to my niece, with the hope to leave her a more
social just world.*

ABSTRACT

This work is about the unexpected spaces of confinement reproduced by the ‘inclusive’ rhetoric in education within humanitarian contexts, where Syrian refugee children with disabilities come to be relegated. It responds to a critical void in the literature, theory, policy and practice concerning education in humanitarian settings, particularly at the intersection of refugeehood and disability. While education for refugees and people with disabilities have been explored separately, there remains a significant gap in addressing the educational rights of refugee children with disabilities. The study originates from this underexplored intersection and contributes to the growing body of work aimed at bridging this gap.

The research explores the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other basic services in Lebanon. It also investigates how ‘inclusion’ is framed for education in humanitarian contexts, and the consequences of this framing of inclusion for Syrian refugee children with disabilities. Moreover, it analyzes the strategies participants have in place to respond to and to deal with the multiple challenges and crises they face daily.

It is an empirical qualitative research project that takes an interdisciplinary and multidimensional approach. Located within an interpretive/social constructionist paradigm, it employs Constructivist Grounded Theory as a data analysis tool (Charmaz, 2006). The data were collected between August and December 2022 and are constituted by semi-structured interviews with 11 Syrian refugee children and youth with different types and severity of disabilities, 25 Syrian families living in Lebanon, and 21 representatives of organizations of people with disabilities (OPDs), international and Lebanese non-governmental organizations, civil society organizations and UN agencies.

The findings reveal that humanitarian actors in the region often employ emergency discourses to justify their failure in implementing inclusive education programs and strategies, contributing to the de-/prioritization and structural exclusion of people with disabilities. Inclusion within these efforts is operationalized according to cost-benefit assessments, whereby the level and nature of inclusion is defined according to people’s capacity to fit within neoliberal and ableist normative standard of productivity, efficiency, and ability. Children who best comply with these standards

are prioritized for inclusion, while those with severe and complex disabilities are systematically excluded due to the perceived higher costs their inclusion would require. Syrian parents denounce the lack of education opportunities for children with severe and complex disabilities, stating that their children are '*left to themselves*', prevented to exercise, and access their basic human rights, and '*treated like if they do not exist*'. It is in this instance that these children come to embody what Agamben calls *bare life*, a life which is stripped of all legal, political, and social rights, being circumscribed in a *state of exception*. Moreover, building on Syrian parents and their children with disabilities' lived experiences, the study addresses different forms of agency and resistance within spatiality of exception, disrupting and challenging the broader Western dominant humanitarian narrative of vulnerability, passivity, and helplessness through which Syrian refugees come to be constructed and represented.

Through this work, I have expanded critical understanding of the co-opted notion of inclusive education in the Global South by introducing and developing the (C)GT's core category of 'Letting die through Neoliberal Inclusion'. In conceptualizing this notion, I argue that education in humanitarian contexts, through the reproduction of emergency discourses, which legitimize the advancement of neoliberal significations of inclusion, contributes to the construction of Syrian refugee children with disabilities, especially with severe and complex ones, as *Homo Sacer*, someone who can be killed, or in this case 'let to die', by anyone with impunity.

The study underlines the urgency to promote more interdisciplinary research and multi-stakeholders' collaboration to critically re-think the ways in which humanitarian actors, and the broader society, define and operationalize inclusion. The recommendations drawn from this work emphasize the need to develop a shared conceptual foundation across different disciplines and actors working on education in humanitarian contexts to advance theory, policy and practice. It also advocates for translating research into accessible formats for non-academic stakeholders to advance critical conversations on the field, and to work more collaboratively with affected communities, OPDs and other partners. Other recommendations suggest the development of interdisciplinary training for humanitarian actors, educators and other stakeholders to strengthen capacity for inclusive education, and to enhance transparency in monitoring and evaluation practices to address the gaps identified in service provision.

ACKNOWLEDGMENTS

First and foremost, I want to thank from the bottom of my heart the participants to this study. Thank you for taking the time to talk to me. Thank you for allowing me to learn about your lives, for your generosity towards me and the interpreter, and for your encouragement both concerning this study and my future. Without you, this work would have not been possible. Thanks also to the organizations' representatives, who agreed to be interviewed, and who shared critical and important insights on their work and on the humanitarian field.

I am grateful for Jasmine, Eliane and all the Miramo family, who have welcomed me during my stay in Lebanon, providing me with support, love and logistic help first when trying to get in contact with Syrian refugee families, and then when reaching them in Beqaa, Tripoli and other Lebanese cities.

I would like to thank both my supervisors Professor Dina Kiwan and Dr. Valentina Migliarini, for their critical guidance, and their constant support during this four-year journey. It has been a rollercoaster, and I am very grateful you were there by my side.

I also want to thank my friend, mentor, and colleague Professor Reza Gholami, who always believed in me and in the work I do. I am grateful for the friendship and guidance received by Dr. Giuditta Fontana, and Dr. Wen-Yu Wu. I also want to acknowledge the guidance and help received by Dr. Kate Woodcock, Dr. Maha Shuayb, and Dr. Rita Giacaman at the very beginning of my PhD path, and Dr. Nawaf Kabbara for his support during my stay in Lebanon.

I thank my friends and colleagues across departments and universities Maram Theodory, Yomna El-Serafy, Josephine La Point, Francesca Basini, Sanket Agrawal, Sharlin Utkar, Tom Morrish, Fernando Zapeda, Deborah Ferri and Isabella Goncalves de Alvarenga, with whom I shared the joys and the challenges of doing a PhD.

My deepest gratitude goes to my friends of a lifetime Paolo Giordano, Alessia Colonnelli, and Laura Morreale, who provided critical emotional support in the most needed time across countries.

A huge thanks goes also to my mum and dad, who sacrificed everything to allow my sister and I to study; to my uncle Claudio, who never stopped supporting me, and has always been there to guide me and at times to challenge me; to my sister for being an inspiration, and to my niece for having brought renewed happiness, and hope in our small family.

Last but not least, I thank Rocco, my partner, my friend, my PhD buddy, and my biggest anchor and love. Thank you for your patience, for your unwavering support, and for your love. I would have not made it without you!

Table of Contents

ABSTRACT	I
ACKNOWLEDGMENTS	III
TABLE OF CONTENTS.....	IV
LIST OF TABLES AND FIGURES	VI
ACRONYMS	VII
INTRODUCTION.....	1
1.1 INTRODUCTION	1
1.2 RESEARCH AIMS AND RESEARCH QUESTIONS.....	2
1.3 THESIS' STRUCTURE AND OVERVIEW OF CHAPTERS	14
PART I: CONTEXTUALIZING THE STUDY	19
CHAPTER 1 SETTING THE SCENE: HISTORICAL, POLITICAL AND EMPIRICAL CONTEXT.....	20
1.1 INTRODUCTION	20
1.2 THE LEBANESE CONTEXT	21
1.2.1 History of the Lebanese-Syrian relationship	22
1.2.2 Syrian refugees in Lebanon: From open door policy to policy of exclusion	24
1.2.3 Post-2019: Compounded crisis and increasing discrimination	26
1.3 EDUCATION RESPONSES TO SYRIAN REFUGEES.....	28
1.3.1 International and National Educational Policy and Legal Frameworks: at the intersection of refugeehood and disability	28
1.3.2 The education response to Syrian refugees in Lebanon	31
1.3.3 What about children with disabilities?.....	35
1.4 EDUCATION IN HUMANITARIAN CONTEXTS AND THE PROMISE OF DISABILITY-INCLUSION: HISTORICAL PERSPECTIVES AND REVIEW OF THE LITERATURE	39
1.4.1 A historical perspective of education in humanitarian contexts	40
1.4.2 Reviewing the literature: Education, disability and forced migration	43
1.4.3 The Disability-inclusive rhetoric of education in humanitarian contexts.....	54
1.5 CONCLUSION	56
CHAPTER 2 CONVERSING WITH THEORIES.....	57
2.1 INTRODUCTION	57
2.2 CRITICAL DISABILITY THEORY: GENESIS, PRINCIPLES AND WAY FORWARDS	58
2.2.1 Genesis of CDT	58
2.2.2 Elements of CDT.....	63
2.2.3 CDT as guiding framework	69
2.3 AGAMBEN'S WORK AND THE LINK WITH DISABILITY AND REFUGEEHOOD	72
2.3.1 The logic of sovereignty: Homo Sacer, Bare Life and State of exception.....	73
2.3.2 At the intersection of refugeehood and disability: 'life devoid of value'	79
2.3.3 Humanitarian aid and sovereign power	90
2.4 'IN CONVERSATION': A WAY FORWARD	94
2.5 CONCLUSION	95
CHAPTER 3 METHODOLOGY	96
3.1 INTRODUCTION	96
3.2 RESEARCH METHODOLOGY	97
3.2.1 An interpretive/social constructionist research	98
3.2.2 CDT: Inter-/post-disciplinarity and multidimensionality.....	101
3.2.3 Constructivist Grounded Theory (CGT)	104
3.3 RESEARCH METHODS	106
3.3.1 Research participants	107
3.3.2 Data collection	116
3.3.3 Data analysis.....	123
3.4 ETHICS.....	128

3.4.1 Consent, assent, anonymization, and data protection.....	128
3.4.2 Reflexivity and Positionalities.....	130
3.5 CONCLUSION.....	134
PART II: LETTING DIE THROUGH NEOLIBERAL INCLUSION.....	135
CHAPTER 4 RE-PRODUCING EMERGENCIZATION.....	141
4.1 INTRODUCTION.....	141
4.2 RE-PRODUCING EMERGENCIZATION.....	142
4.2.1 Discriminatory Rhetoric.....	144
4.2.2 Operationalizing Exclusion in Emergency.....	154
4.2.3 Impacting Education.....	158
4.3 CONCLUSION.....	164
CHAPTER 5 ADVANCING NEOLIBERAL INCLUSION.....	166
5.1 INTRODUCTION.....	166
5.2 ADVANCING NEOLIBERAL INCLUSION.....	167
5.2.1 Hierarchizing Disabilities.....	170
5.2.2 Promoting Exclusionary Inclusion.....	176
5.2.3 Facing and Resisting Barriers.....	185
5.3 CONCLUSION.....	197
CHAPTER 6 ACTUALIZING A STATE OF EXCEPTION.....	199
6.1 INTRODUCTION.....	199
6.2 ACTUALIZING A <i>STATE OF EXCEPTION</i>	200
6.2.1 Politicizing and Marketizing Bodies and Aid.....	202
6.2.2 Denouncing Bare Life.....	211
6.2.3 Resisting Space of Exception.....	218
6.3 CONCLUSION.....	229
DISCUSSION AND CONCLUSION.....	230
1.1 RESEARCH QUESTIONS.....	230
1.2 STUDY LIMITATIONS.....	237
1.3 RECOMMENDATIONS AND FUTURE RESEARCH.....	239
REFERENCES.....	248
APPENDICES.....	282
APPENDIX I: FLYER (ENGLISH AND ARABIC).....	282
APPENDIX II: PARENTS' CONSENT FORM (ENGLISH AND ARABIC).....	284
APPENDIX III: INTERVIEW QUESTIONS WITH PARENTS (ENGLISH AND ARABIC).....	286
APPENDIX IV: EASY-TO-READ FORM (ENGLISH AND ARABIC).....	288
APPENDIX V: INTERVIEW QUESTIONS WITH CHILDREN (ENGLISH AND ARABIC).....	299
APPENDIX VI: ORGANIZATIONS' REPRESENTATIVES CONSENT FORM (ENGLISH AND ARABIC).....	300
APPENDIX VII: INTERVIEW QUESTIONS WITH ORGANIZATIONS' REPRESENTATIVES (ENGLISH AND ARABIC).....	302
APPENDIX VIII: ORAL CONSENT FORM.....	303
APPENDIX IX: NOTICE OF IRB APPROVAL.....	304

LIST OF TABLES AND FIGURES

Table 1: Families' basic information

Table 2: Children's basic information (interviewed)

Table 3: Children's basic information (not interviewed)

Table 4: Organizations-related information

Table 5: Organizations-related information from joint research project (Fontana and Costantini, 2024)

Figure 1: Gadi's artwork

Figure 2: Ferran's artwork

ACRONYMS

CDT	Critical Disability Theory
(C)GT	(Constructivist) Grounded Theory
CRC	Convention on the Rights of the Child
ECW	Education Cannot Wait
EiE	Education in Emergency
EfA	Education for All
GoL	Government of Lebanon
GT	Grounded Theory
IEPP	Inclusive Education Pilot Program
INEE	Inter-Agency Network for Education in Emergency
INGOs	International non-governmental organizations
LCRP	Lebanese Crisis Response Plan
MEHE	Ministry of Education and Higher Education
MOSA	Ministry of Social Affair
MOU	Memorandum of Understanding
NFE	Non-formal Education
NGOs	Non-governmental organizations
OPDs	Organization of people with disabilities
PLO	Palestine Liberation Organization
RACE I	Reaching All Children with Education I
RACE II	Reaching All Children with Education II
3RP	Regional Refugee and Resilience plan
SDGs	Sustainable Development Goals

UDHR	Universal Declaration of Human Rights
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations International Children's Emergency Fund
WASH	Safe drinking-water, sanitation and hygiene

INTRODUCTION

1.1 Introduction

This thesis is about disability, refugeehood and the lived experiences of Syrian refugee children¹ with disabilities and their families in accessing education opportunities and other life-saving services in Lebanon. It is about the unexpected spaces of confinement, reproduced by the ‘inclusive’ rhetoric within educational humanitarian efforts, in which Syrian refugee children with disabilities come to be relegated.

A critical gap has been identified in the literature, theory, policy and practices concerning education in humanitarian contexts, especially where refugee status and disability intersect. While there has been a growing attention to both refugees and people with disabilities as separate constructed categories, these two groups continue to be treated in isolation within scholarly work (Pisani and Grech, 2016). This oversight is particularly problematic in humanitarian contexts, where the refugee status intersects and compound with disability, intensifying people’s challenges in accessing basic services such as education, and healthcare. Humanitarian responses often treat refugees as a homogenous group, neglecting to recognize and address the specific needs of refugees with disabilities, leading to exclusionary practices in what are framed as ‘inclusive’ programs (Costantini and El-Serafy, *under review*).

¹ The term “child” is used according to the definition provided by the UN Convention on the Rights of the Child (1989): “a child means every human being below the age of 18 years”. Participants to this study are categorized as ‘children’ due to their age range; however, their experiences as children, meaning their childhoods, significantly differ from one another. Childhood(s) is here understood as a social construction (Norozzi and Moen, 2016; Biddle, 2017), and as such it is linked to the social, political, economic and historical specificities of different contexts in which children’s experiences and development are defined and constituted. It must be noted that Childhood Studies, as a predominantly Western scholarship, is still grappling with the experiences and childhoods of children living in Southern spaces (Bentley, 2005; Tisdall and Punch, 2012; Twum-Danso Imoh, 2022; Liebel, 2023), such as the ones of refugee children in humanitarian contexts.

The study situates itself in this knowledge gap and it engages in an in-depth analysis of the ways in which the neoliberal and colonial logics underpinning the humanitarian sector operate to signify bodies at the intersection of refugeehood and disability as *bare life*, a life which is stripped of legal, political, and social rights. These bodies are relegated in spatiality of exception, which transcends physical topographies to crystallise within the living biological being and its experiences. In so doing, the work expands critical understanding of the co-opted notion of inclusion and inclusive education in the Global South by developing new epistemological understanding around the notion of ‘Letting die through Neoliberal Inclusion’. ‘Letting die through Neoliberal Inclusion’ is the emerging core category of the (C)GT developed in this work, and it analyzes the processes through which Syrian refugee children with disabilities, especially with severe and complex ones, come to be structurally marginalized within the humanitarian system, and the (inclusive-) education initiatives it implements. The aim is to uncover and expose the exclusionary nature of dominant humanitarian neoliberal forms of inclusion, highlighting the gap between inclusive policies and discourses and their implementation on the ground. As this study focuses on shedding light on the intersection of disability and refugeehood, and on the multiple layers of exclusion experienced by people at this intersection, a critical and multidimensional analysis of the matter is offered, starting from the experiences of Syrian refugee children with disabilities and their families, as well as of national and international humanitarian actors, and representatives of local organization of people with disabilities.

1.2 Research aims and research questions

In this work I aim to:

- Learn about the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other life-saving services in Lebanon.

- Illustrate how children with disabilities, especially with severe and complex ones, continue to be overwhelmingly excluded from humanitarian interventions despite the inclusive rhetoric promoted within the field.
- Critically analyze the homogenization of disability within the humanitarian sector, highlighting its failure to acknowledge and consequently address the multidimensional nature of disability and the compounded forms of exclusion experienced by children at the intersection of refugeehood and disability.
- Critically engage with the root causes that reproduce the exclusion of children with disabilities from education interventions in humanitarian contexts.
- Contribute to the literature: There is little research done with refugees with disabilities and even less with refugee children with disabilities in the Global South, and more specifically in the Middle East. This lack of scholarship is indicative of the frameworks within which refugee children with disabilities are constructed, which tend to signify them as intrinsically vulnerable in need of protection, without seeing beyond the vulnerability, which should come to be re-signified as being inherent to every human being.
- Start bridging the gap between education in humanitarian contexts, forced migration and disability studies, showing how those fields are deeply interrelated with each other, and need to be retheorized through an interdisciplinary lens.
- Critically reflect on the more recent efforts and narratives of ‘disability-inclusion’ promoted at the humanitarian level, and their practical impact on the lives of refugee children with disabilities.

This study’s research questions are:

- 1) What are the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other basic services in Lebanon?

- 2) How is inclusion framed for education in humanitarian contexts?
- 3) What are the consequences of this framing of inclusion for the education of Syrian refugee children with disabilities?

Point to be noted, education in humanitarian contexts is more commonly known as ‘education in emergency’ (EIE). In this work, ‘education in humanitarian contexts’ and ‘education in emergency’ are used interchangeably.

Critical note on terminology

“But if thought corrupts language, language can also corrupt thought.” (George Orwell)

Words carry with them meaning, and they can free as much as they can oppress. Language exerts an undeniable and significant power on the way we produce and reproduce specific meanings and understandings within our society (Dunn and Andrews, 2015), and it is responsible for reinforcing, or in some cases challenging, specific old power-dynamics, influencing the way we signify our surrounding world. For this reason, here, I take the time to problematize, define and critically reflect on some of the language I use in this work.

Refugee

“Within the repertoire of humanitarian concerns, refugee now constitutes one of the most powerful labels.” (Zetter, 1991:39)

In this study, you will often come across the word ‘refugee’. Most of the Syrian families I worked with in Lebanon are registered with the UNHCR, and they are officially recognized as refugees. However, I have always found the refugee label problematic, and here I try to critically unpack the underlining reasons of my reservation in uncritically employing this term. Shedding light on and problematizing the ‘hidden’ meaning and realities that the refugee label brings about, I hope to provide a layer of criticality and awareness in the reading of this work.

Zetter (1991) analyzes the instrumentalization of the refugee label within the humanitarian project, explaining how refugees come to inhabit “an institutionalized world” made of governments and humanitarian-development actors, who administer and control emergency and development aid. He denounces the “extreme vulnerability of refugees to imposed labels” (p.39). Labels hold the power to reshape people’s lives, redefining their political and social limits, establishing new dimensions and dynamics of powers in which they come to be inscribed in de-historicized and apolitical terms (Rajaram, 2002). Thus, refugees are constructed as bodies and souls without history, whose agency and individualities pulverize in spatiality of indistinctions, becoming a single, either vulnerable or threatening, “amorphous mass, faceless and speechless”. (Soguk, 1999:242).

Haddad (2004) underlines how the refugee label has been ontologically and epistemologically defined within Western and Eurocentric frameworks having tangible political and material effects on the lives of those who are re-signified as refugees, this new “imagined community” (Anderson, 1991). Similarly, Shuayb (2019) critically reflects on the socially constructed category of refugee, acknowledging that despite the refugee label is meant to guarantee a specific set of rights and degree of protection within the dominant Western-led international apparatus, it nonetheless forces refugees to enter “spaces without law” (p. 5). In these spaces without law, refugees are constructed solely as ‘victims’, and characterized as intrinsically vulnerable (Malkki, 1995; Haddad 2004). However, when they risk their lives to escape the indistinction of lawless topography their bodies are re-inscribed in Western narratives of criminalization, through which they are ‘re-branded’ from the ‘vulnerable-other’ to the ‘threat-other’. The Western-dominant segment of the international community, and academia have contributed to the objectification, and disempowerment of refugees (Malkki, 1996).

Therefore, the refugee label holds and reproduces a set of predetermined legal, political, and social entitlements, and especially restrictions, such as socio-economic paralysis, absence of employment opportunities, and exacerbated isolation and segregation from host communities, which aggravate prejudices as well as inequalities and discriminatory attitudes against refugee communities (Shuayb, 2019). It must be noticed that the definition and operationalization of the refugee label, and consequent entitlements and restrictions, are determined by institutions and authorities, without any involvement and active participation of refugees within these bureaucratic processes (Shuayb, 2019). For this reason, it is not surprising that many of the people who are referred to as refugees, often do not identify themselves as such (Mazur, 1986; Haddad, 2004; Shuayb, 2019; Wu, 2021), conceiving “their identity in very different terms from those bestowing the label” (Zetter, 1991:40). For instance, Syrian families participating to this study very rarely used the word refugee in our conversations. Thinking back about our encounters, the word ‘refugee’ was mainly employed to refer to policies and aid-related matters, rather than to their daily lives and processes of self-identification.

Later in the present study, I come to further develop some of the point raised in this short paragraph, especially concerning the dimension of the refugee as the ‘threat-other’, and/or as the ‘vulnerable-other’, and I reflect on the different forms of agency and resistance, at the intersection of refugeehood and disability, which are usually erased within humanitarian narratives of vulnerability.

Refugeehood

In this work, ‘refugeehood’ is understood as a complex and multifaceted concept that extend beyond the legal recognition and acquisition of the ‘refugee status’ to encompass its socio-political and economic implications, as well as its experiential dimension. It describes refugees’ holistic experiences of losing membership in the political community of a state, resulting in the loss of the

“right to have rights” and the ability to engage in political action, as noted by Arendt (2001). It also refers to how refugees are socially and politically constructed within global discourses of migration, exclusion and humanitarianism. It is influenced by (geo)political, economic and social conditions, and it involves layers of discourse related to displacement, loss, and exclusion, highlighting their interconnectedness (Demetriou, 2018). Yanary and Abidi (2018) articulate this complexity by describing refugeehood as existing within a “vulnerability-resiliency contradiction” (p.56), where refugees are simultaneously vulnerable and resilient. However, humanitarian and political discourses often emphasize one over the other creating conflicting narratives which complicate how refugee policies are crafted. It is also important to notice that humanitarian approaches to refugeehood tend to overlook the deeper political dimensions of refugees’ experiences. Thus, I employ the term refugeehood to refer to people’s experiences and to underscore the historical, social, (geo) political, cultural, and economic dimensions involved in the definition of certain groups of people as refugees, and how these power structures are implicated in defining the experiences of those who come to acquire the status of being a refugee.

Refugee crisis

“The refugee crisis is not actually a crisis of refugees.”
(Alcalde, 2016:1)

Throughout this study, at times, you will encounter the term ‘refugee crisis’. I feel quite uncomfortable in using this term uncritically mainly because I believe that it misrepresents the factual reality, decontextualizing the situation of refugees, and de-historicizing the driving causes of instability in Global South contexts, which are undeniably linked to past and present Western policies (Alcalde, 2016; Almustafa, 2022). For this reason, I provide a critique of the term, to highlight the critical use I make of it in the present work.

The notion of ‘refugee crisis’ has originated from an Eurocentric perspective. European political elites, building on what Chimni (1998:351) conceptualizes as the “myth of difference”, promote discriminatory narratives against refugees from the Global South, based on xenophobic discourses that found their *raison d’être* in the proclamation of a ‘crisis’. In 2015, UNHCR (2015) reports that more than 1 million asylum seekers arrived at the European shores seeking refuge. Many European politicians, and states’ media, described the event as an “existential threat” to national security, as an “invasion” and a “flood”, a “plight” (Friese, 2017; Krzyzanowsky et al., 2018; Massari, 2021) that poses tangible risks to the identity, as well as socio-cultural homogeneity of Europe (Almustafa, 2022). Through the hyper-securitized politicization of the refugee bodies approaching the European borders, Eurocentric narratives successfully manage to de-historicize the underlining causes of forced migration, which are deeply rooted in the “imbalanced power dynamics of political and cultural subordination, in addition to the economic inequalities imposed on the Global South by the Global North” (Almustafa, 2022: 1072, in citing Bigo, 2002).

Alcalde (2016) explains that the word ‘crisis’ denotes something dangerous, that needs to be addressed with the utmost priority. Hence, the notion of ‘refugee crisis’ calls for exceptional responses to be deployed, and justifies discourses of securitization, which tends to criminalize and otherize the refugees that are too close to the European borders. This narrative has dramatic effect not only on the lives of refugees that cross the Mediterranean, or die in this attempt, but also on the lives of those who remain circumscribed in the Global South. For instance, as I articulate and further problematize in this work, Lebanese political elites, building on the European narrative of ‘refugee crisis’, and the ‘threatening other’, have started using similar rhetoric, justifying the enactment of securitization policies and provisions, which further exacerbate the lives of refugees.

Hence, in this work, when I adopt the term ‘refugee crisis’, I do it consciously, and with the clear intent to signifying it as an instrument used by political elites to promote the construction of exceptional spaces in which refugees are stigmatized and prevented from accessing and exercising their basic human rights.

Disability

In this study, ‘disability’ is understood as a continuum and a relational reality. It is defined not as a fixed or inherent medical or biological state, but rather as one that is dependent on various contextual factors (see Saltes, 2013). This way of comprehending disability acknowledges the biological reality of a person’s impairment, while also highlighting society’s complicity in perpetuating exclusionary and disabling practices against people with impairments, alongside the psychological dimension and experiential background of people with disabilities. Audre Lorde (1982) states that “we do not live single-issue lives” (cited by Saia et al., 2024:3192), meaning that our experiences are defined by the convergence of multiple and overlapping identities – such as race, class, disability and gender to name a few – rather than by a single characteristic in isolation. Everyone is the results of the experiences lived at the intersection of their multiple, fluid and ever-evolving identities. Hence, disability cannot be conceived as a singular, isolated condition rooted solely in an individual’s physical impairment, but as the outcome of the interaction between one’s impairment and the contextual factors, both environmental and personal, which define a person’s experience and life. Disability is recognized as a heterogenous experience that materializes differently according to people’s multidimensional identities and their unique life circumstances.

Lastly, in this work, I employ the person-first language (people with disability), rather than the identity-first one (disabled people). This is because the former resonates with the language used by people with disabilities, organizations of people with disabilities (OPDs), and their allies in the region, as well as with the academic efforts of fellow researchers in the Middle East (e.g. Center

of Lebanese Studies; see also the work done by the Disability Under Siege Programme in collaboration with academics from Palestine, Jordan and Lebanon), and finally with my participants' preference. The latter is used only when directly quoting scholars who, in their work, use identity-first language (disabled people).

Colonialism, coloniality and colonial

The terms “colonialism” and “coloniality” are different but related concepts. In this study, when using the word “colonialism”, I refer to the historical, political and economic processes of establishing and maintaining control over a territory and its people by a foreign power. Colonialism is a historical practice that has had significant impacts on global power relations and socio-economic structures. On the other hand, “coloniality” indicates the enduring patterns and structures of power, knowledge, and identity that originated from colonial domination and continues to shape contemporary global relationships (see Mignolo, 2012, 2013, 2017; Quijano, 2007). Tlostanova and Mignolo (2009) write that “coloniality is the hidden side of modernity ... coloniality is constitutive of modernity and there is no modernity without coloniality” (p.132). Coloniality focuses on how ideologies and hierarchies developed and imposed during the era of colonialism persist in modern institutions, epistemologies and cultural norms, denouncing the ways in which the legacy of colonialism continues to influence global inequalities. In this work, when I use the adjective “colonial”, I do so referring most of the time to the concept of coloniality, to underline the persistent influence of the power dynamics and epistemologies advanced during the era of colonialism on humanitarian practices and policies, shaping the way in which humanitarian assistance is designed, delivered and understood (see Roth et al., 2024). This includes the perpetuation of hierarchical relationship where the Global North continues to dictate the terms and methodologies of aid, where often humanitarian actors “presume to know more about domestic vulnerability and systematic solutions” than affected communities (Carpi, 2023:145), disregarding

local knowledge and contexts. It also involves examining how humanitarian interventions might perpetuate power imbalances and reinforce historical inequalities, failing to recognize biases and assumptions that underpin the humanitarian system and its work.

Neoliberalism

Neoliberalism is an economic and political philosophy. It did not emerge as a “single hegemonic system [or] process” (Birch and Mykhnenko, 2010:1-6), but instead has manifested unevenly in different regions, influenced by varying ideological and political commitments. And yet, despite social, political, and economic policies, practices and discourses, “the neoliberal turn” (Harvey, 2005:9) appears to materialize as a “hegemonic political-economic project” (Birch and Mykhnenko, 2010:6) that emphasizes the value of free market competition, the marketization of all aspect of life, the liberalization of trade, and the deregulation of labor. Critics argue that the neoliberal system has led to increase economic inequalities, the erosion of public welfare systems, as well as the commodification of various aspect of life (see Piketty, 2014; Gilens, 2014).

Within CDT neoliberalism is examined and critiqued as a system that prioritizes market logic, often to the detriment of marginalized groups, including people with disabilities. Neoliberal principles, such the ones mentioned above, exacerbate inequalities by framing disability support as a matter of individual responsibility, eroding public support systems and emphasizing self-sufficiency and productivity, marginalizing those who do not fit into the neoliberal ideal of the “able” citizens. Through this lens, neoliberalism is critiqued for perpetuating ableism by valuing individuals based on their economic contributions, thereby reproducing structural forms of exclusion and marginalization (see section 2.3.2).

In humanitarian contexts, such as Lebanon, neoliberalism is employed to explain the influence of free-market principles on the delivery and organization of humanitarian aid within different

humanitarian sectors, including the education one. This includes the emphasis on efficiency, cost-effectiveness, and market-based solutions in humanitarian interventions (Chimni, 2009; Berghs, 2014; Sözer, 2020; Menashy and Zakharia, 2022). Neoliberal approaches often lead to a focus on measurable outcomes that align with market logics, prioritizing donors' agenda and interests over the needs of affected populations, contributing to the commodification of aid, and of the people receiving it (Lough et al. 2022). In this study, the use of neoliberalism and neoliberal logic is intentionally employed to highlight how a system based on this approach reproduces and exacerbates power inequalities (Barnett and Weiss, 2008; Roth, 2012, 2015; Ward and Bian, 2024) by reinforcing market-driven solutions, rather than focusing on people's needs and critically assessing the root causes of humanitarian crisis.

Global North and Global South

“Centuries of northern ‘dominance over the Global South (...) have converged to produce an intolerable social order.” (Oglesby, 1969 cited by Di Nicola, 2020:21)

The words Global South (Majority World) and Global North (Western or Minority World) are here used to critically expose the imbalanced power relationship among countries and the “intolerable social order”, that have been reproduced over the centuries. In using the notions of Global South and Global North/Western world, I reject and oppose the apolitical and de-historicized conceptualization of these spaces as purely geographical locus, that divide industrialized and ‘civilized’ nations from those that are uncritically constructed as underdeveloped, the so called ‘Third World’ or ‘developing world’. The Global South, in the present work, comes to signify the “colonized, neo-colonized, and decolonized countries (of Asia, Africa, and Latin America) whose economic and political structures have been deformed within the colonial process” (Mohanty et al., 1991:ix, cited by Erevelles, 2011:122). The Global North represents those countries (Europe, North America, Australia) that have historically colonized, oppressed, and exploited Southern lands and

their inhabiting bodies, who came to exist in a dimension of ‘otherness’, deemed as ‘less human’; bodies that became expendable through their racialization, disablement, and commodification. Hence, the notions of Global South and Global North/Western world materialize in the historical-political and economic reality of colonial borders.

Lived experience

The concept of “lived experience” is understood differently in diverse disciplines, and it continues to evolve in a distinctive way in parallel literatures, with little or no explanation regarding its possible meaning or implication (McIntosh and Wright, 2019). Here, I try to briefly delineate how ‘lived experience’ is understood and employed in this work. Within this study, the concept of ‘lived experience’ refers to the embodiment of Syrian refugee children with disabilities and their families’ daily life experiences and interactions within their broader environment and contexts (see Chapple et al., 2021). It is used to shed light on matters of systemic inequalities and power relations, investigating how people’s lives are shaped by multiple and intersectional socially constructed axes of identity (such as race, ethnicity, gender, and disability to name a few) and oppressions (such as patriarchy, colonialism, neoliberalism and other intersecting systems of subjugation) that influence and define their everyday realities (Crenshaw, 1989).

Within this framework, people’s lived experiences are understood as being situated within broader social, (geo)political, historical and economic contexts. Thus, lived experience allows to focus on individual subjects while also considering how their social and material contexts shape their subjective experiences. It views experience as relational and located within a temporal continuum, acknowledging the interconnected cognitive, emotional, motor and motivational aspects of it (Dieumegard et al., 2021). In this work, lived experience is utilized

to indicate an attempt to get closer and to genuinely learn from the lives and concerns of Syrian refugee children with disabilities and their families as they are relegated in liminal spaces through different systems of oppression, and to discuss how they navigate, and resist the conditions imposed upon them by the above-mentioned power structures.

For instance, scholars like De Genova (2013) and Malkki (1995) argue that forced migration extends beyond physical movement, involving complex processes of legal liminality and social exclusion. Focusing on the lived experiences of refugees and forcibly displaced people reveals their strategies for navigating and resisting the conditions imposed by systemic forces, thereby critiquing dominant humanitarian and securitization discourses that often depoliticize forced migration (Crawley and Skleparis, 2018). Similarly, scholars within the disability studies field underscore how centering the lived experiences of refugees with disabilities would be fundamental to understand the intersection of forced displacement, structural violence, and social exclusion (Elder, 2015; Grech and Soldatic, 2016; Ward, 2021). This approach challenges dominant narratives that pathologize refugees with disabilities, highlighting how their lived experiences are a vital source of knowledge able to question global power structures (Meekosha, 2011).

1.3 Thesis' structure and overview of chapters

This thesis is constituted by two main parts followed by a conclusion and discussion section. Part I consists of three chapters: in Chapter 1 and 2, I 'set the scene' of this study, analyzing the political and historical context in which the research was conducted, reviewing the literature, and critically engaging with different theoretical frameworks; and in Chapter 3, I provide an account of the methods and methodologies used. Part II also consists of three chapters, Chapters 4, 5 and 6, where I present the research findings.

Part I

Chapter 1 aims to provide a first roadmap to navigate this work. In the first part of the chapter, I focus on the Lebanese context, offering a snapshot of the political, and historical background of the country, briefly analysing the long and difficult relationship with Syria, which have been politically instrumentalized to redefine the current relationship between the two communities. I also retrace the trajectory of Lebanon's approach to Syrian refugees, and how the situation in the country has been dramatically deteriorating starting from the '*thaura*' (revolution) in 2019, and the subsequent compounded crises (Covid-19, Beirut port explosion, economic crisis). In the second part, I analyze Lebanon's education response to the Syrian refugee children's rights to education. Here, I briefly examine the international and national education policies in place. Then, I discuss the Reaching All Children with Education (RACE) initiative implemented in the region, and the Inclusive Education Pilot Program (IEPP), carried out by UNICEF in collaboration with the Lebanese Ministry of Education and Higher Education (MEHE). In the last section, I review the empirical literature at the intersection of forced migration, disability and education. First, I critically engage with the literature on education in humanitarian contexts, historicizing the emergence and evolution of the modern approaches to education in contexts of conflict and emergencies, and highlighting the gap between its underlining logics, which shape the institutional agenda, and concerns about (disability-)inclusion. This is fundamental to better locate and understand the nature of the literature available on the topic under investigation. Second, I review the empirical literature on education for refugee children with disabilities in different regions of the world, and in the Lebanese context. Finally, I question the meaning of 'inclusion' within the field of education in humanitarian contexts.

Chapter 2 presents the main theoretical and conceptual frameworks that have been in conversation with the data gathered for this work. In the first part of the chapter, I introduce Critical Disability Theory (CDT), reflecting on its genesis, tenants, and evolution, as well as on the role

that has played in the development of this work. In the second part, I consider the work of the Italian political philosopher Giorgio Agamben on *Homo Sacer*, *Bare Life* and *State of Exception*, drawing conceptual links across the fields of forced migration studies and CDT. In this space, I also reflect on how humanitarianism comes to embody a sovereign entity able to administer refugees' bodies. To conclude, I outline the contribution that this research offers to the field of CDT.

Chapter 3 explains the methodological approaches and methods employed to carry out this work. In the first part of the chapter, I focus on the philosophical rationale informing this research, locating the study within the interpretivist/social constructionist tradition, acknowledging its inter-/post-disciplinary and multidimensional nature, and reflecting on the use of (Constructivist) Grounded Theory ((C)GT) as a unique and valuable data analysis tool. Then, I engage with the more practical dimension of the work, providing information on the research methods, including how I connected with participants, their demographics, the location of the interviews and the phases and processes of data collection and data analysis. Here, I also briefly outline for the first time the emerging (C)GT's core and sub-categories of the study, explaining how the data analysis process informed the formulation of the proposed notion of '*Letting die through Neoliberal Inclusion*'. In the last section, I present some ethical considerations regarding matters of consent and assent, data protection, as well as of reflexivity and positionality.

Part II: I provide a first conceptual overview of the emerging (C)GT's core category of '*Letting die through Neoliberal Inclusion*', and its constitutive sub-categories – '*Re-producing Emergencization*', '*Advancing Neoliberal Inclusion*', and '*Actualizing a State of Exception*' – together with their respective elements, which are further developed and articulated in the finding Chapters 4, 5 and 6. Each finding chapter engages with one of the sub-categories of '*Letting die through Neoliberal Inclusion*'. In this transitional space, I also briefly explain the rationale informing my decision to organize the finding chapters according to the emerging (C)GT's core

and sub-categories of ‘Letting die through Neoliberal Inclusion’, rather than structuring them around the study’s RQs.

Chapter 4 is the first finding chapter, and it focuses on the sub-category ‘Re-producing Emergencization’, and its three fundamental elements ‘Discriminatory Rhetoric’, ‘Operationalizing Exclusion in Emergency’, and ‘Impacting Education’. In brief, I explain how emergencization discourses legitimize processes of securitization, exacerbating rhetoric of discrimination against Syrian refugees, and justifying the de-/prioritization of specific groups of people, that come to be excluded from humanitarian aid. I also reflect on and address the effects that a status of declared emergency has on the lived experiences of Syrian refugee children in accessing education opportunities in Lebanon. This chapter provides the basis on which the development of the emerging (C)GT’s notion of ‘Letting Die through Neoliberal Inclusion’ is rooted.

Chapter 5 focuses on the sub-category ‘Advancing Neoliberal Inclusion’, and its three fundamental elements ‘Hierarchizing Disability’, ‘Promoting Exclusionary Inclusion’ and ‘Facing and Resisting barriers’. In brief, I analyze the processes and eventualities through which Syrian refugee children with disabilities, especially those with severe and complex ones, are systematically excluded from educational interventions, even from those which are purportedly ‘inclusive’. The chapter explains not only *how* children with disabilities are excluded, but also *why* they come to be excluded. In so doing, I underline the role played by processes of lives’ qualification following a political economy of bodies, which is rooted in the neoliberal philosophy embedded within the humanitarian sector. I also highlight how humanitarian efforts in education perpetuate ableist understandings of disabilities through their ‘inclusive’ rhetoric, establishing which bodies matter/ are included, and which do not matter/ are excluded.

Chapter 6 articulates the sub-category ‘Actualizing a *State of Exception*’, and its three elements ‘Politicizing and Marketizing bodies and aid’, ‘Denouncing *Bare Life*’, and ‘Resisting

Space of Exception'. In this chapter, I reflect on how the commodification and instrumentalization of the 'refugee' and 'disability' categories are used to serve the political and economic interests of the dominant Western humanitarian system. I analyse how the status of *bare life* unravels within the everyday life of Syrian refugee families, focusing on the lived experiences of *Homines Sacri*. Finally, I present stories of resistance and agency, that challenge the dominant imaginary of the passive, de-agentivized, vulnerable refugee with/out disability.

The final conclusive chapter is organized in three sections. First, building on the epistemological understanding around the notion of 'Letting die through Neoliberal Inclusion' developed across Chapters 4, 5 and 6, I answer and discuss the three study's RQs. Then, I acknowledge the study limitations, and their impact on the overall research. Lastly, I provide policy recommendations, and I give thoughts to possible directions for future research.

PART I: CONTEXTUALIZING THE STUDY

CHAPTER 1

SETTING THE SCENE: HISTORICAL, POLITICAL AND EMPIRICAL CONTEXT

1.1 Introduction

This chapter serves as a compass to introduce the context in which the present study took place, illuminating the intricate landscape wherein the rights and aspirations of Syrian refugee children with/out disabilities intersect and are shaped by international and Lebanese historical dynamics and policy responses. The chapter is divided into three main sections, followed by conclusion. In the first part, I begin by outlining the historical relationship between Syria and Lebanon, which have been instrumentalized to define the current relationship between the two communities. From there, I trace the trajectory of Lebanon's approach to Syrian refugees, considering and problematizing the shift from an open-door policy to a securitized approach that reproduces measures of exclusion and segregations. Here, I also analyze how the compounded crisis experienced in the region have further exacerbated discriminatory rhetoric and practices within the Lebanese society, having dramatic effects on refugees' lives. In the second part, I examine the international and national educational policies available, particularly when they intersect with refugeehood and disability. Moreover, I discuss both the Reaching All Children with Education (RACE I and II) initiative – which represent the biggest effort in the region to ensure equal and quality education to every child –, and the Inclusive Education Pilot Project (IEPP) – a joint effort between UNICEF and the Lebanese Ministry of Education and Higher Education. In the last part of the chapter, I analyze the existing empirical literature at the juncture of education, refugeehood and disability. First, I critically analyze the field of education in humanitarian contexts (which is also known as education in emergency, and encompasses its subset of refugee education), tracing its historical development and highlighting discrepancies between its foundational principles, which guide and define institutional priorities, and concerns on inclusion. This would be crucial for gaining a better

understanding of the type and nature of the literature available. Then, I provide a short review of the empirical literature available on the topic across different regions of the world, and in the Lebanese context, focusing on Syrian refugee children with disabilities. Lastly, I question the meaning of ‘inclusion’ within the field of education in emergency, critically reflecting on the recent rhetoric of ‘disability-inclusion’. This chapter is a first roadmap to navigate this work, and to start familiarizing with the socio-political and historical context of the present research, as well as with the broader field of education in humanitarian contexts.

1.2 The Lebanese context

Lebanon is an Arab-Mediterranean country with a complex and tumultuous history. Maleab (2018) writes that “one of the structural causes of Lebanon’s fragility is its geographical location. The country seaports, moderate weather, and wealth of natural resources (...) in a mostly landlocked region made it attractive to colonists” (p. 6). Here, I briefly retrace the key events of the Lebanese history from the French mandate to contextualize the current Lebanese’s response to Syrian refugees. This historical overview is fundamental to understand the processes that have brought the country to experience the current structural socio-political and economic instability. Moreover, it helps to explain and locate some of the narratives presented in this study: from the widespread discourses of emergency, with the promotion of hate speech and discriminatory rhetoric against Syrian refugees, to the lack of suitable domestic legislative frameworks to respond to the increasing number of refugees crossing the Lebanese border to find refuge. In researching the lived experiences of Syrian refugee children with disabilities and their families in accessing education opportunities and life-saving services in Lebanon, I cannot avoid engagement with the complex history of the country; Syrian refugees’ experiences and lives in Lebanon are dramatically shaped by the shared Lebanese-Syrian history, as well as by the current national and international refugee

policies, which determine their opportunities to access services, as well as the way in which they are seen and treated within the broader society.

1.2.1 History of the Lebanese-Syrian relationship

After World War I, and the fall of the Ottoman Empire in 1918, Ottoman Syria, which included also what later became Lebanon, was under the French mandate (Maleab, 2018). France, after dismantling the Arab government in Damascus, proceeded with the partition of the territory according to sectarian, ethnic and religious lines, trying to establish a federal system. This move created the first frictions with the Syrian nationalists, who were aiming for a united and independent Greater Syria (Hakim, 2019). The situation further deteriorated when France established a separate independent Lebanese entity to meet the requests of the Christian Maronites, with whom they had historically a close relationship (Hakim, 2019). After the separation of “Ottoman Syria”, and the creation of Lebanon, Syria has repeatedly interfered in Lebanese domestic affairs, refusing to recognize Lebanon as a separate state, and trying to re-absorb it (Pipes, 1990; Nisan, 2015).

Lebanon’s independence was declared in 1943, becoming a confessional democracy based on the religious groups’ ratio in the society informed by the 1932 census. In this system, political representation is proportionally divided among religious sects, and the seats in the Parliament are systematized by weighting the percentage of the general population. This political arrangement, which is a heritage of French colonialism, proved to be extremely fragile, especially after the arrival of Palestinian refugees, who were forced to leave due to the *nakba* (catastrophe) in 1948, the Arab-Israeli war in 1967, and the ongoing Israeli settler colonial project in Palestine (see Wolfe, 2006; Veracini, 2015; Amoruso et al., 2019, Snounu, 2019). The presence of Palestinians in the country raised existential dilemmas for Lebanon’s survival, as it was exercising a considerable pressure on the already delicate sectarian structure of the country (Haddad and Jamali, 2003).

Lebanon's stability was dramatically declining under internal and external pressures, and in 1975, the Lebanese civil war broke out. Lebanon's confessional political system, together with the accentuated economic disparities between and among the different groups, and the presence of Palestinian militancy within the Lebanese borders (Mac Queen and Baxter, 2014), contributed to the outbreak of the civil war. During the Lebanese civil war, in 1976, Syria sent its troops to Lebanon, occupying the country. In 1978, during the "100 Days War", Syria bombarded East Beirut, which was predominantly Christian, and between 1980s and the end of the war, it kept expanding its military control over the region. By the end of the civil war all the Lebanese territories, with the only exception from the "security zone" in the South under the Israeli control, were occupied by the Syrian regime (Nisan, 2015). In 1989, with the Taif Agreement, Syria was nominated guarantor of the peace in Lebanon; however, rather than a guarantor, Syria behaved as an occupier, exercising political and military power within the Lebanese borders (Mencütek, 2019). Malik (1997) explains that the Syrian occupation deeply affected every facet of political, economic, and social life in Lebanon:

"One particularly disturbing feature of Syrianization is the presence inside Lebanon of over one million Syrian workers(...). This huge Syrian work force (roughly equivalent to one-third of the Lebanese population) sends some \$10-12 million in hard currency out of the country every day. More alarming is the prospect that many Syrians will remain in the country, legally or not, marry Lebanese, settle in, and perhaps invite other members of their families in Syria to cross the porous border to join them. These workers strain Lebanon's already precarious demographic balance, they introduce a neo-colonial dimension to Syrian hegemony over Lebanon, and may contribute to the Syrian grip through intelligence efforts."

The Syrian regime has been deeply despised for what happened during and after the end of the Lebanese civil war (see Nisan, 2000; Pipes, 2000; Bassil, 2012). Syria managed to achieve in Lebanon an "exceptional level of domestic pacification, with hardly any expression of political opposition" (Sakr, 2005:88), due to the "regime of terror" established through the Syrian

intelligence. During the occupation of Lebanon, Syria employed techniques of arbitrary detention, imprisonment, and torture (same strategy used against its own citizens)², that were instrumentalized to suppress any sort of dissent and protest against the Syrian regime. Gambill (2001) reports that many thousands of Lebanese, during the 25 years of Syrian occupation, were imprisoned in detention centers, subjected to torture, exploitation, and inhuman living conditions. The Syrian occupation ended in 2005, when the assassination of the former Lebanese Prime Minister Rafiq Hariri triggered the “Cedar Revolution”, which combined with international pressures led to the liberation of the country from the Syrian’s yoke. After the Syrian troops’ departure, the relationship between the two countries have never stabilized.

The Lebanese-Syrian complex historical past, dominated by the Syrian occupation and its practices of forced disappearance, exploitation and violence are still well ingrained in Lebanese’s memory. The Lebanese political elite, building on the historical fear towards the Syrian regime, and resentment towards it, have enacted a strong scapegoating policy, promoted by hate speech, and discriminatory rhetoric, which have built on the Lebanese past trauma, to otherize, and criminalize innocent Syrian refugees, who have been victims of the same atrocity experienced by the Lebanese (see findings Chapter 4).

1.2.2 Syrian refugees in Lebanon: From open door policy to policy of exclusion

Many states in Middle East, including Lebanon, have refused to ratify the 1951 Convention on the Status of Refugees and its 1967 Protocol (Stevens, 2014). A common argument to justify the refusal to ratify the Refugee Convention in Lebanon is that “it would require the permanent settlement or local integration of refugees, including Palestinians” (Janmyr, 2016:449) and this would threaten the fragile equilibrium between the 18 different sects inhabiting the country, having dramatic

² The movement franco-libanais, SOLIDA (Soutien aux Libanais Détenus Arbitrairement), in 2005 wrote a report on the forced disappearances of both Lebanese and Syrian citizens. It can be accessed to the following link: https://www.fidh.org/IMG/pdf/Rapport_alternatif_Solida_Syrie_2005_ENG_.pdf

political implications (Suleiman, 2006). However, despite Lebanon not ratifying the UN Refugee Convention, it is still bound by leading principles of refugee protection through the ratification of other major international human rights instruments³, as well as by the same Lebanese constitution, where it is written that Lebanon is an active member of the United Nations Organization and it abides by its charter and by the Universal Declaration of Human Rights (UDHR), which recognizes the right to seek asylum.

At the beginning of the Syrian war in 2011, the country adopted an open-door policy (Turner, 2015), which was not the result of a well-thought-through decision; rather, it was the alarming evidence of a political deadlock, that resulted in the government's lack of strategy to respond and deal with the increasing arrival of Syrian refugees in the country (Janmyr, 2016). Between 2011 and 2014, there was no real attempt to control and/or regulate the entrance of Syrian refugees. The only maneuver the government took was to restrict integration policies to prevent the absorption of Syrians. In 2013, Hezbollah openly aligned with Bashar al-Assad, drastically changing the dynamics and responses to Syrian refugees. The active involvement of Hezbollah in the Syrian war brought renewed violence, and every political leader started to narrativize the presence of Syrian refugees in the country differently. The sectarian nature of the Lebanese political system led to an extreme politicization of refugees, who soon came to be seen as a 'threat' to the country's stability (Tinas, 2020).

In October 2014, a 'Policy Paper on Syrian Refugee Displacement' was adopted, with the aim to prevent Syrians from entering Lebanon, and to restrict residency and work permits for those who

³ International Covenant on Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights; the Covenant against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment; the Convention on the Elimination of All Forms of Discrimination against Women; the International Convention on the Elimination of All Forms of Racial Discrimination and others.

were already in the country (Diab, 2023), pressuring them to return to Syria (Kikano et al., 2021). This new policy has been a maneuver to create a hostile environment when trying to secure legal status in Lebanon for refugees (ICJ, 2020), resulting in more than 73% of Syrian refugees over the age of 15 residing in the country without valid legal residence (LCRP, 2021). As a result, Syrian refugees are at serious risk of exploitation, abuse, arbitrary detention, and deportation (Abumeri, 2020). The lack of legal documents, and the subsequent statelessness status, have had dangerous repercussions also on the ability of Syrian refugees to access basic and life-saving services. For instance, many children cannot be enrolled in school; a great number of refugees, including minors, are forced to enter the informal labor market; and people who might need medical attention are prevented to safely access health care services.

In 2014, Lebanon also started collaborating with the UN to develop the Lebanese Crisis Response Plan (LCRP), which was part of the broader Regional Refugee and Resilience plan (3RP) effort. In 2015, Lebanon closed its border, and requested UNHCR to stop registering new Syrian refugees (Diab, 2023). The suspension of new registration with UNHCR has prevented a considerable number of Syrian refugees to access humanitarian aid, as they remain invisible to the humanitarian system. Despite the funding received since 2015 through the LCRP, which are over US\$9.3 billion (UN and Lebanese Government, 2023), the status of Syrian refugees within the country has been dramatically deteriorating, especially after the compounded crisis experienced since 2019.

1.2.3 Post-2019: Compounded crisis and increasing discrimination

Diab (2023) explains how the historical mismanagement of the country, combined with the lack of clear and solid refugee policy, and the widespread political and economic corruption led the country towards a disastrous present, which fully actualized itself in 2019 with the October revolution. In this prolonged climate of crisis, processes of scapegoating promoted by the political elites, under the terms of ethnic/religious diversity, have been weaponized to produce and

reproduce discourses of ontological ‘otherization’, ‘illegalization’, and ‘criminalization’ of Syrian refugees, who have been constructed as a ‘threat’ to the national security and the Lebanese identity (Fakhoury and Abi Raad 2017). The Lebanese political elite’s instrumentalization of this culture of blame against refugees (Haddad 2004), and their escalating anti-refugee discourses have had a dramatic role in exacerbating the violence against Syrian refugees.

The anti-refugee discourses have resulted in endemic and structural discrimination, physical and verbal abuse, exploitation, prosecution, arbitrary detention, and deportation of Syrian refugees. Amnesty International, in April 2023, denounced the unlawful deportation of dozens of Syrian refugees to Syria by the Lebanese army. Despite Lebanon not being a signatory country of the Refugee Convention, it is still obliged to protect refugees and ensure the principle of non-refoulment through other binding international documents that have been signed and ratified. Since the policy shift in 2014, Syrians return has been on Lebanon’s agenda (Sahin-Mencütek and Tsourapas, 2022). In 2018, state authorities and municipalities increased restrictions for Syrians to access public services, such as healthcare and education, imposing extremely difficult and onerous criteria to renew residency permits, enforcing curfews, and evicting refugees from informal tented settlements, promoting structural policies of exclusion (Kikano et al., 2021), encouraging Lebanese feeling of xenophobia and advancing coercive measure to force repatriation (Diab, 2023).

Following the securitization processes, both in terms of new restrictions’ enforcement and scapegoating discourses depicting Syrians as an existential threat to the country’s equilibrium, Syrian repatriation has been justified as the only available measure to avert the Syrian menace. As a result, between 2019 and 2020, the Lebanese authorities deported more than 6,000 Syrian refugees, and among those some experienced severe human rights violations (Amnesty International, 2021; Human Rights Watch, 2021). The danger of Syrian refugees’ repatriation has

been recognized by many scholars, who sustain that repatriation is neither safe nor a sustainable solution (Estriani, 2019; Fakhoury and Ozkul; 2019), especially since no political agreement has been reached between the parts involved in the Syrian conflict (Assi, 2019), and no plan is place for the safe and lawful return of Syrian refugees (Diab, 2023). Syrian refugees find themselves living at the margin of the Lebanese society, being highly stigmatized, not being able to access services and opportunities, and fearing to be repatriated.

1.3 Education responses to Syrian refugees

Having engaged with the Lebanese historical and socio-political background, I now focus on contextualizing the country's educational response to Syrian refugees within it. Since the beginning of the Syrian war in 2011, Lebanon is hosting more than 1.5 million Syrians. Of these 1.5 million refugees, half are school-aged children between 3 and 18 years old (Hamadeh, 2018). UNESCO, UNFPA, UNHCR, UNICEF, and Save the Children (2014) conducted a study which revealed that only the 6% of the surveyed Syrian refugee children and youth are enrolled in the formal Lebanese education system, underlining how the great majority of Syrians students lack appropriate educational opportunities. In Lebanon, "the education demands exceed the capacity and the resources of the education sector", leaving refugees as well as poorer Lebanese students without an education (Klehr, 2018:1). Accessing education opportunities and learning spaces is even harder for children with disabilities.

1.3.1 International and National Educational Policy and Legal Frameworks: at the intersection of refugeehood and disability

The Lebanese Government has not signed the 1951 Refugee Convention and its Protocol (Janmyr, 2017); however, it has ratified a series of other human rights treaties concerning the protection of refugees, as well as the provisions of education opportunities and services for refugee children with/out disabilities (Shuayb et al., 2014): the Universal Declaration of Human Rights (UDHR), the Dakar Education for All (EFA) framework and the Convention on the Rights of the Child

(CRC), to name a few. Each one of the above treaties recognizes compulsory primary education as a universal human right. Hence, Lebanon still has obligations and responsibilities towards the refugee population within its borders. Article 26:1 of the Universal Declaration of Human Rights affirms that:

“Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.” (UN, 1948)

Similarly, the EFA framework recognizes the need to ensure education rights to everyone, and among its goal, it mentions the expansion of early childhood care and education, the provision of free and compulsory primary education for all, as well as of learning and life skills for young people and adults, and the improvement of quality of education (UNESCO, 2015). Moreover, Article 22 of the CRC clearly states which are signatory nation duties towards refugee population:

“[S]tates Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said State are Parties.” (UN, 1989)

At the national level, the most recent Lebanon’s Memorandum of Understanding (MOU) with UNHCR (2008) affirms that the country does not consider itself as an asylum nation, meaning that refugee status determination is under UNHCR jurisdiction, and that Syrian refugees are classified as ‘foreigners’, ‘displaced’ or ‘migrant workers’ rather than ‘refugees’ (Shuayb et al., 2014). According to this legal framework, Syrian refugees face various challenges in accessing basic services, including education. Moreover, because Syrians are not recognized as refugees by

Lebanese authorities, the already mentioned Article 22 of the CRC is not applicable. However, Lebanon is signatory to other international declarations, that guarantee the right to education for all until the age of 18: the International Covenant on Civil and Political Rights (Article 14)⁴, the International Covenant on Economic, Social and Cultural Rights (Article 13)⁵ and the CRC (Article 28)⁶. While Article 22 of the CRC is primarily concerned with refugee's education and it cannot be applicable to the specific Lebanese context for the reasons mentioned above, Article 28:1 relates to:

1. State Parties' recognition of the right of the child to education based on equal opportunity, and it affirms that State Parties shall:
 - (a) Make primary education compulsory and available free to *all*;
 - (b) Encourage the development of different forms of *secondary education*, including general and *vocational education*, make them *available and accessible to every child*, and take appropriate measures such as the introduction of *free education* and offering financial assistance in case of need;
 - (c) *Make higher education accessible to all* on the basis of capacity by every appropriate means;
 - (d) Make educational and vocational information and guidance available and *accessible to all children*;
 - (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates. (CRC, 1989:9; my emphasis)

Therefore, the Lebanese Government is still tied to the responsibility of providing education for all up to the age of 18. However, despite the joint work of MEHE, UNICEF and other international and national education actors to accommodate Syrian refugee children's educational needs, many children are still facing dramatic challenges in exercising their right to access education. Education Cannot Wait (ECW, 2017) writes that "humanitarian actors are still playing catch-up when it comes to secondary education", highlighting how secondary education is severely underfunded. The Human Rights Watch (2016) reports that in 2015-2016 only the 3% of secondary school age Syrian

⁴ A complete overview of the document can be found at: <https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>

⁵ To know more about Article 13 of the CESCR visit: <https://www.refworld.org/pdfid/4538838c22.pdf>

⁶ Additional information on CRC is available at: <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

refugee children were enrolled in Lebanese public secondary schools. A more recent study shows how the situation did not improve in the past few years, underlining how “less than 4% of Syrians refugee children are enrolled at the secondary stage [of education], and only 1% are in grade 9” (Shuayb and Hammoud, 2021). In the same way, inclusive education represents a considerable challenge in Lebanon; in fact, from the scarce data available, it seems that only the 0.5% of children with disabilities are enrolled in education (Humanity and Inclusion, 2022).

1.3.2 The education response to Syrian refugees in Lebanon

The large number of Syrian refugees arriving in adjacent hosting countries has had important repercussion in the whole region. To face these extraordinary circumstances, UNHCR in collaboration with UNDP implemented different regional response plans for the humanitarian emergency response to the Syrian crisis. In 2012, the Regional Refugee and Resilience Plan (3RP) was launched, also introducing a long-term component to address the challenges experienced by the hosting countries most affected by the arrival of Syrian refugees (e.g. Lebanon, Turkey, Jordan, Egypt). The Lebanese version of the 3RP is the Lebanese Crisis Response Plan (LCRP), which was drafted in 2014, and reviewed periodically in 2015 the first time, and then in 2017, where a shift from an emergency response to a longer-term strategic framework took place (from 2017 to 2020), and again in 2021, re-confirming the “joint plan between the Government of Lebanon (GoL) and its international and national partners to respond to the challenges in a holistic, comprehensive and integrated manner through medium-term, multi-year planning” (GoL, UNDP, and UNHCR, 2022:5).

The LCRP is divided by region (e.g. Lebanon, Jordan, etc.) and by sector (e.g. education, protection, food, etc.), and it promotes an intersectoral response based on the coordination of a national ministry (e.g. Lebanese MEHE or MoSA) with UNHCR and UNDP (Boustani et al., 2016). The sector initiative for education is the Reaching all Children with Education (RACE). In

2012-2013, before the start of RACE, there was already an attempt to provide education for Syrian refugee children. The Lebanese MEHE, after an accord with UN agencies, which agreed to cover refugee children's registration fees, opened the door to register Syrian refugee children in Lebanese public schools. The year after, the 2013-2014 academic year, MEHE changed its policy and decided to open an afternoon shift, known also as "second shift", to compensate for the limited capacity of Lebanese schools, segregating Syrian students from their Lebanese peers (Shuayb et al., 2016). The increasing number of Syrian children requiring education put additional pressure on an already weak and underfunded public education system (Mahfouz et al., 2020), which was already in need of structural reforms before the arrival of Syrian refugees (El-Ghali et al., 2016). To meet the raising educational needs of Syrian refugees in Lebanon, and to support the Lebanese public education system, a three-year strategy, RACE I, was developed to gather for the region educational challenges. RACE I run from 2014 to 2017, and it was followed by a second program, RACE II, carried out from 2017 to 2021.

RACE I was conceptualized with the aim "to develop an expanded and well-coordinated three-year Program" (MEHE, 2014:2), guaranteeing vulnerable school-aged children (3-18 years) equal and quality access to learning opportunities in safe and protective environment (MEHE, 2014). The project was based on three main components: a) ensuring equitable access to educational opportunities, b) improving the quality of teaching and learning, and c) strengthening national education system, policies, and monitoring (MEHE, 2014:23). Since the start of RACE I, the number of Syrian refugee children accessing education steadily increased from around 13.5% in 2012-2013, to approximatively 36% in 2014-2015, and 40% in 2015-2016 (MEHE, 2016). Moreover, a report published by UNHCR, UNICEF and WFP (2017) attests that at the national level, approximatively "70% of children aged 6-14 were enrolled in school, compared to 52% in 2016" (p.13). However, at the end of the first RACE plan, still a considerable large percentage of

children were out of school (MEHE, 2016). El-Ghali et al. (2016) sustains that this failure can be drawn back to the weak coordination among government agencies and NGOs as well as to the insufficient funding available.

Starting from the challenges and successes of the first RACE plan, a second project was launched, RACE II, which proposed a 5-year program, from 2016 to 2021, aimed at increasing “equitable access to quality education and learning for all children and youth aged 3-18 years in Lebanon” (MEHE, 2016:10). RACE II focused on the Education Sector Development Plan’s framework, which involves a) scaling up equitable access to education, b) improving the quality and ‘inclusiveness’ of teaching and learning environments, and c) strengthening institutional development. In RACE II, a growing role was recognized to non-formal education (NFE) in reaching out-of-school children in the region. The NFE pathway was organized to allow school-aged children to enroll or re-enroll in the formal education system, and to provide older students with future employment opportunities through the development of specific skills and knowledge with technical and vocational training (MEHE,2016).

Despite the enrollment rates of Syrian refugee children at the primary level (Grade 1-9) within the Lebanese education system had increased over time (MEHE, 2016, 2019; CRPD, 2018), the quality of education has remained a significant concern, being considered as one of the causes for low retention rates (Jalbout, 2015). Moreover, as noticed by Shuayb et al. (2014), there is lack of statistics and information on the participation rate of students in secondary education, revealing donors and MEHE’s priorities in prioritizing interventions at the primary level. The focus on primary education reveals the short-term nature of education intervention for refugees, which remain very much engrained within the humanitarian rhetoric of emergency, despite the RACE I and II’s aim to build “a more strategic approach to the education sector response, on the premise

of a stabilization and development agenda” (MEHE, 2016:3). Brun and Shuayb (2020), in analyzing the RACE programs, notice that RACE II, despite the emphasis on development, approached the Lebanese and refugee communities as two different and unrelated groups:

“A discourse on moving from a humanitarian towards a development approach has framed the policy transition in Lebanon, but education for refugees is still firmly placed within a humanitarian approach.”
(p.21)

This division could be linked to the intrinsic humanitarian (education) nature (see 1.4 below), as well as to the broader Lebanese nationalistic agenda, which does not contemplate the integration of the refugee population within the social, economic, and political life of the country, resulting in the systematic exclusion of refugees from the societal fabric, and the structural denial of their civic rights.

The RACE programs have been criticized not only for the lack of quality education, and for the humanitarian short-term approach to the education provisions provided to refugees, but also for the lack of transparency in donors and national governments’ reports concerning enrolment rates (Human Rights Watch, 2017), where the number of Syrian students enrolled in schools appear to have been inflated (Dhaybi, 2020). One last consideration has to be made on the level of inclusiveness of the RACE programs, especially concerning children with disabilities, whether they are Lebanese or Syrians. While in RACE I there was no reference to inclusion and/or to disability, in RACE II children with disabilities are briefly mentioned (MEHE, 2016), and the word ‘inclusion’ enters the program’s vocabulary (e.g. contribute to ‘inclusive’, safe (...) environment, MEHE, 2016:14). However, very scarce data are available on the ‘inclusion’ of children with disabilities in RACE II, and those available have not been disaggregated by gender, type, and

severity of disability, nor by educational level, reproducing a homogenized picture of children with disabilities.

1.3.3 What about children with disabilities?

In Lebanon, even before the arrival of Syrian refugees, most children with disabilities struggled to access the education system (UNICEF, 2017). Children with disabilities, whether Lebanese or refugees, are often rejected by both public and private schools, because of the scarce and low schools' resources, as well as by the lack of a regulatory and national administrative framework (Frangieh, 2017, 2019). People with disabilities receive insufficient and scarce level of assistance, benefits, and help from governmental institutions, being cut out from useful and important information concerning accessibility to services, public goods, and available aids (CESCR, 2016). This results in a phenomenon of structural discrimination, violence, and exclusion, which perpetrates negative practices and attitudes towards people with disabilities, enforcing and reinforcing stigma, marginalization, and human rights' violation (UNICEF, Lebanon, 2015). Lakkis et al. (2015) confirm that, in Lebanon, persons with disabilities, as well as OPDs, struggle to access information from ministries about their rights and about the relevant services available, such as education, and healthcare, limiting their active and full participation in the community's life.

In Lebanon, for the past two decades, the only legal document concerning people with disabilities has been Law 220/2000. Law 220/2000 defines a person with disability as:

“[A] person whose capacity to perform one or more vital functions, independently secure his personal existential needs, participate in social activities on an equal basis with others, and live a personal and social life that is normal by existing social standards, is reduced or non-existent because of a partial or complete, permanent or temporary, bodily, sensory or intellectual functional loss or incapacity, that is the outcome of a congenital or acquired illness or from a pathological condition that has been prolonged beyond normal medical expectations.” (Article 2, Qtd. in UNESCO 2013, 8)

Fontana and Costantini (2024) reflect on how the above definition echoes an ableist understanding of disability, being based solely on a strong medical lens, which constructs disability as “an intrinsic feature of an individual’s body that prevents one from conducting a ‘normal’ life”. Law 220/2000 applies only to Lebanese citizens, excluding the refugee populations living in the country, for whom UNRWA, UNHCR and UNICEF are responsible (Baroud, 2017; Combaz, 2018). Moreover, it seems that Law 220/2000 has never been properly implemented (Combaz, 2018; Human Right Watch, 2018; Frangieh and Ramel, 2019; Fontana and Costantini, 2024), negatively affecting people with disabilities’ rights and access to services. Combaz (2018) affirms that

“[A]ccording to a joint assessment conducted by several Lebanese association of person with disabilities in 2015, a major cause behind the violation of the rights of person with disabilities lies with the state of laws in Lebanon (...) [and] the non-ratification of the UN Convention on the rights of person with disabilities, and the lack of development of national legislation that would translate these internationally recognized rights into Lebanese laws and norms.” (p. 29)

In March 2022, the Lebanese parliament authorized the Government to proceed with the ratification of the UNCRPD (UNHCR, 2023), however, to date, no information is available on the status of the UNCRPD ratification (Fontana and Costantini, 2024). Concerning the educational dimension, section 7 of the Law 220/2000 focuses on “the rights of person with disabilities to education and sports”. Article 59 states that

“Every person with a disability has the right to education, meaning that the law guarantees equal opportunity to education for all people with disabilities, children, and adults, within all educational institutions of any kind, in regular classes and in special classrooms if required.” (Art. 59, Law 220/2000, section 7)

Furthermore, Article 60:a, affirms that:

“[D]isability should not constitute an obstacle to apply and/or to access to any educational institution, whether public or private of any kind.” (Article 60:a, Law 220/2000, section 7)

And Article 62 reports that:

“The best conditions to participate in all educational lessons and exams should be secured for students with disabilities at all levels of their education, adapting formal examinations to students’ needs (sign language translator, braille machines, accessibility to scholastic spaces, etc.).” (Article 62, Law 220/2000, section 7)

Despite the abovementioned articles, children with disabilities’ access to education in Lebanon still represents an important challenge. Most children with disabilities struggle to access the Lebanese education system (UNICEF, 2017), and they are often rejected by both public and private schools, being left with the only option of staying home or enrolling in separate specialized care institutions (Combaz, 2018), also called ‘*markaz*’⁷. According to UNICEF (2018) the access to public schools for children with disabilities is very limited due to the lack of safe, inclusive, and welcoming learning environments, and of resources to carry out the needed structural adjustments for inclusion. The situation appears to be even more fragile in rural areas, and in specific region such as Akkar and Beqaa, where there is widespread and endemic poverty, and a shortage of means and supplies available. On the other hand, Human Rights Watch (2018) affirms that, as public settings, also private schools deny access to children with disabilities, and if they accept to enroll them, they ask for inequitable and unfair tuition fees, which are unaffordable for most families. Concerning the *markaz*, according to the Committee on the Rights of the Child (CRC, 2017), there is no rights-based control over these institutions, meaning that the quality of care and of education, as well as the minimum standards needed to meet students’ needs, are not monitored and periodically reviewed, representing a major risk for children’s safety and wellbeing, as they might be subjected to maltreatment and neglect. The Lebanese education system tends to isolate children with disabilities (Combaz, 2018), who appear to be systematically deprioritized by the State education

⁷ The Arabic word “markaz” means “center”. However, in this specific context, it refers to “specialized institutions”.

system, being at a higher risk of dropping out or never enrolling in education. The situation is even more complex for refugee children with disabilities, who, lacking citizenship rights in Lebanon, have restricted access to the very few services available to their Lebanese peers.

To address the severe lack of inclusion within the Lebanese education system, in 2018 MEHE and UNICEF launched an Inclusive Education Pilot Program (IEPP) with the aim to promote inclusion of children with disabilities in mainstream education (ESCWA, 2023). In 2021, UNICEF published a case study on the IEPP in Lebanon stating that the MEHE was ready to scale up the implementation of the IEPP to other thirty schools in the academic year 2021-2022. The case study reports that in the academic year 2019-2020, the 30 public inclusive schools targeted a total of 1,547 students: 75% were learners with learning difficulties, 18% with behavioral difficulties and 5% had intellectual disabilities. From this assessment it also emerged that teachers and school personnel perceived children with severe and complex disabilities as difficult to target in inclusive education. During my fieldwork, the scaled up 60 inclusive schools were largely criticized by organizations' representatives, who highlighted how those school were based on an exclusionary operationalization of inclusion, which resulted in the complete de-prioritization of children with moderate, severe and complex disabilities, and the absence of Syrian refugee children with disabilities from the IEPP (see chapter 5).

To conclude, children with disabilities are still largely excluded from the Lebanese mainstream education system. The additional challenges faced by children at the intersection of multiple matrices of oppression such as refugeehood, disability, ethnicity, gender, and other underlining identity's traits have to be acknowledged and seriously tackled. Children, who find themselves at these socially constructed junctions, experience magnified layers of exclusion, inequality and segregation. For instance, little literature is available on the experience of children with disabilities,

whether they are refugees, Lebanese, orphans, from the Dom community, from different social background and others, in accessing education in Lebanon. This research positions itself in this literature gap, and it aims to enrich the conversation at the intersection of different academic fields through the voices of Syrian refugee children with disabilities and their families, as well as of organizations' representatives, who are working in the education sector.

1.4 Education in humanitarian contexts and the promise of disability-inclusion: historical perspectives and review of the literature

In this work, when talking about education in humanitarian contexts I refer to education efforts conducted by dominant Western humanitarian actors in conflict and/or emergency contexts, targeting both refugee and non-refugee communities. It includes both short-term emergency relief education projects, as well as more long-term initiatives, encompassing both the fields of education in emergency, and of refugee education, which is a subset of the former. The reasons informing this decision of talking about education in humanitarian contexts in more general terms is linked to a critical recognition that education efforts within the humanitarian-development nexus are driven by the same overarching dominant Western logics and agendas, and they are implemented by the same actors (e.g. UN agencies, Save the Children, Oxfam, national NGOs, country's ministry of education and others).

In what follows, I retrace the emergence and evolution of the field of education in emergency, highlighting the discrepancies between its underlining logics and concerns on inclusion. Then, I review the empirical literature available on education, forced migration and disability across various global regions, and in the Lebanese context. Lastly, I question the meaning of 'inclusion' for education in humanitarian contexts, providing my insight on the more recent rhetoric of 'disability-inclusive education'.

1.4.1 A historical perspective of education in humanitarian contexts

Over the past few decades, there has been an increasing interest in the field of education in emergency. During the 1990s, the world witnessed a shift from interstate conflicts to longer lasting intrastate ones, which disrupted the life of millions of people (Paris, 2004). As a response, many organizations provided education support to emergency-affected populations (Sinclair, 2001). It is in this instance that the idea of education as a humanitarian response started to gain attention for the first time (Retamal and Aedo-Richmond, 1998), and at the beginning of the 20th century, in Jomtien, Thailand, different actors came together for the World Conference on Education for All, working towards a framework for action to achieve the basic learning needs of every child, youth and adult (UNESCO, 1990). In the late 1990s, educators and other practitioners, being aware of the gap in the education services provided to population living in contexts of crisis, started to advocate more systematically to increased support to education (Anderson et al., 2006; Karpinska, 2012), and for its signification as a key and necessary element of humanitarian responses, alongside with the more traditional humanitarian sectors of health care, food security and shelter (Machel, 2001). They named this new field of operation “education in emergencies”, “with an emphasis on urgent support for education as a humanitarian need and human right” (Burde et al., 2017: 621).

Building on the momentum of the 1990s, in 2000, at the World Education Forum in Dakar organized by UNESCO, different actors from governments’ representatives to civil societies, INGOs and NGOs came together to assess the progress made since the conference in Jomtien, and to discuss and set agendas for education in the new millennium (Kagawa, 2005). During the same year, a group of practitioners and institutions interested in emergency education formed the Inter-agency Network for Education in Emergency (INEE). The birth of INEE defined the creation of education in emergency as a new and distinct category separated from developmental efforts and inscribed within traditional humanitarian aid initiatives (Burde et al., 2011, 2017).

In 2016, during the UN General Assembly in New York, a global fund for education in emergency was established, Education Cannot Wait (ECW), to address the urgent education needs of children and youth living in contexts of crises and emergencies. The role of ECW is to mobilize resources, to coordinate efforts among the different stakeholders and partners involved, and to provide timely and effective support for education in emergency. It also aims to “pursue the Humanitarian-Development Nexus ... [as] linking humanitarian relief to development in the education sector is an essential contribution to achieving learning outcomes and advancing global efforts” (ECW, 2019:1). Education is now recognized as a key dimension within the humanitarian-development sector. However, despite these efforts, after 24 years from the Dakar EFA and the institutionalization of INEE, and 8 years from the birth of ECW, millions of children are still out of school, and children with disabilities continue to be deprioritized and marginalized from education interventions, especially in contexts of conflicts and emergencies.

The field of education in humanitarian contexts has been largely shaped not only by these international policies efforts, but also and especially by dominant Western interests, materializing and growing within West-centric perspectives, particularly concerned with Western states’ interests and agendas (Burde et al., 2017, 2019; Novelli, 2010; Winthrop & Matsui, 2013). Burde et al. (2017) explain that “within departments of state, emphasis shifted from viewing support to education systems as important for distant children’s well-being to viewing this support as important for preserving the security of the homeland” (p.623). Consequently, international education policies and strategies have received much attention from both Western governments and dominant international actors. The growing interest in education in humanitarian contexts has not only sparked from the awareness of the increasing number of children out of school in crisis-affected contexts, but also and especially from a belief and a fear that lack of education may

contribute to processes of radicalization, and/or instability of already fragile countries, with potential repercussions on global security (Burde et al., 2017). In the aftermath of 9/11, and the consequent “War on Terror” (Novelli and Cardozo, 2008), Western governments started to see countries affected by conflict as a threat to their internal as well as global stability (Barnett, 2009). As a result, at the beginning of the 21st century, education interventions in contexts of conflict and crisis came to be defined in terms of securitization, contributing to processes of ‘otherization’, and perpetuating the idea of the ‘threatening migrant’ (Fassin, 2011; Massari, 2021). Securitization discourses within the field have had significant implication for the quality and nature of education in fragile contexts.

One could argue, understandably, that individual humanitarian actors may not deliberately adopt securitization logic when designing and implementing education projects. Nevertheless, they remain implicated subjects (Rothberg, 2019; Novelli & Kutan, 2023) within a system that has been conceptualized following security concerns. The implementation of securitization policies and frameworks have increased widespread negative attitudes towards refugee and migrant children, who come to be constructed as the ‘threatening other’; it fuels discriminatory and racist perspectives within the host communities; and it heavily determines children’s access to education as well as their learning experiences (see chapter 4). In recent years, there has been attempts to move away from securitization logics, to shift towards more (disability-) inclusive responses. While this is a positive and needed change, the conceptualization of (disability-) inclusion is defined by and bounded to protectionist and charity logics, keeping the humanitarian sector, and its educational interventions, in between a disempowering politics of pity—where refugees with/out disabilities are defined exclusively in terms of vulnerability – and a racialized politics of securitization – where they are constructed as a threat. The two politics work in antagonistic ways, providing uncritical homogeneous construction of refugees with/out disabilities either in terms of

threatening beings or in terms of vulnerable subjects, reproducing exclusionary practices (Costantini and El-Serafy, *under review*).

The binary construction of refugees with/out disability either as threat or as vulnerable subjects raises an important issue concerning the widespread adoption of ‘vulnerability language’ by the humanitarian system to define and signify the populations they assist. For instance, vulnerability discourses instead of challenging disempowering beliefs about disabilities and de-agentivizing rhetoric about refugees with/out disabilities, reproduce ableist and over-politicized biased assumptions. Those conjectures clearly work against more empowering movements that aim to re-signify disability in terms of diversity (Erevelles and Nguyen, 2016), and refugeehood as a state in which acts of resistance and agency exist. To conclude, Western dominant constructions of education in humanitarian contexts largely define education responses, guiding the marketization and politicization of aid, as well as refugees’ experiences and access to education opportunities. Acknowledging the practical impact of specific theorization and operationalization of education in contexts of emergencies within dominant Western logics opens the floor to critically reflect on the actual repercussions that these logics have on the field, and on how they relate to the more recent agenda for inclusive education. In what follows, I provide a brief review of the empirical literature on education in humanitarian contexts at the intersection of forced migration and disability.

1.4.2 Reviewing the literature: Education, disability and forced migration

Across theory and practice, the fields of forced migration, disability and education in emergencies have been separated by disciplinary boundaries (Pisani and Grech, 2015). Looking at the state of the field, clear conceptual and operational contradictions persist both at the intersection of education in humanitarian contexts and (disability-) inclusive education (Costantini and El-Serafy, *under review*); as well as between the fields of forced migration and disability studies – which are still respectively engrained within an ableist understanding of ‘movement’, and a Western

conceptualization of disability that does not account for people with disabilities' experiences in the Global South (Grech and Pisani, 2022; Yeo, 2019).

The literature on education in humanitarian contexts, which as stated above is mostly known as “education in emergency” or “refugee education”, has undergone different shifts over the past few decades, mirroring the historical development and changing trends mentioned above. For instance, before the 1990s, the primary focus of research on the field was centred on the long-term resettlement conditions in more affluent countries (Preston, 1991). Towards the end of the Cold War, a new discourse around education in emergency emerged, reflecting global historical and geopolitical shifts, which reshaped education interventions and ideologies. In 2000, with the establishment of INEE, evidence-based research on education in emergency increased, with the aim to enrich understanding of ‘best practices’ in the field. However, these studies have been framed through a prevalently technical approach due to the intrinsic ‘practice-driven’ nature of the field. This has resulted in researchers having to negotiate the structural tensions between theoretical frameworks and real-world applications and development of education initiatives in humanitarian contexts. Thus, most of the empirical literature on the topic is strictly related to the humanitarian field, being prevalently technical and functional, and responding to policy needs, rather than critically engaging with the underlining structures of power embedded within the humanitarian sector that is promoting and implementing education initiatives. Wright (2009) explains that one of the main challenges faced while conducting a review of the literature on education in emergency was linked to the very biased literature produced by NGOs and international organizations, which tend to “glorify project successes without providing balanced (...) analysis of their genuine strengths and weaknesses” (p. 5). Moreover, most of the empirical research available focuses on the immediate challenges, and barriers to access education, and on strategies and evaluation of specific education policies or initiatives.

It is also important to note that research on this field often reflects Western humanitarian agendas and priorities where donors and stakeholders allocate funding towards investigating specific dimensions of education in humanitarian contexts, such as ‘peace education’, or ‘girls’ education’, and more recently ‘inclusive education’ for children with disabilities (see INEE, 2023), which appears to be an emerging trend (Burde et. al, 2019). For instance, only over recent years, there has been a burgeoning literature addressing the challenges encountered by children and youth with disabilities in accessing education amid protracted displacement scenarios (INEE, 2023; Crea et al. 2022; Trani et al., 2012). It is increasingly acknowledged that children at the intersection of refugeehood and disability identities, living in contexts of conflict and emergencies, are more likely to experience significant level of exclusion and marginalization from education spaces. These children have often remained invisible and marginalized within the broader humanitarian system (Pisani and Grech, 2017; Yeo, 2017), and have been historically neglected in research as well as in policy and service provisions (Walton et al., 2020). Despite this new considerations on children with disabilities and their right to education, most of the literature available tends, again, to focus primarily on immediate barriers and practical obstacles to education access, such as tuition fees, transportation, documentation requirements, curricular and language barriers (Smith-Khan and Crock, 2018; Al-Hawamdeh and El-Ghali, 2017); rather than delving into the lived experiences of refugee children with disabilities in accessing education and other essential services (Mirza, 2019), and/or examining the broader historical, geopolitical and economic frameworks influencing education initiatives in humanitarian contexts, and promoting the structural exclusion of specific groups of children.

A review of the empirical literature confirms this prevalent tendency, highlighting a lack of understanding of the lived experiences of refugee learners with disabilities (Trani et al., 2011), as

well as of reliable data on the “true numbers” of refugee children with disabilities, and on the strategies they have in place to cope with their structural exclusion from education and other services (Miles, 2013). The dearth of data, visibility, representation and recognition of children and youth with disabilities in research, can be attributed to five main reasons: 1) the silencing and lack of meaningful engagement and collaboration with refugee persons with disabilities, which is believed to exacerbate their exclusion, ignoring the valuable contribution, insights and solutions they can provide on issues affecting their lives (Pinnock and Hodgkin, 2010); 2) the lack of international benchmarks on disability in humanitarian efforts, which results in inadequate reporting, monitoring and evaluation processes; 3) the fact that humanitarian actors often fail to reach people with disabilities with their projects, and are hesitant to critically acknowledge this limitation (see Wright, 2009; Pinnock and Hodgkin, 2010); 4) the perceived and practical challenges of conducting research with refugee children with disabilities, due to the limited access to this population, lack of political and economic interest, as well as the inconsistent definition of disabilities across cultures and regions; and 5) the lack of an inter-disciplinary framework, that would trace the red thread between the fields of education in emergency and inclusive education, being responsive to the status of the field at the intersection of refugeehood and disability. Before providing a short review of the empirical literature available, I must emphasize that this lack of data has a highly detrimental impact on the lived experiences of refugee children with disabilities in exercising and accessing their rights to education, as well as on the humanitarian system capacity to respond to the needs and rights of these children efficiently and appropriately. Lack of reliable data hampers policymakers and other stakeholders’ ability to understand the nuances of people’s lives at the intersection of refugeehood and disability, hindering long-term and sustainable responses (GEM, 2020), and reproducing systems of marginalization and oppression.

The empirical global puzzle: compounded exclusions

Walton et al. (2020), in exploring the compounded exclusion experienced by refugee children with disabilities in accessing education in Sub-Saharan Africa, explain that a coherent body of literature on education for refugee children with disabilities does not exist yet. Most studies engage either with a South-focused forced migration literature, which generally assumes an able-bodied person, thus conceptualizing education for refugee students without children with disabilities, or on a Western-focused disability literature, which presumes citizenship, thus theorizing inclusive education for students with disabilities, without forcibly displaced learners (Pisani and Grech, 2017). The lack of a consistent rationale on education at the intersection of refugeehood and disability hampers meaningful understanding of the systems of oppressions reproduced within the field of humanitarian education, thereby impeding significant efforts to rectify structural injustices, and the profound inequalities experienced by refugee children with disabilities living in protracted displacement.

Some research has indicated that education serves as a crucial and protective factor in enhancing students with disabilities' capabilities in conflict-affected contexts (Walton et al., 2020; Trani et al., 2012). However, most of the literature focuses on investigating the rights and immediate barriers to education and 'inclusion' for children with disabilities, such as physical barriers (Smith-Khan and Crock, 2018), attitudinal barriers and stigma (Cone, 2010), lack of stakeholder coordination (Bakhshi et al., 2018), resource barriers (Pinnock and Hodgkin, 2010), as well as family responsibility and economic capacity, overlooking the colonial, geopolitical and economic logics underpinning these obstacles. For instance, studies report that children with disabilities might struggle to access education opportunities because of the structural inaccessibility of school buildings and WASH facilities, of the long and potentially dangerous path to reach schools, combined with the lack of accessible and affordable transportation (Smith-Khan and Crock, 2018;

Buckner et al., 2017). They might face additional legal barriers caused by their refugee status, as it is the case for Syrian refugee children with/out disabilities in Lebanon; as well as communication barriers due to the potential new language spoken in the context of displacement, and more generally by the structural inaccessible and non-inclusive approaches and style of communication that do not account for people's diverse communication needs: lack of information in braille, of sign language interpreters, of easy-to-read forms and others (Smith-Khan and Crock, 2018; Rohwerder, 2017; Pearce, 2015).

The literature suggests that resource barriers largely affect children with disabilities' opportunities to access education, as well as schools and their personnel's readiness to implement inclusion. For instance, families living in displacement often experience endemic forms of poverty, which can be exacerbated by disability associated costs. Lack of financial resources largely influence and determine a family willingness and capacity to send their children with/out disabilities to school (Smith-Khan and Crock, 2018; Bilagher and Kaushik, 2020). When parents are struggling to provide for their family, children might be required to drop out of school, and/or to enter the workforce to support economically their family (Desai, 2020; Tarricone et al., 2021). As a result, parents, due to the very dire and difficult economic situation they experience, would prioritize sending to school their children without disabilities (Al-Zboon, 2017; Shuayb et al., 2016), as they would have more opportunities compared to their siblings with disabilities to find future employment, as well as to be accepted in the education system. Schools and their personnel also play an essential role in the successful (or not) implementation of inclusive frameworks. The literature shows that there is a substantial lack in both human and material resources which negatively influence teachers' perspectives and attitudes towards inclusion, such as lack of appropriate teaching-learning materials accessible to learners with disabilities, of inclusive schools and classrooms design, and of specialized professional support (Williamson and Cetin, 2019;

Chimhenga, 2016; Hakim, 2009; Gaad and Khan, 2007). Moreover, lack of good working conditions for teachers – such as high pupil/teacher ratio, lack of autonomy, insufficient salary, and others – dramatically affects teachers’ ability and willingness to work towards inclusive education (GEM, 2020; see also Al-Sayegh, 2023; UNICEF, 2023).

Lastly, the literature identifies attitudinal barriers, which are strictly intertwined with the others mentioned above. Children with disabilities living in displacement encounter attitudinal barriers from their teachers, peer groups and the wider society, and at times also from their own families (Crock et al., 2017; Pearce et al., 2016). A study conducted by Crock et al. (2017) in different countries, including Uganda, Pakistan and Indonesia, reports that the low enrollment of refugee children with disabilities in education is not only linked to inaccessible facilities and economic hardship, but also to teachers lacking adequate training or awareness to include this group of students. According to Bennet (1997) teachers play a crucial role in the promotion of inclusion in schools. Their knowledge and beliefs determine the ways in which the learning environment is structured, and influence their pupils’ attitudes and understanding of inclusion. A study carried out by Al-Zyoudi (2006) in Jordan highlights how teachers’ attitudes towards inclusion are affected by the type and severity of the child’s disability, where children with more severe, and complex disabilities, as well as with developmental and sensory ones, are perceived as being more complicated to deal with compared to their peers with physical and milder forms of disabilities. Many teachers recognize that their hesitation in implementing inclusive education is due not only to the lack of appropriate resources, but also to their limited skills in teaching to children with disabilities, which make them feel unequipped to deal with them (Anati, 2013). Moreover, the inclusion of children with disabilities can also be hampered by their peers without disabilities, through episodes of bullying, and/or aggression (GEM, 2020). In the same way, parents’ attitudes also play a pivotal role, as they “can drive, but also resist, inclusive education” (GEM, 2020: 178).

Children with disabilities living in displacement can also encounter attitudinal barriers from humanitarian actors (Smith-Khan and Crock, 2018), whether they work towards inclusion or not. For instance, children with disabilities are often constructed as ineducable and overwhelmingly signified as ‘too difficult’ to deal with and to include, especially during humanitarian emergencies, where the needs are too many and the resources are never enough (Lough et al., 2022; Duda-Mikulin et al., 2019; Shivji, 2010). These compounded barriers prevent inclusion in education and in the broader society, hampering children with disabilities’ future opportunities and participation in their community’s life, as well as jeopardizing people without disabilities’ chance to acquire knowledge and understanding of disability (GEM, 2020). Even when humanitarian interventions purport to be inclusive, people with disability remain largely excluded and marginalized. UNESCO recognizes education as being one of the fundamental principles underpinning the Education 2030 Agenda and the SDGs 4. Yet, access to equal and quality education for children with disabilities, especially with severe and complex ones, remains inadequate and poor. The systematic exclusion of these groups of children from education and other life-saving services have a tremendous impact on their lives, reproducing and reinforcing stigmatizing and ableist understanding of disability within society.

Critically, the practice-driven research, by concentrating on identifying immediate barriers to inclusive education for refugee children with disabilities in protracted displacement, results in the risk of oversimplifying the lived experiences of these children, and of homogenizing the specific challenges they face in different context of displacement. Educational experiences in displacement are highly heterogeneous, being shaped and influenced not only by the reason for displacement, as people might be fleeing their countries due to natural disaster or conflict, but also by the specific countries to which people are displaced *to* (Crul et al., 2019). For instance, most refugees are displaced in neighboring countries in the Global South, where resources are already limited and

stretched. In this first asylum countries, refugee educational experiences tend to be more uncertain compared to those who are resettled (Dryden-Peterson, 2017). Moreover, even within the same host-country, education experiences vary depending on refugees' countries of origin (Shuayb et al., 2014), as well as due to individual's intersecting identity dimensions (Burde et al., 2019). Research and policies' disproportionate focus on universal global issues and challenges to inclusion often overlooks and neglects the nuanced historical and geographical factors contributing to educational exclusion in diverse contexts. This oversight fails to acknowledge the unique experiences of refugees with disabilities, as well as the different ways in which contextual circumstances influence these experiences (Walton et al., 2020).

Education for Syrian refugee children with/out disabilities in Lebanon

The Syrian conflict has resulted in one of the largest refugee crises in our contemporary world. Half of the 1.5 million refugees hosted in Lebanon are school-aged children (Hamadeh, 2018), who struggle to access education opportunities within the country, despite the joint efforts of the Lebanese Ministry of Education and Higher Education (MEHE), UNICEF, and other international and national educational actors. The Lebanese education system is currently struggling to provide Syrian refugee children with/out disabilities with proper quality education (Eid, 2023; Akesson et al. 2020). Over the past 10 years there has been an increase in the amount of research conducted on education for Syrian refugee children; however, most of these works are inscribed within the broader global trend of research in the field, focusing on identifying practical and technical barriers.

The literature available on education for Syrian refugee children with/out disabilities in Lebanon highlights the compounded “instrumental, psychological and political barriers” these children face in accessing education and other services in Lebanon (Kiwani, 2021:290). One of the key barriers identified is the Lebanese school system's insufficient capacity to accommodate the learning needs

of school-age children in the country (GoL and UN, 2020). Consequently, the majority of Syrian refugee children with/out disabilities are compelled to rely on informal and non-formal education opportunities provided by NGOs, INGOs and other humanitarian actors, which offer inconsistent and inadequate education to advance beyond primary school (Karam et al., 2017). These education alternatives are often non-accredited and lack certification, hindering children's progression into the formal education system, and their opportunities of pursuing higher level of education at a later stage (Akesson et al., 2020). Another barrier, which is not often acknowledged, is linked to the geographical dispersion of Syrian families throughout the country, and to the differences between the diverse Lebanese regions. For instance, Syrian families living in Akkar, which is an area that has been historically neglected, would face exacerbated challenges in accessing education, health care and other type of assistance, due to the already precarious status of the services available. Rural areas, and distant regions of Lebanon, such as Beqaa Valley, are generally under-served, contributing, together with the high cost of transportation fees, to notably low school enrollment rates (WFP et al., 2019).

Akesson et al. (2020), in a study conducted in Lebanon with Syrian refugees on the right to education, report that the specific contextual barriers unravelling in Lebanon play a dramatic role on families' willingness to enroll their children in the education system. For instance, most of Syrian families are living below the poverty line, with 92% experiencing food insecurity (GoL and UN, 2020). As a result, many children are driven to seek employment to support their families, entering the labour market at a very young age (Akesson and Badawi, 2021). Other studies conducted in Lebanon mention the differences between the Syrian and Lebanese curricula, especially concerning the language of instruction (Kiwan, 2021; Akesson et al., 2020; DeJong et al., 2017). In Lebanon, the curriculum is delivered in Arabic, French and English, while in Syria the only language of instruction is Arabic. The dissimilarities between the two curricula have often

been used to justify the lack of integration of Syrian refugee children with their Lebanese peers, while being identified at the same time as one of the main reasons behind the lack of a smooth transition and enrollment of Syrian children within the Lebanese education system (Karam et al., 2017).

Studies also highlight the widespread problem of school violence and bullying within the Lebanese public education system (Shuayb et al., 2016). The securitization policies, and consequent hate and xenophobic narratives promoted by leading political groups within the country, have contributed to create a hostile environment. As a consequence, Syrian refugee children are often discriminated, mistreated and abused in Lebanese schools (WFP et al., 2019; DeJong et al., 2017; GoL and UN, 2020). In these circumstances, parents stop sending their children to school. Furthermore, lack of legal status has also largely influence parents' possibility to register and enrol their children in the Lebanese education system, hampering children's opportunities to continue their education (Eid, 2023; Brun and Shuayb, 2020; Crul et al., 2019). Akesson et al. (2020) recognize that the abovementioned barriers, which are experienced by most if not all Syrian refugee children in Lebanon, are further exacerbated for children with disabilities, who find themselves completely excluded from education opportunities, despite by law they should be able to exercise their right to education.

Recognizing the practical and technical barriers refugees with/out disabilities face in accessing education within humanitarian contexts is essential for fostering a more inclusive system. However, a narrow focus on these barriers, without critically examining the underlining structural systems and logics of oppression entrenched within the humanitarian framework, and the heterogeneous experiences of refugee children with disabilities in accessing education in displacement, risks perpetuating the structural inequalities faced by refugee children with disabilities. As this literature review shows, there is a dearth of studies addressing these underlining logics. Moreover, most of

the existing research – especially due to the infancy of the field, and the lack of substantial conversation between the research fields of education in emergency and inclusive education –, overlooks the perspectives and expertise of children with disabilities and their parents regarding their own lives and experiences. This study addresses this gap in the literature, and it is positioned within the more recent efforts to re-theorize the field of education in humanitarian contexts (Brun and Shuayb, 2020; Costantini and El-Serafy, *under review*; Bešić et al., 2020).

1.4.3 The Disability-inclusive rhetoric of education in humanitarian contexts

Here, almost through a stream of consciousness, I problematize the concept of ‘inclusion’, and how it is operationalized within the dominant framework of humanitarian education, critically reflecting on the more recent rhetoric of ‘disability-inclusion’. My critique deliberately starts from the word ‘inclusion’: the act or state of including or being included within a group or structure (definition slightly adapted from the Cambridge dictionary). INEE (2023) on ‘inclusive education’ states that “it is built on the principle of equity. (...) and that considers the access and participation of all learners in all their diversity” (p.15), meaning that inclusive education refers to equal and quality education for every child, regardless of their gender, ethnicity, religion, dis-/ability, social class and every other identity’s dimension. Therefore, when we talk about inclusive education, and inclusion in education, theoretically, we are already referring also to children with disabilities. However, many studies have shown that, despite the many inclusive discourses and policies promoted at the international level (see UNCRC, 1989; EFA, 1990; Salamanca Declaration and Framework of Action, 1994, UNCRPD, 2006; Charter on Inclusion of Persons with Disabilities in Humanitarian Actions, 2016), children with disabilities, especially in contexts of emergencies and conflict, remain the most marginalized and neglected when it comes to access education opportunities and learning spaces (Trani et al., 2014; Groce and Kett, 2014; Bešić et al., 2020, Kiwan, 2021), as well as other basic life-saving services. The systematic exclusion of children with disabilities from humanitarian education, and subsequent development efforts, and more generally

of people with disabilities from society and community's life, made necessary to rebrand 'inclusion' within the humanitarian field.

For instance, over the past few years, some international institutions have started using the 'disability-inclusion' rhetoric (ILO, 2016; UNICEF, 2023; INEE, 2023). Here, I try to unpack my uneasiness and concerns with the idea of 'disability-inclusion'. Again, the word 'inclusion' is already supposed to encompass everyone, regardless of people's diversity. Moreover, inclusive discourses have been promoted within the field of education in humanitarian contexts since the adoption of the Education For All (EFA) framework in the 1990s, which should have also already represented 'All', including people with disabilities. Now, if from one side, new disability-inclusive (education) rhetoric and potential efforts are admirable; from the other, it highlights the failure in meeting the needs and ensuring the rights of people with disability despite the inclusive rhetoric promoted at the international level, over the past 35 years. The urgency for and the existence itself of the term 'disability-inclusion' is the symptom of this collective failure. Critically, the focus on the disability dimension of inclusion can reproduce narratives of exclusion, especially if it comes to be understood as something that needs to be addressed separately, almost in a compartmentalized way, rather than being mainstreamed.

In this regard, Dr. Sophia D'Angelo, an inclusive education consultant for the World Bank's Education Global Practice, and I worked with INEE on defining key concepts and guiding principles for practitioners on disability-inclusion in education in contexts of emergencies (see INEE, 2023 'Disability-inclusive Education in Emergencies: Key concepts, approaches, and principles for practice'). In this piece of work, we acknowledge the importance of understanding the heterogeneity of disability and of people with disabilities' experiences and challenges within a due context. We call for the need of working towards relevant solutions that take into consideration

people's types and severity of disability and its intersection with other aspects of an individual's identity, as well as for the necessity to mainstream disability, instead of approaching it solely as something that need to be dealt separately. Despite the renewed efforts to ameliorate children with disability access to education in contexts of emergencies and crises, I remain highly skeptical about the feasibility of a meaningful implementation of disability-inclusive solutions within the field of humanitarian education. The reason behind my doubts on the successful inclusion of people with disabilities within the humanitarian (education) sector, and the new rhetoric of disability-inclusion, is not linked to the good intentions and commitment of the many actors working towards inclusion; rather it is informed by the recognition that humanitarian education, as a subset of the broader humanitarian project, continue to be informed by colonial-securitized, and neoliberal economic logics, which reproduce ableist conceptualizations and practices of inclusion that are essentially exclusionary (Costantini and El-Serafy, *under review*). Therefore, as long as humanitarian (disability-) inclusive efforts remain embedded within these logics, people with disabilities will continue to be excluded and marginalized.

1.5 Conclusion

In this chapter, firstly, I focused on the Lebanese context, providing a brief historical overview of the Lebanese-Syrian relationship, and analyzing the current Lebanese response to the Syrian refugees amid compounded crises. Then, I explore the available education policies and opportunities for Syrian refugee children in Lebanon, also assessing the level of inclusion of people with disabilities in the country. To conclude, I briefly talk about the field of education in emergency, historicizing its emergence and evolution; I provided an overview of the empirical literature at the intersection of education, refugeehood and disability in humanitarian contexts; and I problematized the humanitarian definition and operationalization of inclusion. In what follows, I concentrate on what I call a 'conversation' with and among theories.

CHAPTER 2

CONVERSING WITH THEORIES

2.1 Introduction

In this chapter, I commence with an analysis of Critical Disability Theory (CDT), outlining its genesis, as well as evolution, and way forwards, to set the stage for a critical analysis of ‘disability’. CDT allows to question and re-think the power dynamics, and systems of oppression regulating people with disabilities’ lives, through an intersectional and multidimensional lens. This, in turn, provides an analytical space to recognize and acknowledge the heterogeneity of people with disabilities’ lived experiences in the Global South, and to investigate the multiple and compounded forms of exclusions people at the intersection of refugeehood and disability face on a daily basis. I then move on a critical consideration of Agamben’s key concepts of *Homo Sacer*, *Bare Life* and *State of Exception*, on which I draw in relation to the fields of forced migration and disability studies. This is situated within a broader critical examination of humanitarianism as a sovereign entity, which, through neoliberal and colonial logics, administers and disposes of refugee with/out disabilities’ bodies and lives. Agamben’s work contributes to understanding and analyzing the logics underpinning the dominant humanitarian system, and the mechanisms through which certain groups of people come to be excluded and marginalized within our society and the humanitarian field. It provides conceptual tools to comprehend *how* certain people come to be signified as expendable and excludable. Finally, reflecting on the junctures of CDT and Agamben’s work, in the last section of the chapter, I explain how this study, in conversing with diverse concepts and theoretical perspectives, is contributing to the literature, shedding light not only on the *how* Syrian refugee children with disabilities come to be excluded and marginalized within the humanitarian (education) system, but also on the *why*, uncovering the driving principles and logics guiding and justifying Syrian refugee children exclusion from humanitarian (education) interventions in Lebanon.

2.2 Critical Disability Theory: genesis, principles and way forwards

Critical Disability Theory (CDT) is a dynamic and interdisciplinary framework. It emerges with the aim of challenging and expanding the dominant historical westernized scholarly dimension of Disability Studies, drawing on and being in conversation with diverse theoretical approaches, such as critical theory, feminist theory, queer and crip theory, and critical race theory to name a few, producing a body of contemporary knowledge that is highly interdisciplinary. Despite its name, CDT is not much a theory as an evolving and emancipatory discourse (Goodley et al, 2019; Meekosha and Shuttleworth, 2009), methodology, and approach (Schalk, 2017). CDT offers a set of tools, principles, and methods to critically describe the socio-cultural, political and economic constructions and signification of disability within different contexts, as well as to analyze the impacts of these constructions, and of the broader power structures, on the exclusion and oppression of specific groups of people, including but not limited to people with disabilities. CDT, “working at the intersections, is committed to revolutionary and accountable praxis” aimed at challenging ableist rhetoric (Erevelles, 2014:19).

2.2.1 Genesis of CDT

Across time, space and cultures, disability has been ontologically and epistemologically conceptualized in various ways, largely influencing, and determining people with disabilities’ lives and experiences. Over the past decades, especially since the mid-20th century, interpretations and consequent theorizations of disability have been evolving, and shifting from functionalist theories of disability to theories of social exclusion and discriminations (Abberley, 1987; Davis, 1997; Oliver, 2004; Chand and Reddy, 2012). The Disability studies field started tracing discontinuities with the previous individual and medicalized formulation of disability, advocating for the adoption of new disability frameworks and models, such as the social model, and the right-based approach, that laid the groundwork for more nuanced understanding of disability. However, it became increasingly evident that the field needed a stronger critical lens to properly address questions such

as power dynamics, and intersectionality, in the construction and definition of disability within specific socio-political contexts. Thus, at the intersection of Disability and Critical studies, CDT emerged, pushing the ontological, epistemological and methodological boundaries of disability theorization. To better locate CDT, which has emerged as a response to the shortcomings of existing predominant discourses and models of disability within the disability field, I provide a concise overview of the historical trajectory of Disability studies, examining the shift from the medical model to the social and right-based models of disability, and acknowledging their respective conceptual limitations.

From the mid-19th century onwards, with the rapid technological development of the society, people's worth came to be defined according to notions of productivity, efficiency, and exploitability, redefining concepts of 'normality', desirability, and power (see Finkelstein, 1980; Gleeson, 1997). This new approach led to a hierarchical re-organization of spaces, roles, and authority within the community. The white-abled-young-male body became the main character against which all the "others" were placed as inferior, and deviant. People with disabilities, due to their non-exploitable and non-normative bodies and minds, were constructed merely as object of medical science, in need to be cured, and rehabilitated to contribute to the growth of the economic market. Those who could not be cured and rehabilitated were cast outside the *limites*⁸ of the

⁸ *Limites* is the plural form of the Latin word *limes*. *Limes* derives from *limus*, meaning "transverse, oblique", and the verb means "to bend". In this study, the word *limites* is employed following the linguistic connotation held by the word during the time of the Roman empire, reconnecting it to the work developed by Agamben around the ancient roman figure of the *homo sacer*. As explained by Gentili (2020), the *limes* configure a zone, where between inside and outside, between order and disorder, continuity and contact prevail. The word *limes* as used during the era of the Roman empire "does not represent a "limit" (limen) nor does it demarcate a border". *Limes* is a moving front that presupposes "a qualitative difference between the political-legal order on this side of the *limes* and the disorder of the barbarian lands. It refers to an asymmetry between inside and outside that does not exclusively define the space and way of life on this side of the line, but also impacts the populations and ways of life on both sides of the *limes*, presupposing a qualitative difference between citizen and barbarian" (My English translation from the Italian original version. See pp.236-238 of the original text). The movement of the *limes* frontier produces a zone of indistinction between inside and outside, a zone of contact between civilization and barbarism. This space embodies a paradox of *inclusive-exclusion* (Agamben, 1998), in which the modern barbarian and the not-fully human subject – represented by marginalized groups – are relegated due to their relationship with the state and its political, legal and cultural boundaries. Here, the refugee (the modern *homo sacer*) exists not as a fully recognized member of society but as a subject who is kept at the periphery, excluded from the protections and privileges of the state that governs them. Thus, the use of *limites* goes far beyond the English word "limit", as it retains an historical, political, legal and cultural meaning which can be expressed only through its contextualized Latin form.

*polis*⁹, and labeled as a ‘burden’. The medical model emerged in this specific time frame, gradually replacing the moral and/or religious model (Reief and Letsosa, 2018). The medical model promoted a depoliticized, desexualized, and de-agentivized picture of people with disabilities, which resulted in the structural exclusion of every body and mind that did not comply with the new normative rules of doing and behaving. Within the medical model, disability is constructed as a mere medical problem, a disfunction that resides in the individual. “[Disability] is a defect in or failure of a bodily system and as such is inherently abnormal and pathological” (Olkin, 1999:26), and it needs to be cured and “normalized” (Silvers, 2009; Carlson, 2010), or alternatively eliminated (see Cepko, 1993; Cook and Dickens, 2000; Diekema, 2003; Tilley et al. 2012 on involuntarily sterilization; see Selden, 2000; Pfeiffer, 2006; Overboe, 2007; on eugenics). People with disabilities are signified as a ‘problem’, and portrayed as dependent, passive, and incapable, removed and erased from the social sphere, and subjected to the inquisitive eye of medicine and medical professionals, who hold and exercise complete authority over people with disabilities’ bodies and minds, regardless of their views and opinions.

The social model, inspired by the US and British disability movements in the mid-20th century, challenges the dominant medical discourse, shifting the burden and responsibility of disability from the person with disability to the socially constructed restrictive barriers imposed on non-normative bodies and minds. It sustains that the causal locus of disability is in the surrounding social environment, that “disability is wholly and exclusively social” (Oliver, 1996a, p.35), and it formalizes the distinction between impairment and disability (Shakespeare, 2006). For instance, a person with a physical impairment is now seen as disabled not for the intrinsic impairment, but because the design of the physical and social environment creates barriers and obstacles that

⁹ The literal translation of the Greek word *polis* is ‘city’; however, in this context, *polis* is translated as State.

prevent their inclusion. In the same way, a person with a sensory impairment is made disabled by the limited access to information and the inadequate communication styles adopted within the broader society. The Union of the Physically Impaired against Segregation (UPIAS) defines

- *Impairment* as lacking part or all of a limb, having a defective limb, organ or mechanism of the body.
- *Disability* as the disadvantage or restriction of activity caused by contemporary social organizations which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS, 1976:3-4).

Hence, the causal locus of disability has shifted, the “problem” is not generated by the individual’s physical or mental status; instead, it is produced by the society’s failure to include people with disabilities (Oliver, 1996a). The social model has reshaped how disability is understood and approached in our time (Giddens 2006:282), playing a crucial role in redefining policies both at national and international level. However, it also has its limitations, as it misses to “conceptualize a mutually constitutive relationship between impairment and disability which is both materially and discursively (socially) produced” (Corker and French, 1999:6). For instance, Morris (1991), while recognizing the tremendous impact that socially constructed barriers and attitudes play in shaping and influencing people with disabilities’ lives, argues that personal experiences of pain, restrictions, fears, loneliness, and powerlessness, cannot be diminished or denied.

A further approach that has been applied within the Disability studies field in the latter half of the 20th century is the human rights model. The human rights model is an approach that conceptualizes disability from a perspective grounded in human rights principles, which started to emerge from the United Nation Declaration of Human Rights in 1948, that “recognizes that all people have certain civil, political, economic, social, cultural and development rights, despite differences between individuals” (Rioux and Carbet, 2003:2). Bruce et al. (2002) state “[T]he human rights

perspective means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems toward viewing them as rights holders” (p.1). The human rights model emphasizes the need to rethink the processes through which people’s worth is defined, recognizing the inherent dignity and value of every individual beyond mere and simplistic economic utilitarian criteria. It also urges a shift from the medical model, which focuses only on the “person’s medical characteristics”, to a human right one, where people with disabilities are seen as right-bearer (Bruce et al., 2002:14). “Northern discourses of disability rights have strongly influenced the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)” (Meekosha and Soldatic, 2011:1383), which, to date, is the most prominent international instrument and framework for disability justice.

The human rights model and the UNCRPD have been equally questioned by critical scholars, who underline how human rights discourses are ‘soaked’ in Western principles, reflecting priorities and dynamics linked to industrialized societies, rather than being a universal concept able to relate to the experiences and lives of people with disabilities living in the Global South (de Sousa Santos, 2008). “Human rights discourse is seen as part of the continuation of colonialism, whereby the hegemonic North determines the constitution of human rights, ignoring the inherent global power imbalances”, and furthering these imbalances using the ‘duty to defend’ human rights as a *casus belli* to protect and enhance Western economic and geopolitical interests (Meekosha and Soldatic, 2011:1388). For instance, the U.S. has manipulated discourses of human rights to create a pretext to attack Iraq in 2003 to secure access to the region’s abundant oil and gas resources. The human rights framework, and the international aid organizations at the head of its protection and implementation, played by the side of the perpetrators (the U.S. and its allies), being “deeply intertwined with the forces of inhumanity against which they are being invoked” (Heins, 2005: 846). This raises also another important problem, which is the construction of Western countries

as ‘modern’ and ‘civilized’, and as having the duty and the ‘civilizing’ mission to bring human rights to people in the Global South, whom rights are denied by a ‘retrograde culture’ and state. Once again, people in the Global South are depicted as being passive victims of a barbarian dictator or state, in need of rescue from the brave and ‘rightful’ white savior (Mutua, 2002). As a result, rhetoric of human rights promotes narratives of “victimization and powerlessness in the face of endless atrocities, (...) end[ing] up dehumanizing [and de-agentivizing] individuals living under oppression” (Meekosha and Soldatic, 2011:1389), and at the intersection of multiple dimensions of inequality and exclusion.

Over the past few decades, diverse models of disability have developed, overlapped, and interacted with each other to define and redefine the ways in which disability is constructed, understood and approached within our societies. CDT emerges from a critical analysis and critique of the limits of Disability studies, building new spaces of transgressive possibilities. CDT is “to start with disability but never end with it: disability is *the* space from which to think through a host of political, theoretical and practical issues that are relevant to all” (Goodley, 2016:157, original emphasis).

2.2.2 Elements of CDT

CDT is first and foremost a critical theory. Critical theory emerged from the work of Frankfurt School’s scholars, “a group of Western Marxist social researchers and philosophers, (...) [who] based their work on Marx’s critique of the political economy of liberal capitalism”, and on Freud’s analysis of how the unconscious impact on the human psyche, describing the enduring late capitalism’s dominance, and proposing a path towards human liberation (Hosking, 2008:2). Critical theory aims to analyse and uncover the different forms of oppression engrained within our societies, to challenge them and to transform our social realities with the objective to achieve, through social transformation, human emancipation (Bohman,2005).

CDT, as a subset of Critical Theory, is meant to be simultaneously “explanatory, practical and normative” (Hosking, 2008:3), meaning that it should investigate and explain what is wrong in our current social reality (explanatory), identifying key actors in the position to induce social change (practical), and introducing specific standards into social debates to facilitate the formulation of attainable target for social transformation (normative). CDT’s heritage in critical theory creates the basis for new, transformative, and intersectional spaces of theorization and action within and beyond disability. It acknowledges that “disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to” (Pothier and Devlin, 2006:2), and as such, it speaks to diverse disciplines that engage with the structural foundation of oppression faced by historically excluded, oppressed and exploited groups of people. Differences among diverse groups of people are socially re-/produced, and constructed for political reasons, enacted to maintain dominance and imbalanced power relations between the socially designated oppressed and their oppressors. The aim of CDT is to uncover and disrupt this norm, challenging old power structures, to achieve a more just society.

Hosking (2008), in drawing the underlining assumptions of CDT, identifies seven fundamental elements:

- 1) The social model of disability

CDT supports a version of the social model based on the fact that: 1) disability is socially constructed, and it is not just the mere result of impairment; 2) disability materializes from the interplay of impairment, individual response to the impairment and the surrounding environment; 3) the social disadvantages experienced by people with disabilities stem from the physical, socio-institutional and attitudinal barriers defining our society, which neglect the needs of those diverging from constructed social expectation and norms of “normalcy” (Hoskings, 2008:7). The version of

the social model adopted within CDT proposes a reconciliation between the medical and the social model, which is better represented by what the World Health Organization (WHO, 2002) calls the “biopsychosocial model” (BPS). Disability cannot be defined only as a biological ‘defect’ or as a social victimization. It is a relational phenomenon, and, as such, “disability is ontologically, spatially, temporally, materially, discursively, culturally, socially, politically and economically contingent” (Saltes, 2013:56). The BPS, while recognizing the biological status of disability, it also acknowledges the role of society in creating and exacerbating the exclusion of people with disability from the social sphere, and the psychological dimension, and experiential background, knowledge, and feelings of people with disabilities.

2) Multidimensionality

Multidimensionality theory aims to avoid reproducing forms of exclusions often perpetuated by identity politics, which tends to focus on a singular aspect of a person’s identity, leading to the oversight of other crucial dimensions that contribute to the complexity of individuals’ experiences. It emphasizes the heterogeneity of people with disabilities’ lives, taking distance from oversimplified and homogeneous understanding and construction of disability. “Disability marks different bodies in different and relational ways; systems of ableism come into contact with racialized bodies, queer bodies, classed bodies, gendered bodies, bodies that already have been touched by other (and perhaps multiple) systems of oppression” (McGuire, 2010). CDT, by adopting a multidimensional lens, advocates for a more comprehensive and inclusive approach to understanding and conceptualizing disability, recognizing that “everyone is multidimensional” (Hosking, 2008:10)

3) Value of diversity

Contemporary liberalism upholds the principle of political and legal equality across gender, race, ethnicity, disability, and other identity’s dimensions. However, Hosking (2008) argues that applying a strict equality-before-the-law approach could be ineffective for people with disabilities.

Building on Minow's (1990) "dilemma of difference", Hosking (2008) explains how "depending on the context, equality objectives may be promoted by acknowledging and respecting difference in ways which effectively ignore it or in ways which respond to it" (p.11). In the case of disability, ignoring, and overlooking differences, constructing, and considering them as insignificant and irrelevant, can reinforce processes of marginalization. Instead, a sensible response to disability-related differences would be the removal of physical and social barriers to guarantee people with disabilities' political, social, economic, and cultural rights, as well as their participation in community's life based on equal rights. CDT advocate for an understanding of equality as a value based on diversity, appreciating, and embracing differences as being an inherent trait of being human.

4) Rights

CDT recognize the important role played by legal rights in advancing people with disabilities' equality claims and in promoting their inclusion within the society. At the same time, it is critical of liberal rights, and it exposes the failure of liberal rights theory in recognizing, responding, and addressing the needs of people with disabilities, "failing to incorporate the diversity of the disabled community within the scope of its conception of equality" (Hosking, 2008: 12).

5) Voices

Historically, people with disabilities have been silenced and marginalized from mainstream discourses and understanding of disability, being ostracized from the *polis*, as well as from knowledge production processes. The erasure of people with disabilities' voices have reinforced misconceptions on disability, stripping people with disabilities of their expertise and knowledge on disability matters. Titchkosky (2003) talks about the selective audibility afforded to people with disabilities, emphasizing that their voices resonate only when aligning with preconceived assumptions and misrepresentations imposed by ableist paradigms. Conversely, divergent perspectives, that challenge ableist narratives, are routinely disregarded. Such dismissal reproduces

and maintains skewed interpretation of people with disabilities' experiences, which come to be signified as simply an "inappropriate response of a person who has developed an unhealthy response to the impairment" (Hosking, 2008:12), which is ok to disqualify. CDT is concerned with creating a space where people with disabilities' voices can finally be heard and acknowledged, actively collaborating to the creation and co-creation of disability knowledge, and understanding (Meekosha et al., 2013).

6) Language

Critical theory acknowledges that language is inherently political, and it largely defines the way we signify our surrounding social world and the people inhabiting it. Labels and stereotypical language largely contribute to the negative social connotation of specific groups of people, which in turns influence the level of inclusion of those people within their context. Hosking (2008) reflects on how people with disabilities have been portrayed as inefficient, worthless, dangerous, and dependent. This characterization has alimented the construction of disability in negative terms, defining ableist social attitudes as well as segregating responses to people with disabilities through highly medicalized discourses and language. CDT, as a subset of critical theory, recognizes that language is never neutral, and it always carries with it ideological and political implications, that affect social attitudes and perceptions of disability, as well as of other socially constructed categories of being.

7) Transformative politics

CDT is rooted on an ongoing commitment not only to the critical exploration and understanding of the social world, but also and foremost to the lives implicated in segregating cultural and political practices (Pothier and Devlin, 2005). The commitment to these lives requires a theory and a methodology able to shed light on and to disrupt the many forms of oppression regulating our society, to reimagine and reshape the social world in a more equal and inclusive way.

In addition to Hosking's (2008) seven elements of CDT, there are other four principles that Meekosha and Shuttleworth (2009) conceptualize as foundational: First, "critical social theory is irreducible to facts" (p.52), meaning that it cannot be reduced or simplified solely to factual information. Instead, it involves deeper layers of analysis, interpretations, and critique that consider society's "continual historical and sociocultural transformation" (p.52), and how social relations and cultural meaning change, evolve and shift across time and space. Second, "critical social theory links theory with praxis in the struggle for an autonomous and participatory society" (p.52). The concept of autonomy emphasizes people liberation and emancipation from hegemonic and hierarchical ideologies, which influence and define personal consciousness, as well as social relations, and quotidian comportment. Critical social thought aims to reveal the power dynamics embedded within societies, unravelling the concealed power structures operating both at the individual and social levels, driving for social change. Third, "critical social theory is self-aware of its historicity" (p.53), meaning that it acknowledges its situatedness within a distinctive historical juncture, attuned to the dynamics of the temporal milieu in which it unfolds. Thus, the continual evolution of social relations, cultural significance, and consequently self-perceptions underscore the imperative "to maintain a critical self-reflexivity towards its own theories and praxis" (p.53). Lastly, "critical social theory engages in dialogue among cultures" (p. 54). A critical question to ask is 'among which cultures?'. Held (1980) contends that critical theorists have not adequately acknowledged the perspectives of non-Western societies in global politics. Critical theory remains very much engrained within a Western framework, failing to converse with southern epistemologies, and to address both colonialism and racism. For Edward Said, the failure to engage with colonialism and racism is a significant shortcoming of Critical theory, as those are central to understanding and dismantling systems of oppression. Aware of this, Meekosha and Shuttleworth (2009) call for an "explicit [and productive] dialogue with human rights and emancipatory thinking from the diversity of cultures" (p.54), avoiding the projection of

‘international’ (meaning Western and colonial) conceptualization of disability from the Global North to the Global South.

2.2.3 CDT as guiding framework

CDT emerges with the aim of challenging and expanding the historical westernized scholarly dimension of Disability studies, exploring relationships of power, and how they influence the life and experiences of people with disabilities, especially in countries where colonial legacies still largely shape societies’ structures (Grech, 2015). It highlights the need to decolonize the field, and engages with different narratives (Grech, 2015; Grech and Soldatic, 2015; Meekosha, 2011), becoming more accountable (Erevelles, 2014). A CDT “working at the intersections is committed to revolutionary and accountable praxis” aimed at challenging ableist rhetoric where disabled bodies and minds are deemed abnormal (Erevelles, 2014:19). In what follows, I briefly unpack the value and relevance of CDT for this study, explaining how it has guided and informed my work.

By adopting a CDT lens, this work focuses on the intersectionality and multidimensionality of people with disabilities’ experiences, advocating for an inter-/post-disciplinary approach to researching and theorizing disability in a more flexible, responsive and critical way. CDT allows to connect different and often segregated disciplines, being aware of how disability interacts and intersects with other social identities, uncovering the complex matrix of oppression embedded within our societies. This study, through a CDT lens, focuses on the intersection between disability and refugeehood in the Global South, an intersection that has been largely neglected. For instance, forced migrants and refugees with disabilities “continue to be cast in a shadow, of epistemological, ontological and practical invisibility”, where forced migration is theorized without considering people with disabilities, disability studies without contemplating the migrant, and practice (the humanitarian-development sector) without acknowledging and addressing the rights and needs of migrant with disability (Grech and Pisani, 2015:421). The lack of conversation between disability and forced migration studies, and their respective theorization within a pure Western-centric lens,

have resulted in the complete dismissal and neglect of the lived experiences of migrants with disabilities in the Global South. This has largely influenced the field of humanitarian aid, that has been conceptualized and operationalized according to Western ableist rhetoric, within which people with disabilities have been systematically marginalized. Hence, CDT, through an intersectional and multidimensional lens, represents an important guiding framework to push forward inter-/post-disciplinary research able to engage with the heterogeneity of migrant with disabilities' experiences in humanitarian contexts.

Moreover, CDT critically engages with colonial legacy, advocating for a decolonization of disability knowledge, and providing a space to critique the imposition of Western epistemologies as 'universally' true, urging a dialogue with Southern theories (Grech, 2015; Meekosha, 2011; Ghai, 2012; Puar, 2017). The dominance of Western knowledge has obscured the relationship between specific geopolitical contexts, their colonial past and the bodies and minds of people with disabilities. Grech (2015) argues that "colonialism cannot be ignored because this is probably the only common experience in the complex, fragmented and heterogeneous southern spaces, an experience that defines and constructs these spaces (...) Disability existed and was constructed in the colonial" (p.8). Colonialism has not only reconstructed Southern spaces, but also the ways in which people understand themselves, their bodies and their interactions with the broader environment and the 'Other'. Nguyen (2018) sustains that "colonialism has continued to manifest itself through [Western-led] knowledge practices", which have missed to acknowledge that disability is the product of strategic constructed chronic poverty, precarity and violence, systematic exploitation, and disablement, established by politics of neoliberal state formation, and "global technologies of population management" employed to construct "the disabled, colonized subject" (p.7). The West-centered colonial and neoliberal project have significantly shaped people with disabilities' life experiences in the Global South, and it continues to do so through the advancement

of dominant Western ableist humanitarian and development models (Grech, 2011). CDT offers a space to engage with historically “marginalized imaginaries and alternative epistemologies, surviving and emerging subjectivities, and modes of representation which exist in colonial and neocolonial societies” (Moraña et al., 2008:11). In doing so, it aims to re-write the relationship between the center and its margins, questioning the colonial and imperialist ideologies underpinning the exploitation and dominance of certain groups by others, and challenging Western ableist hegemony (Ghai, 2012).

CDT also recognizes people with disabilities as those who hold knowledge and expertise, shifting the focus from research *on/for/about* people with disabilities to research *with* people with disabilities. In reconceptualizing people with disabilities as active agents, promoting their participation and acknowledging their acts of resistance to ableism, CDT offers a framework to retheorize forms of resistance and agency in the fight against oppression and segregation. Historically, people with disabilities, as well as other minoritized communities have been portrayed and signified through Western, ableist, racist, and heteronormative discourses. The multitude of voices and lives relegated to the margin of society have been systematically and structurally silenced and erased. The lack of engagement with and recognition of the lived experiences of people at the intersection of multiple matrixes of oppression has created narrative of deficiency, and inability, pathologizing and criminalizing bodies and minds that have come to be designated either as a ‘threat’ or as a ‘burden’, in both cases, a being which is not welcomed in the society. CDT, in reframing people with disability as expert of their lives, engages with the hidden forms of resistance and agency that they have had in place to navigate and confront the diverse layers of oppression experienced within the society, which have long remained unexplored and disregarded due to the historical ableist, depoliticized and de-agentivized construction of people with disability.

This shift has opened new transgressive and alternative spaces to reimagine and retheorize agency and resistance within marginalized topographies and at the intersection of social identities.

I have used CDT as a fundamental framework to connect the exclusion of Syrian refugee children with disabilities and their families from humanitarian aid to the larger systems of oppression, and inequalities defining our social world, like colonialism and neoliberalism. CDT has allowed me to converse with different concepts and theories across diverse disciplines, being aware and attentive to the multidimensional and intersectional experiences of the people participating to this study, who have been relegated to the margin of society. Finally, it guided me in centering this work on the experiences and knowledge of my participants, allowing me to hear untold stories, and to challenge dominant narratives of refugeehood and disability in humanitarian contexts.

2.3 Agamben's work and the link with disability and refugeehood

In this section, I present Agamben's political philosophical framework, which is anchored in a set of interrelated concepts, such as *homo sacer*, *bare life* and *state of exception*, that offer a unique and productive perspective on the dynamics of power, sovereignty, and exclusion within political and legal systems. His work allows us to critically engage with the logics of contemporary politics and governance, highlighting how power and politics intersect with the regulation of life and populations. Then, I reflect on the generative impact this work has had on other fields of study such as forced migration and disability studies. Highlighting these already available inter-/cross-disciplinary ties, would help to better locate this work. Lastly, I argue that humanitarian aid has become to act as a sovereign power, administering, and controlling life in humanitarian contexts. In this last instance, I aim to shed light on the colonial and neoliberal logics of humanitarian aid, on the sovereign power it exercises, and on how people, who are forced into *state of exception*, come to be re-/produced as *bare life* within the humanitarian framework.

2.3.1 The logic of sovereignty: *Homo Sacer*, Bare Life and State of exception

“When life becomes the supreme political value, not only is the problem of life's non-value thereby posed, it is as if the ultimate ground of sovereign power were at stake in this decision. In modern biopolitics, sovereign is he who decides on the value or non-value of life as such.” (Agamben, 1998:83)

Agamben's concepts of *homo sacer*, *bare life* and *state of exception* are strictly interconnected, and they represent the key elements to fully comprehend his critique of modern forms of sovereignty and governance, and how those operates to control and dispose of life. The connection among these concepts can be briefly summarized as follows: The *state of exception* represents a “zone of indistinction between law and violence” (Agamben, 1998:25), where the sovereign, which traditionally has materialized in the State, determines who gets to live and who to die, and where the legal and ethical norms that typically protect individuals are suspended. When relegated in a *state of exception*, individuals embody *bare life*, a life where they are stripped of their citizenship and human rights, as well as of their political and social privileges, coming to incarnate the figure of *homo sacer*, a “man who may be killed and yet not sacrificed” (Agamben, 1998:12). In this section, I further dissect each of the concepts mentioned above, to lay the ground for a more in-depth understanding of Agamben's work, which is necessary to better locate some of the reflections proposed in this research.

The concept of *homo sacer* originates from a juridical figure borrowed from Ancient Rome, which was used to identify “someone who could not be sacrificed in religious ceremonies, but who could be killed by anyone with impunity” (Colatrella, 2011:101). Agamben (1998) analysis of *homo sacer* starts with the distinction between the Greek terms ‘*zoē*’ (biological process of living) and ‘*bios*’ (manner in which life is lived). *Bios* and *zoē*, despite both referring to life, are significantly different. While *zoē* refers to the simple fact of living, a trait that is common to all living beings,

bios indicates a form of living which is appropriate for individuals and/or groups. Hence, in the classical world, *zoē* marks what we can call ‘natural life’, a life in its raw form, devoid of any political or social significance; while *bios* comes to symbolize a ‘qualified life’, a life which is included in the political and social sphere of the *polis* – State, contrarily to *zoē* which remain confined to the private realm of the *oikos* – home, in its reproductive and de-politicized dimension. In understanding Agamben’s conceptual development of *zoē* and *bios*, we can reflect on our contemporary society and on how certain groups of people come to be positioned within it. For instance, consider how some individuals are marginalized, and stripped of their rights, being reduced to a mere biological existence, where they are deprived of social and political recognition. These individuals, such as refugees, undocumented migrants, stateless persons, as well as prisoners, embody *zoē*, representing *bare life*. They are kept alive, often without even being able to meet their basic needs, being denied of protection as well as of legal, social, and political recognition. Now, consider those who enjoy full citizenship rights, who are recognized as political subjects with the ‘permission’ and ‘ability’ to participate in the *polis*. These people have *bios*, a live that goes beyond mere survival and biological existence, to embrace a recognized political and social identity. In the case of this study, the concept of *bare life*, which is linked to *zoē*, is employed to interpret the lived experiences of Syrian refugee children with disabilities, and their parents, who are structurally marginalized, and deprived of their rights.

Going back to the conceptual dimension of this theoretical discussion, it is important to ask: what happens when *zoē* is included in the *polis*? Foucault (1978) reflects on how at the threshold of the modern era, men come to be inscribed outside the old Aristotelian paradigm of the “living animal with the additional capacity for political existence; [as the] modern man is an animal whose politics calls his existence as a living being into question” (p.188). Foucault explains how politics and life come to be entwined in modern Western societies, where the management and control over human

bodies and populations become the main concern of modern politics, transforming politics in *biopolitics*, where natural life (zoē) come to be included in State (polis) power's machinations and calculations. Agamben's analysis and development of the concept of biopolitics is substantially different from the one of Foucault, especially in relation to their understanding of 'sovereignty' and 'sovereign power'.

For instance, in Foucault's work the concept of 'sovereignty' and 'sovereign power' remain predominantly marginal in his analysis of biopolitics, where sovereignty, while still persisting in the modern era, appears to be altered and positioned alongside newer forms of technologies of power: "we should not see things as the replacement of a society of sovereignty by a society of discipline and then a society of discipline by a society, say, of government. In fact, we have a triangle: sovereignty, discipline, and governmental management" (Foucault, 2007:107). Foucault identifies three main forms of power, which have emerged in different historical phases of modernity, and that coexist with each other instead of being mutually exclusive: sovereign power, disciplinary power, and biopower. While this study does not focus on Foucault's scholarship, it is still important to briefly mention the forms of power he identifies and develops, as those enter in conversation with Agamben's work. Foucault sees the sovereign power as a power of law and violence, a power 'to 'make' die and 'let' live', based on mechanisms of domination and control rooted in the binary definition of what is admissible and what is not, "which is made manifest through the sovereign's ability to punish" (Pierce, 2020:4) or reward according to the lawfulness of individuals' actions and the value of their same lives. For instance, when a political leader issues an executive order that carry the force of law without legislative approval and it is enforced upon the population, it exemplifies the traditional exercise of state authority and of sovereign power. On the other hand, disciplinary power is the "power of discourse and institutions" (Lilja and Vinthagen, 2014:7), exercised through surveillance and knowledge. This involves techniques used to regulate

behavior and instill norms within institutions such as schools. Disciplinary measures like rules of enforcement, monitoring and even the grading system in education help shape individuals to conform to societal norms and expectations. To conclude, biopower, which is formalized by Foucault as being diametrically opposed to sovereign power, is understood as the power ‘to ‘make’ live and ‘let’ die’, a power used to productively administer and organize social life and populations (Lawlor and Nale, 2014). For instance, during public health crises, such as during the Covid-19 pandemic, measures like mandatory vaccination programs or quarantine regulations were issued and enforced to govern and manage public health concerns at the population level.

Now, while, Foucault considers sovereign power and biopower as fundamentally different forms of power, determined by diverse rationales, which are nonetheless “entangled and co-determining” (Walsh, 2014:2); Agamben understands biopower has always being inherently intertwined with sovereign power, conflating the two, and claiming that Western politics, since the time of ancient Greece, has been defined by the ‘inclusive exclusion’ of *zoē* in the *polis*, suggesting that

“[W]hat characterizes modern politics [biopolitics] is not so much the inclusion of *zoē* in the *polis*—which is, in itself, absolutely ancient—nor simply the fact that life as such becomes a principal object of the projections and calculations of State power. Instead, the decisive fact is that, together with the process by which the exception everywhere becomes the rule, the realm of bare life—which is originally situated at the margins of the political order—gradually begins to coincide with the political realm, and exclusion and inclusion, outside and inside, *bios* and *zoē*, right and fact, enter into a zone of irreducible indistinction. At once excluding bare life from and capturing it within the political order, the state of exception actually constituted, in its very separateness, the hidden foundation on which the entire political system rested.” (Agamben, 1998:12)

The politicization of *bare life* rest in this ‘inclusive exclusion’, where the exclusion of *zoē* from the *polis* is at the same time an inclusion, as *zoē* it is included in virtue of its exclusion. Biopolitics is built into the structure of sovereignty, which, via the ‘inclusive exclusion’ of *zoē*, is always already

biopolitical, as “the production of a biopolitical body [which can be read also as the production of bare life] is the original activity of sovereign power (...) Placing biological life at the center of its calculations, the modern State therefore does nothing other than bring to light the secret tie uniting power and bare life” (Agamben, 1998:11).

For Agamben, Western politics originates from the tension between the categorical pair of “bare life/political existence, *zoē/bios* and exclusion/inclusion” (Agamben, 1998:12), through which *bare life* come to be signified as the life of *homo sacer*. *Bare life* represents the foundational concept of Agamben’s work, as it underpins both the interpretation of *homo sacer* and *state of exception*. *Bare life* is the life of *homo sacer*, and it symbolizes the most basic, and vulnerable form of human existence. It is life reduced to its biological, physiological, and material form, stripped of any legal or political attribute, and devoid of any rights or protection under the law. As a result, *homo sacer* come to be constructed as one who is included within the legal order, and at the same time excluded from its protective mechanisms, who is not recognized as a legal subject, and whose rights, and dignity are negated through the bio-politicization of their forcibly de-politicized body. As stated above, the creation of *bare life* is the foundational activity of the sovereign power, and the *state of exception*, which allows the sovereign to exercise unrestricted power and authority, serves as the operational context in which the concepts of *bare life* and *homo sacer* acquire empirical and political relevance.

Agamben (2008) explains that “the theory of the ‘state of exception’ is wholly reduced to the theory of the ‘status necessitatis’ (state of necessity), so that a judgment concerning the existence of the latter resolves the question concerning the legitimacy of the former”, and he continues “If something is done out of necessity, it is done licitly, since what is not licit in law necessity makes licit” (p.35). It appears that the roots of the *state of exception* are to be found in the historical

declaration of a state of emergency, which justifies, by virtue of the exceptional circumstances it calls upon, the employment of unprecedented responses to “overcome the peril and restore normal conditions” (Rossiter, 1949:5). The *state of exception* is enforced by the ‘sovereign power’, which classically crystallizes in the state authority. It is operationalized through the temporary suspension of the ordinary legal order, legitimized by emergency discourses that allows the sovereign to act outside the boundaries of established laws, deciding on the value or non-value of lives, forcing into *bare life* the ‘valueless’, who come to incarnate the figure of *homo sacer*.

The concept of emergency appears to be crucial in the actualization of the *state of exception*. Emergency allows the sovereign to act in unrestricted ways, reconfiguring power dynamics within the society, as well as its structure and the position individuals come to have in it. In contexts of declared emergency, there is usually a more or less fictitious ‘enemy’ to fight, which justifies the sovereign to adopt drastic and exceptional measures to contrast the identified and socio-politically constructed ‘enemy-other’. In these instances, securitization discourses and policies are promoted to support and reproduce a climate of emergency, dramatizing and hyper-politicizing a specific issue. A practical example can be the arrival of refugees into host countries, which is constructed as a matter of outmost priority that ‘threaten’ the ‘survival’ of the ‘us’, calling for extraordinary procedures to counter the refugee ‘invasion’, that go beyond the everyday politics (Beck, 2017). Securitization speech and policies have been widely used to redefine the narratives of migration within dominant Western frameworks, which construct refugees either as a ‘threat’ to the nation’s stability, or in terms of vulnerability and need, facilitating discourses that leads to the relegation of refugees in a *state of exception*, as it is the case for Syrian refugees with/out disabilities within and outside Lebanon.

Before proceeding, it would be important to clarify why this study draws on Agamben's work, rather than on the one of Foucault, reflecting on the implication of their different conceptualization of (sovereign and bio-) power. While Foucault emphasizes the decentralized nature of power, and how it permeates throughout society, operating at the level of individual bodies and everyday practices, shaping behavior, identities, and social norms; Agamben's analysis shift towards the assertion of sovereign power. He focuses on how sovereignty operates at the threshold between the normal legal order and the *state of exception*, where individuals come to exist outside the protection of the law, subject to the arbitrary exercise of state power, or, as it is articulated in this work, of the 'humanitarian power'. In researching the lived experiences of Syrian refugee children with disabilities, and their parents, in Lebanon, Agamben's work offers an important lens to understand not just the participants embodiment of what he calls *bare life*, but also the structural logics and mechanisms enabling the humanitarian system to wield sovereign power, thereby marginalizing Syrian refugee with/out disabilities. To conclude, Agamben's concepts of *homo sacer*, *bare life* and *state of exception* have inspired and prompted interdisciplinary debates in fields such as political philosophy, forced migration study, and critical theories, in that it provides an interesting framework to critically examine the dynamics of power, control and biopolitical governance of bodies. The next section focuses on briefly outlining these interdisciplinary efforts that bring in conversation Agamben's work with the fields of forced migration and CDT, to start drawing fundamental links that would help to explain *how* and *why* people at the intersection of refugeehood and disability come to incarnate *bare life*, being relegated in spatiality of exception.

2.3.2 At the intersection of refugeehood and disability: 'life devoid of value'

“Why are some people being reduced to homo sacer now? And why those particular people?” (Colatrella, 2011:103)

Colatrella's (2011) thought-provoking inquiries compel us to reflect on *why* and *how* some individuals and groups of people come to be constructed as ontologically and epistemologically

inferior within our highly normative political and neoliberal society. In this section, drawing upon the contribution of scholars in the fields of forced migration studies and CDT in conversation with Agamben's theoretical framework, I aim to re-trace the scholarly endeavors within these domains to better position the present study. Firstly, I briefly delve into the scholarship of experts in forced migration, who explain how refugees come to be relegated into a legal limbo, where they are stripped of legal and political agency, being forced into a state of mere survival (Rabin, 2020; Keereepaibool and Worland, 2021; Kats, 2017). Within this context, my focus lies on elucidating the role of securitization policies and discourses in perpetuating the actualization of spatiality of *inclusive-exclusion*, where refugees are constructed as a threat through the hyper-politicization of their bodies via racist and discriminatory political discourses. Then, I move on to analyze the intersection between Agamben's theoretical framework and CDT, which offers a nuanced understanding of how legal, cultural, and especially economic dimensions contribute to the marginalization of specific populations, that come to embody *bare life*. CDT enriches the legal and political dimensions of Agamben's theory by incorporating reflections on the utilitarian and neoliberal commodification of human bodies. Additionally, it provides a conceptual framework to explore not only the processes by which certain individuals become *homo sacer*, but also the underlying rationales. Lastly, I draw some connections between Agamben's work, CDT, and the field of forced migration studies, shedding light on how *bare life* come to crystallize at the intersection of refugeehood and disability, facilitating a broader critical reflection on both the political and economic dimensions that underpin the construction of some individuals as *homo sacer*. Before proceeding, it is important to acknowledge that 'every-body', to a different extent, is subject to the biopolitical and economic machination of life and death. Hence, my decision to talk about the biopolitics of bodies in relation to refugees' securitization, and about the economy of bodies in relation to people with disabilities' exploitability, is not to say that refugees are not subject to similar rule of economic exploitation and vice versa. Instead, it is to offer an explanation of how

these dynamics, leading to the enforcement of biopolitical economy of bodies, evolve and are enacted.

The (geo)biopolitics of bodies: refugees' securitization

Agamben's work has been widely employed by forced migration scholars, as his concepts of *bare life* and *state of exception* have provided a valuable critical lens to examine the marginalization of refugees' existence, denouncing the state control over refugee camps, the often unhuman detention of migrants and/or asylum seekers, and the exclusion of specific groups of people from the *polis'* life (Ek, 2006; Fresia and Von Kanel, 2015; Zeveleva, 2017; Gonzalez-Gorman, 2022). Moreover, Agamben's ideas gain empirical importance when researching specific dimensions within the forced migration field. For instance, examining the policies and practices of host countries and international bodies reveals how the *state of exception* is not only invoked but also enacted through securitization speech, and emergency rhetoric, leading to the creation of zones where refugees exist only as *bare life* in a legal and political vacuum (Buckel and Wissel, 2010). Agamben's theoretical framework also allows for a critique of the (geo)biopolitical dimensions of forced migration governance, prompting to scrutinize the ways in which governments and international institutions manage displaced populations, questioning the ethical and legal implications of policies that relegate refugees into *state of exception* (Davitti, 2018; Minca, 2023).

In the previous section, it was mentioned how the *state of exception* is actualized through the recognition and declaration of a state of emergency, which is based on the identification of a more or less fictitious threat, that legitimize the use of exceptional measures outside the rule of law (Agamben, 2005; White, 2019; Buzan et al., 1998). The emplacement of the *state of exception* expands the sovereign's power (Delanty 2020), transforming and redefining modes of governance, as well as relationship of powers between and among different actors. Historically, the refugee phenomenon has been politically defined "within discourses of crisis and danger" (Nyers,

1998:16), projecting a sense of emergency, that has consolidated the creation of refugees as a threat to the stability, order and security of host and receiving countries (Huysmans, 2006). The dominant Western delineation of forced migration phenomena as a security-threat has promoted a narrativization of state's protection, legitimizing the enactment of exceptional measures through securitization discourses and policies.

Securitization discourses are based on processes of racialization and otherization of the refugee 'other', that facilitate the construction of refugees as an existential danger and threat for the survival of a designated 'us' versus a discursively constructed criminalized 'other'. The emergency defined by the need to secure the safety of the 'us' from the 'invasion' or 'borders' aggression' of the 'them' calls for exceptional measures, that come to be rationalized as fundamental and necessary, serving as a catalyst for the proclamation of a *state of exception*. Miggiano (2009:2) states that "securitization is presented as a continued technique of governmentality, which has constitutive effects upon the normal, [and where refugees, who are considered as] irregulars inside a border [are in reality] outside the boundaries of citizenship and visibility". Their exclusion from the *polis* is not a "careless expulsion, but a *careful* placing outside of the declared boundaries of the norm" (Rajaram, Grundy-Warr, 2007: XXI, my emphasis). The securitized dimension of *inclusive-exclusion* in which refugees are 'carefully' positioned within a country borders and outside its boundaries of citizenship re-signifies them as *bare life*, relegating them in zones of exception, such as detention camps or refugee camps, where their lives are regulated, and controlled.

The securitization of refugees is performative: it shapes political reality by influencing policies, public perceptions, and resource allocation, ultimately impacting the lives and experiences of refugees, who become *homines sacri*. Moreover, it continues to serve Western colonial interests through the creation of new forms of asymmetrical global governance (Miggiano, 2009), through which the Global North maintain its hegemony and control over the Global South. A practical

example of this can be analyzed starting from Western countries' securitization of refugees beyond their sovereign borders. The extension of Western state's border controls beyond its sovereign territory is known as 'externalization of borders' (Lee, 2022; Gaibazzi et al., 2016), and it can involve agreements with neighboring or transit countries to keep refugees within their borders and far from Western coasts. While this work does not intend to provide an in-depth theoretical analysis of how securitization policies are promoted and implemented within and outside borders (see Lee, 2022; Lemberg-Pedersen, 2019; Stock et al., 2019; Papageorgiou, 2018 concerning externalization); it is nonetheless important to briefly mention it as refugees find themselves trapped in this sovereign 'boarder game', which defines the spatiality of exception in which they fall into. For instance, Syrian refugees in Lebanon are not only subject to Western externalization frameworks and operations, but also to Lebanese internal securitization policies and their application. Through securitization discourses, and the consequent refugee policies, refugees come to be determined as a threat to avert and/or to confine in spatiality of exception.

It must be noticed that the humanitarian system, while balancing the humanitarian imperative to protect vulnerable populations, plays a crucial role in contributing to securitization and discriminatory rhetoric (Vaughn, 2009; Watson, 2011; Riggirozzi, 2023), as well as in actualizing, and maintaining refugees in zones of exceptions (see Chapter 4). As a result of this diametrically opposed discourses of refugee securitization from one side, and refugee protection from the other, seemingly contradictory characterizations of refugees are promoted: refugees come to be signified and constructed either as a 'threat' or as a 'vulnerable' being. The *lines* between the 'refugee threat' and the 'refugee vulnerable' resides on whether they decide to cross borders or not. For instance, Western countries depict 'moving' refugees as a 'threat', while constructing those confined within the borders of the Global South as 'vulnerable' and in need of protection, morally justifying Western humanitarian aid, through which they continue to protect their geopolitical and

economic interests. The logic of humanitarian aid is rooted in this mixture of *'politics of pity'*, and of securitization (Aradau, 2004; Agier, 2011), where the aim is the “security of [potential] host society” (Perkowski, 2018), and the protection of the imbalanced North-South status quo, rather than the preservation of refugees’ intrinsic human rights.

The neoliberal economy of bodies: people with disabilities’ exploitability

The conversation between Agamben’s work and disability scholarship has informed chilling reflections on topics such as eugenics and bioethics (see Overboe, 2007; Donohue, 2023; Arán and Peixoto Júnior, 2007), the confinement and abusive treatment of people with intellectual disabilities in segregated institutions (Adams and Erevelles, 2017), and in this work, the ways in which neoliberal ideologies intersect with and affect the lives and experiences of people with disabilities in humanitarian contexts. In this section, starting from Agamben’s reflection on “Life that does not deserve to live” (1998: 80-83), and from the work of CDT’s scholars on the historical-materialist analysis of disability, I briefly consider how people with disabilities come to be signified as “devoid of value” through a (biopolitical) neoliberal economy of bodies. Agamben, drawing upon Binding’s work on the “Authorization of Annihilation of Life Unworthy of Being Lived” (1920), engages with the mechanisms through which certain individuals come to be constructed as “devoid of value”, setting the stage for a biopolitical structure that categorizes individuals based on their perceived contribution to the (global neoliberal) economy.

In assessing the ‘value’ and ‘worth’ of individuals, Binding asks “Are there human lives that have lost the quality of legal good that their very existence no longer has any value either for the person leading such a life or for society?” (Binding, 1920 cited in Laurie, 2015:23). Binding’s inquiry forces us to consider the criteria by which a society assesses and assigns value to human lives, raising not only philosophical and ethical questions, but also legal ones about the determination of

the worth (or lack thereof) of an individual's existence within a given social and legal order. Today, in our neoliberal globalized world, the answer to Binding's question focuses on an historical-materialist analysis of the biopolitical economy of the body, which emphasizes individual's economic contribution as a gauge of societal worth. For instance, Giroux (2006) writes that

“[The] hyper-neoliberalism is now organised around the best way to *remove or make invisible those individuals and groups who are either seen as a drain or stand in the way of market freedoms, free trade, [and] consumerism (...)*. [Being] excommunicated from the sphere of human concern, they have been rendered invisible, utterly disposable.” (Giroux, 2006:175; my emphasis)

Giroux (2006) employs the term “hyper-neoliberalism” to refer to a form of neoliberal economic and political ideology through which individuals deemed as a ‘burden’ or an ‘impediment’ to the unfettered operation of the market are intentionally marginalized and excluded. Individuals come to be categorized according to their economic value: from one side, there are normative bodies and minds who can comply with neoliberal ableist expectation of doing, hence being exploitable by the globalized neoliberal system. From the other, there are the “incurably lost” and the “incurable idiots”, such as people with disabilities (especially those with mental and/or severe disabilities), and people with terminal illnesses, whose “life is absolutely without purpose” (Binding, 1920 quoted by Agamben, 1998:81), hence disposable. The crafting of people with disabilities as a “drain” not only overlooks their contribution to their communities – which goes beyond mere quantifiable and measurable economic output – (Laurie, 2015), but it also reinforces a capitalist neoliberal model that discards lives deemed ‘incapable of living up to market competitiveness’.

Agamben argues that health plays a crucial role in the politicization of life and in defining the concept of *homo sacer*. He illustrates this intricate relationship among the ‘body’, the ‘political’ and the ‘economy’ by referencing the 1942 *État et Santé* (State and Health), which acknowledge the necessity of establishing a

“Budget to take account of the living value of people (...) We are approaching a logical synthesis of biology and economy (...) Politics will more and more have to be capable of achieving this synthesis, which may only be in its first stages today, but which still allows one to recognize the interdependence of the forces of biology and economy as inevitable fact. Just as the economist and the merchant are responsible for the economy of material values, so the physician is responsible for the economy of human values. (...) it is absolutely necessary that the physician contribute to a rationalized human economy, that he recognizes that the level of the people’s health is the condition for economic gain (...) Fluctuations in the biological substance and in the material budget are usually parallel.” (Verschuer, 1942:31, 48, 40 cited in Agamben, 1998:84)

Critically, the quote above presents some relevant implications concerning the de-/valuation of people with disabilities within our neoliberal system. For instance, the notion of assigning a budget to the living value of individuals underlines how, by narrowly defining people’s worth based on economic productivity and health metrics, certain groups of people, particularly those with disabilities, come to be marginalized and constructed as ‘less human’, and therefore less worthy of citizenship (Kiwan, 2022). Moreover, the role assigned to medical professionals in contributing to a rationalized human economy, where health is positioned as a condition for economic gain, implies an instrumentalization and commodification of health for economic purposes. This commodification is “deleterious to society’s most vulnerable members” (Christiansen, 2017:82), such as people with disabilities, who risk being further marginalized as their contribution to the economy may not align with the neoliberal and ableist notion of productivity. Disability comes to be constructed as a problem that medical professionals – in being positioned as keepers and to a certain extent as administrators of human life and its value within a rationalized economy – are required to cure and to fix, for the individual “to ‘look’ and act as ‘normal’ as possible” (Titchkosky and Michalko, 2012: 128; original emphasis). This reduction of disability to a mere problem to be fixed surrenders authority to ableist medical discourses, with the result that if some bodies and

minds prove to be unfixable, then the person with disability “cannot be conceived as a viable mode of life” (Erevelles, 2011:32 in citing Titchkosky, 2007).

The “disability-as-a-problem frame” (Titchkosky and Michalko, 2017:127) is not arbitrary; on the contrary, as disability’s scholars have argued, it is deeply embedded in historical and material conditions (see Gallagher and Laqueur, 1987; Gleeson, 1997; Clear and Gleeson, 2002; Titchkosky, 2003, 2007; Erevelles, 2011; Russel, 2019). For instance, Gleeson (1997), building on Marx’s work, explains how disability has been historically situated within economic structure, examining the ways in which capitalist economies have shaped and perpetuated a medical model of disability, relegating people belonging to the “‘incapable’ stratum of labor (...) in[to] a new institutional system of workhouses, hospitals, asylums, and (later) ‘crippleages’” (p. 195; original emphasis). In this new neoliberal economy of bodies, as already mentioned, the value of people’s life becomes intricately tied to their value to the economy. This perspective leads to an ontological depiction of the body as mere ‘flesh’, and to an ontological definition of its value purely in terms of its exploitability. Therefore, when in this work I use the expression ‘flesh employability’ or ‘flesh exploitability’, I do so with the intent to highlight how our neoliberal system pursue our construction as nothing but envelops of blood, flesh, and bones on which the economy feeds on, and whose value is established exclusively based on its productivity, employability and consequent exploitability. The hierarchy of survival embedded in this socio-political and economic relations of production and consumption exposes the stark reality faced by people with disabilities, underlining how certain lives are deemed less valuable than others. When the flesh is less exploitable or not exploitable, its neoliberal constructed greater purpose of production remains unaccomplished, and its only option is annihilation. Through the neoliberal economy of bodies, people with disabilities come to incarnate the figure of *homo sacer*, being confined outside the

polis. The value of a person's life lies in their capacity to 'do' what I call a 'neoliberal being', a being 'able' to comply to neoliberal normative requirements of production and exploitability.

The (geo)biopolitical and neoliberal economy of bodies: refugees with disabilities

People at the intersection of refugeehood and disability experience compounded forms of exclusion. In this section, I emphasize the ways in which logics and practices of refugee securitization and disability exploitability converge to create physical and conceptual spatiality of exception, where systemic forms of discrimination and segregation are reproduced, and to a certain extent even formalized and justified. Pisani and Grech (2015) explain that "forced migration is [an] historical, contextual, political and politicized [phenomenon]" (p.424). As such, the experiences of displaced people with disabilities in the Global South needs to be understood and repositioned within broader global processes of neoliberal globalization (Castles, 2003), historical/colonial and (geo)biopolitical factors, which have perpetrated asymmetrical power relationship between the Global North and South, triggering and maintaining poverty and inequalities.

The increasing securitization of borders, especially post 9/11, has had dramatic effects on Southern bodies with/out disabilities seeking refuge in the Global North. National security supersedes human security – Southern bodies, once again, come to be nullified, and signified as 'illegal', and 'uncivilized', criminalized and constructed as the 'dangerous other' – continuing to support and rationalize the imperative for division and separation (see Fanon, 1963). As a result, the rights of the 'threat other' are 'rightly' suspended, and we see a return to a colonial era, where Western countries manage to construct and justify inequalities as natural (Pisani and Grech, 2015). Refugees are increasing labelled as 'economic' or 'illegal' migrants, seen as an unwanted burden. At the same time, paradoxically, the illegalization process to which forced migrants are subject, transform them in low-cost and easily exploitable workforce for the sustenance of the global market (Pisani,

2016). Western states perpetuate “a survival of the fittest scenario that selects the desirables from the masses of the ‘wretched of the earth’” (Fanon, 1963 as cited by Pisani and Grech, 2015: 435). This aligns with the dominant Western neoliberal ideology that prioritizes productivity and efficiency over rights (Soldatic and Meekosha, 2012). The same (geo)biopolitical and neoliberal economic rules and principles apply to the dominant Western humanitarian aid sector, which defines

“[W]ho is considered as ‘assistable’; who can/should be assisted by the international community and how; who will qualify for legal protection and who won’t; where (geography, group etc.) funds should be directed to, and how they should be spent; who will be granted access to rights. (...) The upshot of this is the insidious, but ever-present abuse of power by Northern countries, the imposition of policies and practices too often not in the best interests of the poorest or most vulnerable. Instead, they are directed by political and economic gains, and the reproduction of ‘humanitarian’ spaces where liberal democratic ‘norms’, including human rights, are nonexistent: a depoliticised space wherein, by virtue of their political– and ontological exclusion, lives are suspended, reduced to ‘bare life’ and outside the reach of law (see Agamben, 1998).”
(Pisani and Grech, 2015:426 and 431)

The discriminatory practices entrenched within West-centric securitization and neoliberal frameworks do not operate in isolation; instead, they mutually reinforce and amplify each other. For instance, the ableist biases ingrained in neoliberal economic thinking find resonance in securitization-driven policies, where refugees with disabilities are often overlooked amidst broader security concerns. Conversely, securitization narratives can seep into economic frameworks, framing refugees with disabilities as potential threats to a nation economy. The intertwined biases of securitization and neoliberalism permeate societal perceptions, impacting how refugees with disabilities are perceived and excluded/included. Consequently, refugees with disability, especially those with severe and complex ones, find themselves at the *limites* of the *polis*, facing barriers to education, employment and social participation that go beyond the challenges encounter by other

refugees without disabilities, or by refugees with milder types of disabilities. With this study, I aim to acknowledge and uncover the multifaceted, intricate, and complex lived experience of people who find themselves at the intersection of refugeehood and disability in a world governed by a global biopolitical neoliberal economy of bodies.

2.3.3 Humanitarian aid and sovereign power

“Humanitarian aid can develop into a permanent substitute for public services that should be provided by the state. In the case of a refugee crisis, for example, if a state lacks relevant administrative bodies, the United Nations High Commissioner for Refugees [UNHCR] decides whether someone receives refugee status or becomes eligible for aid. In certain crises, therefore, humanitarian actors may well hold the “power over life and death” of aid recipients, which is another famous definition of sovereignty.” (Hoffmann, 2020:203)

Hoffmann (2020) explains the eventualities through which humanitarian actors come to exercise sovereign power in context of humanitarian crisis, substituting *de facto* states that lack administrative and economic resources and infrastructures to manage unfolding emergencies. She recognizes that in humanitarian contexts, sovereignty may be layered – or hybrid as Ramadan and Fregonese (2017) articulate –, “with different actors controlling different elements of life” (Hoffmann, 2020:202). In the absence of an effective state administration, humanitarian organizations, such as UNHCR, and other UN agencies and INGOs, take on crucial decision-making roles: this involves determining who qualifies for refugee status, or who is eligible for accessing aid and other services. Essentially, these organizations come to administer, control, and dispose of people’s lives, wielding a significant influence over the well-being and the survival of the individuals affected by a crisis. These dynamics raise some important concerns. For instance, when humanitarian actors become a permanent substitute for state services there is a risk of perpetuating a cycle of dependency on external assistance (Barnett, 2005; Belloni, 2007), which does not only hinder the development of local governance structures, but it also relegates

populations in need in a status of chronic dependency, a *state of exception*, reinforcing and preserving humanitarian actors' sovereignty over aid recipients' life and death.

Before proceeding, it is important to question: whose interests and agendas are being protected and advanced by the humanitarian organizations exercising sovereign power over refugees' lives? "Humanitarian aid has been instrumentalized to serve the continuation of centuries of colonialism, warmongering, and economic exploitation; all of which continue in different shapes and forms" (Aloudat and Khan, 2022:3). The humanitarian aid industry has its roots in the Western colonial era, its *mission civilisatrice* (Barnett, 2011), and it represents an extension of it (Chimni, 2009), through which unequal power relationship between the Global North and the Global South are maintained and reproduced (Saleem, 2023). The historical relationship between humanitarian aid and Western power has been largely documented (see Barnett, 2011; Davey et al., 2013; Donini, 2014), and humanitarian aid came to be perceived as being a tool of Western imperialism, "deeply embedded culturally, politically and financially in the Western sphere"; rather than "benign agents" (Terry, 2011:176). Donini (2014) points out that "[the] Northern/Western humanitarian enterprise . . . [is] . . . central to the conceptualization and management of the relations between the citadels of the North and the borderlands of the vast Third World periphery", underlining how humanitarian actions go beyond their 'apolitical' mandate, and have broader implications for the global understanding and management of international socio-economic and geopolitical dynamics. Acknowledging the genesis of humanitarian aid as a West-centered project of governance, and its political and economic instrumentalization by the West – to advance dominant donors' agendas and interests – helps to shed light on: a) the actual affiliation of the humanitarian actors exercising sovereign power in constructed spaces of *inclusive exclusion*, and the interests of whom they are protecting; b) the underlining colonial, geo-(bio-)political and neoliberal logics through which

people in need are signified, and then controlled and dominated; and c) the dangers of a sovereign humanitarian aid constituted by the abovementioned logics.

Barnett (2011) offers a critical analysis of the points raised above, explaining that:

“Humanitarian governance occasionally has a chummy relationship with the very empires that it supposedly resists. *Powerful states* (Western countries) *generously fund humanitarian organizations, and the agendas of Great Powers and humanitarian groups have overlapped over the decades.* (...) *humanitarian organizations have taken on state-like functions* such as providing public goods and serving as de facto government ministries. *[Humanitarian aid] has become a big business, and increasingly aid agencies are administered by executive offices that focus on the bottom line and market share* (...) [humanitarian aid] has become more centralized, more distant from those it wants to help.” (p.222; my emphasis)

The quote above highlights the intricate dynamics between humanitarian aid and Western “powerful states”, underlining the strict relationship between humanitarian organizations and donor countries in the Global North. It critically reflects on the cooptation of humanitarian efforts by Western (geo)biopolitical interests, as well as on the business-like transformation of the sector, and the potential consequences on the lives of the people they are supposed to help. Donini (2014) affirms that humanitarian actors have now reached a critical juncture, where they have surpassed the threshold of power, gaining significant degree of influence and authority within the contexts they operate, as well as at the international level. Barnett (2011), through an historical analysis of the transformation of UNHCR’s mandate, explains how UN agencies and other international humanitarian actors have come to exercise sovereign power, deeply changing their initial ‘apolitical’ imperative: “The 1990s and its new security environment created new pressures and opportunities for the UNHCR, [and other humanitarian organizations], to become more deeply involved in the affairs of states” (p.207). Humanitarian organizations started undertaking practices and activities that were once decried as politics, enacting a process characterized by the increasing

convergence of politics and humanitarianism (Fassin, 2007). The gain of sovereign power by humanitarian organizations is connected to this shift, where the new colonial (geo)biopoliticization and neoliberal marketization of humanitarian aid and its beneficiaries create new landscape of domination and control over constructed topography of exception.

It must be noticed that the extent to which humanitarian organizations come to play a sovereign role is strictly connected to the strength and sovereignty of the states in which they operate (Hoffmann, 2020). For instance, in a sovereign state where significant gaps in refugees' protection subsist, the transfer of "responsibility for managing refugee policy [and operations] from the sovereign state to the UN agencies" (Kagan, 2011:1) establishes and reinforces humanitarian actors' sovereign activity. Lebanon offers an interesting case to understand how humanitarian and other non-state actors could start exercising sovereign power within a state's sovereign borders. Lebanon is considered as a "weak state" (Fregonese, 2012). Its sovereignty appears to be eroded and compromised by non-state actors – such as armed groups (e.g. Hezbollah), as well as international humanitarian organizations (UN agencies and INGOs) –, and by other states' external interventions (through humanitarian actions and aid), which undermine the country's sovereignty (Ramadan and Fregonese, 2017). Fregonese (2012) explains how Lebanese sovereignty results from a complex process of hybridization between the different state and non-state actors acting in the region, where non-state actors have become *de facto* practitioners of sovereignty: "they are not the state but resemble it, collaborate with it, or overpower it" (p. 661). International humanitarian organizations and UN agencies, becoming responsible for refugees, and to an always major extent also for the Lebanese population, have been acting as a sort of "surrogate state" (Kagan, 2011:1), providing public services to both refugee and Lebanese communities, exercising sovereignty within the Lebanese hybridized sovereign system.

Mbembe (2003) states that “sovereignty means the capacity to define *who matters* and *who does not*, *who is disposable* and *who is not*” (p.26; my emphasis). The inclusion of refugees as *bare life* in the (geo)biopolitical and global economic realm of aid and security constitute the original nucleus of humanitarianism as a sovereign power: Humanitarian actors’ sovereignty is enacted through their authority in determining, through (geo)biopolitical and economic calculations, which bodies and minds matter (or not), qualifying for refugee status, and for accessing aid and other services. Refugees with/out disabilities, constructed as *homines sacri*, and embodying *bare life*, in this system are at the mercy of the sovereign humanitarian sector, that disposes, controls, and administers their bodies and lives through the paradigm of ‘make live’ and ‘let die’. To conclude, understanding how the humanitarian aid sector and its actors come to be defined as and to exercise sovereign power is fundamental to better locate and comprehend the later claims and arguments made in the finding Chapters 4, 5 and 6 of this work.

2.4 ‘In conversation’: a way forward

This chapter engaged with the main theories and concepts *conversing* with the lived experiences of the people taking part to this study. That I am aware of, this is one of the first studies that bring in conversation Agamben’s theory with CDT, at the intersection of refugeehood and disability. People’s experiences at these intersections are often silenced. The humanitarian (education) system has largely overlooked the needs of refugees with disabilities, despite the pompous inclusive rhetoric adopted. As a result, refugee children and youth with disabilities remain disproportionately neglected by the system, coming to incarnate what Agamben calls *bare life*. This work, *in conversation*, contributes to the literature in the following way:

- It responds to the disjuncture between forced migration and disability studies (Pisani and Grech, 2015), providing a narrative that disrupt the homogenization of refugees with disabilities’ lived experiences in humanitarian contexts.

- It acknowledges the interconnectedness of global economy and (geo)biopolitical discourses in the signification of certain bodies as *bare life*.
- It highlights the contradictions and discrepancies between international humanitarian inclusive policies and their implementation on the ground by the humanitarian aid sector, which is underpinned by neoliberal and securitization logics.
- It encourages a re-theorization of the field of humanitarian education, as well as of the broader humanitarian sector, in more inclusive terms, taking distance from old colonial and neoliberal ableist construction of inclusion, towards a more right-based approach. It recognizes refugees with disabilities' rights based on their intrinsic humanity and not on their perceived economic exploitability and political value.
- It offers a methodological and theoretical framework to acknowledge the diverse and transgressive dimensions of agency and resistance materializing in spatiality of exception, contributing to challenge traditional socially constructed images of refugeehood and disability, as well as the mechanisms through which these images are re-/produced.

2.5 Conclusion

In this chapter, I traced the main theoretical and conceptual frameworks conversing in this work. I analyzed the genesis, constitutive elements, and evolution of Critical Disability Theory (CDT), focusing on its theoretical and methodological advantages. Then, I moved to present Giorgio Agamben's work and how it has productively interacted with the fields of forced migration and disability studies. I also briefly reflected on how the humanitarian aid sector come to exercise sovereign power over refugees with/out disabilities in humanitarian context of exception. Finally, I explain how this study, in conversing with diverse concepts and theoretical perspectives, is contributing to and beyond CDT's scholarship. The next chapter focuses on the study's research methods and methodology.

CHAPTER 3

METHODOLOGY

3.1 Introduction

“He is relying after the study, so that you can publish it, and give access to this information also to the broader community, so that the community can start slowly changing and providing for children like his son. He knows that the study might not directly help them, but it would be important also just to work to change the society so that other families in the future might not struggle as them”.

(Interpreter’s translation of Farug’s words)

During the fieldwork, I experienced a highly critical process of questioning my role as a researcher with a renewed and at times painful awareness. I have always felt I was not the right person to conduct this research, partially because being a Mediterranean-European woman I did not wish to reproduce biased understandings of the participants’ lives. The interview with Farug represented the official start of my fieldwork, and it left an indelible mark. A mark so profound that when I started analyzing the data, I was scared to disappoint the families, to fail in what they wished to achieve with their participation to this study. For the whole time, I was concerned that my positionality and subjectivity would have led me to misinterpret the data, or to prioritize the wrong things. I was frightened, and I really wanted to highlight what these parents were telling me, without reproducing a discourse of victimization, or depicting the participants as vulnerable and powerless people, because this is not how they presented themselves to me.

My research journey with this project can be described as labyrinthic, as I often found myself lost in the maze of different lives. The ‘realities’ I was entering were way too far and alien from the theoretical discourses approached prior the fieldwork. A strong feeling of uneasiness populated my days, and I came to know that research is never linear, and never easy; rather it is a process, and as

such, its ongoingness allows for exploration, reflection, mistakes, regrets, and ultimately learning (Wu, 2021). It requires you to re-position yourself through a constant and critical reflexive dialogue *with* the ‘self’, and *among* the multiplicity of lives that populate the research, being conscious and critical of how privileges, powers, and at times misconceptions shape and re-shape our constructed understanding of the surrounding social world.

This chapter is divided into three broader sections, followed by the conclusion (3.5). It aims to guide the reader through the philosophical rationale informing this project (3.2), underlining the research methods and processes (3.3), and critically reflecting on ethical dilemmas (3.4). Section 3.2 focuses on the project’s design. It locates the study within the interpretivist/social constructionist tradition (3.2.1), underlining its inter-/post- disciplinary and multidimensional nature (3.2.2), and reflecting on the choice of employing (C)GT as a valuable analysis tool (3.2.3). Section 3.3 engages with the more practical dimension of the study, providing detailed information on the research participants (3.3.1), and the phases of data collection (3.3.2) and data analysis (3.3.3). Section 3.4 presents important ethical consideration regarding processes of consent and assent (3.4.1) and matters of reflexivity and researcher and interpreters’ positionalities (3.4.2).

3.2 Research Methodology

For a rationalized and contextual framing of the study, it is fundamental to clarify the philosophical stance within which the research unfolds. In social sciences there are different philosophical approaches, and each of those influence the nature of the inquiry, as well as the methods, the researcher’s positionality within the entire research process, and the knowledge produced. In this section of the chapter, I focus on the chosen philosophical rationale, the interpretive/social constructionist paradigm, briefly mentioning some of the main differences with the positivist approach. Then, I move on to analyze the multidimensional and inter-/post-disciplinary nature of

the study, and lastly, I highlight the theory-context gap perceived during the fieldwork, which led me to adopt (C)GT as a data analysis tool.

3.2.1 An interpretive/social constructionist research

In social sciences there are two main approaches to research: subjectivist and objectivist. These two approaches appear to be diametrically opposed, and they are based on diverse ontological, epistemological, and ultimately methodological assumptions. Objectivists tend to follow the positivist paradigm, while subjectivists are more in line with the interpretive one. As a young researcher, I position myself (meaning the way I approach, see, and interact with the world) and my research efforts within the interpretive/social-constructionist paradigm, being also inspired by critical theory. Social constructivism is one of the many traditions within the interpretive paradigm; for this reason, throughout this section I talk about an interpretive/social constructionist approach to research.

The interpretive paradigm has gained relevance starting from the 1960s, with the spreading of social constructionist principles, which emphasizes the process through which “people, including researchers, construct the realities in which they participate” (Charmaz, 2006). While the positivist paradigm, depicts the world as an ‘external’ entity, and the reality as something objective, and completely unrelated to the contingency of human relationship (Murphy and Perez, 2002); the interpretive/social constructionist model adopts a different perspective. It believes that despite an external and independent physical reality might exist, our knowledge of it could never be absolute and objective, but only socially constructed, as we have no assurance that the way we depict reality is accurate and relevant (Smith and Hodkinson, 2002). Hence, reality is seen as a product of intersubjective discourses (Shutz, 1962), negotiated through individuals’ subjective shared understanding of the surrounding social world (Goodley, 2011), where interactional meaning and interpretation of reality are co-constructed and agreed on (Guba and Lincoln, 2005).

May (2011) and Crotty (2010) believe that it is not possible to investigate the social world adopting a detached position from the research process. For them, social phenomena are not separated from human subjectivity; rather, they are constructed through the interaction between people and between people and their specific context and environment. This view has important repercussions on the perceived role of researchers within the research process. As opposed to the positivist paradigm, which sees researchers as being separate from the object of their analysis (Neuman, 2003); the interpretive/social constructionist model acknowledges the active participation of researchers in the fact-finding process: “inquirer and inquired are fused into a single entity and (...) findings are literally the creation of the process of interaction between the two” (Guba, 1990, p.26).

Researchers within the interpretivist/social constructionist paradigm admit moral taint, recognizing the impossibility to maintain a value-free approach, as “an intersubjective view of reality, knowledge construction, and mutual description necessitate acknowledgement of individual values and valid interpretation of experience” (Strand, 2013:47). Weber (1949:72) affirms that “there is no absolutely ‘objective’ scientific analysis of culture (...) or ‘social phenomena’ independent of special and ‘one-sided’ viewpoints according to which (...) they are selected, analyzed, and organized for expository purposes”. Moreover, interpretivists, highlighting the role that human subjectivities play in the construction of social phenomena, reject the idea that human behavior is predetermined by universal laws (Cohen, 2007). Individuals are understood as agentic beings, who, responding to the unraveling of social circumstances, shape, and re-shape their environment, rather than being solely a mere deterministic product of it. The reason why I use the word ‘solely’, is to acknowledge that, while it is unarguable that individuals have agentic power through which they transform their social world, their identity and historicity are also subject to the broader societal structure of power, within which they interact.

Therefore, this study lies within the interpretive/social constructionist paradigm, taking a subjectivist and anti-positivist stance. It recognizes that reality is tied to the set of interactional meanings and understanding that people create and ascribe to their world to make sense of their environments, lives, and experiences. Charmaz (2006) affirm that “people, including researchers, construct the realities in which they participate”, having an active role in their definition. As such, it is fundamental to critically reflect on the role played by the different actors involved in the research process (see 3.4.2)– researcher, participants and interpreter – and how their identity, positionality, and historicalities interact and participate in delineating what we come to know, and how we come to know it. This is especially relevant in multicultural and multilingual research, “where researcher and interviewees do not speak the same language, (and) verbal understanding and communication can only take place with the presence of an intermediary – an interpreter” (Edwards,1998:197).

It must be noted that acknowledging the subjective dimensions of our identities does not mean that we are free from them. Social phenomena are shaped by human narratives, dreams, aspirations and especially interactions. Each person would share a personal and unique account of their world and experience. Therefore, to investigate social phenomena, it is necessary to embrace our own subjectivities, to study and work reflexively and critically through these, to deconstruct and rebuild them in the effort to comprehend other people’s subjective understanding, without being absorbed by them, but rather negotiating the plurality of these understandings with them. De-subjectivizing humans’ realities could only lead to a misrecognition of the realities approached.

Here, I also want to highlight that this study, despite being primarily and mostly rooted within the interpretive/social constructionist tradition, is also influenced by critical theory paradigm using

Critical Disability Theory (CDT) as both a conceptual overarching theoretical framework, and a research methodology. Critical theory, as well as CDT as one of its subsets is defined by its partisan commitment to political change. It is characterized by a strong emancipatory dimension, which appears fundamental in problematizing society's historical structures and processes of exclusion, discrimination and misrepresentation. Burghardt (2011:13) states that at the core of critical theory, there should be an "ongoing commitment to the lives implicated in cultural and political practices". The framing of CDT within critical theory delineates, as it is further explained in the next section, the decompartmentalized nature of the discipline, bringing together theory and praxis, to uncover the different matrix of oppression, and to build a more social just society. What follows focuses on the use of CDT as a research methodology, highlighting the inter-/post-disciplinary and multidimensional approach of this research.

3.2.2 CDT: Inter-/post-disciplinarity and multidimensionality

This work draws on Critical Disability Theory (CDT). CDT provided a first theoretical lens to start making sense of the different and multiple concepts that have populated this study. Grech (2011) believes that to understand the global experience of disability, transcending West-centered hegemonic epistemology, it is necessary to adopt a disciplinary approach that is "willing and capable of making its boundaries permeable to become not only interdisciplinary but paraps post-disciplinary" (p.98). Sayers (1999) states that

"[P]ost-disciplinary studies emerge when scholars forget about disciplines and whether ideas can be identified with any particular one; they identify with learning rather than with disciplines. They follow ideas and connections wherever they lead instead of following them only as far as the border of their disciplines." (p.5)

CDT provides a fertile terrain to promote more inter-/post-disciplinary research. Its interdisciplinarity and potential post-disciplinary nature is already evident by its aim to "analyze disability as a cultural, historical, relative, social, [economic], and political phenomenon" (Hall, 2019). Moreover, it underlines the need to create alliances among different field and disciplines to

explore disability in its complexity (Sleeter, 2010), going beyond a compartmentalized and monolithic understanding of disability, which would cast a shade on its intersectional and multidimensional nature. Hosking (2008) defines multidimensionality theory as an important tenet of CDT. He sees multidimensionality

“[B]oth as a means to avoid the pitfalls of exclusion and conformity, which identity politics tends to perpetrate, and to reflect the reality that disabled people are a diverse and variable population within any particular social structure (country, ethnic group, class, etc.) who are also members of all other social classifications.” (Hosking, 2008:9)

Hutchinson (1999:9) explains multidimensionality as a framework to uncover “the inherent complexity of system of oppression (...) and the social identity categories around which social power and disempowerment are distributed”. He acknowledges that multidimensionality originates and develops from intersectionality theory (Crenshaw, 1989), recognizing the great theoretical impact that intersectionality scholarship has had in destabilizing a monolithic understanding of different oppressed groups. Furthermore, he highlights how intersectionality has challenged the belief that it is possible to examine one form of subordination (e.g. disability) without taking into account how this interacts, intersects and is interconnected with other system of domination (e.g. race, age, gender, ethnicity, class and others). The ‘interconnectivity’ of subordination appears fundamental to develop a more complex understanding as well as responses to oppression, fighting an essentialist stance (Valdes, 1995). “Multidimensionality, therefore, permits a more nuanced examination of the operation of privilege and subordination among oppressed social groups” (Hutchinson, 2001: 313), underlining how every group is characterized by multidimensional members (Hoskin, 2008). Members belonging to the same group cannot be homogenized and reduced to a caricature of themselves, defined and reproduced through heteronormative, ableist, classist, racist and sexist processes of ‘otherization’, used to justify and reproduce oppression. Everyone has a multidimensional identity. Hence, thinking purely within and through socially

constructed categories of being, without critically analysing and challenging the nature, history, materiality and role of these constructed categories, brings with it the seed of oppression, and the risk of reproducing it.

This research, exploring the lived experiences of Syrian refugee children with disabilities, and their parents, employs a multidimensional lens. This approach helps to uncover the structural inequalities at the limits of refugeehood and disability, reflecting on the multiple and unique matrix of oppression that originate from their intersections. It recognizes how oppression is created and reproduced within the refugee, individual with disabilities and refugee with disabilities' groups. For instance, as reported by the participants, refugee children with severe and complex disabilities would experience further marginalization compared to refugees with mild to moderate disabilities. The same apply to the types of disability, where physical disabilities appear to be usually prioritized over psychosocial, developmental, and sensory disabilities. Attention to these differences is fundamental to overcome a homogeneous approach to disability, which is responsible for the lack of awareness, provision and responsiveness to the needs of people with more severe, and historically over stigmatised disabilities (e.g. developmental and psychosocial disabilities). To conclude, I want to restate how people's lived experiences can be further complicated by the person's social class, gender, ethnicity, age, religion, and others, which can influence whether, how and to what extent they manage to access services, and to meet their basic needs. Therefore, the multidimensional lens helps to shed light on the multiple experiences of oppression between, among and within these socially and politically constructed categories (Hutchinson, 2001; Hoskin, 2008), critically problematizing and challenging monolithic depictions of vulnerability, which reproduce value/less forms of humanness.

3.2.3 Constructivist Grounded Theory (CGT)

“Our grounded theory adventure starts as we enter the field where we gather data. We step forward from our disciplinary perspectives with a few tools and provisional concepts. A grounded theory journey may take several varied routes, depending on where we want to go and where our analysis takes us.” (Charmaz, 2006:13)

(C)GT entered the scene at a quite later stage in this study. The choice to engage with it was dictated by a strong feeling of uneasiness both during and after the fieldwork. Before leaving for the fieldwork, I read extensively about many different theories and concepts within the field of Refugee and Forced Migration Studies, Childhood and Disabled Children’s Childhood Studies, Disability Studies and Education – with all its different subsets from Refugee Education to Education in Emergency and Inclusive Education. I was confident I had enough theoretical knowledge to understand and start making sense of the data I would have gathered. However, little did I know that all my certainty went missing after only three days from my arrival in Lebanon. The fieldwork appeared to be a disruptive and controversial experience (some of the challenges encountered are detailed in the conclusion), where I soon realized that everything I had read and written in my theory chapter’s draft was quite far from the realities I was entering, and it felt overwhelming.

While transcribing the first interviews during the fieldwork, I found myself wondering how I would have approached the data, how I would have analyzed and interpreted them. These questions originated from two main concerns I had:

- 1) I was petrified and at time scared of misrepresenting participants’ lives, perspectives, priorities, and realities.
- 2) I perceived an abysmal gap between theories and lives, and I was uncomfortable in trying to fit participants’ stories in prevalently West-centered theorization and discourses of refugeehood and disability.

And it is in this way that, as Charmaz says (2006), I stepped forward from my disciplinary perspectives, and I immersed myself, with just few tools, in the complex stream of participants' lives.

My two concerns were solved when I started reading Charmaz's (2006) book "Constructing Grounded Theory: A practical Guide through Qualitative Analysis". Charmaz (2006) states that "We are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspective, and research practices" (p. 10). And she adds that "We (researchers) try to understand but do not necessarily adopt or reproduce their (participants) views as our own; rather we interpret them. We attempt to learn but we cannot know what occurs in people's head" (p.19). Therefore, my theoretical reading of the world, would have only depicted an interpretive picture of it, rather than an accurate one (Charmaz, 2006; Guba & Lincoln, 1994; Schwandt, 1994). The representations of participants' stories are an interpretation that carries with them not only participants' narratives, but also my subjective understanding of these narratives, as well as the type and strength of relationship built with them, which would have allowed for more or less in-depth conversations on specific topics.

Concerning the fear of imposing a theoretical framework to the data, which would have Westernized and simplified the complexity of participants' lived experiences, again Charmaz (2006) came in help: "grounded theorists start with data" (p. 3). I stopped being concerned about which theoretical lens would have best fitted the data, and I decided to focus only on the data, following them wherever they would have led me, using (C)GT as a powerful data analysis tool. Data guided my analysis, bringing in conversation new ideas and different concepts, opening a multitude of readings and interpretations, as well as links and connections across different disciplines that I was not expecting. Section 3.3.3 provides more detailed information on the data

analysis process which lead to the (C)GT *'Letting die through Neoliberal Inclusion'*. Here, it is important to notice that (C)GT allowed to work in an inter- and maybe post-disciplinary way, depicting a complex framework that draws from multiple fields of studies, and disciplines, through a critical lens.

The focus of the research on the intersection of disability and refugeehood in accessing education opportunities in Lebanon, calls for a re-positioning of issues of social justice within the humanitarian structures providing education initiatives. The critical stance in social justice, combined with the analytical focus of (C)GT, and I would add with the CDT methodology, broadened the scope of the inquiry (Charmaz, 2005). Moreover, it opened a space for further conceptualization to understand and to locate experiences of exclusion, discrimination and ableism reproduced within the larger humanitarian structure, which promotes colonial and neoliberal construction of inclusion. A last consideration to be made concerns the decision to engage with (C)GT, rather than Grounded Theory (GT). Both GT and (C)GT are focused on developing theory from data, through an inductive and emergent process. However, (C)GT acknowledges the subjective and active involvement of the researcher in the collection, construction, and interpretation of data (this aligns with the philosophical underpinnings of this work), underlining the constructed and interpretive nature of knowledge. In addition, (C)GT is more flexible and not prescriptive in its methodology as the original GT conceptualized by Glaser and Strauss (1967).

3.3 Research Methods

Most of the research conducted on disability involves parents/carers of people with disabilities, and/or adults with disabilities. Very few research engages with children with disabilities, and even fewer with refugee children with disabilities in contexts of conflict and/or emergencies. This research project started with the idea to work with Syrian refugee children with disabilities and

their families in Lebanon, to learn about their lives and experiences in accessing education opportunities and learning spaces in the country. As part of the project, I also worked with Lebanese OPDs, national and international organizations, and UN agencies. The fieldwork was planned to be conducted in four months, from August 2022 to November 2022. However, due to diverse circumstances, which are addressed in the conclusion, I had to come back after only 2 months, in October 2022, and continue my data collection with organizations from remote via zoom, until December 2022. This section aims to: 1) provide information on sampling procedure, research participants' demographics, and organizations' specificities (3.3.1); 2) describe the data collection process (3.3.2); and 3) guide the reader through the analysis of the data using (C)GT as a data analysis tools (3.3.3).

3.3.1 Research participants

To conduct an in-depth study, I decided to work not only with Syrian refugee children with disabilities and their parents, but also with Lebanese OPDs, national and international organizations and UN agencies. This allowed me to uncover the gap between national and international efforts to inclusive education and the lived experiences of Syrian refugee children with/out disabilities and their parents. For the sake of clarity, in this work, I use the word participants to refer to Syrian refugee parents and their children with disabilities; and the word interlocutors to identify UN agencies, international and national organizations, and OPDs' representatives. The reason behind this distinction is not only functional, as it helps to highlight the main differences in recruitment processes, challenges encountered, and interviews' dynamics; but also ontological, as my commitment is towards Syrian parents and their children, and the relationships I developed with them have had a broader impact on this work, as well as on my life.

a) Syrian refugee parents and their children with disability

The recruitment of Syrian participants turned out to be very challenging, especially due to the lack of previous meaningful connections with both the Lebanese and the Syrian communities. After two

weeks trying to contact organizations and sharing with them the flyer of the study (Appendix I), in a desperate attempt to create a network and reach some families, the interpreter's mom introduced me to a Syrian man with a child with disability, whose pseudonym is Suleiman. Suleiman showed great interest in the study, and he invited us (the interpreter and me) to go to Beqaa and talk with his family and many others who gathered in a neighbour's tent to share their experiences. The first trip to Beqaa was on the 18th of August 2022. That day we interviewed 6 families, and we went back after a month to talk to 4 other families. In Beirut and in the North of Lebanon, both Tripoli and Sir el Danniyeh, the recruitment process was different. Towards the end of August 2022, two organizations came in to help, sharing the contacts of a few Syrian families who had previously accessed their services.

Sampling methods

Participants were recruited through a combination of purposeful and snowballing sampling methods. Purposeful sampling is a widely used technique in qualitative research, and it aims to strategically select participants (Patton, 2015), identifying the most knowledgeable and experts on specific phenomena under investigation of which they have direct and practical experience (Cresswell and Plano Clark, 2011; Agar, 1996). One of the foundational requirements of purposeful sampling is the willingness and availability to take part in the study (Spradley, 1979). The criteria to participate in the study were shared in advance with our contacts, who then started the snowballing sampling process, allowing for new connection with additional families.

The inclusion criteria to take part to the study were: a) being a Syrian refugee living in Lebanon; b) having a child with disability (age between 2 and 18 years old); and c) the child should have been able to communicate with me and the interpreter, with or without the help of their parents, siblings, or other family members of their choice. The third criteria became very quickly an optional one for the following reasons:

- 1) parents of children with severe and complex disabilities, who had children who were often non-verbal, were very eager and keen to participate, even if they knew that it might not be possible for us to speak with their children. When faced with the responsibility to choose the families to include, I did not feel comfortable in excluding these families, as they shared with us that no one ever asked about their children with disabilities, and they wanted to talk about their children.
- 2) in many cases, the information shared by the organizations on the child with disability was inaccurate. For instance, they guaranteed me that the children were verbal, and I could have had articulated conversation with them; however, when I met them, I realised that not only the children were non-verbal, but also the general information about them was not always accurate (in three cases, I met young people with disabilities aged 19 and 20 years old. Due to communication barriers, the interpreter and I were not able to interview them, we only interviewed their parents, who are part of the sample).
- 3) I very soon realised that I would have reproduced the same practices of exclusion and disability-hierarchization I was trying to challenge. I would have missed to learn and to acknowledge the lived experiences of historically hyper-neglected children and families, without understanding the level of exclusion entrenched with constructed neoliberal rhetoric of inclusion for children with severe and complex disabilities.

An important observation to be made is linked to the process of reaching other families outside the network established through our contact points. On many occasions, when the interpreter and I tried to approach Syrians in shops, and/or restaurants, the first questions we were asked were *'Fī filūs? Fī safār?'* (Are there money or the chance to travel?). Being this a research project conducted by an unfunded PhD student, neither of the two options constituted a possible scenario. Some Syrians clearly stated that *'they were tired of people going there, asking just the few questions they need, without even really listening to their answers or sticking to good cultural manners'*

(fieldnotes from different occasions). Nayel (2013) in an article published in “The Electronic Intifada” underlines how refugees are often repeatedly interviewed by different actors, who lack any sort of cultural sensitivity, and who come with their own set of questions, without respecting and/or caring for the refugees’ narratives considered as being ‘non-relevant’ for their scope. This of course was not always the case, and on many other occasions, the Syrian families approached decided to take part to the study, even after explaining that as a researcher, I could not offer or guarantee any tangible benefit from participating to the study.

At this point, I want to underline that no generalization can be made from the data gathered, despite the effort to have a heterogeneous group of participants in terms of gender, social class, type and severity of disability, area in which they live, and consequently might be accessing services. The lack of generalizability of findings in this study is not only linked to the nature of the sample, but also to the philosophical and methodological interpretive/social constructivist rationale underpinning this work.

Location

The 25 interviews with Syrian parents and their children took place in three main areas: Beirut, North Lebanon (Sir el Danniyeh and Tripoli), and Beqaa (near to the Syrian border there are many small unofficial refugee camps). The areas visited were very much defined by the snowballing sampling method, through which the first participants created a network of parents, who, knowing about the project, expressed their willingness to participate. The interviews were conducted in participants’ homes and tents, with the only exception for the six families in Beqaa, interviewed on the same day, who gathered in one of the participants’ tents.

Families’ demographics

A total of 25 Syrian families were interviewed for this study. Table 1 provide an overview of some basic participants’ information.

Table 1. Families' basic information

#	Family code/participant pseudonym	Area	Year of arrival	#of children	Children accessing/having accessed education
1	1408221/Farug and Atiya	Beirut	2011	3 (1 with disability)	2 (public school)
2	160822(1)/Faiza	Beirut	2014	3 (1 with disability)	N/A (all older than 18yo)
3	160822(2)/Fadela	Beirut	2012	4 (1 with disability)	N/A
4	170822/ Bushra	Beirut	2012	3 (1 with disability)	3 (one in special school)
5	180822(1)/ Suleiman and Asma	Beqaa	2014	5 (1 with disability)	4 (public school)
6	180822(2)/Faisal	Beqaa	2011	2 (1 with disability)	none
7	180822(3)/Halim and Jana	Beqaa	2013	6 (1 with disability)	5/ (1 in public, 4 in private)
8	180822(4)/Lakia	Beqaa	2012	5 (1 with disability)	2 (informal school)
9	180822(5)/Manar	Beqaa		9 (1 with disability)	2/ (public school)
10	180822(6)/Kadin and Lamy	Beqaa	2013	10 (1 with disability)	4/ (public school)
11	300822(1)/Mouna	Sir el Danniyeh(N)	2012	3 (1 with disability)	3/ (1 in a markaz, 2 before in public now in private school)
12	300822(2)/Maysa	Sir el Danniyeh(N)	2013	3 (1 with disability)	3/ (1 used to go to a markaz, 2 go in private school)
13	310822(1)/Maram	Sir el Danniyeh(N)	2013	1 daughter and 3 nephews (1 nephew with disability)	none
14	010922/ Nada	Sir el Danniyeh(N)	2018	4 (2 with disability)	2/ (1 in public, 1 in informal school)
15	020922/Mariam	Sir el Danniyeh(N)	2012	3 (1 with disability)	1
16	040922(1)/ Carim and his mother Fatema	Beqaa	2014	5(1 with disability)	none
17	040922(2)/Emir and Amal	Beqaa	2014	2 (1 with disability)	none
18	040922(3)/Dabir (brother)	Beqaa	2015	10 (1 with disability)	N/A
19	040922(4)/Hashim and Layla	Beqaa	2014	5 (1 with disability)	2/ (public school)
20	170922(1)/ Amina	Tripoli (N)	2020	6 (3 with disability)	2/ ALP programme
21	170922(2)/Qadira	Tripoli (N)	2013	8 (2 with disability)	In Syria all 8 kids went to school. In Lebanon only 4 used to go.
22	240922(1)/Samira	Beirut	2018	9 (1 with disability)	2 (used to go to public school)
23	270922/Halimah	Beirut	2015	6 (1 with disability)	1 (public school)
24	280922/Suleika	Beirut		5 (1 with disability)	
25	220922/Samer	Beirut	2011	7 (1 with disability)	1 (in public school)

It must be noticed that Syria is a mosaic of ethnic and religious groups. The majority of the country's population is Sunni Muslim with an Arab background (70%) (see the DLIFLC, 2019); however, it is ruled by Shia (Alawite) minority (12%) (see Jasser, 2014). Other ethnic groups considered a minority within the country are Kurds, Turkmen, Armenian, Assyrian and Druze

(Kannike, 2018). Sectarian, ethnic, as well as economic class and different geographical areas further contribute to the highly heterogeneous tapestry composing the Syrian society. The participants to this study originally came from the governorates of Homs, Raqqa, Aleppo, Rif-Dimasq and Damascus. The families interviewed in Beqaa are all from Arab tribes, primarily from Raqqa and Aleppo. In Syria, these families owned and cultivated land, engaging in farming and raising livestock such as goats. Meanwhile, the Syrian families interviewed in Beirut and northern Lebanon are from Rif-Dimasq, Damascus, Homs, and only one from Aleppo that recently moved from the camp in Beqaa to Beirut.

All the participants are Arab Muslim. No specific information about their religious affiliation was shared by participants during our conversations, and I deliberately avoided asking to avoid any pressure on participants that they had to share specific personal details to discuss their children and their experiences. Only on one occasion, a parent, Suleyman, mentioned that in some cases, belonging to a particular religious group might make it easier to access certain services, especially when those are run by organizations affiliated with a specific sect – he was referring to a Syrian Christian family living in Beirut supported by one of the local Churches. However, he quickly clarified that this advantage does not extend to services for people with disabilities, who are generally neglected by all groups.

In some instances, the husbands used to travel regularly for work between Syria and Lebanon before the war started, which made it slightly easier for their families to navigate the new environment once they crossed the borders. Most of the families interviewed come from a modest socio-economic background and from rural areas. The families who participated to this study share a similar ethnic-religious background. This might be due to the reliance on the snowballing sampling method to reach out to participants.

Children's demographics

Syrian refugee children with disabilities were selected starting from the families that agreed to take part to the study. Not every child was interviewed for two main reasons: 1) some of the children were non-verbal, and both the interpreter and I were not skilled enough to efficiently communicate with them; 2) other children were not very eager to talk to us despite their parents' encouragement. Given the voluntary nature of the participation, I was more than happy to respect their decisions of not taking part in the study, spending some extra time explaining to the parents that no negative consequence would have derived from their children refusing to be interviewed. I highlighted how it would have been ethically wrong for me to interview a child who did not express their assent to participate, and at the end the parents were comfortable in respecting their children's choices.

A total of 11 Syrian children with disabilities were interviewed. Their ages ranged from 6 years old up to 19 years old. Table 2 and 3 below respectively present some basic information about the children who agreed to take part to the study, and the children who were not interviewed for the above-mentioned reasons.

Table 2: Children's basic information (interviewed)

Children interviewed					
#	Child family code/pseudonym	Area	Gender/Age	Dis/ability	Accessed education/ where
1	180822(2)c Hamra	Beqaa	F/7yo	Lack of clear diagnosis	No
2	180822(5)c/Khaliq	Beqaa	M/11yo	Lack of clear diagnosis	No
3	310822(1)c/ Jamal	Sir el Danniyeh (N)	M/9	Partially blind (disability acquired due to stepdad violence against the child when he was 2yo)	No
4	020922c/ Mahmood	Sir el Danniyeh (N)	M/12 yo	Lack of clear diagnosis	No
5	040922(2)c/ Fadil	Beqaa	M/ 6 yo	Due to meningitis at young age	No
6	040922(3)c/ Hana	Beqaa	F/16	Mental disability	No
7	170922(2)-1c/Ferran	Tripoli (N)	M/14yo	Physical disability	Yes/public school
8	170922(2)-2c/Gadi	Tripoli (N)	M/18yo	Physical disability	Yes/public school
9	240922c/Mahdi	Beirut	M/13yo	Partial blindness	Yes/public school

10	270922c/ Raja	Beirut	F/14yo	Partially deaf	Yes/public school
11	280922c/Saarah	Beirut	F/14yo	Partial blindness	Yes/public school

Table 3: Children's basic information (not interviewed)

Children not interviewed					
#	Child family code/pseudonym	Area	Gender/Age	Dis/ability	Accessed education/where
1	1408221/Qasim	Beirut	M/7 yo	Lack of clear diagnosis	No
2	160822(1)/Randa	Beirut	F/19yo	Severe intellectual disability	No
3	160822(2)/Thana	Beirut	F/ 2yo	Spina bifida (potential Trisomy 21)	No
4	170822/Qudamah	Beirut	M/ 13yo	Visual and hearing loss	Yes/Markaz
5	180822(1)/Timin	Beqaa	M/2yo	Lack of clear diagnosis	No
6	180822(3)c/Ubaid	Beqaa	M/NA	Lack of clear diagnosis	No
7	180822(4)/Zada	Beqaa	F/14yo	Lack of clear diagnosis	No
8	180822(6)/Khadija	Beqaa	F/10yo	Due to meningitis	No
9	300822(1)/Utba	Sir el D. (N)	M/5yo	Lack of clear diagnosis	Yes/ markaz
10	300822(2)/Zia	Sir el D. (N)	F/8yo	Lack of clear diagnosis	Yes/markaz(used to)
11	010922/Yub /Zelmira	Sir el D. (N)	F/ 14yo and 3yo	Oxygen deficiency at birth	No
12	040922(1)/ Zubeida	Beqaa	F/NA	Lack of clear diagnosis	No
13	040922(4)/Yazid	Beqaa	M/19	Oxygen deficiency at birth	Yes/markaz in Syria
14	170922(1)/Murad/Yamina	Tripoli(N)	M/17yo – F/16yo	Lack of clear diagnosis	No
15	220922c/Adam	Beirut	M/20s	Cerebral Palsy	No

The children with whom we talked all had different communication styles. In some cases, parents intervened in their children's answers providing some clarification for us. In other occasions, parents became 'translators', paraphrasing our questions in easier ways, using more Syrian specific words and expressions, and then helping us to navigate the child's responses. Some of the older children especially teenagers, expressed the desire to conduct the interviews without their parents around. More information on how the interviews played out, are further discussed in section 3.3.2.

b) Lebanese OPDs, international and national organizations, and UN agencies

As part of this PhD project, I also interviewed 13 organizations among which Lebanese OPDs, local and international organizations and UN agencies. Working with local OPDs, and other

national and international organizations provided me with a broader view on the approaches and attitudes towards Syrians, as well as whether and how they are meeting the education rights and learning needs of Syrian refugee children with disabilities.

Sampling methods

The interlocutors were sampled purposefully based on their professional standing and current activities in the region. The entire process was much smoother and quicker, as I was already in contact with some Lebanese OPDs and other organizations which were previously interviewed for another research project conducted in the country, almost in parallel with my PhD fieldwork. Starting from this pre-existing network, I invited by email the already known OPDs for an online interview. The OPDs contacted were extremely friendly and interested in my research efforts, being very engaged during the interview process. Also, almost every NGOs, INGOs and UN's representatives showed interest in taking part to the research, allowing me to access different perspectives and disability understandings, as well as to explore the diverse approaches. Thanks to some OPDs that shared with me additional contacts of partner organizations, I was able to reach informants from different working backgrounds, enriching the picture I was trying to explore, and creating a meaningful network in the region.

Location

The OPDs and organizations involved in the study are operating in different areas, among which Beirut, Mount Lebanon, Beqaa, and Akkar. The original plan was to have in person meetings with each organizations' representative; however, due to economic and time constraints, with the only exception of 1 interview, all the others took place online on zoom. As anticipated, my fieldwork ended at the beginning of October 2022, but interviews with organizations continued until December 2022.

Table 3 below provides some basic information related to the organizations interviewed in this study.

Table 3: organizations-related information

#	Organizations' code and representatives' pseudonyms	Date	Organization specificities
1	o1 Charbel	04/08/22	o1 local organization
2	o2 Cyla	17/08/22	o2 local organization
3	o3 Ferazia	25/08/22	o3 local organization
4	o4 Elias	13/09/22	o4 local organization
5	o5 Ghasif	14/09/22	o5 local organization
6	o6 Ijaaz	20/09/22	o6 local organization
7	o7Aahad	21/09/22	o7 local organization
8	o8 Aleyna	04/10/22	o8 local organization
9	o9 Majedah	05/10/22	o9 UN agency
10	o10 Kiswar	28/11/22	o10 international organization
11	o11 Merjan	28/11/22	o11 local organization
12	o12 Amanda	30/11/22	o12 UN agency
13	o13 Kitana	01/12/22	o13 UN agency

3.3.2 Data collection

In-depth semi-structured interviews represented the key research method employed during the fieldwork. Interview transcriptions, and extensive field notes, derived from the meeting with the participants and interlocutors, were the main data gathered. Despite using the same method to collect data, the interview process played out quite differently between the two groups. The differences were due to: 1) the language used to conduct the interviews, and 2) how the different languages shaped the encounters' dynamics. For instance, interviews with Syrian parents and their children with disabilities were conducted with a Lebanese interpreter in Arabic; while the one with organizations' representatives were in English, hence no translation was needed, meaning that I was able to follow up with the interlocutors in a more fluid and direct way.

Interviews allow to learn from different perspectives, through constant negotiation of multiple, complex, and diverse meanings and understandings derived from peculiar and subjective

construction of the explored phenomenon. Fontana and Frey (2005) state that interviewing, as a research tool, is never neutral; rather, drawing from my epistemological stance, it is a unique, convoluted, unrepeatable and co-constructed human interaction determined by people's fluid identities, their past and present lived experiences, and their internalization and understanding, as well as discursive reproduction of these experiences. Here, I acknowledge the constructed and intersubjective nature of interviews, and the need to remain reflexive throughout the entire research process, reflecting on the questions asked, on how those were formulated, on the meaning attached to the questions, on how participants and interlocutors perceived and understood the questions they were asked, what type of answers they gave, and how I tried to make sense of these answers, negotiating meanings and perspectives to understand and to reach 'a' knowledge. Therefore, interviews, and especially semi-structured interviews would have allowed me to explore more in-depth the questions asked, favouring flexibility, and providing "a more appropriate format for discussing sensitive topics" (Fylan, 2005:67).

a) Syrian refugee parents and their children with disabilities

Before the interviews with the families, I reviewed the questions to ask with the interpreter, testing the accuracy of the Arabic translation, and discussing about what vocabulary to use when talking about disability with children and their parents. All the interviews with Syrian families were in Arabic, and they started with the translator explaining all the essential information in the consent form (Appendix II). Some of the parents are illiterate, so we took extra time to make sure that the aims and scope of the research were well understood, and to answer to any additional question they would have had. All the parents expressed their consent to be recorded.

Being the interviews semi-structured, and conducted with the help of an interpreter, we decided to adopt the following strategy: The interpreter asked the first bunch of questions focused on biographical information, the participants took their time to answer and then the translator

translated into Arabic for me, giving me the change to formulate follow up questions according to the participants' narratives. In some cases, it was not necessary to wait for the translation of what was shared as I was able to grasp participants' answers. During the interviews, I took extensive field notes reflecting on parents' narratives and trying to register some information on family dynamics (when possible), accessibility of the environment, participants' body language, and my personal feelings and thoughts. These proved to be extremely helpful when trying to re-construct the interviews' pictures, analyzing my presence within the interview process, which was quite limited due to language barriers.

Interview questions for parents (Appendix III) started by asking about general information on family composition, when they arrived in Lebanon, how was to flee Syria, and their current economic status. Then, we would focus more on their understanding of disability, on the value they attribute to education, on whether they benefit or have had access to specific services for their children with disabilities provided by UN agencies and/or other organizations, asking also about their network and relationship with both the Syrian and Lebanese communities. I would also encouraged them to raise any issue of interest or significance to them.

During the fieldwork, I was already transcribing the interviews with families, trying to pay attention to the main themes and concepts that were emerging. I took notes of them, and then tried to adapt the interview questions according to the emerging participants' priorities. For instance, I wanted to explore how parents and children are navigating learning spaces and educational opportunities in the country; however, from the narrative shared by the parents, I ended up concentrating much more on the complete lack and absence of education opportunities and other basic services for their children with disabilities, which I was not expecting at such great extent.

The interviews with parents varied according to their availability and to their willingness to share their stories with us. The conversations spanned from 50 minutes to 2 hours and a half, and they were all audio recorded. Generally, interviews with both parents were shorter, as the husbands needed to rush back to their jobs, as shown in the excerpt below:

“I saw the father checking his phone multiple times to make sure he still had time for the interview. He explained to us that he took few hours off to attend this meeting with his wife and two sons. He wanted to talk to us too and explain his family’s situation (...). Couple of minutes before we were finishing the interview, he received a call, and he informed us that in few minutes he had to head back to his work in the field. Five minutes later, a white pick-up truck came. Inside, together with other men, there was also one of the fathers we interviewed earlier that morning. Our Syrian guide, explained to us that even if it was on a Sunday, they would have worked the whole day to earn some money, and provide for their families, and he highlighted how important they considered this interview, because never before someone asked about their children with disabilities.” (04/09/2022 fieldnotes)

As part of the interview data, I also took notes about the interpreter’s attitude, emerging biases and preconception, and specific readings of the situations encountered. Part of the data is also coming from the debriefing session I had with the interpreter after each interview, where we talked about what went well, and what could have been improved. I was the only person responsible for interviews’ transcription. My approach was perhaps unusual as I can understand Arabic to a certain extent: I would play the recorder and start transcribing into English the information shared by the participants in Arabic. Once they finished answering, the English translation followed before the next group of questions, helping me to fill the gap in the transcript.

With children the process was different. To introduce the research to our younger participants, I prepared an easy-to-read form. However, when their turn arrived, almost all of them already understood the research aims, being present during their parents’ interviews. As a thank token, I brought some candies, a few colours for them and their siblings, and printed some animal design

colouring pages to colour together. Younger children seemed to enjoy a lot the small activity, and they were very eager to show their work to me, and especially to the interpreter, whom they knew by then being a *‘anse* (teacher). Teenagers appeared to appreciate the candies and the colours too; however, they were much more focused on the interview itself and in some cases on showing us their creative work (like the two brothers Ferran and Gadi).

Before starting the interview, we made sure to have their assent, and we reassured the young participants that if they did not want to participate, or to answer to any of our questions, nothing bad would have happened, as this was their own choice, and we would have respected it. Interviews were quite different from one to another, being shaped by the age of the child, theirs and our communication style, and personal narratives. Conversations spanned from 15 to 35 minutes. Interview questions with children (Appendix V) would start from general information about themselves, and their families, such as their name, age, things they like and they dislike, and whether they go along with their siblings. Then, we would introduce more complex and sensitive topics about their education experiences or lack thereof, whether they would have like to go to an inclusive or specialised school (for younger children this was phrased as ‘would you like to go to school with your brother or with other children that have more in common with you?’, explaining what we meant for more in common accordingly), what they would like to do in the future, and additional questions tailored to the child’s answers. Interviews were then transcribed following the same method adopted for their parents’ interviews.

b) Lebanese OPDs, international and national organizations, and UN agencies

All the interviews, but one, were conducted online via zoom. Conversations spanned from 50 minutes to 1 hour and a half, and some side notes were taken concerning the perceived tone of the interlocutors’ voice, their availability and willingness to address specific topics, as well as my

impression of how the conversation went. Some of the notes were written during the interviews, other were a result of *a posteriori* reflection.

Interview questions (AppendixVII) started by asking general information about the organization, what they do, their values, and whether/how they began to work with Syrian refugees. Then, more specific questions were asked about their understanding of disability, the educational projects and/or other services implemented for people with disabilities, and whether those services were reflecting principles of inclusion. I included inquires on their perspectives about Syrians' repatriation, on the main refugee narratives promoted in the Lebanese society; and tried to explore the level of cooperation among different organizations, as well as the relationship with the government, and especially the MEHE and the MoSA. Questions were re-adapted according to interviews' emerging themes and ideas. All the interviews were audio recorded and transcribed in English. I believe it is relevant to acknowledge the failure in setting up a meeting with the MEHE's representative despite my numerous emails and follow up sent through official routes.

Desk-based research and additional mini-dataset

Together with semi-structured interviews and fieldnotes, further information and data were collected on the national and international responses to Syrian refugees' needs, particularly focusing on education in emergency and Disability-Inclusive education in emergency. These data were fundamental a) to map the situation on the ground, b) to set up a broader conceptual and policy framework to understand which international instruments are available, and c) to explore how and to what extent Lebanon is aligned with the international action and policies' corpus. An in-depth, prior to fieldwork, analysis of national and international policy documents partially informed the nature of the questions asked during the interviews with organizations. After having analysed interview data, I went back to the same policy documents reviewing them on the light of

the findings to recontextualize them. As part of the desk-based data analysis, I relied on sources published online by the Centre for Lebanese Studies (CLS), UN agencies, Lebanese government, and other relevant empirical studies. Most of the documents accessed are in English and only a very small part in Arabic.

The study also draws on some of the data I collected for a joint research project on “Disability in Intra-State War-to-Peace Transitions: Understandings, Policies, ad Challenges to Implementation” (Fontana and Costantini, 2024). The dataset is constituted by 15 semi-structured interviews with practitioners from INGOs, NGOs and Lebanese OPDs, as well as academics working in the field. The data collection was carried out simultaneously with my PhD fieldwork. I draw from this dataset only when the interlocutors reflected on the current status of disability and inclusive education in the country, directly referring to the GoL and international communities’ responses to the educational rights of children with disabilities, whether Lebanese or refugees, in the country. Interlocutors were informed that the data shared during the interview could have been used for different academic purposes. Below, I provide a table with some basic information on the interlocutors’ included in this work.

Table 4: organizations-related information from joint research project (Fontana and Costantini, 2024)

Interview code/ interview modality	Position covered by the interviewee and their pseudonym
IN1/ (online)	International expert in inclusive education, Bariqa
IN3/ (online)	Ferazia from o3
IN4/ (in person)	INGO’s representative, Shanifa
IN5/ (in person)	Lebanese inclusive institution’s representative, Zaigham
IN6/ (in person)	Aybak from o1 above
IN9/ (online)	Disability specialist, Zoonaa
IN11-IN12/ (online)	2 UN agency’s representatives, Soad and Sobia
IN13/ (online)	Local organization, Zaib
IN14/ (online)	INGO’s representative, Zabian

3.3.3 Data analysis

(C)GT as a data analysis tool presents a great advantage for novice researchers, as it provides explicit and clear guidelines on how to proceed in the data analysis process. This section describes how data have been approached and analyzed, following step by step Charmaz's (2006) guidance on how to conduct (C)GT research. Before delving into a more detailed account of the data analysis process, it would be beneficial to briefly mention a key feature of GT: theoretical sensitivity. Theoretical sensitivity can be understood as a necessary precursor of the theoretical rendering derived by one's analysis. It implies being aware of a vast range of theoretical constructs and concepts across different disciplines and being able to employ them in the theoretical construction. There are some major debates within GT concerning the development of theoretical sensitivity, due to the idea that the researcher has to enter the fieldwork without having conducted any prior literature review (which is recommended in GT). This concern does not apply to this study. For instance, the extensive literature review conducted prior the fieldwork helped me to develop the much-aspired theoretical sensitivity prior to the fieldwork, providing a background to start my inquiry. This background, as explained in section 1.3, represented a point of departure to study the empirical world I was accessing; rather than an ending point where there was no space for open exploration, and reconceptualization of the study's theoretical stands.

The data analysis process was conducted manually. In the initial stages, I analyzed the data through Nvivo, a software which is commonly used in qualitative research. However, after a first round of coding, I felt I was struggling to remain close to the participants' narratives, and to engage critically with the data. After talking to my supervisors, they suggested printing out the interviews' transcript and work directly on the printed version, coding manually. This proved to be an extremely beneficial and productive approach, as I felt immersed in the data. My creativity and analytical

thinking started flowing, leading me to new ideas. The analysis consisted of the following steps, all of which are introduced in Charmaz's (2006) book:

- *Immersion*: I read and re-read the transcripts, while also listening to the audio-recordings to make sure to keep myself close also to the emotional dimension that participants' voices were bringing back through their tone, speed, and at times trembling of their voices. Before engaging with participants' narratives, I went back each time to the fieldnotes written for each one of them, which provided in-depth account of their environment, family dynamics and my personal feelings concerning the encounters with them, and the interpreter's behavior.
- *Initial coding*: Line-by-line coding represented the first step of analysis. All the codes identified were written directly on the printed transcripts, using gerunds to highlight processes and actions (Charmaz, 2006) or In-vivo codes, and then registered in an excel file (which facilitated the subsequent phase of focus coding).
- *Focus coding*: line-by-line codes were organized in an excel file, divided in three different sheets 'family', 'children' and 'organizations'. Each column in the sheet identified a participant, and under each participant all the line-by-line codes were collected. At this point, being a very visual person, I used colors to start grouping the codes which I found being the most recurrent and/or most significant, trying to understand which initial codes "make the most analytic sense to categorize the data incisively and completely" (Charmaz, 2006:57). Important to highlight here is that focus coding was not a linear process. Constant back and forth characterized this phase, and the focus codes identified and reported in this work were not always the one considered being the most appropriate in earlier stages.

- *Memoing*: Memos were written both during line-by-line and focus coding, summarizing the emerging concepts interviewee by interviewee, across the same group of interviewees, and across different groups of interviewees. While the early memos were more descriptive and shorts, the advanced one started to integrate analytical dimensions to the picture, conversing with and reflecting on diverse theoretical frameworks, and explicating the properties of emerging categories, and concepts. Charmaz (2006: 72) explains how “writing memos expedites your analytic work and accelerates your productivity”, offering a tool “to raise focused codes to conceptual categories”. Both clustering and freewriting techniques were used to start conceptualizing in more analytical and abstract ways the data. At the end of this process, several descriptive and conceptual memos were written on each of the following:

1. Living discrimination
2. ‘Letting children to themselves’¹⁰
3. Enacting exclusionary inclusion
4. Experiencing barriers to education
5. Otherizing: reproducing hate discourses
6. Hierarchizing disability
7. Politicizing and marketizing bodies
8. ‘No one cares about my child’¹¹
9. Losing faith in organizations
10. Reproducing discrimination in education
11. Emergency and deteriorating circumstances

The 11 descriptive and conceptual memos were then sorted, and integrated (Charmaz, 2014). A back-and-forth process of memo-integration took place. The memos were firstly sorted and

¹⁰ Adapted from in-vivo code.

¹¹ In-vivo code.

integrated by group of participants, conceptualizing in a clustered manner. At first, I couldn't see a coherent narrative that would have embraced all participants and interlocutors' concerns. It appeared that each group of interviewees were talking about intersecting but different problems. Going back to the codes, and re-reading the memos, I then realized that a different and more comprehensive reading was being delineated. A reading which was encompassing interviewees' concerns across similar categories. The long process of sorting and integrating the 11 memos above, lead to the following division:

- 1, 5, 10 and 11 were grouped into a category named: *Re-producing Emergencization*. Building on Carpi's definition of 'emergencization' as the "official declaration of crisis and the emplacement of international humanitarian actors" (p.159), I conceptualize 'emergencization' as an unraveling process which enacts a perpetual state of emergency, and a routinized status of crisis, based on the identification of a more or less fictitious 'dangerous other', for whom exceptional responses and securitized measures, are required to protect the integrity of the 'us'. The exceptional responses are articulated through the "emplacement of international humanitarian actors" as well as through the implementation of securitization policies both at the national and international level.
- 3, 4, and 6 were grouped into a category named: *Advancing Neoliberal Inclusion*. The concept of 'neoliberal inclusion' is here to be understood as an inclusion which is *in practice* exclusionary. This study sees the exclusionary nature of inclusion being dictated by old structure of ableism and evolving neoliberal economies of bodies.
- 2, 7, 8 and 9 were grouped into a category named: *Actualizing a State of Exceptions*. The concept of *state of exception* is borrowed from political philosophy, and it is here employed according to Agamben's work, which sees the state of exception as a spatiality where the sovereign determines who gets to live and to die.

While further conceptualizing the discourses of the participants and interlocutors across the three categories identified, an unexpected overarching framework or core category emerged: ‘*Letting die through Neoliberal Inclusion*’. The three categories became strategies and eventualities through which humanitarian structures are reproducing, through neoliberal and colonial logics, ableist understanding and conceptualization of inclusion. Neoliberal inclusion brings with it the germs of an exclusionary operationalization of inclusion based on a hierarchized construction of humanness. This hierarchization appears to be justified through emergency rhetoric that maintains and reproduces emergencization, which in turns legitimizes the exclusion of refugee children with disabilities, especially with severe and complex ones, from education and other basic life-saving services, positioning them in a *state of exception*. This realization restructured the logic of the analysis as follow:

Core category: Letting die through Neoliberal Inclusion

Sub-categories: Re-producing Emergencization

Advancing Neoliberal Inclusion

Actualizing a *State of Exceptions*

It is important to reiterate that the emerging CGT’s notion of “Letting die through Neoliberal Inclusion,” stems from my interpretation of my participants and interlocutors’ experiences, shaped by their historicities, subjectivities, and concerns, as well as by the physical, conceptual and emotional spaces we came to live together. This process unfolded in conversation with various theoretical concepts, as well as through the interplay of my ideas, resources and experiences. The data collected played a fundamental and transformative role in the development of this concept, which, in turn, enriched and deepened my theoretical understanding. In Part II of this work, I present the (C)GT’s notion of ‘Letting die through Neoliberal Inclusion’.

3.4 Ethics

For this project, I sought ethical approval from both the University of Birmingham and the Lebanese American University (LAU). This choice was driven by a personal desire of promoting a decolonial approach within my research, trying to comply with both the UK and the Lebanese research ethics and practices. The research proposal was approved by the University of Birmingham Humanities and Social Sciences Ethical Review Committee on research involving humans in May 2022; and by the Lebanese American University ethical board in July 2022. As part of the ethical approval process, I had to submit additional risk assessment forms due to the Lebanese geopolitical specificities, and review multiple times the documents translated into Arabic, to make sure that the translations were appropriate and relevant to the contexts and the participants. The process unfolded a bit differently between the two university, having to take additional research modules to comply with LAU requirements.

3.4.1 Consent, assent, anonymization, and data protection

To conduct this project, I needed both the informed consent of Syrian parents and organizations' representatives, as well as the informed assent of Syrian children with disabilities. It is worth here to spend few words on the concept of informed assent. According to the UNCRC (2989), minors are considered to have the capacity for self-determination, meaning that their right to be heard and to express their opinion is recognized and considered. However, legally, a minor cannot express informed consent. To account for this limitation, and to support children's autonomy and inclusion in the decision-making process and participation to the study, I sought their informed assent. To gain informed assent, an easy-to-read form was prepared. In case the child expressed dissent, where the parent consented to the child participation to the study, I respected the child dissent. The consent and assent procedures worked differently according to the groups of interviewees. As part of the ethical approval, consent forms for both Syrian parents and organizations, as well as the easy-to-read form for children, were prepared and translated into Arabic (Appendix II, IV, and VI). These

documents contained the essential information regarding the research project as well as interviewees' rights, and potential use of data.

Parents first approach with the consent form coincided with the day of the interview. As part of the interview process, the interpreter and I took between 20 and 30 minutes with each family, explaining the consent form, going through all the above-mentioned points, making sure that everything was clear, and answering any additional question parents might have had. With families, we used the Arabic consent form. Some of the parents were illiterate, and they felt a bit shy of not knowing how to sign the form. In these cases, we asked if they would have been happy with us writing their name and surname on the consent form, and then they could do a little scribble next to it; otherwise, we could have used the oral consent form (Appendix VIII). Parents seemed to welcome the former option better. Moreover, as part of good practice, we explained to families that each familial nucleus would have had an anonymized archival number, and that I would have used pseudonym when reporting excerpt from the interviews, to protect their identities. They all agreed with this procedure, and they all clearly stated their preference to be anonymized.

Concerning children, after receiving parents' consent to interview them, we sought children's assent, emphasising the importance of their voluntarily participation. In one case, the mother expressed consent, but the child refused to be interviewed, clearly stating his lack of interest in participating to the study. The mother and the interpreter tried to convince the child, but I gently explained them that it would have been highly unethical and unprofessional to interview someone who did not want to participate, and who clearly stated his dissent. I told the child and the mother that refusing to participate was his rights, and I would have not forced him; however, I would have remained at his disposal should he have changed his mind, thing that did not happen. In other cases,

children were very curious, and they were waiting attentively their turn to talk and share their opinions. All the interviews were audio-recorded.

With organizations the consent process played out differently. All the organizations were invited to participate through an email which contained details on the purposes of the research. Only after receiving an expression of interest to take part to the study, I sent the consent form, which was then signed and sent back by email during or after the interview. At the beginning of each interview, I made sure to go through the consent form with the interlocutors again, giving further details on the research and allowing space for any additional clarification. All the interviews with organizations, but one, were conducted through zoom, in English, and audio recorded. Organizations' representatives were all anonymized, as well as the organizations themselves, despite not everyone expressed their preference to remain anonymous. This was not an easy decision; however, I felt it was the most sensible one, as some of the interlocutors talked without any restraint, being critical and analytical of situations of corruption, malpractices, and power imbalances within the country. I want to share a practical example that informed this decision. Nowadays, many Lebanese organizations are surviving through UN agencies' fundings to work with Syrian refugees. Some of the organizations' representatives I had the pleasure to meet, and interview expressed strong position and well-articulated critiques to these same funding bodies through which they are surviving. If identified, these people could lose their jobs, or even worse, the entire organizations for which they work could lose fundings and consequently they could be forced to close.

To conclude, all the data collected, including fieldnotes on my notebooks, the audio-recording files and word transcripts files were safely stored both during and after the fieldwork.

3.4.2 Reflexivity and Positionalities

In section 3.2.1, I discussed the philosophical underpinnings of this study, mentioning the role that researchers, and in this case also the interpreter, hold in the research processes within the identified paradigm. England (1994) states that research is not just a product, but it is a process. A process which involves multiple and different actors, with diverse values, opinion, prejudices, and priorities. Recognizing the intersubjective, socially constructed, context-based and historically situated nature of reality and social phenomena (Mauthner and Doucet, 2003), it is fundamental to embrace a practice of ongoing reflexivity, through which we are required, as researchers, to constantly examine and be critically aware of our own positionalities during the whole research process, and how these could influence and shape the research.

Reflexive research necessitates an “explicit self-aware meta-analysis” (Finlay, 2002:209), with a solid and constant self-examination. It involves a continuous internal introspection formed on an endless process of self-scrutiny and self-awareness and consciousness of the relationship between the researcher and the participants (Pillow, 2003). According to Berger (2015) being reflexive indicates that the researcher thinks through, analyzes, and deconstructs personal characteristics such as race, gender, beliefs, political affiliations, and ideologies, as well as lived experiences, background and other defined nurtured assumptions linked to the environment to which the researcher belongs, trying to explore and address how those may impact the research. Moreover, Hertz (1997: vii-viii) sustains that reflexivity is determined by “detachment, internal dialogue, and constant scrutiny of ‘what I know’ and ‘how I know it’”.

Here, through a reflexive stance, I reflect on the interpreter I worked with, analyzing both the challenges and benefits derived from working with her. I also add some insights on how being a young female researcher influenced the fieldwork. Inquiring about the interpreter positionality is central to deconstruct and understand some of the dynamics and events explained below that took

place during the interviews. The interpreter I worked with is a Lebanese woman in her late 30s. She is a single mother, and a teacher in the Lebanese public education system. Before the Lebanese crisis in 2019, she identified herself as belonging to the lower-middle class; however, she is now living in worse economic condition than before, having to work multiple jobs to sustain her daughter and herself. When I interviewed her for the position, aware of the tensions between the Lebanese and the Syrian communities, I asked specifically how she would feel in working with Syrians, if she would have been comfortable in working with them, as I needed someone respectful, trustworthy, and friendly to interview both Syrian refugee children with disabilities and their parents. She reassured me that she was happy to work with me on the project and to translate the Syrians' lived experiences in Lebanon to her best abilities. I also inquired about her approach and understanding of disability.

Despite the long induction, during the interviews, sometimes she did not respect the ethical directions I defined on how to conduct interviews, respecting participants' voices, and prioritizing their experiences over her own preconceptions. In certain cases, her behavior, and her way of reacting to some of participants' narratives were inappropriate, and it created distress among the participants as they felt judged, or pitied, or contradicted about the truthfulness of what they were sharing with us. During the interviews, I could easily identify such circumstances as I have a reasonable understanding of the Arabic dialect spoke by the participants and the interpreter, even though I am not confident in speaking it.

For instance, one of the participants was telling us how Syrians are constantly harassed both physically and verbally, hated and mistreated by the Lebanese communities, and how this makes them feel. The interpreter, as a Lebanese woman, felt she had the duty and the right to disagree, insisting on the fact that it is not true that Lebanese mistreat Syrians and hate them, that her for

instance, had nothing against them. I had to stop the interview and apologize to the participants, asking the interpreter to abstain from any future personal opinion that would have obscured participants' narratives. This is a clear example of how the interpreter's identity, and the past complex history between the two communities negatively impacted the interview process. Needless to say, it followed a long and exhausting debriefing session.

Working with her, also brought some benefits. Being a teacher, she proved to be extremely skilled in dealing with children, being friendly and proactive with our younger participants. Thanks to her skills, we managed to create a safe, fun, and relaxed environment for the children to share their experiences. She also played a fundamental role at the end of the fieldwork, when the Lebanese public education system re-opened, in informing the families we interviewed on the public-school opening, and the possibility to register their children in the nearest public school to them.

My identity and subjectivity also shaped the research process. As a Mediterranean/European woman, in her late 20s, and a relatively inexperienced researcher, my choices, the direction I gave to the study, and my presence in the field influenced the overall research. One of the main challenges I faced relates to my physical presence as a young female researcher; this added further challenges of my perceived credibility, especially with the interpreter I worked with, to have professional conversations that were not imbued with patronizing attitudes and approaches towards me and my position as a researcher. My identity was also often inquired into by the participants. For instance, I was often bombarded with questions about my life choices as soon as they discovered I was in my late 20s, with the typical questions '*Are you married then?*', '*Do you have children?*'. They were intrigued by my life choices, and generally they assumed that soon after the end of my PhD I would settle down and become a mother. I neither confirmed nor rejected this

normative narrative, still dominant in many societies around the world, including many rural Italian villages, as the one where I grew up.

3.5 Conclusion

In this chapter, I have delineated the philosophical, methodological, and ethical dimensions of the research. I presented the project design, locating the study within the interpretive/social constructionist tradition, underlining its inter-/post- disciplinary and multidimensional nature, and explaining the decision to employ (C)GT as a valuable analysis tool. Then, I engaged with more practical aspect of the study, providing detailed information on the research participants and interlocutors, as well as on the processes of data collection and data analysis. Finally, I reflected on procedures of interviewees' consent, assent, anonymization, and data protection; and matters of reflexivity and researcher and interpreters' positionalities.

Part II: Letting die through Neoliberal Inclusion

Conceptual overview of the (Constructivist) Grounded Theory - (C)GT

The (C)GT's core category 'Letting die through Neoliberal Inclusion' emerges from these conversations between lives and theories. It aims to provide an additional lens of analysis, within Critical Disability Theory (CDT). While it does not propose a brand-new theory, it enriches and adds to the CDT's theoretical discourse, through the work of the political philosopher Agamben. 'Letting die through Neoliberal Inclusion', as an inter-/post disciplinary notion emerged from the data collected for this study, starts with disability, but does not end with it, creating links among the research and theoretical fields of disability, forced migration, and humanitarian education. This work intends to explain how humanitarian education, which is taken as a 'representative' example also for the broader humanitarian system and for the wider global neoliberal society's structure, contributes to the construction of Syrian refugee children with disabilities, especially with severe and complex ones, as *homo sacer*, situating them in a *state of exception*. 'Letting die through Neoliberal Inclusion' is constituted by three sub-categories identified during the data analysis phase: 'Re-producing Emergencization', 'Advancing Neoliberal Inclusion' and 'Actualizing a *State of Exception*'. Below, I briefly introduce these sub-categories, which are respectively articulated and further developed in the finding Chapters 4, 5 and 6.

Chapter 4: 'Re-producing Emergencization'

Carpi (2023) defines 'emergencization' as "the official declaration of crisis and the emplacement of international humanitarian actors" (p.159). Building on Carpi's definition, I conceptualize 'emergencization' as an unraveling process which enacts a perpetual state of emergency, and a routinized status of crisis, based on the identification of a more or less fictitious 'dangerous other', for whom exceptional responses are required if the integrity of the 'us' is to be preserved. These exceptional responses are articulated through the "emplacement of humanitarian actors" (Carpi, 2023:159), as well as through the implementation of securitization policies both at national and

international level. In this study, the concept of emergencization is fundamental to explain 1) the processes through which refugee bodies are constructed as a ‘threat’; and 2) how, in contexts of emergency, the de-/prioritization of specific groups of people appears to be justified, and even necessary, by the intrinsic ontological nature of emergency, which is defined by high demands and limited resources. Through emergencization, the securitization of refugee bodies is enacted, promoting discriminatory rhetoric and practices to ‘otherize’ and ‘criminalize’ the perceived ‘them other’/ ‘them threat’. Moreover, as I explain in chapter 4, building on the lasting status of emergency, humanitarian and state actors legitimize their failure to work towards efficient inclusive policy reforms, and to implement inclusive programs and strategies, justifying the de-/prioritization and structural exclusion of non-normative bodies and minds, hiding intrinsic systems of ableism.

From the data analysis, I identified three main elements constitutive of the sub-category ‘Re-producing Emergencization’:

- Discriminatory Rhetoric
- Operationalizing Exclusion in Emergency
- Impacting Education

Chapter 5: ‘Advancing Neoliberal Inclusion’

In this study, I conceptualize ‘Neoliberal Inclusion’ as a form of inclusion which is *in practice* exclusionary, and where bodies and minds who do not comply to constructed Western neoliberal normative depiction of humanness are deemed as disposable, and un-/worthy. It underlines the inherent paradox of an inclusive rhetoric soaked in neoliberal principles, where inclusion appears to be not for “*every ‘body’*” (Grech, 2011:96: original emphasis), but only for those bodies and minds who can best fit the interests of the global economic market. The concept of ‘neoliberal inclusion’ builds on the idea that “bodies do matter in political economy”, and it tries to explore

“why some bodies matter more than others” (Erevelles, 2011:6). ‘Neoliberal inclusion’ is here fundamental 1) to explain how the processes of disability-hierarchization are enacted and legitimized through emergencization and within the humanitarian structures, according to neoliberal logics of cost-benefit, ‘flesh’ employability, measurable outcomes, and others; 2) to analyze how the hierarchization of disability promotes exclusionary forms of inclusion, which systematically and structurally exclude Syrian refugee children with disabilities, especially with severe and complex ones, from most, if not all, humanitarian (education) interventions that claim to be inclusive. This sub-category also briefly introduces Syrian children with disabilities and their parents’ strategies to resist and face the daily challenges and barriers in accessing education.

The data informed my construction and interpretation of the emerging sub-category ‘Advancing Neoliberal Inclusion’ through the following identified elements:

- Hierarchizing Disabilities
- Promoting Exclusionary Inclusion
- Facing and Resisting barriers

Chapter 6: ‘Actualizing a State of Exception’

State of exception is a concept borrowed from political philosophy, which indicates, according to Agamben (1998), a spatiality where the sovereign power determines who ‘gets to live’ and who is ‘left to die’. ‘Actualizing a *State of Exception*’ explains how the rhetoric of neoliberal inclusion, reproduced by humanitarianism, and legitimized through emergencization, constructs Syrian refugee children with disabilities, especially with severe and complex ones, as *homo sacer*, forcing them in a *state of exception* (Agamben, 1998). Syrian refugee children with disabilities come to embody what Agamben calls *bare life*. In this study, the status of *bare life* is not actualized within a circumscribed physical locus, such as a refugee camp, instead it crystallizes within the “biological body of every living being” (Agamben, 1998:81), at the intersection of refugeehood, childhood,

ethnicity, and disability. The chapter, through participants' accounts, shows how life unravels in spatiality of exception, denouncing the condition of *bare life*, as well as presenting stories of resistance, that challenge the common imaginary of the passive, de-agentivized refugee with/out disability.

The elements I identified as constitutive of the sub-category 'Actualizing a *State of Exceptions*' are:

- Politicizing and Marketizing Bodies and Aid
- Denouncing *Bare Life*
- Resisting Space of Exception.

Here, I want to reiterate that the notion of 'Letting die through Neoliberal Inclusion' does not only apply to the education in emergency sector, but also to the broader humanitarian system and the wider global neoliberal society. It uses education as a practical example to explain how neoliberal forms of inclusion, promoted and legitimized through the re-production of emergencization, operate to construct non-normative refugee bodies and minds as disposable, relegating them in spatiality of exception, where they are '*not actively killed*', but they are '*left to die*'.

To conclude, it would be important to acknowledge the intrinsic structure of the next three finding chapters and their relations to this study's research questions (RQs). The study, as you already know by now, delves into the lived experiences of Syrian refugee children with disabilities and their parents in accessing education and other services in Lebanon, and started with an effort to answer the following RQs:

- 1) What are the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other basic services in Lebanon?
- 2) How is inclusion framed for education in humanitarian contexts?

3) What are the consequences of this framing of inclusion for the education of Syrian refugee children with disabilities?

By focusing on presenting the (C)GT's notion of 'Letting die through Neoliberal Inclusion', and its respective sub-categories and elements, the study's RQs have been addressed across all three chapters, structured around themes arising from the data which I explicitly align and consolidate in the conclusion. I have made this decision given the emergence of the key code from the data, reflecting my openness to the emergence of the data through the analysis process. The (C)GT's core category of 'Letting die through Neoliberal Inclusion', being driven by and rooted in the data, went far beyond this study's initial RQs. The use of (C)GT allowed for a diverse and complex interpretation and rendering of this work, where the data pushed me towards unexplored and previously unknown paths. When analyzing the data, I had to choose between analyzing the data with the purpose of answering a set of questions, or analyzing the data to discover where they could have led me. I chose the second option, which eventually also provided answers to the questions with which I first started this 4-year long journey. Thus, in the writing of this work, I wanted to recreate my experiential and academic voyage, where the data defined my journey, and the RQs became only the starting point of this research, rather than its final destination.

CHAPTER 4

RE-PRODUCING EMERGENCIZATION

“Emergency politics is the politics of fear and urgency.”
(Warner, 2013:8)

4.1 Introduction

In this chapter, I present the sub-category ‘Re-producing Emergencization’, and its fundamental elements ‘Discriminatory Rhetoric’, ‘Operationalizing Exclusion in Emergency’, and ‘Impacting Education’. In ‘Discriminatory Rhetoric’, I analyze how discourses of emergencization, reproduced at regional and global level, building on the “politics of fear”, legitimize processes of securitization, where refugee bodies are constructed and identified as a ‘threat’. In ‘Operationalizing Exclusion in Emergency’, I explain how the same emergencization discourses, driving on “politics of urgency”, justify the de-/prioritization of specific groups of people, actively contributing to the replication of old system of exclusion. Finally, in ‘Impacting Education’, I reflect on the tangible effects that the politics of fear and urgency have on the direct experiences of Syrian refugee children with/out disabilities in accessing education opportunities in a context where their bodies are highly politicized, otherized, and de-prioritized in the name of emergency, and under a global banner of inclusion promoted through the humanitarian (education) sector. This chapter provides the basis on which the development of the emerging (C)GT’s notion of ‘Letting die through Neoliberal Inclusion’ is rooted. For instance, without emergencization, spatiality of exception would not subsist, and without those spaces of “inclusive exclusion” (Agamben, 1998:12), exceptional responses could not be ‘rightfully’ enforced and ‘morally’ justified (my emphasis).

The next section, building on Carpi’s work in Lebanon, aims to provide a brief background to understand how emergencization is reproduced specifically within the Lebanese context. This

would help to better locate the following paragraphs which are more data-led, where I engage with participants and interlocutors' experiences, as well as their attitudes and daily life challenges.

4.2 Re-producing Emergencization

“Emergency rule involves appeal to exceptional circumstances as the basis for exceptional measures. It involves identifying a sudden onset of problems, leading to situations out of keeping with the world as it was before. Present and past are cast as discontinuous, and the unexpected character of the challenges arising is emphasized.”
(White, 2019:109)

The identification of a problem (Syrian refugee crisis), and its formulation as a threat (‘invading’/ ‘penetrating’ European shores or Lebanese territories), allows for an instrumental constructed account of emergency (‘unbearable refugee influx’), which calls for exceptional measures (closing borders, letting people die in the Mediterranean, financing neighboring host countries to retain refugees), that justifies discourses of securitization, and promotes massive humanitarian interventions (responsible for the maintenance of a status of emergency), to protect the status quo. In international politics ‘emergency’ appears to be mostly approached as an imaginary serving political and colonial capitalist powers (Heupel et al., 2021). Emergency is structured as a form of governance. The exceptional measures to manage and control the emergency are rationalized as fundamental and necessary, contributing to the creation of exceptional spaces of *inclusive exclusion*, which serves and reproduces Western securitized colonial interests.

Carpi (2023) affirms that international actors tend to construct crisis as “unpredictable shocks”, completely de-historicized, and de-politicized; when, “in reality, they are rooted in colonial and geopolitical history” (p. 6). It is of extreme importance to keep this in mind when approaching the Lebanese context, to reflect on the impact of global and local emergencization on both refugee and host communities. For instance, the global response to the Syrian refugee crisis has been

characterized by two main approaches: 1) international policies of securitization and militarization (Squire, 2015; Riggirozzi et al. 2023); and 2) massive implementation of humanitarian programs in neighboring countries. Fassin (2013) explains that the combined international and national politics of securitization and humanitarian intervention has created a “new logic of humanitarianism”, where the humanitarian machine embodies colonial and neoliberal values, representing a valuable tool of risk management, to withhold the ‘risky uncivilized other’ from the ‘civilized’ and ‘peaceful’ Western shores.

Carpi (2023), in her work, analyzes how emergencization has been re-produced within the Lebanese contexts, acknowledging the securitization of Syrian bodies, and the promotion of widespread discriminatory rhetoric against the Syrian community:

“This divisive climate is reinforced by the official acknowledgment of crisis that emerges through global political discourses, as well as the emplacement of international humanitarian actors in the region (...) In a geopolitical scenario where a state of emergency is officially acknowledged, safeguarding the home comes into play as an in-crisis strategy of local self-determination. The otherization of Syrians resulted in local people developing new social meaning of the physical border between the two countries.” (p. 124-125)

In Lebanon, emergencization is then re-produced through 1) global political rhetoric of ‘otherization’, and ‘criminalization’ of refugees’ bodies; 2) national overly-politicized and instrumentalized construction of Syrian refugees as a threat for the country fragile sectarian stability; and 3) the pervasive presence of international humanitarian actors, which plays the double role of responding to the emergency and perpetrating it, making the crisis evident, and often exacerbating relationship between host and refugees’ communities. As it is explained in this chapter, the re-production of emergencization has disastrous effects on the Syrian refugee community, and their opportunity to exercise their human rights, as well as to access life-saving

services. The next section, ‘Discriminatory Rhetoric’ dissects the tense and difficult relationship between the Syrian and Lebanese communities.

4.2.1 Discriminatory Rhetoric

“Lebanese people don’t like Syrians, and Syrians don’t like Lebanese. This is not new, and it is because of the history of the two countries.” (Ferazia)

During the fieldwork, I came across widespread anti-Syrian discourses more or less unconsciously reproduced also by some organizations’ representatives. The extensive discriminatory attitudes and discourses I witnessed in Lebanon against Syrians have to be critically dissected, and traced back to the legacy of colonialism, the subsequent unravelling of the past shared history between the two countries (the Syrian occupation 1978-2005), as well as the already mentioned international and national securitized responses to Syrian refugees, and the massive presence of humanitarian actors in the country. Ferazia, during our interview, suggests that the current troubled relationship between Syrians and Lebanese has to be historicized. The two countries shared past plays a considerable role in the way narratives around Syrian refugees are constructed and re-defined both at the social and political level in Lebanon, where Syrians come to be signified as a ‘threat’ to the stability of the country, as well as to the wellbeing of its citizens, being widely discriminated.

Ahmed (2014: 51, 72) states that

“Through the generation of ‘the threat’, *fear* works to align bodies with and against others. (...) *Hate* is [then] involved in the very negotiation of boundaries between selves and others, and between communities, where ‘others’ are brought into the sphere of my or our existence as a threat.” (Ahmed, 2014: 51, 72; my emphasis)

In Lebanon, broadcast media have been propagating false and inaccurate narratives to fuel resentment against the Syrian refugee community (Diab, 2023). Aleyna, a Lebanese physical

therapist from a local organization working both with Syrian and Lebanese children with disabilities, recognizes that discriminatory discourses against Syrians are very often fueled by Lebanese politicians, who “uses this language, this talks in their political publicity”. Syrian refugees have been systematically instrumentalized by the Lebanese political elites and used as a scapegoat to redirect Lebanese’s frustration and discontent from the internal corruption and mismanagement of resources to the ‘external’ Syrian enemy (McClearn et al., 2023; Laughlin and Speetjens, 2022; Thorleifsson, 2016).

Within the Lebanese context, the refugee-related *politics of fear* have been built on a temporal continuum, which span from the past Syrian occupation to the present anxiety for the country’s fragility, and the projection of a catastrophic future of instability. These fears cannot be extrapolated from the country’s unravelling history, as Ferazia tries to articulate when she states that the tense and fragile relationship between Syrians and Lebanese “is not new, and it is because of the history of the two countries”. The weight of the Lebanese-Syrian history, in the definition of the current relationship between the two communities, is easily identified also in Charbel’s words, a Lebanese father of four children, who works for a local civil organization. During the interview, he states:

“I don’t know if you know but we had the Syrian army in Lebanon for 30 years. They are taking money, every decision, I have some person from my family they have been kidnapped in Syria. So how can we manage to accept them, and to be one family?” (Charbel)

Charbel highlights the difficulty of living alongside Syrians, underlining a traumatic past. This temporal axis that merges past-present-future is fundamental to understand how the current resentment and xenophobic feelings against Syrians are rooted in the historical Lebanese hatred toward the Syrian regime (see Awada, 2016; Baylouny, 2013; Geisser, 2013), which interfered in

the country's internal affairs during the Lebanese civil war, and occupied Lebanon until 2005, perpetrating brutal action against the Lebanese population (Halawi, 2022), including torture, forced disappearance and exploitation (Nisan 2000; Bassil, 2012).

Lebanon's political elites have instrumentalized this past, building on the trauma and specter of the Lebanese civil war and the Syrian occupation, which are still very much engrained in the population's memory, to create the perfect 'external enemy' threatening the 'internal survival'. Huysmans (2006) explains that securitizing speech "draws upon a historically constituted and socially institutionalized set of meanings" (p. 25), where the context's specificities represent a key element in the development of securitizing speech (Balzacq, 2005). Moreover, already institutionalized discourses prove to be easier to securitized compared to new one (Peoples and Vaughan-Williams, 2014). Hence, the hyper-politicized historicization of the Syria-Lebanon relationship occurs in a line of continuity, where the signification of 'Syrian refugee' appears to be destined to collide with the one of 'Syrian regime'. Refugees, through securitizing discourses and hate speech, come to embody the phantom of the same regime they are trying to flee from, embodying the role of Lebanon's enemy *par excellence*.

For instance, Syrian refugees are re-defined by political elites through discourses of 'otherization', and even 'criminalization', with the aim to depict them as the main causes of Lebanon's structural collapse and systemic failure. Kiswar, and Ijaaz, representatives of local organizations, respectively share:

"The Lebanese, let me give you a big picture, they are blaming the Syrians for spreading cholera. Because of this because of the camp, because the informal settlement, this this these things start to rise up as they mentioned, like the corona was there because of them, which is not the case like this is the pressure from the hosting community on the Syrians. And, on the other hand, we do have definitely, you

know, some practices from some of the refugees that's affecting the others. It's a complicated situation in Lebanon.” (Kiswar)

“Syrians behave in a way that give reasons for organizations or other people, especially those who have a great deal of prejudice. There are several crimes committed by Syrians like murder, rape, etc. giving a reason to those who have prejudice to get their frustration out.” (Ijaaz)

Syrian refugees within the Lebanese borders become the ultimate political scapegoat to justify the lack of employment, of services, of electricity, and even of medical emergencies, enacting processes of ‘otherization’ and ‘criminalization’. The criminalization of the ‘*other*’ is not new, and it has been historically used to efficiently create the dichotomic ‘we – civilized’/ ‘them-uncivilized’ (Hoyer, 2016). Moreover, since the outbreak of the financial and economic crisis in 2019, which compounded with the Covid-19 pandemic, and the Beirut blast in 2020, the situation in the country dramatically deteriorated. ESCWA (2021) reports that “the multidimensional poverty rate in Lebanon doubled from 42% in 2019 to 82% of the total population in 2021” (p. 2). More than 90% Syrian refugees (Vasyr, 2021), and 77% of Lebanese (ESCWA, 2021) are living under the poverty line. This growing instability resulted in the increase of discriminatory discourses against Syrian refugees, which further destabilized the already fragile and antagonistic relationship between the two communities. Some of the interlocutors agree that the driving reason for the renewed and exacerbated tensions between the two communities is to be found in the cash assistance, and other basic services provided to Syrian refugees by humanitarian actors. For instance, Elias, who work for a Lebanese organization, and Cyla, representative of a Lebanese grassroots organization of people with disabilities, respectively explain:

“According to me, the international community through the UN agencies and other organizations, when they provide financial support to Syrian refugee families and these families have more resources than the Lebanese families. Lebanese families are suffering from shortage of economic resources because now the Lebanese lira, its value is nothing; so they see how the Syrians are living better than the Lebanese, and there is something that should

be done in this regard, because you cannot convince the local community to accept this situations.” (Elias)

“One of the main tensions now between Lebanese and Syrian is related to the availability of services because it's now in Lebanon you can see availability of service for Syrian more than Lebanese people, and this make tensions on the ground on the field.” (Cyla)

Elias and Cyla, as well as other national and international organizations’ representatives, acknowledge the negative impact that humanitarian ethnicized support has had on the stability and cohesion between Syrians and Lebanese (see Carpi, 2023, 2022 and 2014; Zaccara and Gonçalves, 2022). Carpi (2023) critically reflects on how humanitarian aid can dramatically change the social relationship between individuals and groups in context of crisis and emergency, reshaping dynamics and fueling resentment. She explains how in Akkar, an historically vulnerable and deprived region in Lebanon, the initial decisions to only provide humanitarian aid and programmes to refugees, completely ignoring the needs of local communities, as well as the already in-place structures of coexistence between Lebanese and Syrians, marked the “disruption of local empathy and informal arrangement of hospitality” (p. 37). The effects of this initial humanitarian ethnicization of aid have been substantively instrumentalized by political elites and media operators to further exacerbate the relationship between the two communities, promoting a narrativization of aid which sees Syrian refugees as having more privileges than Lebanese. These narrativizations are then reproduced within the broader society, building on the Lebanese’s daily struggle and deteriorating living conditions. For instance, Kiswar, and similarly also Aahad, who works for a Lebanese organization, report that

“We are aware that we have this big pressure (discrimination) from the Lebanese community on this because of the situation we're living in. We do have this pressure on the people, on the others, and sometimes you feel that at this stage they have the right to feel that the refugees are better off.” (Kiswar)

“Lebanese, now, now that they live in a very bad economical situation. And now they are asking to get to get the same advantages as refugees.” (Aahad)

In the Lebanese context, it appears clear how the initial ethnicization of aid has exacerbated resentment and division between host and refugee communities. Humanitarian interventions are contributing to the ‘otherization’ of Syrian refugees in the country, reinforcing discriminatory practices and discourses (Carpi, 2023), which legitimize the construction of refugees as a threat for Lebanese’s survival. In turn, this appears to justify the promotion of securitization policies, as well as a wide feeling of resentment towards the Syrian community, which is perceived to be living in better conditions than the Lebanese, as mentioned by the interlocutors.

Ahmed (2014:80) argues that “The containment of the bodies of others affected by this *economy of fear* is most violently revealed in the *literal deaths of those seeking asylum*” and refuge (my emphasis). The narrativization of Syrians as an ontological threat legitimizes extreme measures of containment, which deprive refugees of their basic political, social and human rights, impacting on their access to life-saving services, including education and healthcare. Securitization is then produced through discriminatory discourses based on *fear* and *hate*, and at the same time it reproduces and exacerbate discrimination, all under the emergency rhetoric, having dramatic repercussions on the lives of Syrian refugee. The high rate of discrimination in the country against Syrian refugees was also articulated by many of the refugee families interviewed.

Manar lives in the Beqaa area. She came to the meeting with her husband’s second wife, Salam, and her young son Khaliq. Khaliq is the only sibling with a disability. The family does not have a clear diagnosis of Khaliq’s disability, but they think it is due to the traumatic experience the family faced before fleeing the war. Manar explains that they were forced to leave their house in Raqqa,

because it was destroyed by a *sarukh* (missile). When the missile hit the house, they were all inside. They remained stuck inside for a while and the house was full of smoke. Khaliq, who was just a few months old, had a cardiac arrest that night. Manar explains that when they managed to leave the house, she stayed for one month with Khaliq in the hospital, while the other children were brought to different family members, who could look after them while she was away with Khaliq. They spent one month at the hospital and then they were forced to move from one hospital to another because “they (fighters of unspecified faction) started targeting hospitals”. Manar and her family decided to cross the Lebanese border after a couple of years from that event, because there was “nowhere safe in Syria”. In Lebanon, their economic situation remained extremely precarious, but “at least there is no war”. Manar is worried for Khaliq’s health, which is constantly deteriorating, and the family is scared and worried to lose Khaliq. Manar and Salam decided to work on the land to provide for their family, as their husband has a severe health condition, and he cannot work. She shares that

“as Syrian women working on the land, they are not treated in a good way, the manager is mistreating them or addressing them with bad words and bad language. So they feel they are obliged to work to support their families and especially to provide their child with disability.” (Manar)

Then she adds

“in Lebanon it is impossible to live with dignity, you cannot access any service, even medication or bread. They are treated in a really bad way by the Lebanese even when they go just to buy bread. When they go to the supermarket to buy the essential with the UN card, and the Lebanese see them packing their stuff, they start screaming ‘Go back to Syria! We don’t want you! You are taking our money, you are taking our resources, we don’t want you and we don’t need you!’. So they feel humiliated every time they need to go and buy the essentials and basics things. They mentioned that they are obliged to accept the UN support and to live here because their country is not stable. ‘Once our country is stable, we are willing to go back to Syria’.” (Manar)

Many other parents shared similar lived experiences, as well as this feeling of humiliation, and they explained that even their children are subject to the same treatment, and they are often harassed both verbally and physically. For instance, Fadela, a young Syrian mother of 4 living in Beirut, despite acknowledging the good relationship her family has with a Lebanese shop owner, who helped them during the pandemic, she remains extremely critical of how the overall Lebanese society treats her family, and Syrians in general. She shares that:

“They (Syrians) are not respected at all in Lebanon. She mentioned that she sent her son to buy some bread. He came back to the house with no teeth anymore, and he had blood all over his body, so no, Lebanese are not respecting their presence here. And also, with her sick child¹², she went with her to the dispenser and the child was crying because she was sick, and the Lebanese lady told her ‘get out or get your child to stop because she is bothering everyone here’, even though she explained that her daughter was sick, and she wanted the daughter to be checked by a doctor. So she was in the right place to do so, but they did not accept her presence or her daughter’s presence and it was very painful for her.” (Fadela)

Many parents expressed great concerns for their children’s safety, and in many cases, they decide to keep them home, and not even send them to school to protect them from harm. Samira, used to live in Aleppo with her husband and nine children. When the war started, her older sons were asked to join the army. As a response, the family decided to focus on finding a way to let the older sons leave the country. They were forced to opt for illegal routes, which are very expensive and dangerous, as they rely on human traffickers. Samira said that she just wanted “to save her children”. In the meanwhile, she remained in Aleppo with her husband and her two younger children. In 2018, the family could not stay in Aleppo anymore, as the situation further deteriorated. A missile hit the area where the family was living. Samira recalls that they were surrounded by dead people and Mahdi, who was only 5 years old at that time, had shreds of dead bodies on himself. He was deeply traumatized, and the family could not stay there anymore, so they decided

¹² Fadela never referred to her child as having a disability. She always talked about her as being marīda, sick.

to cross the Lebanese border. However, their life remained very precarious. After they moved, her husband died because of a severe heart condition. They struggled to access medical care and the needed medication. The family now lives in a renowned dangerous area of Beirut in a two-room apartment which is completely unfurnished. They often struggle to afford even the basics, such as food and water, and Samira is forced to ask for little loans from the people she knows to survive. During the three hours we spent with Samira and her children, a lady from the neighborhood kept showing up to the door asking for her money. Samira explains that as soon as Mahdi receives his next salary, most of the money will be used to repay this lady, and for this reason they will never have enough money to properly follow up with doctors for Mahdi's sight.

Samira is scared because she and her children have been harassed many times, and also threatened by their Lebanese neighbors. She explains that

“The Lebanese neighbours don't like us, they don't like us. They don't. They don't have any good relationship with neighbours. The Lebanese hate them.(...) once they (Lebanese neighbours) took her son, and they were very abusive to him. She is afraid that Lebanese might report her older sons and deport them. She is afraid of this because it is their time to serve in the army, so for her she has no relationship with the neighbours, and she prefers to stay in the house and to keep both her younger children in the house with no relationship with the surrounding to avoid problems. (...) She is always afraid to let her daughter go out because there are drug dealers. And the region on the security level is not available to have kids on the street, and this is also why she doesn't send her daughter to school.” (Samira)

Syrian refugees appear to be politically narrativized as the main causes of Lebanon's decline, including the Lebanese economic crisis, which has dramatically affected refugee as well as host communities. Some of the participants and interlocutors have acknowledged that since 2019 the tensions between the two communities have dramatically increased, exacerbating discriminatory

discourses and practices towards Syrians (Cyla, Ijaaz, Aahad, Aleyna, Majedah, Amanda, Faiza, Farug, Fadela, Carim, see also EuroMed Rights, 2023).

Despite the broader climate of discrimination, it is important to acknowledge that positive relationships between the two communities still exist, surviving the broader divisive narrative promoted at the political level. Bushra, a mother of 3, managed to cross the Lebanese borders in 2012, and she settled with her family in Beirut. She lives with her family in a two-room concrete container surrounded by similar constructions scattered in the land. She explains that when they arrived in Beirut, they found, with other families, these empty containers in an abandoned land. They tried to make a house out of it, but unfortunately, it is not very safe for her son Qudamah, who is blind and cannot move freely around, especially because of the presence of lots of snakes in the land, that often manage to enter inside. When we asked about the relationship with both the Syrian and the Lebanese communities, she said that of course sometimes it is difficult, because everyone is under a lot of pressure, but overall “their relationship with the neighbors is very good, both with Lebanese and Syrians”. Then, going back to her son Qudamah, she shares that she wished to be able to offer him a better life, because “she knows he can have a better life, her father was blind too and he was a sheikh”. She said that

“There is a nice Lebanese lady who registered Qudamah in the Ba3abda school for the past 3 years, and she never asked anything in return. Unfortunately, this year she will not be able to help with Qudamah’s education, she is also facing the economic crisis, and struggling.” (Bushra)

Similarly, Suleika, who lives in Beirut with her husband and 5 children on the fourth floor of a very old building, told us that one of her Lebanese neighbors, despite struggling herself, she always tries to help with food, as she knows that most of the time they cannot afford to eat and “she wants to help the kids”. Bushra and Suleika’s experiences offer an important counter narrative to the wider

discriminatory climate enforced, and it would be important to build on these positive relationships to start deconstructing the divisive narrative promoted at the national level.

In this section, I have illustrated how emergencization is used to legitimize processes of ‘otherization’, which result in the identification of a fictitious ‘*threat*’/‘*enemy*’ and the justification of securitization policies, and exceptional responses, which further marginalize refugees. I also introduce the role of humanitarianism in reproducing state of emergency, and in further deteriorating the already fragile relationship between refugee and host community. The recognition of a state of emergency allows for the creation of spaces of *inclusive exclusion*. In what follows, I aim to examine how these spaces of *inclusive exclusion* come to be, and how forms of exclusion are operationalized and enforced by humanitarian actors in context of emergency.

4.2.2. Operationalizing Exclusion in Emergency

“Inclusion and exclusion are *relational* processes. The root causes of why some individuals and groups have more urgent needs, or struggle to access assistance, are often grounded in long histories of marginalization by other people, whether in the form of prejudice, social norms, or political manoeuvre.” (Lough et al., 2022:14; original emphasis)

Discourses of emergencization are instrumental to justify the systematic failure in promoting inclusion within the humanitarian system. The nature itself of ‘emergency’ appears to legitimize the reproduction of intrinsic system of exclusion, leaving unchallenged historical forms of segregation. Exclusion, as stated by Lough et al. (2022), has to be historicized and analyzed in light of specific socio-cultural, economic and political traditions and structures, both within the contexts of emergency, and within the humanitarian system itself. Here, I analyze how humanitarianism employs the concept of emergency to ‘morally’ rationalize and enact exclusion.

To better understand how exclusion is operationalized in the context of emergency, it is fundamental to briefly reflect on the ontological essence of humanitarianism: its ‘apolitical’ mission, bureaucratic dysfunction, marketization of aid, and its short-term life-saving rhetoric. During the interview with Aahad, we had an interesting conversation on what he called the “humanitarian game”. He explains that

“When they (humanitarian actors) have to monitor and to report on their activity, and when they have to report on number of cases, of course they choose to report on easy cases (mild disabilities) for the report for bigger numbers, than hard cases (severe and complex disabilities) and smaller numbers. So this is the game.” (Aahad)

The humanitarian focus on countable, tangible and quick visible outputs as measures of success, rather than on the effectiveness and sustainability of the project implemented for the community living the emergency, contributes to the systematic failure to achieve real inclusive responses. For instance, the quantifiable indicators/output-driven rhetoric, pushes humanitarian actors to concentrate on the numbers of ‘children reached’, rather than on the quality of the intervention implemented, highlighting the abysmal inconsistency between humanitarian ‘inclusive’ discourses and practices. The intrinsic prioritization essence of this approach appears to be incognizant of pre-existing structure of exclusion, and as such it often uncritically reproduces these same exclusionary structure (Lough et al., 2022). Moreover, in this climate of reaching the most people as quickly as possible in a cost-efficiency/cost-benefit manner, being inclusive is considered as impractical, and therefore not a priority. The supremacy of ‘life-saving’ discourses as an emergency imperative legitimizes the de-prioritization and hierarchization of aid. Hence, “by contrasting saving lives with being inclusive, such assertions set achieving speed and breadth of coverage at odds with questions of quality and equity” (Lough et al., 2022: 5). Majedah, a UN representative, and Cyla, further articulate the processes through which refugees with disabilities are deprioritized in contexts of emergencies and crises under the emergency rhetoric

“With the current situation in Lebanon, it is hard to reform, but also to discuss inclusion when the the situation is that fragile but also when the all the Government institutions are collapsing right uh like, if you, as you said like, if you don't have public schools, even like we're not sure that they will be opening. *Then how can we even work on inclusion in the first place?* (...) There is a challenge to reform during the crisis.” (Majedah, *my emphasis*)

“We know Syrian refugees with disabilities who are registered in the UN, and they are not benefiting at all from the UN program. One of the fights I had previously with UNHCR It is related to the criteria of selection for maybe cash assistance programs. They are not taking disability into account once preparing the file for that, What I get from them from our meeting it is that there is a lot of needs, and the budget is not, cannot be afforded for all persons.” (Cyla)

Majedah and Cyla clearly explain that inclusion does not represent a priority and highlight how the emergencization of the context allows and justifies statements such as “How can we even work on inclusion in the first place?”. Inclusion is seen as an additional feature, rather than a pillar of humanitarian responses and social reforms, and as such its exclusion from humanitarian interventions, in times defined by crisis, is not only accepted but even ‘rightfully moralized’ as the only possible option in context of emergency, where available resources are limited, and needs are overwhelmingly high. Cyla explains:

“We are working for sure on emergency level, because it's a high priority for the persons and persons with disabilities are facing challenges to access the services and the programs.... Access to medication, Access to doctors, access to hospitals is really challenging. People with disabilities cannot access diapers, medicines, anything. And you can listen to many bad stories, or, if I can say strong stories, how the dignity of persons is not anymore a priority in Lebanon.(...) Now, most of organizations stop to provide assistive devices., and this represent one of the main gap now for persons with disabilities.” (Cyla)

With limited resources available, and the prioritization logics of humanitarianism exposed above, the inclusion of people with disabilities, and other historically marginalized groups, is seen as being *de facto* less worthy of funding. This results in a hierarchization of inclusion, in terms of disability,

as well as of ethnicity and other identity's dimensions, which can be identified analyzing donors' agenda. For instance, in Lebanon, the current donors' focus on Syrian refugees not only has weakened the already fragile equilibrium between the Lebanese and Syrian communities but is also having dramatic consequences for refugees from other countries, such as Palestinians, Iraqi and Somali people, who are cut out from aid programs as they do not meet the requirements (being Syrian) to qualify for receiving assistance (Lough et al., 2022). Some of the organizations' representatives confirmed this ethnic-based prioritization and the consequent exclusion of other groups of people, disclosing that fundings are always very political, and in Lebanon, the great majority of them are coming for Syrian refugees, meaning that they have to be used to implement projects with this specific population (Ferazia, Aahad, Aleyna). Moreover, as explained by Kitana, a UN agency's representative:

“We cannot provide all these educational services for those children with disabilities, but then we have done our best over the past 3 years (...) If we have a severe disability case, they are not able to have them in the project because they need specialized and sometimes one-to-one support. And it is very costly, and it is not easy to provide it given the limitation.” (Kitana)

When it comes to disability the logic of exclusion is predominant, and it appears to be ‘morally’ justified by the paradigm ‘limited resources - high needs - too costly’. Healy and Tiller (2016) find that there is an essential reluctance in funding precarious “higher cost-per-beneficiary activities”. Furthermore, Grech (2011:96) explains how “the push for quick outcomes demanded by donors makes disabled people an unattractive proposal, especially since these require a long-term commitment and resources, and the results may not be immediately evident”. Consequently, people with disabilities are systematically excluded, despite the altisonant discourses on inclusion and human rights adopted and promoted by humanitarian structures over the past 20 years (Miles and Singal, 2010; Grech, 2017; Rohwerder, 2017; Lough et al., 2022; Young, 2023).

The cost-benefit/cost-effectiveness rationale highlights the neoliberal nature of inclusion within the humanitarian industry, uncovering the intrinsic ableist principles underpinning the operationalization of inclusion/exclusion in context of emergency. Hence, it appears legitimate to say that the operationalization of exclusion in emergency contexts is enforced through structural as well as discursive processes of securitization, and marketization of aid and of the humanitarian sector (see Chapter 6). In the next section, I provide a tangible example of the effects of emergencization discourses – both in terms of securitization policies and discriminatory rhetoric promoted at the local level, and in terms of the broader humanitarian rationalization of exclusion – on the education experience of Syrian refugee children with/out disabilities.

4.2.3. Impacting Education

“The Lebanese authorities are very restricted on the idea of inclusion for Syrian refugees. They have serious concerns that if they facilitate their inclusion in education or in any sectors, these refugees will be part of the Lebanese community, and this is not acceptable to the Lebanese authorities now. It is very clear that Lebanese people don’t want the Syrian refugees to remain in Lebanon for many reasons.” (Elias from o4, local NGOs’ representative)

“She wished to be able to integrate her daughter with disability in the education system. She tried many times with public schools, she even tried to enroll her in any private school. Last time she even offered to pay double fees to the private school to integrate her (two registration fees), but they didn’t accept.” (Maysa)

The combination of the marketization of humanitarianism- which follows neoliberal rules (see Chapter 6), and the security logics, produced and reproduced through and by emergencization, appear to prevent Syrian refugee children with/out disabilities to exercise their basic human rights, such as accessing healthcare, medical treatment, and education. This section sheds light on how securitization, discriminatory discourses, and the nature itself of humanitarianism influence Syrian refugee children’s access to and experience of education in Lebanon.

The historical tensions between Syria and Lebanon, and its political instrumentalization to exacerbate securitization policies, have negatively affected the integration of Syrian refugees into the Lebanese society (Buckner et al. 2018). This has had important repercussions also on the overall country's educational response to Syrian refugee children, who are segregated from their Lebanese peers, through a double-shift system. As it has been explained by the interlocutors, the main reason to prevent Syrian integration in the Lebanese education system is linked prevalently to political matters. After the civil war, with the 1989 Taif Agreement, Lebanon's political structure was restructured following the lines of corporate power-sharing, re-enacting a multi-confessional system, where all the 18 ethno-sectarian groups in the country are included, to a different extent based on the 1932 census, in decision making processes (Ghosn and Khoury, 2011). Most of the Syrian population is Sunni Muslim, meaning that if Syrians are officially integrated within the Lebanese societal fabric, the demographic balance would largely change in favor of the Lebanese Sunni Muslim community. This contributes to the widespread strong repulsion for any form of integration. As a result, the double shift system has been implemented in collaboration with UNICEF to provide education for Syrian refugees; however, the segregated system proved to further exacerbate the tensions and frictions between Lebanese and Syrian students (Shuayb and Ahmad, 2021).

It must be noted that on top of the segregated educational response, securitization discourses and the widespread anti-Syrian discriminatory rhetoric have been reproduced inside schools, negatively affecting Syrian refugee children's educational experience, as well as the quality of education received in Lebanese public schools. If on the one hand, the post-2014 securitization policies have made it extremely difficult for Syrian families to meet the necessary criteria to be able to enroll their children in public education (Janmyr, 2016; Shuayb et al., 2014); on the other, the extensive discrimination toward Syrian refugees, perpetrated within school environments, has had disastrous

effects on children's wellbeing. For instance, Samira's daughter, Layla, shares her children's experience in a Lebanese primary public school:

“She has 4 children going to school (public school) but unfortunately, they are abused. She said that the principal forbids all the Syrian kids to go to the toilets during the afternoon session. And when the parents go to the school to ask why their children are not allowed to go to the bathroom, and they keep the toilet locked, they answered ‘ah we are facing a lot of problems with the toilets. So to protect your children we decided to close and lock them’. (...) her daughter started to suffer from urine infection and pain because she cannot enter the toilet. The second thing she said, (...), the teachers started to have rulers just to hit the kids, and they are obliging all the boys to cut their hair saying that ‘ah in the Syrian army all the man cut their hair’. And they answered ‘sorry but there is a cold weather and you are asking us/forcing us to cut their hair’. Her 4 children informed her that if she is going to register them in the same school, they will not go. They don't want to go to school anymore, not in that school.”
(Layla)

Layla's insight raises different issues concerning some Lebanese public schools – which have been reported also by other national and international actors, as well as academics working in the region (see Bahou & Zakharia, 2019; Akesson et al., 2020; Antoun, 2021) – such as use of corporal punishment, discriminatory attitudes against Syrian students, and the impact that these practices and attitudes have on Syrian children. Layla explains that Lebanese children who attend in the morning can access the toilets, while the Syrian children attending in the afternoon are prevented from using them. Then, Layla showed me a scar on her son's head, and nervously said “he was hit with a big ruler by one of the teachers”.

Unfortunately, Layla's experience is not an isolated one, and many other parents expressed concern for how their children were treated at school, especially by their Lebanese peers. In the same way, Mahdi, Ferran, Gadi and Raja, the only children with mild disabilities who managed to temporarily be enrolled in the Lebanese public education system, reported similar narratives of discrimination and bullying. For instance, Mahdi, who left school to provide for his family after his father died,

said that “he is targeted by bullies that tell him bad words. Not only to him but to all Syrians. All Syrians are bullied everywhere”. Mahdi experience of being bullied was not circumscribed to the school environment, and he explained that since he started working, the situation did not change. He sees this problem as a structural one.

The quality of education received by Syrian refugee children was also often raised as a major problem by parents, who all agreed on the disinterest of Lebanese teachers in providing good quality education to their children, despite being paid and supported by UNICEF.

“Lebanese do not care and are not willing to educate Syrian refugees and families, because he registered his kids to school, public school, and teachers just register their hours, they get paid monthly by the UN, and they don’t care if the children are receiving a good level of education or not. He mentioned that one of his kids went to school for 5 years and he still doesn’t know how to read and write. Is it possible that you register a child 4-5 years in school and they are not able to write and read their own name? This is a fraud from the system just to receive money from the UN.” (Dabir)

“The UN provide help with the education for both girls in the afternoon, but she knows that in this school they are not receiving the proper level of education. She knows that many kids are just playing and not studying. The school is not serious at all.” (Mouna)

“Teachers just sit on the chair and stay with their phone or reading their things, without providing any education for the kids. And they give in advance to the kids the test and the answers, so that they can score well for the UN when they come to check how the school and the kids are doing, and they can see that “oh the kids are performing well, and learning”. But in fact, the school does not provide a good service. And teachers do this only with Syrian children in the afternoon, never with the Lebanese kids. And he knows about many students of his friends that confirmed the teachers’ behavior. And this is why some Syrian families are taking out the children from the schools and put them to work. Because it is useless to send them to school if no one is teaching them and working on their education.” (Farug)

These narratives are also confirmed by Majedah, UN representative, who affirms

“I know that that when it comes to the quality of education for Syrians we constantly hear that the second shift the quality of the education is not as good as the first shift, and I wouldn't be surprised, especially that you're asking school teachers that are Lebanese in uh that that are most of the time racists. so, of course, there is a lot of question mark on the quality. But at the end, obviously, when you look at the system at what you have, you try to do the most with what you can do and what you have.” (Majedah)

The low-quality education provided to Syrian refugee children is highly criticized by Syrian parents, who make great sacrifices to ensure their children receive adequate education to have access to better opportunities in the future. Unfortunately, many Syrian families, due to the low-quality education provided to their children, and the increasing dire economic circumstances in which they live, as explain by Farug, decide to remove their children from school and to introduce them in the informal labor market.

Despite the narrative of abuse reported by Syrian parents and their children, this work does not aim to criminalize and/or undermine Lebanese teachers' work, overgeneralizing on their alleged racism. Lebanese teachers should not be seen as perpetrators of racist instances, rather as a casualty of a broader securitized system, predicated on discrimination, scapegoating Syrians and reinforcing divisive narratives. Lebanese teachers' behaviors have to be critically contextualized within the broader climate of intolerance, as well as within the current grinding economic crisis, which has had dramatic repercussion on the living conditions of both refugee and Lebanese communities. Since the Lebanese economy collapsed in 2019, the country's public institutions have been crumbling, pushing most of its population in severe poverty. Teachers as a result, are amongst one of the most affected groups in the country, and the prolonged failure of the Lebanese Government to find a sustainable solution is having dramatic repercussions on the education system. For instance, one of the interlocutors shares “I don't think that the teachers will have enough from their salaries to go to schools by their own and pay for their fuel” (Aahad from o7). Hammoud and

Shuayb (2022) report that Lebanese “teachers’ salaries have lost over 90% of their value since 2019” due to the devaluation of the Lebanese pound. Currently, teachers struggle not only to pay for the fuel to reach their workplace, but also to manage their living expenses, having to work multiple jobs and to borrow money. The dire economic situation and great pressure under which teachers have found themselves contribute to reinforce feelings of hate towards the Syrian ‘other’, who is seen as a recipient of international aid. Kelcey and Chatila (2020) report similar findings, explaining how despite the majority of teachers and principals acknowledge the refugees’ right to education, as well as the hardship of refugeehood, “their views were also shaped by discriminatory public discourse and the complex and often fractious history of Syrian-Lebanese politics” (p. 13).

As stated at the beginning of the section, Syrian children’s experiences of education in Lebanon are heavily influenced by the nature and logics of humanitarian education, which are defined and re-defined through ‘emergency’ language. Brun and Shuayb (2020) state that “Emergency education is clearly an oxymoron that expresses tensions between education and humanitarianism” (p.22). This is because, as briefly explained in section 4.2.2, humanitarianism is based on a temporary response, where the rule is ‘saving the most life’; while education is a long-term project aimed at the development and empowerment of the child. The emergency philosophy entrenched within humanitarian education, leads to what Brun and Shuayb (2020:26) call “purposeless, exceptional and segregated” education. The short-term solutions appear to promote a philosophy of occupying ‘seats’ to fit funding quotas – underlining the process of commodifying Syrian refugee children in the education market, rather than focusing on quality and inclusive education (Costantini and El-Serafy, *under review*).

The education challenges presented in this section are specific to Syrian refugee children without disabilities and with very mild physical and sensory disabilities. For children with more moderate to severe disabilities, as explained by Maysa, there are no opportunities to be enrolled within the

Lebanese public education system, nor within the private one, regardless of their citizenship status. Among the 25 Syrian children with disabilities I worked with, only 5 children accessed at some point and for a very short period the Lebanese public education system. All of them have very mild physical or sensory disabilities and are considered among those who have ‘easy cases’, for whom additional resources are not necessary. For all the other children with more moderate to severe disabilities there were no opportunities. They appeared to be invisible, and to fall into the cracks of an ableist and hyper-securitized conceived system of humanitarian neoliberal inclusion. This is, *de facto*, indicative of the failure to include children with disabilities within the humanitarian system.

4.3 Conclusion

In this chapter, I have examined the role of emergencization discourses in legitimizing processes of securitization, as well as justifying the de-/prioritization of specific groups of people. I have explored how the reproduction of emergencization is enacted 1) through policies of fear and hate, which promote securitization policies, exacerbating discriminatory practices against Syrian refugees; and 2) through the presence and operation of humanitarian agencies, which adopting an ethnic-based approach to aid further deteriorate the relationships between the Lebanese and Syrian communities. I then analyzed how humanitarianism manages to operationalize exclusion in context of emergency. To conclude, in the last section, I presented an empirical account of the effects of emergencization on the educational experiences (or lack thereof) of Syrian refugee children.

It must be noted that while securitized humanitarianism has been often discussed, its ableist intrinsic nature remains mostly hidden, especially since inclusive discourses have been promoted so vehemently within the field. However, an uncritical inclusive rhetoric risk to reproduce historical ableist understanding and construction of ‘inclusion’, resulting in an ‘exclusionary inclusion’. The next chapter engages with the ableist exclusionary forms of inclusion promoted

through neoliberal inclusive discourses within the system of education in humanitarian contexts. It explains how disability becomes commodified within the humanitarian sector, and how people with disabilities continue to remain excluded and de-prioritized through hierarchical construction of humanness and 'inclusion'.

CHAPTER 5

ADVANCING NEOLIBERAL INCLUSION

“Why do some bodies matter more than others?”
(Erevelles, 2011:6)

5.1 Introduction

In this chapter, I present the sub-category ‘Advancing Neoliberal Inclusion’, and its fundamental elements: ‘Hierarchizing Disability’, ‘Promoting Exclusionary Inclusion’, and ‘Facing and Resisting Barriers’. I explain the processes and eventualities through which Syrian refugee children with disabilities, especially those with severe and complex disabilities, are systematically excluded from humanitarian (education) interventions, even from those which are purportedly ‘inclusive’. It is important to note that in the past few decades, the concept of inclusion has permeated the humanitarian (education) field. However, despite the many international inclusive policies promoted at the educational level – such as the Education for All (EFA, 1990), the Salamanca Statement and Framework for Action on Special Needs Education (1994), the UNCRPD (2008) and many others – a great number of children and youth with disabilities, especially in contexts of conflict and emergency, remain largely excluded from any education opportunity, and neglected from most, if not all, humanitarian (education) interventions.

The reasons for this structural exclusion are multiple, such as the securitization processes embedded within the humanitarian mission itself, aimed at protecting the status quo (Watson, 2011); the marketization and politicization of aid, which reproduces and advances Western interests (Krause, 2014; Burde et al. 2017; Collinson, 2016, see chapter 6); and the intrinsic colonial and neoliberal roots of humanitarianism (Berghs, 2014; Grech, 2015). The sub-category ‘Advancing Neoliberal Inclusion’, and its elements, help us to understand the logic behind the construction of Syrian refugee children with disabilities in Lebanon as *homo sacer*. This first sub-

category explains not only how children with disabilities are excluded, but also *why* and *how* they come to be excluded, underlining the role played by processes of lives' qualification according to a (geo)political economy of bodies which is rooted in the neoliberal philosophy embedded within the sector of education in emergency. It also highlights how emergency education reproduces ableist understandings of disabilities through its 'inclusive' rhetoric, establishing which bodies matter/ are included, and which do not matter/ are excluded.

The element 'Hierarchizing disability' sheds light on the neoliberal 'inclusive' discourses and praxis serving the interests of global capitalism, analyzing the commodification of disability, and the logics of 'cost-benefit', 'easy-fit', and 'saving the most life', which are entrenched in the construction of specific groups of people as 'worth/less', and therefore de-prioritizable. The disability-hierarchization process is a fundamental step to legitimize exclusionary forms of inclusions, following the emergencization discourse. According to the context, exclusion can take different forms, reproducing and even exacerbating old structures of power and oppression. Exclusionary forms of 'inclusive education' pose serious challenges and barriers for Syrian refugee children with disabilities and their families. However, as it is also further explained in Chapter 6, in these exceptional spaces, there are different forms of resistance, where Syrian refugee children with disabilities and their families continue to transgressively resist and to oppose to the exclusionary climate re-enacted through neoliberal ableist promises of inclusion.

5.2 Advancing Neoliberal Inclusion

"In 2020 I was invited to speak in Geneva about humanitarian actions, and I went there and there were so many organizations, and I spoke to them and I said 'look! I don't know what you guys are doing, but whatever you are doing, you are not reaching or supporting or helping more than 10% of the people who are in need. You are wasting your money on things that are not worth it. Ok, you include, you are paying so much money to include students and

children with disabilities, but *what about those with severe disabilities? No support, nothing to them!*'. And I heard no response. (...). *They spend so much money, but they are leaving other people behind.* The first line of the agenda 2030 and SDGs is leaving no one behind, but *they are leaving people behind, and especially those with severe disabilities.*" (Ijaaz)

My conversation with Ijaaz, a Lebanese man who has been extremely invested for several decades now in advancing the rights of people with disabilities in Lebanon, proved to be fundamental in my theorization efforts. His clear and strong critique, as well as indignation towards the dominant Western humanitarian framework of inclusion, critically resonated with the words and experiences shared by Syrian parents with children with severe disabilities. During the interview, he highlights the heterogeneity of disabilities, and how this heterogeneity comes to be homogenized, and almost hidden, in what the humanitarian sector calls 'inclusive education', or more recently 'disability-inclusive education'. His question "but what about those with severe disabilities?" kept firmly coming back during and after the fieldwork. My attempt to rationalize and answer his question pushed me to explore not only the underlining reasons on which children with different types and severity of disabilities are considered and in-/excluded, but also the logics through which certain practices of in-/exclusion come to be operationalized within the field.

Russel (2019: 42) defines disability as a term "used to *classify* persons deemed *less exploitable* or *not exploitable* by the owning class who control the means of production in a [neoliberal] capitalist economy" (my emphasis). The difference between *less exploitable* and *not exploitable* appears to largely influence the level and status of 'inclusion' in humanitarian interventions, as also transpire from the excerpt above, transforming disability into a commodity. For instance, inclusive humanitarian programs need the involvement of specific groups of people that can fall in pre-determined socially constructed categories which have been historically excluded and would then respond to the 'criteria for inclusion'. An inclusive education program, according to the context in

which it is implemented, would probably focus on incrementing and/or ameliorating enrollment and retention rates for girls, children with disabilities, and/or children from deprived background and ethnic minorities. Hence, inclusive education programs must work with children who are at risk of exclusion. If these children are not factored into the project proposal, the implementing organization could miss the access to fundings. It follows that certain category of ‘beneficiaries’ become indispensable, and commodified in the humanitarian industry, and disability, as one of the dimensions of inclusion, also turns into a commodity. However, not all commodified bodies and minds appear to have the same value. The question “what about those with severe disabilities?” helps to critically engage with matters of bodies and minds’ exploitability, which are essential to analyze the neoliberal political economy of bodies both within and outside the humanitarian project.

The knowledge I came about, which is not new, is that not all disabilities are the same in the eyes of donors and implementing actors, and not all beneficiaries with disabilities hold the same economic value in the neoliberal humanitarian market. Therefore, it is legitimate to ask: Who are the children with disabilities included in humanitarian interventions, and why? Which are the commodified bodies with disabilities that hold the highest economic value for the humanitarian industry? The answers appear as simple as disturbing and odious: the children with disabilities included in humanitarian ‘inclusive’ education efforts are those who are ‘*less exploitable*’, but ‘*more exploitable*’ of those who are ‘*not exploitable*’. Meaning that inclusion is based on a disability-hierarchization process, that aims to assess which bodies and minds with disabilities would better fit and embody ableist normative forms of normalcy, and functionality, without requiring expensive alteration of the ‘normal’ environment and its established practices. It follows that inclusion is a matter of ‘cost-benefit’ assessment (Trani et al., 2012), and that not every child with disability would be suitable for inclusion in such a neoliberal utilitarian system (Costantini

and El-Serafy, *under review*). This perspective was informed by many other international and national organizations' representatives interviewed, who highlighted the political economic nature of fundings, underlining the widespread tendency to prioritize children with mild to moderate disabilities in both emergency and development projects, leaving behind children with more severe and complex disabilities, whose lives appear to have little value in our neoliberal capitalist world. In what follows, building on participants' insights, I focus on explaining how processes of disability-hierarchization are operationalized within the Lebanese context, and the broader humanitarian system.

5.2.1 Hierarchizing Disabilities

“‘Disability’ has become a prime site for the constitution of the neoliberal version of the individual - ‘the abled-disabled’ whose participatory power is tied to an ability to conform to normal society.” (Titchkosky, 2014:517)

Titchkosky (2014) talks about “the abled-disabled” – a concept used to denote people with disabilities “who are deemed by others to have the best chance to reflect, desire, or imitate ‘normal people’, or at least ‘normal functioning’” (Titchkosky, 2003:527) –, and the “ability to conform to normal society”. This neoliberal version of the individual with/out disability is constructed once again in terms of independence, functionality, and productivity. This means that those who are ‘too disabled’ to be successfully integrated in the market economy, namely people with severe and complex disabilities, are seen as a ‘problem’, a ‘burden’ for the neoliberal society, and if they cannot be ‘corrected’, the only possible solution is to ‘remove’ them, as disability continues to fall “outside the normative remits of utility, economic growth and development indicators” (Grech, 2015: 15). Organizations’ representatives were quite open in denouncing neoliberal-based practices of ‘inclusion’ enacted within the broader humanitarian system, which continues to reproduce the same structures of segregation and discrimination against people with disabilities. For instance,

towards the end of August 2022, I had the opportunity to interview Ferazia, representative of a Lebanese organization of people with disabilities. Ferazia presented herself in the following terms:

“First, I am a mom, and my daughter has intellectual disability, and I think that she teaches me a lot! And second, I am working with Lebanese association for self-advocacy, we started this organization because young people asked, they wanted their own organization, and they wanted to know better about their rights, and advocate for themselves.” (Ferazia)

As a Lebanese mother of a “young strong woman with disability”, and an activist with years of experiences in both the national and international arena, Ferazia is extremely critical of the Lebanese as well as humanitarian responses and efforts towards inclusive education for both Lebanese and refugee children in the region. She clearly states that

“There is distinction (among type and severity of disabilities). For example, people with physical disabilities are the first to be enrolled because *they just need a ramp*, it is easy. (...) But the big problem is people with intellectual disabilities, and with severe disabilities, and I had a discussion with the representatives from the ministries and they said ‘it is impossible, we cannot include them in the school!’” (Ferazia, my emphasis)

A similar position was also shared by Merjan, representative of a Lebanese organization that work with people with disabilities:

“The system is not ready. But still, we are trying our best, because we believe that these children, maybe we are trying for now to include mild cases, because we we believe that they, other children who are moderate or severe has to receive the services in centers like markaz (specialized center) because the system is not ready. The mild cases maybe can be accessing the schools (Lebanese public schools) easier than the moderate and severe cases.” (Merjan).

People with mild disabilities appear to be generally prioritized in ‘inclusive programs’ compared to people with more moderate and severe disabilities. In the same way, inclusive education practices seem to prevalently target children with physical disabilities as they require cheaper interventions, which ‘fit within the budget’ and the cost-benefit logic. Trani et al. (2012) share similar findings, where they acknowledge the reproduction of inequalities through the education

practices implemented, which appear to be rooted in “implicit cost benefit analysis that determines who should be educated” (p. 20), hence, included. Ferazia critically states that children with physical disabilities “just need a ramp”, raising an extremely problematic issue concerned with the risk of transforming inclusion from a “fashionable agenda to a tick-box item without a serious shift in norms or approach” (Lough et al., 2022: 26). The reduction of disability inclusion to ramps, and ‘accessible’ facilities not only risks becoming a mere performative exercise to access fundings, and to revendicate a deceptive commitment to inclusion, but it also endangers meaningful efforts towards sustainable and relevant inclusive practices, reproducing ableist forms of marginalization and structural oppression, which end up sustaining exclusion. Ferazia, in a previous interview, also shares that:

“It's easy to include person with physical disability rather than visual disability, or hearing disability. You do not need much. But they will not accept (school personnel) or they didn't accept the inclusion of persons with intellectual disabilities.” (Ferazia)

Similarly, Trani et al. (2012) report that in Afghanistan, children with physical disabilities were more likely to access education opportunities compared to their peers with sensory, or developmental disabilities, as accommodating the needs of the latter would have incurred in additional costs, an option that is not contemplated in a system based on utilitarian neoliberal logic. Lack of mainstreamed and intentional inclusive efforts results in patchy and disability-hierarchized responses, where only students who manage to conform to ‘normative forms of being’ are seen as ‘includable’.

Another Lebanese interlocutor, Shanifa, working in an INGO, highlights the crude reality linked to the implementation of inclusion as a sterile neoliberal-driven box-ticking exercise:

“A very concrete example comes to mind in our last project with UNICEF something that had been overlooked or was a very common

problem was that children with disabilities were not able to use the bathroom independently OK so uh they so very often this would be the case where we have children with disabilities who were not able to use the accessible bathroom independently, and because this was not factored into by the program division, to the project, we had to exclude them and this is a very common occurrence and co-occurrence. When they write the projects (INGOs and UN agencies), it feels like they don't understand what's happening on the ground yeah it feels unfair sometimes to the beneficiaries, especially for children with disabilities.” (Shanifa)

Her insight confirms the concerns regarding the risks of seeing inclusion as just an uncritical element to be incorporated in project proposals to appear ‘competitive’ allies of marginalized groups, and to have access to donors’ fundings; instead of a fundamental requirement to ensure people’s human rights. The failure to understand people with disabilities’ real needs not only hampers progress towards the realization of authentic inclusive programs, but it also creates distrust towards implementing organizations, that come to be seen as indifferent to people’s priorities and necessities and interested only in pursuing their own agenda.

Consequently, children who are deemed as ‘too disabled’ to comply with neoliberal standards of humanness, and humanitarian aid priorities, remain excluded as explained respectively by Bariqa, a Lebanese disability expert, and by Aahad, Lebanese representative of a local organization, in the below excerpts:

“Teacher in the school will say I cannot take this child because it takes too much time. They are supposed to be integrated but only few are. The mild forms (of disability) are integrated, but one with severe disability forget it.” (Bariqa)

“It's not easy to work with severe disabilities. (...). we don't have programs, educational programs, at least for severe disabilities. And this is a big gap, not only in Beqaa, but in all Lebanon. [On children with severe disabilities] it's it's complicated and hard. But organizations had to commit to respond to the needs that that are harder to provide than others. Of course it's more expensive, but we have all to commit to provide.” (Aahad)

Education initiatives promoted in humanitarian contexts prioritizes children with ‘easier cases’, for whom major changes in practices are not required, and minor environment adaptation are sufficient for their ‘effective’ integration/assimilation in ‘inclusive programs’ (Costantini and El-Serafy, *under review*). The result is a disability-hierarchization process based on the type and severity of people’s disabilities, aimed at identifying and classifying the more ‘suitable’, ‘exploitable’ and ‘valuable’ individuals for ‘inclusion’. The disability-hierarchization process is used to sort and select children with disabilities who better comply with predetermined standardized neoliberal norms, dividing them in over-simplified and homogenized categories, marginalizing those who do not fit in them. It serves as a discriminant to decide who is included and who is excluded. It follows that a neoliberal ableist operationalization of inclusion is used, which focuses on what bodies and minds can best serve the global economic market, and the humanitarian industry, hence deserving to receive services and being ‘included’. This point is fundamental to critically reflect on how refugee with disabilities’ bodies and minds are constituted within inclusive neoliberal humanitarian rhetoric, and which are the consequences of this neoliberal humanitarian game in identifying and defining bodies that matters (or not).

Titchkosky (2014:129) writes that “some humans need to ‘do’ human if they are to be seen to ‘be’ human”, explicating that the division between human and non-human determines whether one is seen as a bearer of rights or not. The humanitarian apparatus, made of policy makers, donor agencies and other actors, becomes the one drawing the lines of humanness. The humanness of a person’s life appears to be measured in terms of doing a ‘neoliberal being’ rather than just being human. This justifies the prioritization of certain disabilities over others. The result is a hierarchization of humanness that sees people with severe, and complex disabilities as the least human, whose systematic exclusion from education opportunity is acceptable. Participants’ narratives show that exclusion not only from education, but also from health care, medication and

other emergency and development interventions, means that Syrian refugee children with severe, and complex disabilities are ‘left to themselves’ (In-vivo code), forced in a status of *bare life*, where their life as *homo sacer* can be killed, or in this case ‘let to die’, without any legal repercussion, but a futile lightning-fast disdain to the best.

This process of disability hierarchization in terms of ‘ability’ and of neoliberal political economy of bodies – based on disability’s type and severity –is at the basis of the implementation of neoliberal inclusive programs. Chaudhry (2015:7), in her study on inclusion and participation in leadership roles for people with disabilities, states that

“only those disabilities which could be capacitated enhanced to achieve active and productive participation were incorporated in leadership roles, whilst other debilitated disabled people faced exclusion. (...) The inaccessible nature of participation made it challenging for people with severe disabilities to actively participate, and this served to create a disability hierarchy of sorts.” (p.7)

It follows that only bodies and minds able to embody desirable normative behaviors and models of productivity, which would guarantee the autonomous functioning of ‘inclusive projects’ without requiring structural changes and accommodations to facilitate participation, are valuable for and welcomed in the neoliberal economy of inclusion promoted within the humanitarian (education) industry. Therefore, hierarchizing disability means to hierarchize humans’ worth in terms of normative ability, commodifying bodies, and defining their political economic value. The lesser your abilities are, the lesser your worth is (see also Kiwan, 2010 and 2022). This process defines why and how some bodies matter more than others in our ableist society, enacting renewed forms of domination and control. ‘Neoliberal inclusion’, through disability-hierarchization processes, promotes forms of ‘exclusionary inclusion’, which operationalization is further discussed in the next section. It also provides the precondition to support the establishment of spatiality of exceptions, where people deemed as not exploitable, and worth/less come to incarnate the figure

of *homo sacer*, being relegated in a status of *bare life* and left to die outside the margins of the *polis* and of humanness.

5.2.2 Promoting Exclusionary Inclusion

“Material effects of ableism result in the removal and/or erasure of disability even in social practices that purport to be inclusive.”
(Erevelles, 2011: 33)

The neoliberal forms of inclusion promoted within the Western neoliberal and colonial educational efforts operationalized by the humanitarian system appear to advance and strengthen practices of ‘exclusionary inclusion’ based on ableist conceptualization and understanding of disability. As mentioned in the previous sections, the neoliberal marketization of aid has transformed inclusion in ‘exclusionary inclusive’ practices, where inclusion, as explained by Erevelles (2011:33) is reproduced according to neoliberal and colonial methods of 1) “assimilation”, where only ‘able-disabled’ bodies are deemed worthy and suitable for ‘inclusion’; and 2) “annihilation”, where bodies that are ‘too disabled’ are left behind and deemed un/worthy and value/less. Based on logics of cost-benefit, ‘flesh employability’, commodification of bodies, and notions of ‘able-disabled’, disability-hierarchization processes are used to identify which are the exploitable bodies and minds to select for ‘inclusion’. In ableist exclusionary-inclusive systems, people with severe and complex disabilities pay the highest price.

This section focuses on a critical analysis of the biggest inclusive education effort in the country: the Inclusive Education Pilot Project (IEPP), implemented by UNICEF in collaboration with the Lebanese Ministry of Education and Higher Education (MEHE). The IEPP was systematically brought up, criticized, and questioned by national and international actors, who highlighted its exclusionary nature, despite its inclusive claims. Majedah, a Lebanese UN agency’s representative,

reflects on the exclusionary structure of Lebanese society, problematizing the level and status of inclusion within governmental and international inclusive education projects, such as the IEPP:

“You know that in Lebanon now the main issue, when it comes to disability, and inclusion is really the *system of exclusion that we have in Lebanon with these uh uh (international) organizations and system itself that is promoted by many of our Government institutions and ministries to reinforce exclusion of children with disability*. So I think now it's even more challenging to reform that system because of the crisis uh, and of course, limited capacity of the public school system. So I think the whole system is under a lot of uh uh pressure uh which makes disability and inclusion even uh, even harder. However, the pilot schools (the 30 inclusive pilot schools of the IEPP) are *only including Lebanese children at this point*. And when it comes to the severity of the disability, *they don't take severe*. If you look at how the system is set up is that you get the mild to moderate (disabilities) to go to MEHE's pilot school and non-formal education, while *the moderate to severe (disabilities) will go to specialized partners or will remain at home*.” (Majedah).

Majedah explains how in Lebanon, inclusive efforts are directed towards exclusionary practices, which appear to be reproduced within Lebanese government institutions as well as international organizations operating in the country. The UN's representative underlines how the entire Lebanese system is ingrained in this exclusionary response and explains that “much of the funding and money available go to this (exclusionary practices), the vast majority of budget and resources of the Ministry of Social Affairs is actually going to specialized institutions that enforce exclusion and segregation”. She also acknowledges the difficulties in trying to advance reforms amid compounded crisis, where of course the emergency rhetoric legitimizes the lack of capacity to promote more inclusive practices.

She also provides another important insight into the different layers of exclusion reproduced within the IEPP. In Lebanon, Syrian refugee children with disabilities experience “multiple axes of exclusionary intersectionalities” (Kiwan, 2021: 283), with their legal (refugee) status and disability

representing the most significant drivers of exclusion both from education and from other life-saving services, even when those services claim to be inclusive. Majedah clearly affirms that the IEPP has only been including Lebanese children, leaving behind their refugee peers. She also describes how Lebanese children with disabilities come to be included according to their type and severity of disability, underlining practices of disability-hierarchization, where only children with mild and physical and/or learning disabilities are considered for inclusion. The IEPP is promoting inclusion based on intersectional and multidimensional exclusionary practices, where children are excluded from ‘inclusion’ not only according to their citizenship status, but also to the type and severity of their disabilities. Another interlocutor, Kiswar, member of a Lebanese organization which work with adults and children with disabilities in the region, confirmed Majedah’s statement on the exclusion from the IEPP of children with severe disabilities, and adds on the structural lack of inclusion for refugee children within these 30 inclusive schools, affirming that “they do not accept to integrate refugee children with disabilities as it is only for Lebanese” (Kiswar).

As mentioned in chapter 2, in 2018, the MEHE and UNICEF launched the IEPP in 30 public school. The aims of this pilot project are to increase enrollment rates of children with disabilities, as well as to strengthen the capacity of the Lebanese public school system, providing inclusive education training for schools’ staff and education personnel to create inclusive education environments (UNICEF Lebanon, 2018). In June 2021, an official assessment of this pilot project affirms that despite the exceptional compounded difficulties encounter between 2018 and 2021, “MEHE is ready for a full-scale implementation of the IE project” (Merhej, 2021: 82), as the data shows that the schools involved have developed a strong culture of inclusion and have been able to provide inclusive education opportunities for children with disabilities. The report suggested to scale up the project to other 30 schools between the scholastic year 2021-2022.

The case study on the IEPP (2021) presents the statistics of the children with disabilities included in the pilot project disaggregated by type of disabilities for the academic years 2018-2019 and 2019-2020. However, in the report, there is no information related to the severity of the disability, or of the citizenship status of the students. In June 2023, the IEPP entered its second phase, with an additional scale up aimed at increasing the number of inclusive schools in the country to a total of 90 first shift and 20 second shift rotations. The second shift would respond to the educational needs of refugee children with disabilities. When I conducted my fieldwork, between August 2022 and October 2022, the IEPP was still in its first phase. Before the start of the fieldwork, I had read about the 30, and then 60 inclusive schools and their success in enrolling children with disabilities; however, despite the positive achievements noted in the report, I remained critical of its overall narrative. I acknowledge that this is probably due to the parallel experience I had that same year working as a monitoring and evaluation intern at the United Nation Global Fund for Education in Emergency, Education Cannot Wait (ECW), where I was appointed to the review, assessment, and analysis of large numbers of emergency and development projects' reports. The internship helped me to develop a certain level of knowledge as well as appreciation on how reports are written, and data are gathered and shared according to donor's framework and agenda, raising a fundamental question, that came up also during my research, concerning the real place of inclusion for education in humanitarian contexts.

The fieldwork confirmed my somewhat initial critical position towards the abovementioned case study. The interviews with organizations' representatives deepened my understanding and knowledge on the Lebanese IEPP and allowed me to add a solid layer of criticality to the emerging conceptualization of 'neoliberal inclusion'. For instance, Ferazia states:

"As I told you before, they used to enroll people with learning disabilities and say they were intellectual disabilities. And they thought that everyone will accept this. But I was among the one who

asked what type of intellectual disabilities do you accept here, so when you ask specific questions, they don't know how to answer and they say that they accept people who have some problem at school, and I argued about what problems as everyone might have problem at school, and then we find out that people with learning disabilities were considered as having an intellectually disability" (Ferazia)

Practices of children's misdiagnosis within the IEPP mentioned by Ferazia were also denounced by other interlocutors, who confirmed that many students classified as having 'learning difficulties' were misdiagnosed, in that they did not have any disability, but they were included under that 'disability category' to report on higher numbers for the project (Elias and Ijaaz). In general, most interlocutors appeared to be extremely critical of this initiative, denouncing not only the lack of inclusion within the project, but also the level of widespread corruption in its implementation, highlighting the exclusionary nature of the Lebanese IEPP, and problematizing the effects of exclusion on children with severe and complex disabilities, who are systematically neglected and left behind. For instance, Cyla, a Lebanese organization's representative, and Zoona, a Lebanese disability specialist, respectively share

"Two years ago, they (MEHE and UNICEF) started this pilot project in 30 schools. This is the first big step from the ministry, but they are starting type of disability per type of disability. It's all about it. They are starting with light and easy (mild) disabilities in the inclusion. To Reach in 2030, the inclusion of all children with disabilities. So we are fighting, [because] during these ten years children with severe disabilities will lose their rights to access the education, the school, what they can do? So they (MEHE and UNICEF) didn't have answers to that so, as OPD, we are against this methodology, but we started seeing something from the ministry." (Cyla)

"With these 30 schools people tend to be marginalized again, because only mild disabilities are the ones who can access, but when we talk about multiple disabilities, severe disabilities definitely they are not included. There is a risk that, instead of being progressive and going towards inclusion now we're going backwards to institutions organizations, special organizations and so forth." (Zoona)

It is evident that the Lebanese IEPP is still far from achieving inclusion, and it is actively excluding children with more severe and complex disabilities, for whom education is still a mirage. As stated by Cyla, inclusion is being actualized by type and severity of disability, prioritizing children who better comply with neoliberal normative requirements of doing and being. The IEPP follows the rule of the humanitarian neoliberal political economy of bodies, enacted through a disability-hierarchization process aimed at identifying suitable, optimizable and commodifiable subject that would guarantee the achievement of prefixed project's targets, and its quantifiable and measurable outputs (in this case enrollment of children with disabilities). Trani et al. (2012:20) explain that the neoliberal criteria established to be considered 'educable', appears to follow the equation

"investment required in financial and human resources to send a child to school, and it is measured by basic indicators (enrolment, drop out, completion rates, etc.)'. (...) [meaning that] the utilitarian [neoliberal] approach will only accept to accommodate some special needs as long as they call for easily implemented measures and yield [measurable] learning outcomes." (p. 20)

Another interlocutor, Elias, from a Lebanese organization, building on the lack of inclusion within the IEPP mentioned above, explains:

"I am deeply disappointed from UN agencies, specifically at this time. You will not see big differences between the public sector and the UN agencies. When you go inside the UN agencies, you will see that they have the same mentality, and bureaucracy and system as in the public sector. Because, I raised the question what is the role of UNICEF with public schools, when these public schools are still not inclusive, and UNICEF is funding and monitoring this program since 2018. So when you know that also who is the key person in UNICEF and what is their professionalism and experience in inclusive education, you will find the same, that you can see their very good job title as inclusive education specialist, but when you see these people you notice that they do not have any experience and that they do not know inclusive education, so how they are supposed to support the MEHE?" (Elias)

He then continues with additional remarks on the IEPP:

"These 60 inclusive schools are not prepared to include moderate or severe disabilities. They are now inclusive mainly for children with learning difficulties, and not for children with moderate disabilities and those, whom we call with severe disabilities. These schools are not inclusive for them till now. Then how comes that you have an inclusive school, but you do not include blind children? Deaf children, children with intellectual disabilities, so inclusive for whom?" (Elias)

Elias not only challenges the widespread misuse of the concept of inclusion, but he also denounces the lack of knowledge and awareness on disability, inclusion, and inclusive education, both at the government and at the UN level. Majedah, UN agency's representative interviewed, confirmed Elias' concerns, disclosing that both UNICEF and UNHCR do not have disability specialists in their teams, and this of course is counterproductive and represents a significant challenge when trying to ensure that all UN's activities comply with disability-inclusive frameworks.

The exclusionary nature of the Lebanese IEPP raises an important and legit question: which are the actual education opportunities in Lebanon for Lebanese and refugee children with moderate, severe, and complex disabilities, who are excluded from inclusive education efforts? Interviewees explain that

"In severe cases we refer them (children with severe and complex disabilities) to specialized school. If we refer a child to a specialized school, it means that the child has very severe disability, and there is no hope to enroll them in formal or non-formal education. Like for example, a child has motor and moderate to severe intellectual disability, with additional associated problems, we refer them to specialized settings." (Aleyna).

"The education system in Lebanon, and we have seen with children with disabilities, teachers even in the organizations, specialized organizations, if we have a severe disability case, they are not able to have them in the project." (Kitana).

The only option left for children with disabilities, especially with severe and complex ones, who are excluded from inclusive education efforts, is being enrolled in segregated institutions, where

they are isolated from the rest of the community, and separated from their families through the live-in system, which completely remove them from the society's public sphere. However, as further explained in the next section, institutionalization is a very rarely contemplated option for the refugee families interviewed. Many parents refuse the idea of sending their children to live in a *markaz*, far from the rest of the family. Moreover, *marakiz*, for the many refugee families who do not manage to access them through UN's funded projects, are very expensive, and very few people can afford the high fees requested. As a result, in most cases, children and youth with disabilities remain confined to their home, being excluded from education, as well as from other services and opportunities. OPDs' representatives acknowledge that, unfortunately, inclusion has been marketized, and the inclusion of people with disabilities has become a business, rather than a fundamental human right, and this applies to every sector, from education to health care. Consequently, following the neoliberal and utilitarian logic intrinsic to humanitarianism, physical and mild disabilities are prioritized in humanitarian-led education interventions, resulting in perpetrated biases and misconceptions, as well as structural exclusion of people with psychosocial, developmental, sensory, severe and complex disabilities (Disability Under Siege, 2021), with serious repercussion on the signification of the concept of inclusion.

For instance, inclusive education as a philosophy and practice advocate for equal and quality education opportunities for every child, regardless of their gender, ethnicity, religion, dis/ability, and other socially constructed categories which have been historically instrumentalized to marginalize certain groups of people. Elias' question "Inclusive for whom?" appears not only legitimate, but also fundamental to critically reflect on how inclusion is being improperly employed to refer to exclusionary practices. I will come back to this at the end of this section with some additional considerations. In the meanwhile, it is important to reflect on what happens at the intersection of refugeehood and disability in an 'exclusionary inclusive' system. Elias provides an

important insight to start problematizing the quality and availability of education opportunities (or lack thereof) for Syrian refugee children with disabilities in the country within the dedicated second shift in Lebanese public schools:

“When you talk about Syrian refugees and inclusion and education, the situation is worse, is more bad than what we have in the public schools, because also the you know local and international organizations, which have education programmes for Syrian refugees, mainly non-formal education programs and those who support Syrian refugees in schools in formal education, you can notice that they do not have any experience in disability. According to me, the opportunities to include Syrian children with disability in formal education is very limited and very difficult. when you ask these organizations what you do after these children graduated from your program, they said that they try to refer them to formal schools. But ok formal schools are not inclusive so to which formal school are you referring the kid? And this is what they do.” (Elias).

The quality of education provided both in the formal and non-formal education sectors is inadequate to meet students’ learning needs. Other interlocutors expressed similar concerns about the scarce quality of education provided for Syrian refugees (Aahad, Aleyna, Majedah), especially for those with severe and complex disabilities, who are completely neglected and left behind, falling through the cracks of an exclusionary inclusive system.

Hence, all these inclusive education efforts are “Inclusive for whom?”. It appears clear that the ‘inclusive’ discourses promoted by the humanitarian system, and more generally by global political elites, are based on exclusionary ableist conceptualizations and operationalizations of inclusion, which erase disability from the same practices that purport to be inclusive (Erevelles, 2011), as shown by the Lebanese IEPP. As a result, we have an inclusion that is not made to achieve social justice and to challenge the colonial neoliberal equilibrium; rather, it maintains and reproduces inequalities, controlling and disposing of bodies deemed as a ‘threat’ and/or as a ‘burden’ (refugees, citizens with disabilities, or refugees with disabilities), through emergencization rhetoric aimed at

‘morally’ legitimizing exclusion. Therefore, ‘neoliberal inclusion’, enacted through disability-hierarchization processes, re-creates exclusionary inclusive systems, reproducing and maintaining inequalities, creating spatiality of exceptions, as well as exacerbating barriers for people with disabilities. In what follows, I present some of the challenges and barriers Syrian children with disabilities and their families face, highlighting their coping mechanisms, as well as forms of resistance to practices and spaces of exclusion.

5.2.3 Facing and Resisting Barriers

“She loves to learn, and all her brothers and sisters teach her on a daily basis what they learn in school.”
(Lamya, Khadija’s mom)

Lamya was the last mother we interviewed during our first trip to Beqaa. It was around 5pm when we started the interview. Lamya and her husband Kadin had hosted all the other families in their tent that day, and they patiently waited for everyone to share their lived experiences, offering a safe and welcoming space to everyone. Lamya’s daughter, Khadija, is 10 years old. She is very smiley. While we were talking with her mom, she was very attentive, and when Lamya mentioned that she is *shattura* (clever), she started giggling and nodding in sign of approval. At some point, with Lamya’s help, we asked Khadija what and where she would have liked to learn, and with a smile she addressed her mother, who then translated for us, saying that she would have liked to learn English to be able to speak with me, and that she would have enjoyed learning from home as it would have been easier for her. Khadija’s mobility is extremely reduced, as her health condition dramatically deteriorated since they fled Syria, and it is now quite severe. She is relegated inside, and she manages to go out only when accompanied by her mom or one of her siblings. The surrounding environment is not very accessible as there is only land around, and Khadija does not have a wheelchair or walking aid that would allow her to move a bit more freely.

Lamya explains that Khadija does not only have the will to learn, but she is also doing her best to improve herself every day, learning from her brothers and sisters. “All the progress she is making are due to her willingness to be better, to improve herself, and to learn. She does it by herself, despite the lack of everything” says Lamya. Every year Kadin and Lamya, when they register their other children to school, ask if there are opportunities for Khadija, and every year, Khadija is excluded.

Erevelles (2011:6) affirms that “bodies do matter in political economy”, and she recognizes that in our neoliberal transnational capitalist society some bodies appear to matter more than others. Following a value-scale based on people’s capacity to perform a neoliberal being, people with disabilities are often considered valueless, and are left behind to resist barriers imposed by ableist societies and reproduced by the humanitarian aid market. Here, I reflect on the multiple challenges Syrian refugee children with disabilities and their families encounter in accessing education opportunities due to the material effects of ableist neoliberal forms of inclusion. Most of the children who took part to the study have never had the chance to go to school, but in one way or another they all experienced transgressive forms of learning. I define it as transgressive as their learning practices transcend narrow and traditional understanding of what learning ‘should be’, and how it ‘should happen’, to reposition it as an inherent inclination, which can take different forms, and happen in diverse ways and spaces. For instance, as explained by Lamya, her daughter Khadija, who has a severe disability which largely limits her movement, and influences her communication style, never loses an occasion to learn from her siblings.

It must be acknowledged that accessing the education system in Lebanon, whether private or public, has become extremely challenging for Syrian children, regardless of the disability dimension. Some of the barriers and challenges reported in this section are equally experienced, even if to a different extent, also by Syrian refugee children without disabilities, as for example the

lack of available education opportunities and/or transportation services (Buckner et al., 2017; NRC, 2020), or bullying practices perpetrated by Lebanese children and school personnel against Syrian students (Shuayb et al., 2014; El-Ghali et al., 2016; UNICEF, 2021). During the interviews, Syrian parents highlighted five main challenges hampering the access to education opportunities for their children with disabilities: a) the Lebanese exclusionary education system (including formal education, both public and private, and non-formal education); b) high cost of *markaz*'s fees; c) lack of education services for children with disabilities; d) high cost of transportation fees; and e) bullying.

The education sectors, both public and private, including also non-formal education alternatives delivered by humanitarian actors, are far from being inclusive, despite the renewed commitment to inclusion, and to disability-inclusion in their philosophical approaches. Many Syrian parents report experiences of exclusion, explaining how their children with disabilities remain invisible to humanitarian actors. For instance, Amina, mother of two children with severe disabilities, explains that

“Her children were refused by every institution because they were and still are wearing the diapers. She tried to register the kids in a special institution for children with disabilities, but they refused the kids saying that they don't take such cases. She tried her best (...), but unfortunately, she failed.” (Amina)

Amina also described how her children's health has been deteriorating since the start of the war in Syria due to lack of access to services, especially physiotherapy and medical treatment. She revealed that once in Lebanon, she was hoping to provide her kids with better opportunities, being able to enroll them in a school or a *markaz*, so they could improve their situation, learning to be more independent, as well as to achieve new milestones improving their skills. However, she never managed to find a place that would accept her children. As a result, her children's health

dramatically deteriorated, further aggravating their already severe conditions. As Amina, also other mothers expressed this sense of failure for not being able to find education opportunities for their children with disabilities despite actively trying their best. For instance, Fadela during the interview asked me to push the international community to take seriously the right of children with disabilities, not only their right to education, but also to other basic services, such as physiotherapy, and healthcare and medication, because without those, their health deteriorates, with serious repercussions on their lives. She then added on education

“Education is fundamental to help them (children with disabilities) to be independent and be able in the years coming to serve themselves and be more confident. If you can push for this at the international level (...) she tried to register her daughter in different schools, but they answered her that she is not suitable for the normal schools, and she is also still young.” (Fadela)

Most of the Syrian parents interviewed, not only highly value education as a life-changing opportunity which can improve their children’s life, but also strongly believed that their children, if offered the opportunity to learn, would be able to improve and to challenge society’s understanding and perspectives on people with disabilities, which are still largely based on a widespread medicalized model, which is reproduced through deficit-language.

Maysa, a mother of three, explains that unfortunately “there is no integration for any child with disabilities, and even though there are many schools in the surrounding, she could not see any example of integration”. Maysa tries her best to sustain her daughter Zia, organizing activities at home like drawing, or by taking pictures and describing the picture to the child helping her to learn new words. She also made us aware that despite all her efforts, she is not a specialist, and she does not even have the means to better support her child’s education, highlighting how all the progress her daughters have made over the years are exclusively due to her eagerness to learn. She explains

“She (Zia) is very clever, she understands everything, but no one gave her the chance to be integrated in the education system. As a mom of a child with disability, her dreams and hope is that her child will have the possibility and the chance to prove herself/himself in the society, and to be able to receive the needed services. Zia only need and want a possibility, and then the society will accept her.”
(Maysa)

Maysa is sure that if her daughter is given the chance to be educated, she will be able to do great things. But unfortunately, no one is accepting her, no one is ready and willing to see her potential and to integrate her, not even when she offered to pay to a private school double fees to enroll her daughter. Manar, similarly to Maysa, has never doubted that her son Khaliq would do very well in school, as she recognizes that her child is very clever, and he can learn despite what other people think.

“He is able to learn, and she believes that if the child can receive the right support, he will surely be in a better situation later on.” (Manar)

Similarly, Farug, who would prefer his son Qasim to go to a specialized school, thinks that his child can learn with some extra help, and he would benefit from the experience

“He believes that if his son can get in a specialized school and receive specific services and education especially to improve his way of communicating, his communicative skills, of course he would be better.” (Farug)

The exclusionary inclusive education system, reproduced by both the humanitarian structure and the Lebanese MEHE and MoSA, leaves little opportunity to enroll children in inclusive learning spaces, highlighting the material effects of ableist approaches on Syrian children with disabilities, who continue to be excluded from inclusive education efforts. As stated above, in Lebanon, children with disabilities, especially severe and complex ones, are usually directed towards *marākiz*, which are particularly expensive, and tend to isolate and segregate children labelled as ‘different’, ‘a burden’, ‘the other’. The great majority of Syrian families are not able to afford the price of this segregated settings, being left with the only choice of keeping their children with

disabilities at home. Some of the parents, like Nada and Farug, explained that they were considering every opportunity just to make sure their children could learn

“She tried to register her child with disability in a markaz here for orphans and children with disability. She thought that here in Lebanon is like in Syria, that is cheap, and they could afford it, but she cannot afford it because they asked her to pay in dollar (...) so she told the child with disability that she did not have any possibility to register her in the school. So the daughter has been living for 4 years in a room without education.” (Nada)

“One of the doctors told him that there are some institutions who provide education services for kids like his son, but he said “to be honest you cannot afford it, and you might not be able to take your child there”. He (the doctor) refused to share with the family the contact, address, and other information about the school/institution.” (Farug)

Farug’s account of their struggle to find a school to educate his son revealed the medicalized approaches used to conceptualize and relate to disability, as well as the patronizing attitudes towards refugees, where people in position of power feel they have the right to make decisions in their behalf. Farug explained that he was very disappointed by the doctor’s behavior because it is not his decision to determine how the family uses its money. He said that it would have probably been the case that they would have not been able to afford the school, but it should have been ‘his call’. Similar narratives were shared also by other parents, who reported that when consulting NGOs and other international organization on the education opportunities for their children, some workers would answer that their children were not able to learn, and they should have not been bothered. Lakia shares

“An organization came and looked for the situation of the child with disability and they told the mom that her daughter is not able to learn because she cannot use the pens, pencils, etc. And this organisation is supposed to help children with disabilities. The organization was not cooperative with her.” (Lakia)

My encounter with Lakia prompted some reflections on the meaning our current society attributes to the words ‘learning’ and ‘education’. As it has been previously explained, in a system that is based on neoliberal forms of inclusion, people are classified and hierarchized according to their ability to perform a neoliberal being, meaning that the people included are those who can comply with normative rules of behaviours and fit within socially constructed accepted forms of living that do not require a change in the status quo. If we read the act of ‘learning’ in these terms, only a type of learning appears to be possible, namely conventional, curriculum-based, grade-driven learning. Hence education becomes a mere space of performativity, of normative neoliberal performativity. Constructing education in these terms, and understanding learning through an ableist narrow lens, contribute to the disqualification of atypical and transgressive learners, who ask for a reconceptualization and redesign of the signification of learning and education, as well as of their practices. Education in humanitarian contexts currently lacks the capacity to theorize education in these terms.

Also, among the children with disabilities, who are considered to be still teachable in segregated institutions by the ableist system, many are struggling to access these restricted environments due to the lack of available services in their areas. Some of the families explain that the only opportunities to send their children in these marākiz is through the ‘live-in’ system, because the centres are so far from their houses, that it would be impossible for them, and also for the child to manage the trip on a daily basis, as it would take hours. All the parents interviewed expressed their unwillingness to ‘abandon’ their children in the live-in system.

“She would not be happy if her child will be institutionalized, like in the live-in system, but she prefers that he goes and come back on a daily basis. In this case she would be supportive. But she doesn’t want him to stay in the live-in. (...) in the surrounding there is a school that take such cases (referring to her son’s disability), but it is

a live-in system, and she doesn't accept to send her son there because it is her child and she wants to raise him." (Jana)

"The school tried to register her son full time, to live in the school, but she said no because she prefers to have him with her and see him every day." (Bushra)

"She wanted to register him in a markaz in Tripoli because he (the child) started feeling a bit sad, unhappy and alone when he saw the other kids going to school, and he started asking "why I am not going to school?". They (the markaz) told her that they can take the child, but he will be enrolled in the live in system and they can take him only for one day per week. The aunt said that the grandma doesn't feel comfortable with this, and she doesn't think it is the good choice because in the institute there are a lot of children with disabilities, and some of them are severe cases, and she felt that she was putting her grandson in an inconvenient position, and she felt guilty because she doesn't want him to live such a life." (Mariam)

This last excerpt is quite important because it shades light on the serious stigmatization that exclusionary systems create and re-creates at the society level, reinforcing ableist understanding of and approaches to disability and reproducing phenomena of segregation, inequalities, and isolation. In this specific case the grandmother was against the live-in system because she did not want her grandson to live among peers with disabilities, "she doesn't want him to live such a life". A life of isolation, exclusion from society, and stigmatization. The fear of raising her grandson in an institution gives an idea on the effects that institutionalization has on the life of people with disabilities: they are stripped away from the familial and societal fabric, reclused in a de-identificatory space, where they are prevented from any sort of participation in social life. The grandmother in refusing the live-in system, was refusing to cut out her nephew from the family socialisation process.

An option that the grandmother was keen to accept was for the child to go to the same specialised centre daily, coming back home every day. This possibility was given, but due to the family's dire economic situation, and the considerable geographical distance of the centre, it was not possible

for Mariam to cover for the transportation costs. Transportations fees were mentioned by many families as an important barrier to access education opportunities for their children with disabilities. Some of the parents explain that finding suitable transportation services for their children, and more generally for people with disabilities, is impossible, as the great majority of *mashrua* (small white van) are not accessible, and taxi services are too expensive, especially since the price of the fuel drastically increased (Mouna, Mariam, Lakia, Faiza).

The last major challenge participants mentioned was bullying within the Lebanese education system. Bullying, as explained in chapter 4, seems to be a widespread phenomenon against Syrians, fuelled by xenophobic and hate discourses, and reinforced by securitization rhetoric, which tend to ‘criminalize’ and ‘otherize’ Syrian refugees. Syrian refugee children with disabilities experience a double layer of discrimination, and different forms of bullying which alternates in an erratic fluctuation between their disability and Syrian-refugee identities. Among the 25 Syrian children with disabilities included in the study, only 5 managed to access the Lebanese public education system for a short period of time. Of these 5 children, 4 experienced severe forms of bullying. For instance, Qadira shares with us her sons’ experience in the Lebanese education system

She sent both brothers with disabilities in the same school. The youngest had a better experience, but the oldest since he was using the walking stick, other children used to make fun of him, and he used to react in an aggressive way, so the school called the mom and said that they didn’t have space anymore for her kid. The teachers in school were very respectful towards her son with disability. One of the teachers used to hold him and help him in case he lost his balance or when he was in need. So the teachers were great with him, but the problem was from other kids. Some of them were afraid of her son, others were bullying him, so the kid suffered a lot because of the bullying, he attempted suicide twice and this is also why he was obliged to leave the school (Qadira).

Gadi, Qadira’s oldest son, was often targeted by bullies with dramatic effects on his mental health and wellbeing. During the interview with Gadi, he disclosed that he feels upset because he cannot

walk, and because he cannot walk, he is angry with himself, with his parents and with doctors. Gadi sees his disability as an impediment, as something that prevents him from being ‘normal’ and from being accepted. Due to the constant bullying, Gadi started to react in aggressive ways and to isolate himself, ultimately losing the opportunity as well as the willingness to go to school. Gadi’s feelings emerge from societies’ ableist and highly stigmatized understanding of disability, which promotes a language of deficit rather than possibilities, and which sees disability as an undesirable trait, rather than a desirable human feature.

Raja experienced similar circumstances, and she opened up with me and the interpreter on her short time in school

“She was severely bullied at school especially before wearing the hijab. Kids were targeting her on a daily basis, inventing bad rumors and going to the principals to accuse her of things she didn’t do. And back then the principal didn’t know she was suffering from a hearing problem, neither the kids, but since she was not able to act normally because she couldn’t hear, the kids used to target her, and then the mom decided to remove her from the first school and register her in another school, but unfortunately, they refused to register her. And she mentioned that once some kids locked her in the bathroom, and she was not able to go out, and when she went to the principal to address this problem, he said he could not believe that this was the truth because she already had a long history of problems. So she said that she lost the opportunity to learn because she was bullied, and she was bullied because she was not understood by other people, and by her community.” (Raja)

Raja and Gadi were bullied because of their disabilities, and both of them lost the opportunity to receive an education due to the exclusionary nature of the learning spaces available for children with disabilities. To a different extent also Saarah reports being bullied because of her glasses, and she disclosed feeling useless and worthless when people judge her and underline that she has problems with her eyes. Despite facing exclusion, discrimination and bullying, children perform articulated forms of resistance, through which they try to overcome, manage, and even negotiate

the terms of their existence in unfriendly and ableist spaces, which constantly scream ‘you do not belong’.

For instance, children’s dream to learn pushes them to adapt and re-adapt employing different strategies to improve themselves and to learn new things. Many children also used the interviews as a space to ask questions they were curious about. One child asked me to draw a political map of Europe because he wanted to understand where Italy is located (Utba and his brother). Other children asked me for the Italian translation of few words such as ‘cat’, and ‘sun’, or wanted to practice a few English words they learned from their siblings (Jamal, Fadil, Hamra and Khaliq). Older children, especially girls, asked me about my education, and wanted to know how it was to be a girl in academia (Raja and Saarah). Younger children also employed other strategies such as learning from their older siblings while they do their homework (Zia, Khaliq, Utba); while others learn the Qur’an independently from their parents’ phones (Qudamah, Jamal, Khaliq).

Ferran and Gadi, the two brothers with physical disabilities, use their artistic work as a strategy of resistance. Thanks to their incredible creativity, they manage to realize small creation with very few tools, just a pencil and paper for Ferran, and recycled materials, such as plastic bottles’ lid and cardboard, for Gadi. The pictures below show Ferran and Gadi’s artwork.



Figure 1: Gadi's artwork



Figure 2: Ferran's artwork

The strategies mentioned above represent just some of the methods employed by Syrian refugee children with disabilities and their families to cope with the difficult circumstances they experience. Syrian refugee children with disabilities appear to adopt different forms of resistance to the exclusionary ableist forms of inclusion implemented, which contrast the general tendency of seeing children only in terms of vulnerability and protection. The propensity of seeing children with disabilities through a vulnerability language and a deficit lens is even more accentuated in the construction of children at the intersection of different historically socially constructed stigmatized categories of being, such as those of disability and refugeehood, which are ontologically conceived in negative terms, embodying the ‘unwanted other’. Erevelles and Nguyen (2016) reflect on how humanitarian organizations re-produce ahistorical disempowering images of racialized, gendered, and disabled southern bodies and minds, constructing these bodies as the direct result of “tragic harm, injustice and deprivation” (Kim, 2014:140), instead of a determination of the colonial and neoliberal political economy of bodies, aimed at defining humanness to administer and control life. Acknowledging people’s agentic power is fundamental to disrupt ableist and colonial practices of aid. These children’s forms of resistance provide clear examples of their active agency, and it highlights the need of replacing the humanitarian language of passivity, vulnerability, and

victimhood, with one that recognize children's' resourcefulness, strength, 'ability' and agency. This would also imply that the humanitarian structure has to commit to shift its paradigm of aid.

5.3 Conclusion

In this chapter, I have explained how neoliberal forms of inclusion, promoted within the humanitarian (education) system, and maintained by emergencization discourses, reproduce the systematic and structural exclusion of children with disabilities, especially with severe and complex ones. Firstly, I have showed how neoliberal forms of inclusion enacted through the hierarchization of disabilities operates to define which bodies matter and which bodies do not, defining who is 'suitable for inclusion'. Disability-hierarchization is conceptualized here as a process of human disqualification based on an individual's capacity (or lack thereof) to perform a 'neoliberal being', a being 'able' to comply with dominant socially constructed rules of normalcy. I then analyzed how people, whose bodies and minds resist discourses of normativity and material optimization of productive beings, are destined to be overlooked, falling into the cracks of an exclusionary inclusive system guided by ableist principles of functionality, normalcy, productivity, and neoliberal standard of exploitability. To conclude, I have reflected on the material effects of ableism – which is an inherent trait of neoliberal inclusion. This highlights the challenges in accessing education opportunities for Syrian refugee children with disabilities and their families, highlighting some of the barriers to access education services, as well as the forms of resistance that Syrian children with disabilities adopt to challenge normative understanding of learning and education. Moreover, I have drawn attention to the risks of uncritically constructing people with disabilities as ontologically vulnerable, depended, and de-agentivized beings, without addressing the intersectional historical, social and material foundation of their exclusion, segregation, and characterization as 'burdensome' and 'worthless being'. Neoliberal inclusion is here

operationalized as an ‘exclusionary inclusion’, rooted in historical/colonialism and material/neoliberalism ableist traditions.

In the next chapter, I present the last sub-category of ‘Letting die through Neoliberal Inclusion’: ‘Actualizing a *State of Exception*’. Building on the humanitarian (education) conceptualization and operationalization of ‘neoliberal inclusion’, legitimized and reproduced through emergencization discourses, I explain how spatiality of exceptions are actualized. I discuss the mechanisms through which Syrian refugee children with disabilities, especially with severe and complex ones, come to embody the figure of *homo sacer*, where their transgressive highly non-normative bodies and minds are forced in a status of *bare life*. While discussing the actualization of spatiality of exceptions through organizations’ representatives and participants’ experiences, I also aim to disrupt the idea that the *state of exception* encapsulates the de-agentivization of the *homo sacer*, providing an alternative narrative of resistance, which is rarely considered and acknowledge.

CHAPTER 6

ACTUALIZING A STATE OF EXCEPTION

Bare life is no longer confined to a particular place or a definite category. It now dwells in the biological body of every living being (Agamben, 1998: 81).

6.1 Introduction

In this chapter, I articulate the sub-category ‘Actualizing a *State of Exception*’, and its fundamental elements: ‘Politicizing and marketizing bodies and aid’, ‘Denouncing *Bare Life*’, and ‘Resisting Space of Exception’. In ‘Politicizing and marketizing bodies and aid’, I reflect on how the commodification and instrumentalization of the ‘refugee’ and ‘disability’ categories are used to serve the political and economic interests of the dominant Western humanitarian system. Aid is always political, and it is a means of control and domination. The interaction between the political and economic dimensions constituting the humanitarian system cannot be overlooked and must be understood as the foundational structure actualizing and reproducing spatiality of exceptions. In ‘Denouncing *Bare Life*’, I analyze how the status of *bare life* unravels within the everyday life of Syrian refugee families, transcending a prescribed physical locus to crystallize in the biological living being (Agamben, 1998). I take distance from the humanitarian political games and economic calculations of aid and bodies, to challenge the processes of dehumanization, de-historization and de-politicization enacted to silence the people inhabiting spatiality of exceptions. Too often we have read about the processes that lead to *bare life*, but we have not heard enough about what living in these liminal spaces looks like. This section is fundamental to disrupt the impersonal depiction of *bare life*, and to become aware of people’s experiences in the constructed state of exceptions they actively inhabit. Finally, in ‘Resisting Space of Exception’, I present stories of resistance and agency, that challenge the dominant imaginary of the passive, de-agentivized, vulnerable refugee with/out disability, calling for a reconceptualization of the state of exception as a space for different

forms of resistance. Syrian children with disabilities and their families, despite being structurally neglected and marginalized by the system, continue to resist, to exist and to ask and revendicate their rights. Failing to acknowledge their voices and agency within these exceptional spaces would serve to reinforce and uphold ableist, colonial and neoliberal construction of humanness.

6.2 Actualizing a *State of Exception*

“Life is biologized, politics is biologized and biology is politicized, life and politics have been economized, and making life is intertwined with making death.” (Bird and Lynch, 2019: 1)

Bird and Lynch (2019) talk about a biopolitical economy of body, highlighting the weight that neoliberalism has had on the redefinition of our biopolitical era, where bodies are valued according to their capacity to produce and to serve the neoliberal capitalist market. Life has been thoroughly politicized and economized in every sector and aspect of our society. “Valuable lives are [now] enriched by exploiting the life of invaluable lives. Life today is a bio-capitalist resource, colonized and commodified” (Taşkale, 2022: 3). This chapter, building also on the previous research finding chapters 4 and 5, underlines the (geo)biopolitical economy of bodies promoted within and by the humanitarian regime, shedding light on how certain groups of people come to embody *bare life*, and to occupy spatiality of exception. Krause (2014) critically reflects on the different ways in which the humanitarian system exercises power over refugee with/out disabilities’ bodies, recognizing that the influence and control it wields can also manifest in subtler, indirect forms – such as overlooking or omitting specific groups of people from humanitarian relief coverage. This directly refers to the authority that humanitarian agencies possess, which allows them not only to determine who receive assistance, but also, significantly, who does not.

Barnett (2011) explains how humanitarian organizations have come to exercise ‘state-like functions’, compromising states’ authority within their borders, and acting as a sovereign power.

Ijaaz, a Lebanese organization’s representative, confirms Barnett’s position:

In Lebanon, I can tell you that the government does nothing. So whatever happen here in Lebanon, whether it is positive or negative it’s OPDs and other organizations and NGOs and INGOs. They are service providers they support people with disabilities, some of them work in inclusive education, some of them concentrate on lobbying with the government, or for advocacy, other organizations support in the health sectors, others try to find jobs for people with disabilities. Whatever happen, every achievement in Lebanon can be related to OPDs and other organizations INGOs and NGOs. (...) We are behaving right now like if the government doesn’t exist. We know that there is always a place for the government, and we believe and hope that one day we will get back our government and the government will take over starting from the point we reached. (Ijaaz)

Ijaaz explains how, in Lebanon, humanitarian organizations, as well as local OPDs and other civil societies organizations provide public services, supplying public goods and assistance such as healthcare and education to both refugees and to a minor extent to Lebanese communities, operating as *de facto* government ministries. Humanitarian organizations, such as the UNHCR, leveraging their recognized expertise, authoritative position in refugee affairs, and the mandated responsibility to enforce international refugee conventions and law, have gained significant power, to the point that they do not only control and administer aid, but in doing so, they also make critical “life and death decisions about refugees without consulting the refugees, themselves” (Barnett and Finnemore, 1999:710), exercising sovereignty over refugees with/out disabilities’ bodies and lives.

Neoliberalism, which is the main logic guiding the economization of biopolitics, has to be understood as “a new configuration of the relationship between sovereignty and governmentality” (Lazzarato, 2015: 94), whose realization can be seen in the humanitarian management of aid and of the refugee crisis and its subject/object, the refugees. We learnt how life comes to be biologized,

and biology politicized, and the two of them economized, leading to a dehumanization of 'Life'. Maybe what is now necessary is to re-humanize 'Life', to take distance from old, and sterile construction of human bodies as solely expendable flesh, and to regain awareness of the agentic being hidden beyond the (geo)biopolitical economic fabrication of human life. Aybak, founder and director of a local organization for people with disabilities, during the interview told me:

Do people with disabilities have the right to live like just others? No!
Because what is needed is not provided. (...) Disability should be a
human rights issue. People with disabilities' needs are not luxury,
they are actual needs, human needs! (Aybak)

His words keep reverberating in my head, perhaps because he humanized needs instead of merely politicizing and marketizing them.

In what follows, I openly address the logic and impact that processes of politicization and marketization of humanitarian aid and bodies have in producing and maintaining *bare life*. I focus on the political game and economic calculation of humanitarianism, shedding light on how spatiality of exception come to be actualized.

6.2.1 Politicizing and Marketizing Bodies and Aid

"For me everything is politically planned. This is what I believe actually in everything. Everything is politically planned and internationally, not only on the national level." (Merjan)

Stoddard (2004) explains the highly politicized nature of aid, highlighting how humanitarianism is driven by geopolitical interests, rather than needs. He observes that international assistance is inherently discriminatory, as "aid dollars flow to areas of geopolitical importance to the donor group while leaving other areas and activities critically under-funded" (Stoddard, 2004: 3). The humanitarian aid system has been historically instrumentalized by the Global North to serve dominant Western interests and agendas. It has reproduced political and economic structures of

inequalities, maintaining unequal power relations entrenched with the aid flowing (Saleem, 2023), and protracted power imbalance in the broader relationship between the Global South and Global North, which sustains, reproduces, and fuels disaster (Barnett, 2011; Davey, 2020). Similarly, Krause (2014) acknowledges that humanitarian aid is strictly linked to Western foreign policy interests and “national boundaries play an important role in determining the conditions for the production of humanitarian relief” (p.29). As a result, we see a delineation of geopolitically-lead hierarchies of aid, where certain areas of the world are prioritized in virtue of their political and economic value for the Global North.

Merjan’s words resonated with the insights shared by other interlocutors, and the “everything is politically planned” came to assume a deeper meaning than the one I initially thought. The politicization of the ‘everything’ not only defines aid, but it also ontologically re-designates the material, political and conceptual existence of those who come to be labelled as ‘refugee with/out disability’. The highly politicized nature of aid has been raised by many of my interlocutors. During the interviews, some organizations’ representatives critically reflected on the political reasons and the economic impact of aid inconsistency on the capacity to meet the growing needs of refugees with/out disabilities in the region, denouncing the economic and political game of which they are part of. For instance, Majedah, UN agency’s representative, explains

“[S]ince 2020, I think it's because of the economic collapse, the explosion in Beirut, but mainly for the economic crisis. Because they see that if they don't support the entire system will collapse. And it has to do with the refugee issue too, as Europe is concern and scared in seeing arriving refugees in the European costal areas. This is why, I think, like I've been working with the humanitarian here for a while now, and I've seen that in 2014 the funding started uh decreasing. But then you started having these boats of refugees arriving to Europe, and then in 2015 this is when the funding increased a lot. So it's like, you see, directly that a lot of it has to do with when refugees start taking the boats, that then the funding would increase, so that they stay in the hosting country.” (Majedah)

Majedah provides an important insight on how and why aid flows have changed over time in the region. She describes how funding is linked to specific donor countries' interests. For instance, the Western world, and especially Europe has been paying its way out from the responsibility to host refugees, supporting Syria's neighboring countries to keep refugees within their border, aiming to reduce the number of those who would have crossed the Mediterranean to enter Europe. However, as noted by Brun and Fakihi (2022), the foreign funding does not seem to better people's living conditions, who continue to risk their lives, trying to cross the Mediterranean Sea, with the promise of a better future.

Other interlocutors reflect on the more recent changing funding situation in Lebanon due to the war in Ukraine, which led to a redistribution of humanitarian aid to address the new conflict.

"Now, if you can see when the war in Ukraine started, the budgeting or fundraising to Lebanon decrease around sixty percent. So no, it's not a priority. Lebanon is not a priority." (Cyla)

"If the donor funding is not here, tomorrow, the children will remain without access to any service, because the integration into the government sector is almost... priorities are shifting with the war in Ukraine continuously shifting." (Sobia)

"Now with the war in Ukraine we're getting much less funding now because of course the world priorities are shifted. so uh we need to start figuring it out on our own." (Shanifa)

While this work does not aim to enter the specificities of the different treatment Europe and the broader humanitarian system have reserved to Syrian refugees compared to refugees coming from Ukraine (see Düvel and Lapshyna, 2022; Alsabeti, 2023), it is nevertheless important to acknowledge the existence of these differences. This is not only because they are indicative of a double standard in the humanitarian administration of aid and assistance, but also because it provides an empirical example of the prioritization of Western geopolitical interests over actual

needs, where areas which are not of geopolitical importance for the donor group remain underfunded (Stoddard, 2004). For instance, Colombo (2022) underlines how, since the outbreak of the war in Ukraine, “donor governments have been shifting their humanitarian commitments from other crisis to support Ukraine and the countries hosting Ukrainian refugees, (...) which are relatively wealthy” (p.132) compared to Lebanon, and other regions in the world. Lebanon, compared to Ukraine’s neighboring countries, has a more fragile and unstable situation, being in the midst of a political, economic and social meltdown, while also hosting the highest number of refugees per capita. However, as also explained by the interlocutors, Lebanon is receiving less and less funding to meet the needs of Syrian refugees in the country. The focus on the preservation of Western geopolitical interests and the advancement of their agendas, rather than on the actual needs of the populations living in context of humanitarian crisis, demonstrates the political nature of humanitarianism, which is in stark contrast with its ‘apolitical’ rhetoric and commitment (Cooley and Ron, 2022; Barnett and Weiss, 2008; Weiss, 2013). The location of population in need matters to define who is worthy of receiving aid, and who is not. Those at the end of the Western geopolitical hierarchy are the ones who come to embody *bare life*, being relegated into spaces of *inclusive exclusion*.

The politicized and unresponsive nature of funding, as well as the weak accountability to crisis-affected population (Ramalingam and Barnett, 2010), result in sterile efforts to meet the real needs on the ground. Smillie and Minear (2004: 225) observe that “the political economy of humanitarianism is based to a great extent on the needs and demands of those with the resources - the donor governments – [while] the actual needs of those in trouble (...) are given fairly short shrift in the overall scheme of things”. Ferazia, a representative of a local organization, reports a similar narrative, explaining that:

“Refugees tend to tell us, they used to say that people came to us with already an agenda, and people came to us just to implement their agenda, they never listen to us. One lady said that someone asked her to go to a workshop, so she said that they teach them how to use a computer, that is very good, but she said that they don’t have computers. (...) and worse than this is that when they come they have a project, and they come to refugees to implement their project more than really listening to them and helping them, and they (refugees) used the word ‘humiliation’ a lot during our discussions.” (Ferazia)

Ferazia’s observation translates quite accurately the experiences that Syrian parents shared during our encounters. The feeling of *humiliation* was often mentioned by Syrian refugees, who reported feeling disrespected, humiliated, and exploited by organizations and humanitarian actors, especially by UN agencies’ representatives. Organizations are often depicted by participants as entities going to look for information, asking their questions and filling their papers, without ever coming back to follow up with the families, or directing them towards services, or helping in general. This has created a strong feeling of distrust towards organizations. Kadin explains that “people working for international organizations, especially the UN, never enter their tent, they never interact with them on a human level. They just remain in the car, they ask the few questions they need, and they go away”. Many Syrian parents affirm that organizations’ representatives do not really listen to what they have to say, to which are their needs, and expectations. As Syrians, they are just required to accept whatever is thrown at them, when it is thrown, even if it is not what they need. The lack of refugees’ involvement in defining the main needs and areas of concern within the humanitarian sector, re-enforce the strong feeling of distrust towards humanitarian organizations, which are perceived as extraneous to refugees’ needs, and very much focused on their own interests and agendas. For instance, Bariqa, international expert in inclusive education, shares:

“I mean they (international actors) come from international organizations and they have the power, because they come from international organizations, where the money also comes from so so

they make decisions on what will be applied locally or nationally.”
(Bariqa)

Bariqa highlights how dominant international organizations shape and control the narratives of aid, as well as its operationalization on the ground, advancing specific political agendas and interests rather than focusing on the needs of the people they purport to support.

Aid and bodies within humanitarian contexts are not only highly politicized, but also deeply marketized, following colonial-neoliberal principles of cost-benefit, ‘flesh employability’, and quantifiable measurable outcomes. Krause (2014) states:

“Practically speaking only a subset of populations in need becomes relevant as potential or actual ‘beneficiaries’ (...) [in that] some beneficiaries are easier to produce, and some are easier to sell than others, which leads to inequities in the allocation of aid.” (p. 40-41).

Krause (2014) explains that refugees with/out disabilities, who represent the beneficiaries *par excellence*, come to be both the ‘*means*’ and the ‘*end*’ of relief work in humanitarian context. For instance, beneficiaries are a fundamental and necessary element of any humanitarian and/or development project. Without beneficiaries, humanitarian actors would be out of work. In this sense, refugees are the *means* without which humanitarian organizations would not be able to operate. At the same time, refugees are also an *end*, as the ones who are identified as easier to produce and to sell to donors benefit from the interventions and or services implemented. The ontological signification of refugees with/out disabilities as both a *means* and an *end* of the humanitarian sector highlights the processes through which refugee bodies and minds are commodified, underlining the logics of humanitarian aid, which transcend principles of humanity to materialize in the doctrine of neoliberal political markets.

In the previous chapter, ‘Advancing Neoliberal Inclusion’, I explained how humanitarian organizations tend to distribute aid according to the potential performativity of beneficiaries in

relation to the project's outcome. Therefore, not everyone is considered as a 'convenient' and 'valuable' beneficiary. When it comes to disability, it is clear how neoliberal normative standards of being and doing influence the level of inclusion of refugees with disability within the humanitarian sector. Berghs (2014: 40) critically reflects on how people with disabilities, despite the fact that they "can be created and be symbolic of a conflict or disaster, are never humanitarian aid priorities in the rehabilitation of a state, NGO or donor funding" (Berghs, 2014:40). Organizations' representatives share similar insights, reflecting not only on the commodification of disability, and inclusion, but also on the structural exclusion of refugees with disability from funding and more generally from humanitarian interventions. Cyla reports:

"Disability is not a priority for organizations. International NGOs, UN agencies, public sector, it's not a priority. So when you go to mobilize someone to reflecting disability issues, they are always saying that 'disability is not our priority'." (Cyla)

Cyla acknowledges the widespread lack of sincere interest and commitment towards the inclusion of people with disabilities, denouncing how disability, instead of being mainstreamed in humanitarian efforts, is seen as something 'other', to be addressed and managed separately, if at all. She explains:

"Two months ago the Gender based violence (GBV) sector did a study or assessment regarding GBV issues, and they mentioned woman with disability, a percentage about women with disability. However, they didn't discuss or analyze what types of specific abuse and GBV related challenges woman with disabilities face. There was no information. So I had a discussion with them, and I asked 'what about the other information? What about this thirty percent of women with disabilities?'. I'm not exactly sure about the number. They did not analyze those challenges for women with disabilities who are experiencing GBV. And so I asked 'why you did not analyze this as the other issues?' So what she told to me is that they have this information, but it is not their priority to reflect on this." (Cyla)

Cyla's account offers an incredible insight on how disability and inclusion are constructed and operationalized within humanitarian contexts, providing an empirical snapshot of overt exclusion and disability-deprioritization. Elias, a local organization's representative, while recognizing the absence of a serious engagement to achieve sustainable and authentic inclusion of people with disability, denounces the commodification of refugee with disabilities' bodies and minds, revealing how organizations have started caring about inclusion only for their own benefit.

“In some cases, even if they start the change because of financial resources, after these years, I can see how organizations are caring about disability. Ah, how they want their programs to be inclusive, even if they don't know how. But they care. They start caring because there is funding on the number of children with disabilities you have in your program. So, it is as unit cost.” (Elias)

Then, reflecting on the operationalization of inclusion within humanitarian inclusive projects, Elias explains that even when disability is addressed in a project, the real concern for the implementing organizations is not on the quality, and usefulness of the activities for the children with disability; rather, it is their capacity to demonstrate that certain activities took place, and that those activities can be quantitatively documented and reported, regardless of their actual value.

“They (international organizations) care about documents more than they care about what is happening on the ground and with the children. So, whatever your documents are, they evaluate you and your work according to the documents, second, what they want to see in inclusive schools is that there are children with disabilities inside the schools. This is what they want to see, but what kind of services you are providing for these children to get their education, Are they really participating in learning activities in the school? Do they have the specialized services? All these matters I do not think they care about it. When they support the training and workshops and they fund all the costs of these trainings. But all what they care about is that these trainings took place, and they can say that they happened. So, you can see that yes, they have the evidence that 9 days of trainings happened.” (Elias)

Elias critically analyzes organizations' approaches to inclusion, recognizing that everything is done to serve the humanitarian market. Having “the evidence that the 9 days of trainings happened” is

fundamental for the implementing organizations not only to report on the measurable and quick outputs requested by the donors, but also to appear more competitive within the market, as achieving certain targets and realizing good projects according to donors' priorities and standards are fundamental prerequisites to work in the humanitarian industry.

Slim (2003) states that “humanitarianism is always politicized somehow. It is a political project in a political world. Its mission is a political one—to restrain and ameliorate the use of organized violence in human relations and to engage with power in order to do so” (p.1). Humanitarians, by dissimulating an apolitical vocation, hide the embodiment of “a politics of arbitrary life imposing its values and visions” (McFalls, 2010: 17). Humanitarianism is not only driven by politics, it also actively operates and bring forward its own political-colonial and economic-neoliberal mission, coming to exercise a sovereign power. Through the marketization and politicization of aid and bodies, the humanitarian regime controls, administers, and dominates the lives of refugees with/out disability, creating spaces of exception where *bare life* transcends the physical circumscribed locus of the camp, to materialize in the biological bodies of those who do not represent what we can call the ‘performing beneficiary’. *Bare life* comes to be inscribed on a conceptual dimension at the intersection of refugeehood and disability, where bodies and minds are ontologically redefined in virtue of their *inclusive exclusion* from the (geo)biopolitical economy of humanitarian aid. Everyone can come to embody *bare life*. The *limites* of *bare life* are precarious as humanness is defined through colonial and neoliberal logics and attributes. In other words, the historical, political and legal boundaries between being recognized as fully human and being reduced to *bare life* are elusive. Those boundaries are often defined and constrained by colonial and neoliberal logics embedded within dominant power structures, and they shift depending on societal, (geo)political and economic contexts. Humanitarian education, which is a subset of humanitarianism, operates within these same logics of *inclusive exclusion*, contributing to the determination of refugee

children with disability, especially with severe and complex ones, as *homo sacer*. In what follows, I analyze *bare life* through the lived experiences of Syrian refugee families and their children with disabilities, considering how it unravels in their everyday lives.

6.2.2 Denouncing *Bare Life*

“There’s really no such thing as the ‘voiceless’. There are only the deliberately silenced, or the preferably unheard.” (Roy, 2004:1)

Malkki (1996) explains how through humanitarian logics and dominant media representations, refugees with/out disabilities come to be constructed and described as ‘speechless emissaries’ – “in abstracting their predicaments from specific political, historical, cultural contexts – humanitarian practices tend to silence refugees” (p. 378). People with disabilities, as well as refugees and other minoritized communities, have been historically constructed through the voice of others. Depicted as ‘abnormal’, ‘criminal’, a ‘burden’ for the society, and a ‘threat’ for the survival of the ‘us’. The voices of the ‘them’ have been intentionally suppressed and utterly removed from the space of the *polis*, being relegated to the silenced spatiality of exception. The stories of the “preferably unheard” become the stories of professionals, caregivers, humanitarian actors, state security apparatus, and at times researchers, being re-interpreted and stripped from the living marginalized subjects. This research aims to learn about and from the voices of those who have been ostracized from the *polis* and forced into *bare life*. Learn through the silenced voices, comprehend the unheard stories, and try, at the best of my capacity, to understand and to acknowledge them, recognizing that “people have heterogeneous experiences of migration [and disability] and are active agents whose capacity to act is restricted by diverse [and intersectional] systems of inequality and violence (Fiddian-Qasmiyeh, 2024:64) that must be addressed and considered. In this section, I provide a different account of *bare life*, one that it is not made of ‘political games’, and ‘economic calculation’, but of lived experiences of ‘living *homines sacri*’, who decided to share their stories with me and the

interpreter, allowing us to enter and to learn about their lives. This space focuses on participants' accounts and denouncements of *bare life*, and on how their daily lives unravel.

During the fieldwork, many Syrian parents unexpectedly thanked me for having taken the time to go to their houses, sit with them, and talk *about* and *with* their children with disabilities. Families appeared to be eager and keen to share their experiences in dealing with their children with disabilities' daily challenges to access essential and basic life-saving services in the country. During my first trip to Beqaa, I found myself in a big tent, together with the interpreter, and seven Syrian refugee families. They all gathered with their children with disabilities waiting to discuss with me. One of the parents explains

“That even if we (the translator and I) told them that the interviews were in the middle of the sea, they would have taken a boat and reached us only to talk to us about their children with disabilities, because no one ever asked about them and they want to find a solution, they want someone to know.” (Suleyman)

All the other parents confirmed Suleyman's statement and told me that they would have spent the entire day there, waiting for me to interview everyone. During my second trip to Beqaa, Layla, a mother of two boys, reveals that

““No one care about my son with disability! You are the first who came to talk and to learn about my son!’ No national or international organization ever came to visit them or follow up or did anything for them. ‘No one care about children with disabilities.’” (Layla)

The lack of engagement with Syrian refugee children with disabilities and their parents is, *de facto*, representative of the deliberately planned de-prioritization of specific groups of people within the broader humanitarian aid system. As a result, children with disabilities are completely neglected and deprioritized, and they are prevented from accessing basic life-saving services.

Nada is a mother of four and lives with her children and her sister's family in an unfurnished small apartment in Syr el Danniye. When I entered her three-room apartment, I could only see a pile of children clothes, an empty-non-functioning fridge, and a few mattresses on the floor. She has two daughters with disabilities (14 and 3 years old) and a daughter with thalassemia (12 years old). She entered Lebanon in 2018, when the war reached their region, Rif Dimashq, and they felt that there was nowhere safe in Syria anymore. She explains that once they crossed the border, they registered with the UN¹³, and they received some help at the beginning. However, after few months the UN stopped the support and removed the family from the program without giving any justification or notice. The only provider of the family is her husband, who has a physical disability which resulted from an accident where his leg was "smashed by a tractor" a few years before. She shares that "if her husband manages to work then they can eat, if he doesn't then they cannot afford to buy even basic things". The situation is even harder concerning the needs of her daughters. She cannot afford to buy the needed medications, nor the diapers or food; and she does not have enough money to bring the children to the doctor. Nada explains

"Very often they struggle to provide medication for the child. Apologizing she (the mother) said that sometimes if her daughter is not having seizure, she doesn't give her the medication to her in order to keep them for another bad day. And when she does this management of medication, she can afford to pay for the detergent to clean the 'fouta' (pieces of fabric to replace diapers), or to eat. And then she added that either they eat, either they buy medication, either they buy diapers." (Nada)

Nada started apologizing for the poor conditions in which she was forced to make her children live, and she felt ashamed of having to rely on strategies such as medication management. She asked if she was a bad mother for not being able to offer more to her kids. We spent quite some time talking off the record about the challenges she is experiencing, and how she is already doing her best.

¹³ All families do not make distinctions between UNHCR and UNICEF. They tend to identify the two organizations simply as UN.

When she felt calmer, she expressed her desire to resume with the interview, as there were other things she wanted to talk about, and she asked me if I could address the international community, referring especially to dominant Western-European actors, and share her message:

“The UN should reconsider the file of families with children with disabilities, instead of discarding them. We are trying to do our best to provide for our children, but with no success. Do I hate my children? No, but I am obliged to let them sleep on the floor. Am I supposed to starve my children only to keep a small amount of food for the day after? No, but if I do not do it, then we will not be able to eat. This is not even living. If you don’t want to give us money, then give us opportunities. If you don’t want us to resettle, at least give us the chance to register our children in school. And if you do not have the resource for this, then at least provide children with disabilities with the treatment and medication they need.” (Nada)

As Nada, many other parents said that they would prefer to have opportunities to provide for their families, rather than relying on external help, which is scattered, and most of the time does not even reflect the needs of the families. Most of the Syrian refugees interviewed are daily workers, meaning that if they are not called to work, they do not earn money. The lack of a stable income, and of permanent employment opportunities dramatically affect the family capacity to meet their daily needs, especially when they have a child with disabilities, who might require extra care. Moreover, starting from 2019, with the financial and economic crisis, which compounded with the Covid-19 pandemic, and the Beirut blast, the living conditions of refugees, as well as of Lebanese citizens, drastically deteriorated. Lebanese infrastructures and the welfare system started to collapse resulting in lack of access to basic services. For instance, the country has been facing a significant shortage of medications (Das, 2021; Jawad et al., 2023), which has equally affected refugee and Lebanese communities. Gibon (2022), in an article published by Al Arabiya English, reports that “the lifting of subsidies on many drugs across the country by the Lebanese Ministry of Public Health (MOPH) led to a sharp rise in the price of medicine. Many drugs became unavailable or unaffordable for a large part of the population”.

As a result, families are forced to adopt different strategies to manage the balance between needs and expenses, such as the one of medication management adopted by Nada and other parents. For instance, Faisal presents the challenges he faces to provide for her daughter's specific medication, and he describes how quickly her health deteriorate when the family does not manage to afford the required treatment:

“The child has to take a specific medication 3 times per day, every day, for the rest of her life. When they can afford the medication, they buy it for her and she can take it. When they cannot afford for it, she remains without medication and treatment. She also needs physiotherapy on a weekly basis, but he cannot afford it. And they said that if she can have access to physiotherapy, her life would be much better. When she stops receiving the medication she stops eating and all her muscles contracts. Sometimes they cannot afford the medication, so she remains without it for 2 days and she stops eating.” (Faisal)

Faisal explains how Hamra's health deteriorates when she does not have access to the medication she needs. The lack of access to medical treatment falls within the broader process of de-prioritization of children with disabilities, having detrimental consequences for children's lives. Many parents, while discussing their situation, often affirmed: *'No one cares about children with disabilities!'*. Their statements were in stark contrast to all the inclusive success stories reported and promoted by humanitarian actors to sponsor their programs and advocate for more fundings. Parents critically redefined the meaning of inclusion as a complete exclusion of their children with disabilities. Suleyman, during our trip by car to reach Beqaa, told me that he felt that international organizations were purposefully “leaving children with disabilities to themselves”. He gave the example of his son, Qasim, who was born with a congenital disability, and he is the only one of his five kids who has not been registered in the family file by UNHCR, despite his constant follow up to legally record the child as his son and a member of the family. Similarly, Hashim states that

“The international community should care about children with disabilities! They should take care of them and work with them in order to make them part of the community. But unfortunately, they are not even seeing children with disabilities as individual in the society. They are absent.” (Hashim)

Amina shares a similar position: She thinks that “children with disabilities are treated like if they do not exist”, being excluded from their community and the broader society. On September 2022, the interpreter and I went to Tripoli to meet Amina. We did not know that she had recently lost her older son, Samir. He was born with a severe disability, and despite the family’s efforts to provide for all the needed care and treatments, her son died just three weeks before our encounter. Amina, decided to participate to the study for her other two children with disabilities, Murad and Yamina. Amina and her six children came to Lebanon in 2020. When their home in Idlib was destroyed, they moved to Hama, and lived there with her parents until 2020. She describes how their living conditions were very precarious in Syria, especially for her 3 children with disabilities, who never managed to leave the room where they were living because they did not have wheelchairs, and the environment was not only inaccessible, but also very dangerous. In 2019, her husband found a suitable place for his family in Lebanon, and after collecting enough money for the family to cross the border, Amina and her six kids started their journey to reach Lebanon.

“From Hama to Lebanon, they came through an illegal way, and the husband was obliged to pay a large amount of money to the human traffic organization to make sure that his family could enter the Lebanese territories. The family after they entered in Lebanon tried to register with the UN; however, they never received any help, no cash money, or food portion, nothing. Her husband is trying to follow up with the UN, but they didn’t manage to receive any help till now. The UN knows that the family had 3 children with disabilities, 2 now. All NGOs and the UN came and checked their situation, but they never gave them any tangible support.” (Amina)

Then she added

“No one among the NGOs and institutions care about children with disabilities. They are not providing any help or support. It might be possible that they will accept and work/help children with mild and

minor cases, but for sure not her children, and children with severe cases.” (Amina)

Amina, as also organizations’ representatives and other Syrian parents, highlights the structural deprioritization of children with severe and complex disabilities, recognizing the same process of disability-hierarchization explained in Chapter 5, which defines who is included and who is excluded from humanitarian aid. For instance, she mentioned how her two children without disabilities are being supported by UNICEF through accelerated learning programme (ALP); while, when it comes to her children with disabilities, organizations behave like they do not exist. Her children with disabilities have never received any support, not even for diapers or medication, nothing, “there is no support available for them”.

Similarly, Qadira, mother of two children with disabilities, states:

“In general organizations don’t care about children with disabilities. She has to fight every day to try to secure some support for her two sons. They are discriminated just because they have a disability. She registered Gadi in the British institute to repair computers, but when they saw him that he has disability they refused him. She tried everywhere, and whenever they know he has a disability, he cannot walk, they refused him. So no, they do not care about children with disabilities.” (Qadira)

My conversations with Qadira and other parents raised important questions, which acted as ‘the’ compass to orient my theorizing efforts. During and after the encounters with the families, I often found myself re-thinking about the meaning of ‘inclusion’, and who appears to be its subject, or critically its ‘object’. I found my answers in the ‘silenced absences’: The absence of learning opportunities for children with disabilities; the absence of attention to their needs by the humanitarian system; the absence of children with disabilities, especially with severe and complex ones, from the broader picture of inclusion; and the absence of the knowledge itself about what has been historically silenced. Syrian parents denounce how their children with disabilities are

constructed as ‘invisible’, and how ‘*they are left to themselves*’, being deliberately de-prioritized compared to their siblings without disabilities and excluded from their community and the broader society. Parents’ narratives provide empirical accounts of how lived experience of *bare life* unravels in actualized state of exception, transcending the circumscribed physical locus of a refugee camp to materialize in each and every Syrians’ body within the humanitarian regime. In what follows, I aim to disrupt the widespread uncritical discourses and language of passivity and vulnerability, calling for a re-signification of the concepts of resistance, and agency at the intersection of refugeehood and disability.

6.2.3 Resisting Space of Exception

“The experiences of refugees (...) points to the way that the ‘bare life’ of exclusion is continually resisted even as sovereignty is inscribed on their bodies.” (Bousfield, 2005:13)

Bousfield (2005) underlines the need to acknowledge the personal forms of agency and resistance exercised by subjects embodying *bare life* in humanitarian space of exceptions, challenging the dominant narratives that picture refugees as being merely passive, vulnerable and dependent subjects/objects of humanitarianism. He sustains that the characterization of refugees as “apolitical non-subject in the site of exclusion is resisted by the refugees at the micro-political level – the personal level – where the logic of sovereignty’ is challenged by refugees’ experiences” (p. 10). Hence the spatiality of exception, in which bare lives are located and reproduced, comes to represent sites of possible actions and constant resistance. The space of exception, while being defined by a sovereign power, cannot be governed by it, opening a space that, despite being outside the *polis*, functions as a political and social site for the *homines sacri* inhabiting it (Bousfield, 2005). However, it is important to acknowledge that in spaces of *inclusive exclusion* acts of resistance and agency materialize through different forms, departing at times from the Western conceptualization of a measurable and subversive act (Mahmood, 2001; Madhok, 2013). A

reconceptualization of refugees with/out disability as ‘agentic *homines sacri*’, rather than solely as humanitarian subjects/objects, is fundamental to disrupt the construction of refugees as perpetual victims devoid of agency (Bragg, 2022). In this section, I share some refugees’ experiences and acts of daily resistance, as well as their messages to push the international community to consider and address the needs of refugee children with disabilities.

My encounters with Syrian parents and their children with disabilities completely disrupted the broader humanitarian narrative of vulnerability, passivity and helplessness through which refugees are usually constructed and represented. Participants allowed me to enter a world made of hardship but also of too often silenced actions. Actions that redefine the limits of refugees’ active responses to confining exclusions. For instance, Maysa, during the interview, told me that she cannot, and she does not want to give up on her daughter, even if the society and the international community already have.

“She wants her daughter to say in the future when she will be a successful woman, that she became one because her mom always believed in her!” (Maysa)

Maysa actively challenges every day the misconceptions that society holds about her daughter with disability. She constantly follows up with UN agencies, even if most of the time unsuccessfully; she advocates for her daughter’s rights and the rights of other children with disabilities to be educated, and to access services, looking for opportunities and resisting the barriers along the way. She passionately supports her daughter, helping her to develop new skills and learn new things, also when her surroundings question her efforts. She shares that

"The doctor when analyzed the RMI he told her immediately that her daughter cannot walk. It ends here. But she believed that if she pushed her daughter to do it, she would have been able to do it. So she mentioned the very long road that we took to arrive, and she used to take her daughter every day and to walk up and down, up and down with her. And she was criticized by everyone, by her husband and

the neighbors too, who used to tell her ‘what are you doing to your child? She has a disability she cannot walk, the doctor said she cannot walk!’. But after two months when she went for the visit to the doctor, the doctor was totally shocked that the child entered the clinic walking by herself.” (Maysa)

Maysa explains how her daughter just needs a chance to prove herself as everyone else, for this reason, she keeps looking for opportunities, trying every year to find a school that would accept her, reaching out to organizations, and doctors. Maysa is not passively waiting for help to come her way. On the contrary, she is actively resisting and challenging ableist barriers and understanding of disability within her community, and the broader humanitarian framework, that continue to exclude Zia.

As Maysa, also Qadira, Ferran and Gadi’s mother, while talking us through the family’s experiences, highlights her active engagement in finding solutions and opportunities for her children with/out disabilities. She explained how their life was peaceful and good before the war. All her children were going to a ‘normal’ school, also Ferran and Gadi, and despite the school was not very accessible at the infrastructure level, they were still integrated in the system. However, the war changed everything, and they were forced to leave. Qadira, as many other parents, underlined how leaving Syria was not an easy decision, but it was one that had to be made if she wanted to protect her children and her family, even if she had to leave a life behind. Her husband was already living and working in Lebanon prior to the war, and he used to go back and forth to visit his family for a week every few months. When the war started, the situation changed.

“The husband was already in Lebanon, and he told her that he was not able to send her money, and not able to go back to Syria as he would have been forced to either served in the military or obliged to be with the mu3arada (rebels). He didn’t want to be part of this war so he asked his wife to move to Lebanon with the kids. At first, she refused. But then her late brother reasoned with her and told her that she still has young children, and it would be better for them to leave. He told her that if they will still be alive, they will update her, if not,

she will know they are gone. So she decided to join her husband.”
(Qadira)

Qadira explains that when they moved to Lebanon in 2013, they registered the whole family with the UN. She hoped that registering with the UN she would have been able to help her children to have an education, and to access services, such as physiotherapy, to support Gadi and Ferran’s health. However, she soon realized that no services and opportunities were available for children with disabilities. Her two sons with disabilities have always been deprioritized. When we asked her what she would ask and advocate for children with disabilities, she said that

“She went to protest in front of the UN, because she is desperate. She went with both her children with disability to protest in front of the UN. They asked her to move, and she refused. She went to protest by herself, and she would like to organize a bigger protest with also other families. She had enough, she is following with everything for her sons, and even her husband told her to stop. She wants and needs a solution, she is desperate, and she wants to provide her children with the best services. When she went to protest in the UN, she asked both her children to block the road. They blocked it for 1 hour and a half, and she said that they wouldn’t move until a social worker would come and talk to them. And she added that if they don’t listen to her needs and help her, the week after she would come with all the families and kids and block all the roads here.” (Qadira)

Qadira, as also many other mothers I had the opportunity to interview, is a very resolute woman, ready to take action and to disrupt and resist the narratives depicting her and her family as vulnerable and helpless. While she acknowledges the difficult situation in which they are forced to live, and the many challenges they have to face, she also denounces the spatiality of exceptions in which they are relegated. Political in her *bare life*, Qadira is determined to challenge and resist the invisibility and ‘exceptionality’ imposed on her and her family, confronting one of the major institutional symbols of power and authority that control and administer refugees’ lives: the UN building.

In the same way, Mouna is committed to ensure that the rights of her child and other children with disabilities are respected and achieved. She explains that even though she has not had the opportunity to do activism for disability in the same way she does through the awareness campaign and programs against early marriage in which she is involved, she constantly advocates within her network for the rights of children with disabilities. Mouna got married when she was 16 years old, and while she is proud of her family, she regrets the missed opportunity of continuing her education. She clarifies that while the main reason she stopped going to school was not because of her marriage, but because of the war that forced her family to flee the region, being a young mother made it difficult for her to go back to school once she entered Lebanon with her husband and first child. Mouna believes that education is fundamental and life-changing, and for this reason she constantly advocates for children with disabilities as well as girls' rights to education. Within her community, Mouna actively engages with other parents of children with disabilities, underlining the necessity to follow up with doctors on children's conditions, and to actively seek education opportunities for their children, to support their development and future inclusion in society. The interpreter, in translating Mouna's words, reports:

“She recommends all the parents that if they notice any symptoms at any time on their child, to follow up immediately with the doctors because it can get worse. ‘Please follow up about your child conditions. They deserve to live a good life’. She wishes that all the family would have the possibility to follow up for their children.”

(Mouna)

Mouna recognizes that not every family is in the position to follow up with doctors on their children's health. She acknowledges that compared to other Syrian as well as Lebanese families, their economic situation can still be defined as acceptable, despite being forced to borrow money at times to meet the family's basic needs. Before the war, her family was wealthy, and her husband was in a “good economic position”. The good economic situation they enjoyed before the war helped them to leave Syria, however, once in Lebanon, they lost almost everything, and their lives

changed. Despite the hardship, she does her best to make sure that all her children, including Utba, can access education opportunities, even if those might be different (Utba goes to a *markaz*, while his sibling to a public school). She also tries to help other families

“A neighbor told her that there is a case here in the area of a family that have twins with autism. She is planning to go and visit them and encourage them to sign the kids in the specialized institution in Tripoli, the same where her child goes. She mentioned that she is willing to bring with her the 2 children in the institute in Tripoli, as she already pays for the transportation for herself and her son.”
(Mouna)

Mouna is actively advocating and actively trying to look for alternative solutions to support other Syrian parents with less resources in the area, despite her own economic struggle. Towards the end of the interview, she revealed that

“She would also like to be part of an organization to advocate for children with disabilities’ rights and to raise awareness in the community about disability.” (Mouna)

Other mothers expressed the desire to create a broader network and to work alongside with organization of people with disabilities to advocate for their child and other children’s rights both at national and international level (Amal, Layla and Atiya). These mothers want to be heard, involved, recognized and addressed by the same international structures that preach inclusion while excluding their children. These mothers are political, they are active within the exceptional spaces of exclusion they occupy, and they resist the *bare life* inscribed into their bodies every day to protect and find solutions for their children.

While Maysa, Qadira and Mouna are more vocal and active within the exceptional spaces they live in, other parents display different approaches and forms of resistance which are less visible and more circumscribed. For instance, “‘resistance’ can be voiced clearly but also kept private, or seem withdrawn’ (Renkens et al., 2022:3). Resistance is characterized by multiple and very diverse

action, negotiation and strategies that people employ when confronting challenging situations (Mahmood, 2001; Clare, 2009; Madhok et al., 2013). Foucault (1981) states that

“A plurality of resistances [exists], each of them a special case: resistances that are possible, necessary, improbable; others that are spontaneous, savage, solitary, concerted, rampant, or violent; still others that are quick to compromise, interested, or sacrificial; by definition they can only exist in the strategic field of power relations. But this does not mean that they are only a reaction or a rebound, forming with respect to the basic domination an underside that is in the end always passive, doomed to perpetual defeat.” (p. 95)

People’s agency and acts of resistance can differ quite a lot according to a person’s position, their circumstances as well as personality. For instance, Qadira and Mouna are more confrontational, and overt in their daily forms of resistance. Maysa is also overt, and confrontational, but she is more solitary in her actions, and at times more careful as well.

Syrian refugees in Lebanon have developed different strategies to resist the spatiality of exception they inhabit. Here, I want to briefly mention again that refugees, within the humanitarian regime, are constructed either as ‘threatening’ or as ‘vulnerable’ beings (Costantini and El-Serafy, *under review*). There is nothing else in between the ‘refugee-threat’ and the ‘refugee-vulnerable’. This binary distinction is functional to the de-humanization and de-agentivization of refugees, instrumental to the systematic control exercised on their bodies, which also defines who is ‘worthy’ of receiving humanitarian aid. As explained across the chapters, children with disabilities, especially with severe and complex ones, despite one would think they match the criteria of vulnerability, are almost never addressed and considered within humanitarian efforts, being relegated into the lowest hierarchical machination of *bare life*. Syrian families actively fight for their children’s right to live, and not just as *bare life*. Some parents displayed collective forms of resistance, where they help each other at the best of their possibility.

For instance, in Beqaa, during one of the short breaks in between interviews, I saw parents taking notes of the names of some medications. They later explained that it is very difficult to find medications in Lebanon due to the general widespread drugs' shortage, and when they find them, the price is very high and often they cannot afford it. For this reason, at times they ask family members and/or friends back in Syria or in Turkey to send them the needed medications. This is not always possible, but parents try to help each other when they can. They share contacts of doctors, of organizations that might be able to help with physiotherapy or diapers, and they circulate information that could be relevant for other parents to access some services for their children with disability. Most of the Syrian parents interviewed explain that they do not trust organizations, because they never help (Suleyman, Faisal, Jana, Samer). When they manage to access some services, it is most of the time because they have actively searched and kept following up with organizations.

Skorzak (2019), building on Butler and Athanasiou's (2013) work, states that "resistance to enforced precarious living pertains to the forced of survival and endurance, which are no mere self-preservation but the exercising of contingencies of freedom even in unfree, bare life conditions" (p. 3). The daily forms of resistance I came to learn from refugee families challenge and disrupt the imaginary of the passive and helpless refugee, who is unable to act and completely depended on the 'humanitarian-savior'. Refugees continue to demonstrate that they are determined, resourceful and active in navigating the spatiality of exception in which they come to embody *bare life*. Reproducing refugees exclusively in terms of vulnerability or as a threat, and refugee with disabilities as mere victims to be saved, has dramatic effects on the conceptualization and implementation of humanitarian aid. To shift the paradigm, it is now fundamental to start acknowledging the multiplicity of strategies refugees enact to resist and challenge *bare life*, to

recognize their daily acts of resistance and their political agency. The fact that refugees are constantly silenced, does not mean that they have nothing to say. The parents interviewed were willing to take a boat and meet with me in the middle of the sea, *just* for me to know about their children, *just* for me to hear about and from them, *just* for me to address the dominant Western international community and ask them to engage and confront this truth. And this is a form of resistance to the silenced spaces of exception, it is a form of agency flourishing from *bare life*. ‘*We have things to say! We want the international community to know. It is them that do not want to hear!*’ (rephrased from different conversations with parents).

I want to conclude this chapter sharing some of the perspectives of Syrian children with disabilities on their exclusion from education and other services, and foregrounding their messages to the humanitarian actors working in the region and to the dominant Western international community. Raja, as every other child interviewed, has dreams, and hopes for her future, that are not being met. She reveals “she wishes to be able to go back to school and learn”, and she hopes that children with disability would be included and supported, in order for them to know that “they can be”. Raja explains:

“She would like society (organizations, communities’ members, and others) to treat people with disability in a gentle way, with kindness, and to encourage child with disabilities, so that one day they can become someone important. She wants the society to support and respect them. They should receive education; she supports their rights to learn as for everyone else.” (Raja)

Similarly, Saarah advocates for the rights of children with disabilities, and asks society to treat people with disabilities with respect, “like other ‘normal’ people”, because “with support we can live normally. If one has a hearing problem, with hearing aid, one can listen, with glasses one can see, even if one cannot walk, if you integrate them, they will be able to live in the society”. She explains:

“People with disabilities, when you address them in a positive way, making them feel appreciated and useful, they will have the power and the will to do more, because they feel they can do it. Giving them hope, this is what the people and the society should do, they should never let people with disability feel that they are useless.” (Saarah)

Towards the end of the interview, we asked Saarah “if you could share a message with the world, what this message would be?”. She did not have to think much. With a smile, she addressed me directly, and she said “Society should know that people with disabilities are able to be. This is my message!”. She did not seem angry, or hopeless. On the contrary, she appeared decisive and positive.

Lastly, I want to talk about Mahdi and his strong sense of justice and duty. Mahdi is 13 years old. A few months before our encounter, he lost his father because of a severe heart condition that he was not able to treat. Since then, Mahdi has become the sole provider for his family composed of his mother, who is also sick, and his sister, who is 14 years old. Mahdi is partially blind. The family managed to get him a pair of glasses through the medical consultant of the UN, but his sight has been quickly deteriorating since then, and he now sees only shadows. They cannot afford to follow up with doctors. Mahdi is very mature for his age, and when I asked him about his thoughts on disability and the role of society and humanitarian organizations in ensuring people with disability’s rights, he was very articulate, and he made a distinction between children like him, who have ‘easier disabilities’, and children like his two cousins, who have more severe disabilities. He explains:

“He doesn’t think that children with severe disability have a future here because there is no one taking care of them or providing them opportunities... the government and the international community should provide opportunities, treatment, and care for them to have a better future. He would love to advocate for these rights. They should have the opportunity to live a normal life, but unfortunately no one is taking care of them, and no one is giving them the opportunity to live a normal life. He then gave me an example: You have children

in a class, one that he doesn't have any difficulties and the system takes care of them. Then you have another child with learning difficulties, and no one cares about his abilities, and the system neglects him." (Mahdi)

And he continues:

"Organizations must focus on children with disability because they need more help. (...) And even between refugee families there are families that might need more support. We need to focus on people's needs." (Mahdi)

Mahdi denounced the lack of attention and services for children with disability, and especially with severe and complex ones. He is critical of the education responses for children who do not comply with normative standards of 'learning', highlighting how they are structurally deprioritized and neglected by the society and the humanitarian organizations working in the region. He also provides insights on the heterogeneity of experiences and challenges faced by people with disabilities, acknowledging the multidimensionality and intersectionality of oppression and inequalities.

Syrian refugees, especially those with disabilities, come to be signified and discursively constructed as vulnerable, passive and in need of protection within the humanitarian system (Costantini and El-Serafy, *under review*). It would be naïve to negate the extreme vulnerabilities in which refugees are confined; however, it would also be erroneous to believe that vulnerability precludes the capacity to resist and act, these two dimensions are not mutually exclusive, but equally inherent to our human nature. Syrian children with disabilities and their families are constructed as *homo sacer*, they come to embody *bare life* through the intersectional and multidimensional forms of oppression and exclusion they experience. However, across these chapters, we did not only read about how they happen to become *homo sacer*, how they are excluded from the same initiatives that purport to be inclusive, how vulnerable they are. Children and parents allowed us to enter their daily struggle, to learn about them, to hear from them, and to

understand how they resist *bare life*, how they manage and deal with the many daily barriers they face, how they act to counter the lack of learning opportunities, of medication, and of other essential services. It is time that refugees with disabilities and their families are heard and included and consulted and recognized as human beings, and not as commodifiable non-subject of a neoliberal and colonial humanitarian system.

6.3 Conclusion

In this last chapter, I reflected on the driving factors responsible for the actualization of a *state of exception* within humanitarian contexts, and I explored participants' acts of resistance within *bare life*. Firstly, I acknowledged the political and economic nature of humanitarianism, focusing on the politicization and marketization of aid and bodies. Then, building on Syrian participants' experiences, I analysed how systems of power and exclusion affect the everyday lives of individuals living at the margins. This section provides an empirical account of what lives in a *state of exception* look like, of which are the challenges, and barriers that Syrian refugee children with disabilities and their families have to face. It is a space where participants highlight their *bare life*, while at the same time denouncing it. Finally, I focused on stories of resistance and agency, aiming to disrupt and challenge the dominant narratives of the passive, de-agentivized refugee with/out disability. The next chapter concludes this work.

DISCUSSION AND CONCLUSION

This concluding chapter has three sections: The first provides an overview of responses to the study's research questions building on the knowledge shared in previous chapters; the second notes some limitations of this work; and finally, the last section presents a few recommendations, possible directions for future research, and some final considerations.

1.1 Research questions

Here, building on the conceptual development of 'Letting die through Neoliberal Inclusion' and on the knowledge shared in the previous chapters, I consolidate my analysis chapters in relation to this work's original research questions, while at the same time summarizing the key finding of the research.

1. What are the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other basic services in Lebanon?

The lived experiences of Syrian refugee children with disabilities and their parents in accessing education and other life-saving services in Lebanon have reflected a deeply entrenched system rife with discrimination, ableism, and structural inequalities. Their experiences are defined by the humanitarian aid approach to disability and inclusion, as well as by international and national securitized migration policies, which perpetrate xenophobic sentiments and discriminatory attitudes towards refugees with/out disabilities. Some of the challenges identified in this study are common to both children with and without disabilities, based on their shared Syrian identity. Others are purely disability-related and vary according to the child's type and severity of disability. For instance, children with milder forms of disabilities, and with physical and sensory disabilities are more easily targeted and involved in what humanitarian aid actors call 'inclusive' education projects, compared to their peers with severe and complex disabilities, who are completely

neglected and structurally excluded. Syrian refugee children with disabilities' experiences of segregation from education and other life-saving services, such as healthcare, medication, food, accessible shelter, and others, are considerably determined by ableist and hyper-securitized conceived systems of humanitarian 'neoliberal inclusion', through which children who do not comply with expected normative forms of being and doing are marginalized and made invisible.

In chapter 4, I discussed how securitization discourses and the widespread anti-Syrian discriminatory rhetoric have been reproduced inside schools, negatively affecting Syrian refugee children's educational experience, as well as the quality of education received in Lebanese public schools. Parents raised issues linked to corporal punishment (children being hit by teachers), to bullying from both school personnel and Lebanese peers (children prevented to use toilet facilities, being discriminated because of their Syrian identity, or targeted by other children), to low quality education (many parents denounced how their children are not receiving good quality education), as well as to lack of inclusion for children with disabilities, especially with severe and complex ones. Of the 25 children involved in this study, only five of them, who have milder disabilities, managed to access for a very short period the Lebanese public education system: Gadi and Ferran have physical disability, Sarah, Raja and Magdi have sensory disabilities; while all the other children were either attending a *markaz*, or were staying home without receiving any form of education.

In chapter 5 and 6, Syrian parents denounced the lack of education opportunities and other services for their children with disabilities, explaining how their children are not only excluded from education, but also from other essential services, such as physiotherapy and medical treatment, without which their health severely and quickly deteriorates. All parents shared that they fled Syria with the hope and the intention to protect their children, to give them a better life, to save them

from the war and be able to provide for their needs. However, when they arrived in Lebanon, they did not find the life they wished for their kids. Syrian children with disabilities, especially with severe and complex ones, remain completely marginalized, being refused from both public and private schools, and very rarely managing to access segregated institutions due to their very prohibitive cost. As a result, children with disabilities are kept home. It must be noticed that despite the lack of education opportunities and other services, children have developed and have in place different strategies to learn, trying to study with their siblings, or from their parents' phones, presenting alternative and transgressive reconceptualization of the concept and action of 'learning'.

To summarize, I interpreted the lived experiences of Syrian parents and their children as the experience of Agamben's *homo sacer*: lived experiences that unravel at the *limites* of the *polis*, where they are stripped of their political and civil rights, and where they exist and are included only in virtue of their exclusion. Having been historically excluded, these lived experiences have, for too long, remained neglected, or alternatively homogenized through Western discourses. This study shows how the lived experiences of Syrian refugee children with disabilities and their families in accessing education and other services in Lebanon are complex and multidimensional, being largely influenced by national and international xenophobic feelings and ableist understanding and approaches to disability. These are experiences soaked in injustices, segregation, discrimination, and abandonment. At the same time, these are also experiences of resistance, and daily struggle, where participants resist and confront *bare life*, juggling responsibilities, challenges, and hopes. Participants lived experiences are experiences of survival and invisibility, of resistance within a power-system that completely de-prioritize and neglect them.

2. How is inclusion framed for education in humanitarian contexts?

In exploring the framing of inclusion for education in humanitarian contexts, particularly concerning Syrian refugee children with disabilities in Lebanon, this study revealed the structural

challenges and systemic flaws within the humanitarian field, which hinder the realization of sustainable and meaningful inclusion for the education of children at the intersection of refugeehood and disability. Here, reflecting on the findings of this research, I critically explain *how* inclusion is framed and operationalized for education in humanitarian contexts.

Across the various chapters, I retraced the genesis and development of education in humanitarian contexts, being critical of the neoliberal and colonial logics underpinning the field. Inclusion is determined by and framed through these logics, which pursue Western geopolitical/colonial interests, and dominant neoliberal economic principles. For instance, in chapter 4, I reflected on how the humanitarian field, through emergencization rhetoric, echoes a troubling trend that prioritizes quantity over quality. The supremacy of ‘life-saving’ discourses as an emergency imperative legitimizes the de-prioritization of certain groups of people, as well as the hierarchization of aid. The emphasis on reaching the most people in the shorter time possible and in a cost-efficiency/-benefit manner constructs inclusion as impractical, and as something to be implemented separately, instead of being mainstreamed, as it does not represent a priority. By framing inclusion as secondary to urgent life-saving measures and initiatives, humanitarian organizations justify overlooking the needs of children with disabilities, perpetuating a cycle of exclusion and marginalization. Moreover, I analyzed how the prevalent focus of humanitarian actors lies on countable and visible projects’ outputs as measures of success, rather than on the effectiveness and sustainability of the interventions implemented. This narrow perspective, which translates into a philosophy of occupying ‘seats’ to meet funding targets, instead of working towards genuine inclusion, sidelines the importance of holistic and sustainable solutions, exacerbating the systematic failure to achieve inclusion in educational responses.

In chapter 5, I provided a more in-depth analysis of how humanitarian neoliberal forms of inclusion, which are *de facto* exclusionary, determine who is included and who is excluded. First, within the realm of education in humanitarian contexts, inclusion is often superficially incorporated into project proposals as a means to secure funding and appear competitive, rather than being recognized as a fundamental requirement to uphold people's human rights. This approach not only undermines potential progresses towards authentic inclusion, but it also fosters distrust towards implementing organizations, which come to be perceived as being interested only in their agendas, rather than in people's needs and priorities. Furthermore, organizations' representatives and Syrian parents highlighted how the educational responses implemented by humanitarian actors tend to prioritize interventions for children with 'easier cases' of disability, neglecting those with more severe and complex ones, who remained largely ignored. This exclusionary approach, perpetuated by both the humanitarian system and the Lebanese authorities, severely limits the opportunities for Syrian as well as Lebanese children with disabilities to access inclusive learning spaces.

In chapter 6, I discussed the marketization and politicization of aid and bodies within the humanitarian sector, which have a considerable impact on the extent to which education interventions are inclusive for children with disabilities. For instance, the aid sector operates within a deeply politicized framework, where humanitarian efforts are often influenced more by Western geopolitical interests, rather than by the needs and priorities of population living in emergency contexts. Similarly, the market-driven approach employed by the humanitarian sector results in the commodification of disability and inclusion, where beneficiaries are 'included' in virtue of their potential performativity against humanitarian projects' outcomes. The intrinsic political/colonial and neoliberal/economic logics guiding the humanitarian field promote exclusionary and ableist practices, further marginalizing refugees with disabilities, who are systematically excluded from funding and humanitarian interventions.

To summarize, critically inclusion appear to be framed in exclusionary terms, where (disability-inclusive) education efforts reveal deep-seated systemic challenges that undermine the inclusivity and quality of education for Syrian refugee children with disabilities. (Disability-) inclusive education projects, promoted and implemented by the humanitarian sector, are still overwhelmingly exclusionary. The ‘inclusion’ promoted within the field is framed through neoliberal, colonial and ableist principles, which uncritically reproduce inequalities, further discriminating refugee children with disabilities, especially with severe and complex ones. The humanitarian system has still a long way to go to ensure that every child’s right to education is met and achieved, regardless of their type and severity of disability.

3. What are the consequences of this framing of inclusion for the education of Syrian refugee children with disabilities?

Humanitarian neoliberal forms of inclusion, and the consequent exclusionary dimension of education efforts in contexts of conflict and emergencies have critical consequences for Syrian refugee children with disabilities, as they face systematic exclusion. In chapter 5, I explained how people who do not meet neoliberal standards of humanness are often deemed as ‘too disabled’, thus excluded from aid priorities, exacerbating their marginalization. Syrian refugee children with disabilities in Lebanon experience “multiple axes of exclusionary intersectionalities” (Kiwan, 2021: 283), where their legal status and disability define their access to education and other life-saving services. This exclusion is exemplified by the Inclusive Education Pilot Project (IEPP), implemented by UNICEF in collaboration with the Lebanese MEHE. The IEPP, as explained in chapter 5, caters only to the educational needs of Lebanese children, leaving refugee peers behind, while further perpetuating practices of disability hierarchization that favor children with milder disabilities.

In chapter 6, I focused on Syrian parents' criticism of the widespread lack of inclusion within and beyond the education system, underlining the increasing challenges they have to deal with on a daily basis. They explain that lack of access to education, and especially to health care and medical treatments is tremendously affecting their children's health and wellbeing. Many parents stated that "No one care about their children with disabilities!", and that organizations behave like if their children do not exist. They denounced the complete neglect and de-prioritization of their children with disabilities from (education) interventions, noting that no support is available and in place for them. In this chapter, I also engaged with participants' strategies and different forms of resistance performed to respond to the multiple crisis, and layers of exclusion they face. For instance, some of the parents constantly try to help each other's out through sharing information, and opportunities. Some of the mothers, in their small circle, advocate for their children's right to education and other services, trying also to sensitize other parents. Children themselves, are not passively waiting to receive education, but they are actively seeking alternative ways to learn from their siblings.

To summarize, the framing of inclusion in exclusionary terms, following neoliberal and colonial logics, has disastrous consequences on Syrian parents and their children with disabilities' health, well-being and lives. However, despite the dire circumstances they experience, participants are not passive and de-agentivized being as they are often described by Western humanitarian discourses. Syrian parents actively fight for their children's rights, displaying individual and collective forms of resistance where they help each other at the best of their possibilities, sharing information as well as opportunities. Similarly, children do not passively accept the fate imposed on them by ableist dominant systems, and they develop alternative ways to learn and to respond to the structural exclusion they experience.

1.2 Study limitations

As every research, also this study has its limitations. I must recognize that some of these limitations were easier to accept and to process compared to others, that constantly made me doubt of my competence as well as my right to conduct this research. Below, I present few of the limitations that I believe have had a considerable impact on this work.

Language limitation: language represented one of the biggest challenges in this research, and my inability to independently communicate with Syrian families and their children fluently and efficiently was an overwhelming reality, which has made me question constantly my appropriateness in conducting this research. Working with an interpreter also proved to be not always a very ‘easy’ experience, and at times, it created some tensions as explained in chapter 4. Moreover, I have the constant feeling that some of the meanings shared went lost, and I often wonder how this work would have been if I was an Arabic native speaker or if could speak the language fluently without needing the help of an interpreter.

Unstable context: The country has been experiencing a severe and ongoing economic crisis which has compounded with the Covid-19 pandemic, and the Beirut port explosion creating an extremely fragile climate. On the 22nd of September 2022, it was reported that a migrant boat from Tripoli, Lebanon, sank in the Mediterranean, resulting in the death of at least 94 people (Al-Jazeera, 2022). On this boat, there were not only Syrian and Palestinian refugees, but also some Lebanese, who were trying to escape from a life of extreme poverty. Moreover, during the same days, we witnessed different bank heists, where armed Lebanese citizens went to their banks to ask for their money, their savings back (Al-Jazeera, 2022). The death of Lebanese citizens in the Mediterranean Sea and the arrest of the people carrying out these bank heists resulted in different protests in the

North of the country. The following excerpt from my fieldnotes provides a clear example of the situation in Lebanon in September 2022, and how this impacted the fieldwork:

“Today in Tripoli there are protests! People blocked the main road; we cannot travel safely according to the interpreter. The Lebanese army is on the place. The reason for this is that some Lebanese families lost contact with their family members, who left on a boat the day before to reach Europe through illegal channels crossing the Mediterranean Sea. It is always painful to see how much death our sea is forced to bring...how much blood Europe has between its hands. Moreover, other protests are being organized in the North for this weekend to openly protest against the imprisonment of the armed people who went to reclaim their money in their banks to pay for cancer treatment for their family members. The situation is quickly deteriorating daily. It is always more difficult to afford even basic needs, and the fuel reached absurd prices. Reaching the participants has become harder and harder... the whole situation is extremely precarious.” (23/09/2022)

Compounding this very unstable situation, the lack of economic resources and the non-very suitable living conditions in which I found myself in greatly influenced how the fieldwork played out.

The economic dimension: It is well known that young researchers experience constant economic pressure, and this is very rarely addressed, despite the great impact it plays in shaping and re-directing their research. This is especially true for non-funded PhD students as in my case, who are required to make important research-related choices with a small or non-existent budget. A more substantial budget would have allowed me to organize my work differently, spending more time with families, and being able to reach people in other areas. Another important example of how the lack of financial resources influenced this study concerns the interpreter. The interpreter I worked with is a Lebanese single mother and a teacher. Her economic situation is quite precarious, and she has to work different jobs in order to provide for her daughter and herself. I immediately empathized with her, and to meet her needs I agreed on a very flexible schedule. However, she ended up not always respecting what we agreed on due to her overlapping commitments, and this

had some repercussion on my work. Due to the lack of economic resources, I did not have the possibility to hire someone else to help me with the interviews and to cover for the days in which the appointed interpreter was not available. This situation, combined with the not ideal accommodation arrangement, and the paucity of resources resulted in the decision of shortening my fieldwork, as I had no means to keep sustaining myself.

I want to conclude with a last ethical consideration, which I consider being an additional relevant limitation to this study: The impossibility of following up with participants. At the beginning of the fieldwork, I aimed to transcribe all the interviews with Syrian families and their children and have a second meeting with each family, trying to conduct a more participatory research. However, despite managing to transcribe all the interviews on time, my second meeting with the families proved to be unfeasible due to the lack of resources, and the unfolding adverse circumstances I was dealing with.

1.3 Recommendations and future research

Theoretical recommendations:

Adopting a more interdisciplinary approach to bring into conversation different field of studies

The current fragmentation between the fields of CDT, forced migration, inclusive education and education in humanitarian contexts reproduces deep conceptual and operational contradictions. An interdisciplinary approach is critical to dismantle these conceptual boundaries, and to re-theorize these fields creating and advancing critical links and discussion. A more theoretically complex and interdisciplinary understanding of the experiences of children with disabilities in accessing (inclusive) education in humanitarian contexts would provide a common language and conceptual foundation for these fields to engage in meaningful conversation, identifying gaps, guiding policies, and developing integrated approaches. More interdisciplinary work can be fostered by

creating a solid network through which academics working in different fields can start addressing these gaps. Knowledge can be shared through academic conferences, special issues dedicated to inclusive education at the intersection of forced migration and disability in humanitarian contexts, and workshops. A ‘knowledge collective’ at the intersection of these fields of study would also benefit the development of interdisciplinary efforts.

Policy recommendations:

Re-defining ‘inclusion’, as well as ‘inclusive’ policies and practices within the field of education in humanitarian contexts.

It is fundamental that humanitarian actors – including donors, practitioners, governments, and other aid workers – acknowledge the neoliberal and colonial logics underpinning the humanitarian field, purportedly working to critically address “the tensions and power relations examined between technical solutions, political agendas, and security interests” (Teh, 2022:311). For the field of education in humanitarian contexts (which encompass again both education in emergency and its subset refugee education), it is paramount to re-theorize and re-operationalize inclusion, taking distance from the securitized and neoliberal ableist paradigm of the ‘includable because exploitable for the market’, to promote an understanding of inclusion based on equal rights for all, which appreciate and embrace the value of diversity, regardless of a person’s perceived ‘commercial’ and ‘productivity’ value, resignifying "disability as an embodiment of critical diversity" (Erevelles, 2024 - AERA conference).

Mainstreaming inclusion throughout all facets and phases of humanitarian and development projects

For donors, funding for inclusion and inclusive practices must be factored and available from the inception of a policy or program to guarantee that the needs of everybody are accounted for during all the phases of emergency and development programs: planning, implementation, monitoring,

and evaluation of the projects. Moreover, “funding mechanisms and sources also need to consider the long-term costs of disability inclusion in Education in Emergency (EiE) settings and ensure that financing is sustained, even beyond the completion of a donor-funded project” (INEE, 2023). In this work, the risks of approaching inclusion as something to be dealt separately, rather than mainstreamed, have been largely discussed, underlining how the failure to mainstream inclusion promote and actualize exclusionary practices, resulting in inconsistent and disability-hierarchized responses.

Enhancing inclusivity and transparency in Monitoring and Evaluation (M&E) practices

It is imperative to strengthen the inclusivity and transparency of M&E systems within humanitarian and development projects. In chapter 4, interlocutors shared how humanitarian actors tend to monitor and report on “easy cases” of disabilities, to present “bigger numbers” in their reports. This prompts reflections on how lack of reliable data on the children reached by humanitarian interventions hampers more sustainable and inclusive planning and delivering of future programs. Without transparency and disability-disaggregated data (not only by gender, but also by type and severity of disability), it is hard to identify the gaps and to respond and address them efficiently and promptly. Such data is essential for designing effective (disability-) inclusive programs, enhancing planning and budgeting for inclusive practices, and informing the review of education policies and legislations. For humanitarian aid actors, it is fundamental, especially in emergency contexts, to conduct initial rapid assessments, and subsequent comprehensive assessment to identify people with disabilities and ensure their inclusion in emergency responses. Implementing these measures would help to critically reflect on who are the people reached by the interventions, and who are the ones excluded from them, being more aware and responsive towards the needs of those who have been historically neglected, and more or less consciously removed from humanitarian and development interventions. It would improve the effectiveness and inclusion of

humanitarian and development education projects, upholding the rights and dignity of every individual, including those with disabilities.

Practical recommendations

Translating research to engage with affected communities and stakeholders outside academia

Making research accessible to partners and stakeholders outside academia is crucial for driving change. While theoretical frameworks offer extremely valuable insights, they often remain confined within academic discourse, limiting their practical impact on policy and practice. To bridge this gap, it is essential to translate complex theoretical ideas into accessible language and actionable strategies that resonate with policymakers, humanitarian organizations, educators and affected communities. Research should be shared using formats that go beyond academic publications, such as policy brief, training manuals, easy-to-read materials and community workshop, disseminating the findings in a more direct and practical form. Moreover, collaborative partnership between researchers and non-academic stakeholders are also vital for co-producing knowledge and advance theory development.

Working collaboratively with OPDs and people with disabilities

Participants in this study often mentioned that most of the time they are forced to accept ‘help’ they do not need, while being deprived of what is essential for them and their children (see also ALNAP, 2022). When it comes to disability, the situation is further exacerbated, as explained by the participants who denounced how “no one ever want to talk to them about their children with disabilities” and potential services and solutions to meet their needs. This reality call for a more collaborative work between and among humanitarian actors, local OPDs and people with disabilities from affected communities. Inclusive decision-making must be always fostered to avoid perpetuating top-down de-agentivizing narratives and to create meaningful inclusion, as well as relevant and sustainable interventions. Affected communities, including people with disabilities,

and local OPDs should be actively engaged in conducting needs assessments, as well as lobbying activities, and policy discussions. Moreover, both OPDs and disability-focused community-based organizations (CBOs) can play pivotal role in ensuring inclusion, actively working with people with disabilities from affected communities and collaborating with them to identify and outreach other people with disabilities and their families, offering international organizations and UN agencies firsthand information on the ground-level needs, and insights into local barriers and potential enablers to inclusion, as well as the necessary skills to deal with and to address them (INEE, 2023).

Interdisciplinary training

To foster more inclusive and effective humanitarian efforts able to gather for the educational needs of refugee children with disabilities in contexts of conflict and emergency, it is imperative to develop and implement interdisciplinary training programs for humanitarian actors, educators, and disability advocates. These programs should provide a collaborative space where people coming from different sectors can learn from each other and co-design more inclusive and sustainable educational projects. For instance, disability specialists can provide expertise on accessibility, inclusive educators on adaptive learning methods and pedagogies, and humanitarians can ensure that programs are feasible and responsive to the specificities of different crisis contexts. These interdisciplinary training programs can become part of academic curricula and can be equally organized as training workshop for practitioners and other stakeholders working on the field.

Interdisciplinary and multi-stakeholder collaboration

Fundamental would be to advance interdisciplinary collaborations both within and beyond academia to advance the educational responses for refugee children with disabilities in humanitarian contexts, bridging the gaps between the research-practice divide. On the research side, as already mentioned, collaboration between scholars from different field of studies would allow to develop a more comprehensive conceptual framework to challenge the limits of our current

disciplines and their operationalization. Practically, multi-stakeholder partnership – including academics, educators, humanitarian actors, disability advocates, policy makers and especially affected communities – would enable the co-creation of knowledge and of inclusive programs that are contextually relevant and responsive to the needs on the ground. By combining research insights with on-the-ground expertise, these collaborations would foster policies and practices that are not only theoretically sound but also operationally feasible, culturally sensitive and sustainable.

Directions for future research

Concerning the directions for future research, a first important step would involve going back to the groups of participants separately to share the final version of this research and to discuss together their feedback and views on the work, which would surely prompt additional reflections and potentially further theorization. Then, I would organize a series of group interviews, meetings, and workshops to bring Syrian refugee children with disabilities and their parents together with organizations' representatives. The aim would be to use a more participatory approach and start creating meaningful networks. Lastly, I would conduct a multi-stakeholder participatory research project with Syrian children with disabilities and their parents, as well as with local OPDs, and other humanitarian aid organizations, to research whether and to what extent conversations and collaboration between and among these different actors can result in meaningful and sustainable inclusion for refugee children with disabilities within inclusive education initiatives. Unfortunately, due to time and economic constraints, following up with participants and then bringing them together for further reflection and work was not possible. However, I believe that it would be extremely useful and important to create collaborative spaces where children with disabilities, especially with severe and complex ones, and their families can expose their concerns, needs and expectations, while actively collaborating with humanitarian aid actors, OPDs and local government to implement more inclusive approaches and initiatives.

I am also interested in working with Lebanese and different refugee groups in the region, such as Palestinians, Iraqis, Sudanese, and others living in Lebanon, to better understand how aid is distributed among and across the different refugee groups, exploring the diverse groups' attitudes and approaches towards each other, as well as the humanitarian and Lebanese institutional educational responses to their presence in the region. For instance, organizations' representatives mentioned that most of the fundings that are coming to Lebanon are for the Syrian refugees, meaning that refugees from other background might not 'qualify' to access aid. I believe that working collaboratively with refugees from different backgrounds and Lebanese people would not only serve as a platform to start addressing issues of cohesion but would also create a space for refugees to unite, and to advocate for a change. I hope that this work, through the adoption of a multidimensional critical lens, has contributed to bridging the gap on the lived experiences and lives of people at the intersection of disability and refugeehood, as well as to advancing the research on inclusion and inclusive education within the field of education in contexts of emergencies. Much work remains to be done, especially considering the growing instability in the Middle East, where a growing number of people have been forced to flee their homes. For instance, Israeli attacks on Lebanon in late September 2024 led to a humanitarian crisis with nearly 3,500 civilians killed, 14,000 injured and over 1.3 million displaced. Over 500 public schools have been repurposed as shelters, and by November 2024, the education of over 1 million students, both Lebanese and refugees, have been disrupted and directly affected by the conflict (Shuayb et al., 2024).

Final considerations

I am aware of the potential critique this work might incur. I appreciate the fact that some people might disagree with the conceptual development of the (C)GT's notion of 'Letting die through Neoliberal Inclusion' because it can sound rhetorical, as one can argue that people do not die for lack of education. In this regard, I believe it is fundamental to highlight that the concept of 'Letting

die through Neoliberal Inclusion’ is as much rhetorical as practical. For instance, in context of emergencies and crises, going to school and having access to education can “reduce children’s exposure to threats including sexual exploitation, physical attack and military recruitment. Classrooms can also be effective forums for conveying life-saving information about other risks including landmines, and HIV/AIDS” (Mooney and French, 2005:1); children might receive meals, and/or they have access to psychosocial support. Having received an education would help people to access more easily information about services, to follow up with organizations and UN agencies, as well as to be more involved within the community. Many of the parents interviewed during this study were illiterate, and they talked about fearing to sign something that can ruin their lives, because they cannot read, and they do not know what they are signing. They mentioned being unable to follow up with the UN as they do not know how to write or read the messages they receive from time to time on their phones, and the UN never answers to their calls when trying to reach their hotline. They also explained how hard it is for them to find information, which consequently impact their possibilities to access life-saving services for their children and their families. Thus, the lack of education might not ‘kill’, but it surely ‘let die’ people who are excluded from it.

Despite potential critiques, this study is undoubtedly unique in that there is no existing research to my knowledge that has enabled the perspective of Syrian refugee children with different types and severity of disabilities, as well as their parents, to be heard. In this work, I investigated the experiences of Syrian refugee children with disabilities in Lebanon, bringing together identity’s dimensions such as refugeehood, and disability, which in humanitarian contexts are often seen as compartmentalized categories of being, rather than intersectional and multidimensional. Drawing on a CDT lens, I shed light on the ontological, epistemological, and practical invisibility and exclusion of refugee children with disabilities within the emergency education sector, as well as the academic realm.

Moreover, thanks to the rich empirical data gathered, it was possible to explore the role of education in emergency in excluding and confining in a *state of exception* Syrian refugee children with severe and complex disabilities. This category of children has been historically neglected both in academia and in humanitarian contexts, experiencing greater level of exclusion and marginalization compared to their peers with mild or moderate disabilities. Most of the work available on the topic do not critically engage with the main humanitarian structures reproducing exclusionary practices; rather, they engage with practical barriers faced by learners with/out disabilities. Furthermore, there is a dearth of empirical studies with refugee children with severe and complex disabilities, who continue to be marginalized both within the humanitarian sector and within academia. With this study, I contribute to the literature at the intersection of refugeehood, disability and education, aligning with the more recent efforts to bridge the gap at the juncture of these disciplines, and drawing what I believe being critical considerations to link the theory-practice divide within the humanitarian field.

In addition, I shed light on the neoliberal nature of humanitarianism, and on the ableist understanding and construction of inclusion within the field, highlighting its impact on the lives of Syrian refugee children with disabilities, especially with severe and complex ones, in the region, and underlining the urgency to critically re-think the ways in which humanitarian actors define and operationalize ‘inclusion’ and ‘inclusive education’ initiatives. I offer a methodological and theoretical framework to acknowledge and recognize the heterogeneous lived experiences of people at the intersection of refugeehood and disability living in protracted displacement, challenging the widespread dichotomic signification of these lives as either ‘vulnerable’ or ‘threatening’, and offering stories of very diverse forms of resistance and agency.

REFERENCES

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society*, 2(1):5-19.
- Abou-Zahr, S. (2017). Refugees and the Media in Lebanon. *Peace Insight*. DOI: <https://www.peaceinsight.org/en/articles/refugees-and-media-lebanon/?location=lebanon&theme=conflict-prevention-early-warning>
- Abumeri, J. (2020). Lebanon's Refugee Crisis, Part II: The Consequences of Lebanon's Refugee Policies. *Immigration and Human Rights Law Review Blog*. DOI: <https://lawblogs.uc.edu/ihr/r/2020/04/30/lebanons-refugee-crisis-part-ii-the-consequences-of-lebanons-refugee-policies/>
- Adams, D. L., and Erevelles, N. (2017). Unexpected spaces of confinement: Aversive technologies, intellectual disability, and "bare life". *Punishment & Society*, 19(3), 348-365.
- Agamben, G. (1998). *Homo Sacer: Sovereign Power and Bare Life*. Stanford University Press: California.
- Agamben, G. (2005). *State of Exception*. Chicago and London: The University of Chicago Press.
- Agar, M. H. (1996). *The professional stranger: An informal introduction to ethnography*. Emerald Group Publishing Limited.
- Agier, M. (2011). *Managing the undesirables*. Polity.
- Ahmed, S. (2013). *The cultural politics of emotion*. Routledge.
- Ahmed, S. (2014). *Cultural politics of emotion*. Edinburgh University Press.
- Akesson, B., Badawi, D. and Elkchirid, A. (2020). 'I am mostly concerned about their education': Syrian refugee families and the right to education in Lebanon. *Canadian Journal of Children's Rights*.
- Alcalde, J. (2016). Why the refugee crisis is not a refugee crisis. *Peace in Progress*, 29, 1-6.
- Al-Hawamdeh, A., and El-Ghali, H. A. (2017). THE REGIONAL CONFERENCE ON HIGHER EDUCATION IN CRISIS SITUATIONS.
- Al-Jazeera (2022). Lebanon banks will remain shut indefinitely after 'heists'. DOI: <https://www.aljazeera.com/news/2022/9/22/lebanon-banks-will-remain-shut-indefinitely-after-heists#:~:text=Hafiz%20has%20been%20lauded%20as,attempting%20to%20retrieve%20his%20savings.>
- Almustafa, M. (2022). Reframing refugee crisis: A "European crisis of migration" or a "crisis of protection"? *Environment and Planning C: Politics and Space*, 40(5), 1064-1082.

Aloudat T., and Khan T. (2022). Decolonising humanitarianism or humanitarian aid? *PLOS Glob Public Health*, 2(4): e0000179. <https://doi.org/10.1371/journal.pgph.0000179>

Al-Sayegh, S., E. (2023). Professional Challenges for Lebanese Teachers: Exploring the Relationship between Salary, Job Satisfaction, Mental Health, and Academic Achievement in Aley District. *Global History Dialogues*. DOI: <https://globalhistorydialogues.org/projects/professional-challenges-for-lebanese-teachers/#:~:text=One%20of%20the%20major%20issues,and%20provide%20for%20their%20families>

Alsbeti, D. (2023). "A Double Standard in Refugee Response: Contrasting the Treatment of Syrian Refugees with Ukrainian Refugees," *Human Rights Brief*: Vol. 26: Iss. 2, Article 4.

Amoruso, F., Pappé, I., and Richter-Devroe, S. (2019). Introduction: Knowledge, power, and the “settler colonial turn” in Palestine studies. *Interventions*, 21(4), 451-463.

Al-Zboon, E. (2017). Childhood fears among children who are blind: The perspective of teachers who are blind. *Early Years*, 37(2), 158–172. <https://doi.org/10.1080/09575146.2016.1168789>

Al-Zyoudi, M. (2006). Teachers' Attitudes towards Inclusive Education in Jordanian Schools. *International journal of special education*, 21(2), 55-62.

Amnesty International. (2021). “‘You’re Going to Your Death’: Violations against Syrian Refugees Returning to Syria.” DOI: <https://www.amnesty.org/en/documents/mde24/4583/2021/en/>

Amnesty International. (2023). “Lebanon: Authorities must halt unlawful deportations of Syrian refugees”. DOI: <https://www.amnesty.org/en/latest/news/2023/04/lebanon-authorities-must-halt-unlawful-deportations-of-syrian-refugees/>

Anati, N. (2013). The pros and cons of inclusive education from the perceptions of teachers in the United Arab Emirates. *International Journal of Research Studies in Education*, 2(1), 55-66.

Anderson, A., Martone, G., Perlman Robinson, J., Rognerud, E., and Sullivan Owomoyela, J. (2006). Standards put to the test: Implementing the INEE minimum standards for education in emergencies, chronic crisis and early reconstruction. *Humanitarian Practice Network Papers*, 57. DOI: <http://www.odihpn.org/download/networkpaper057pdf>

Anderson, B. (1991). *Imagined Communities: Reflections on the Origin and Spread of Nationalism*. London, Verso Books.

Andrews, E. E., Kuemmel, A., Williams, J. L., Pilarski, C. R., Dunn, M. and Lund, E. M. (2013). Providing culturally competent supervision to trainees with disabilities in rehabilitation settings. *Rehabilitation Psychology*, 58, 233–244. DOI: <http://dx.doi.org/10.1037/a0033338>

Antoun, Z. (2021). *Examining the Educational Experiences and Obstacles of Syrian Refugees in Lebanon* (Doctoral dissertation, University of Pennsylvania).

Aradau, C. (2004). Security and the democratic scene: Desecuritization and emancipation. *Journal of International Relations and Development*, 7(4), 388-413.

Arán, M., and Peixoto Júnior, C. A. (2007). Vulnerability and bare life: bioethics and biopolitics today. *Revista de Saúde Pública*, 41, 849-857.

Arendt, H. (2001). *The Origin of Totalitarianism*. New York: Harcourt.

Assi, A. (2019). International Politics of Syrian Refugee Return: The Case of Lebanon. DOI: https://www.mei.edu/publications/international-politics-syrian-refugee-return-case-lebanon#_edn6

Awada, F. (2016). Une vacuité présidentielle au coeur de la crises (Doctoral dissertation, Saint Joseph University of Beirut, Lebanon).

Ayoob, M. (2002). Humanitarian intervention and state sovereignty. *Int'l J. Hum. Rts.*, 6, 81.

Bahou, L., and Zakharia, Z. (2019). “Maybe that’s how they learned in the past, but we don’t learn like this today”: Youth perspectives on violent discipline in Lebanon’s public schools. *International Journal of Educational Development*, 70. <https://doi.org/10.1016/j.ijedudev.2019.102098>

Bakshi, P., & Trani, J. F. (2006). Towards Inclusion and Equality in Education? From Assumptions to Facts, National Disability Survey in Afghanistan 2005.

Balzacq, T. (2005). The three faces of securitization: Political agency, audience and context. *European journal of international relations*, 11(2), 171-201.

Barnett, M. (2009). *The international humanitarian order*. New York, NY: Routledge.

Barnett, M. (2005). Humanitarianism transformed. *Perspectives on politics*, 3(4), 723-740.

Barnett, M. N. (2011). *Empire of Humanity: A History of Humanitarianism*. New York: Cornell University Press.

Barnett, M.N., and Weiss, T.G. (2008). *Humanitarianism in Question: Politics, Power, Ethics*. Cornell Paperbacks. Ithaca: Cornell University Press.

Barnett, M., and Weiss, T. G. (Eds.). (2018). *Humanitarianism in question: Politics, power, ethics*. Cornell University Press.

Barnett, M. N. and M. Finnemore (1999). ‘The Politics, Power and Pathologies for International Organizations’. *International Organization*, 53:4, Autumn.

Baroud, M. (2017). Improving healthcare access for persons with disabilities in Lebanon: together for justice in service provision. *Beirut: AUB Policy Institute*.

Bassil, Y. (2012). Syrian hegemony over Lebanon after the Lebanese civil war. *Journal of Science*, 136(2), 136-147.

- Bastagli, F., Hagen-Zanker, J., Harman, L., Barca, V., Sturge, G., Schmidt, T., and Pellerano, L. (2016). Cash transfers: what does the evidence say. A rigorous review of programme impact and the role of design and implementation features. *London: ODI*, 1(7), 1.
- Baylouny, A. M. (2013). Building an integrated military in post-conflict societies: Lebanon. In *The routledge handbook of civil-military relations* (pp. 242–254). Routledge
- Beck, M. (2017). Securitization of the recent influx of refugees from the middle east to Europe. *News Analysis of SDU's Resource Center on Middle East Studies*, 2017(september).
- Becker, P. (2009). What Makes us Modern(s)? The Place of Emotions in Contemporary Society. In *Theorizing Emotion: Sociological Exploration and Applications* by Hopkins, D.; Kleres, J.; Flam, H. and Kuzmics, H. (eds.) 195-220.
- Belloni, R. (2007). The trouble with humanitarianism. *Review of International Studies*, 33(3), 451-474.
- Bennett, T., Deluca, D., and Bruns, D. (1997). Putting inclusion into practice: Perspectives of teachers and parents. *Exceptional children*, 64(1), 115-131.
- Bentley, A. K. (2005). Can there be any universal children's rights? *The International Journal of Human Rights*, 9(1), 107-123.
- Berezin, M. (2002). Secure states: towards a political sociology of emotion. *The Sociological Review*, 50(S2), 33-52.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), 219-234.
- Berghs, M. (2014). The New Humanitarianism: Neoliberalism, Poverty and the Creation of Disability. In C. Scholand-Vials and M. Gill (eds.). *Disability, Human Rights and the Limits of Humanitarianism* (pp. 27-44). Aldershot: Ashgate.
- Berghs, M. (2015). Radicalising 'disability' in conflict and post-conflict situations. *Disability & Society*, 30:5, 743-758, DOI: 10.1080/09687599.2015.1052044
- Bernard, H. R. (2002). *Research Methods in Anthropology: Qualitative and Quantitative Methods* (3rd ed.). Walnut Creek, CA: Alta Mira Press.
- Bešić, E., Paleczek, L., and Gasteiger-Klicpera, B. (2020). Don't forget about us: Attitudes towards the inclusion of refugee children with (out) disabilities. *International Journal of Inclusive Education*, 24(2), 202-217.
- Biddle, S. K. (2017). Social constructions of childhood: From not-yet-adults to people in their own right. *Anthós*, 8(1), 3.

Bilagher, M., and Kaushik, A. (2020). The potential of Accelerated Learning Programmes (ALPs) for conflict-ridden countries and regions: Lessons learned from an experience in Iraq. *International Review of Education*, 66(1), 93–113. DOI: <https://doi.org/10.1007/s11159-020-09826-1>

Birch, K., & Mykhenenko, V. (2010). The Rise and Fall of Neoliberalism. The Collapse of Economic Order. London & New York.

Bird, G and Lynch, H (2019). Introduction to the politics of life: a biopolitical mess. *European Journal of Social Theory*, 22(3), pp. 301-316. <https://doi.org/10.1177/1368431019838455>

Blaska, J. (1993). The power of language: Speak and write using “person first.”. *Perspectives on disability*, 25-32.

Bohman, J. (2005). We, heirs of enlightenment: Critical theory, democracy and social science. *International Journal of Philosophical Studies*, 13(3), 353-377.

Bousfield, D. (2005). The logic of sovereignty and the agency of the refugee: recovering the political from ‘bare life’. DOI: <https://yciss.info.yorku.ca/files/2012/06/WP36-Bousfield.pdf>

Boustani, M., Carpi, E., Gebara, H., and Mourad, Y. (2016). Responding to the Syrian crisis in Lebanon: Collaboration between aid agencies and local governance structures. DOI: <http://pubs.iied.org/pdfs/10799IIED.pdf>

Boveda, M., and Annamma, S. A. (2023). Beyond making a statement: An intersectional framing of the power and possibilities of positioning. *Educational Researcher*, 52(5), 306-314.

Bragg, B. (2022). (De)constructing Refugee Vulnerability: Overcoming Institutional Barriers to Ethnographic Research With Refugee Communities. *Journal of Contemporary Ethnography*, 51(2): 197-222.

Brown, S. E. (1995). A celebration of diversity: An introductory, annotated bibliography about disability culture. *Disability Studies Quarterly*, 15, 36 –55.

Brun, C. and Shuayb, M. (2020). 'Exceptional and Futureless Humanitarian Education of Syrian Refugees in Lebanon: Prospects for Shifting the Lens', *Refuge: Canada's Journal on Refugees*, 36(2): 20-30.

Brun, C. and Fakih, A. (2022). Debunking the dangerous myth that refugees are an economic burden in Lebanon. *The New Humanitarian*. DOI: <https://www.thenewhumanitarian.org/opinion/2022/09/26/Syrian-refugees-Lebanon-economics>

Bruce, A., Quinn, G., Degener, T., Burke, C., Quinlivan, S., Castellino, J., ... and Kilkelly, U. (2002). *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability*. United Nations Press.

Buckel, S., & Wissel, J. (2010). State project Europe: The transformation of the European border regime and the production of bare life. *International political sociology*, 4(1), 33-49.

- Buckner, E., Spencer, D. and Cha, J. (2018). Between Policy and Practice: The Education of Syrian Refugees in Lebanon. *Journal of Refugee Studies*. 31(4): 444–465.
- Burde, D., Kapit, A., Wahl, R. L., Guven, O., and Skarpeteig, M. I. (2017). Education in emergencies: A review of theory and research. *Review of Educational Research*, 87(3), 619-658.
- Burghardt, M. (2011). The Human Bottom of Non-Human Things: On Critical Theory and its Contributions to Critical Disability Studies. *Critical Disability Discourse/Discours critiques dans le champ du handicap (CDD/DCCH)*, 3(art. 2): 1–16
- Butler, J., and Athanasiu, A. (2013). *Dispossession: The performative in the political*. Cambridge: Polity Press.
- Buzan, B., Wæver, O., and De Wilde, J. (1998). *Security: A new framework for analysis*. Lynne Rienner Publishers.
- Campbell, F. K. (2009). *Contours of ableism: The production of disability and abledness*. New York: Palgrave Macmillan.
- Carlson, L. (2010). Who's the expert? Rethinking authority in the face of intellectual disability. *Journal of Intellectual Disability Research*, 54, 58-65.
- Carpi, E. (2023). *The Politics of Crisis-Making: Forced Displacement and Cultures of Assistance in Lebanon*. Indiana University Press: US.
- Carpi, E. (2022). Ethnocracies of care and humanitarianism in Lebanon. *REMHU: Revista Interdisciplinar da Mobilidade Humana*, 29, 87-106.
- Carpi, E. (2014). The everyday experience of humanitarianism in Akkar villages. *Civil Society Knowledge Center, Lebanon Support*, 1-20.
- Casey, P. J. (2023). Lived Experience: Defined and Critiqued. *Critical Horizons*, 24(3), 282–297. <https://doi.org/10.1080/14409917.2023.2241058>
- Castles, S. (2003). The international politics of forced migration. *Development*, 46, 11-20.
- Cepko, R. (1993). Involuntary sterilization of mentally disabled women. *Berkeley Women's LJ*, 8, 122.
- Chapple, R. L., Bridwell, B. A., & Gray, K. L. (2021). Exploring intersectional identity in black deaf women: The complexity of the lived experience in college. *Affilia*, 36(4), 571-592.
- Charmaz, K. (2005). Grounded Theory in the 21st Century. Applications for advancing social justice research. In Denzin, N. and Lincoln, Y. (Eds.), *The Sage Handbook of Qualitative Research*. 3rd Ed., Thousand Oakes, California: Sage. (pp. 507- 535).
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: Sage.

- Charmaz, K. (2014). *Constructing Grounded Theory*. Second Edition. London: Sage.
- Chaudhry, V. (2015). Neoliberal disorientations: changing landscapes of disability and governance in India. *Disability & Society*, 30(8), 1158-1173.
- Chand, D., and Reddy, C. R. (2012). Disability and Social Exclusion: a study on State initiatives towards people with impairments. *IASSI-Quarterly*, 31(3and4), 123-140.
- Chaudhry, V. (2015). Neoliberal disorientations: changing landscapes of disability and governance in India. *Disability & Society*. DOI: 10.1080/09687599.2015.1081093
- Chimhenga, S. (2016). Resource material barriers. The challenge of implementing inclusive education in primary schools of Zimbabwe. *Global Journal of Advanced Research*, 3(6), 526-532.
- Chimni, B. S. (1998). The geopolitics of refugee studies: A view from the South. *Journal of refugee studies*, 11(4), 350-374.
- Chimni, B. S. (2009). The birth of a 'discipline': From refugee to forced migration studies. *Journal of Refugee studies*, 22(1), 11-29.
- Christiansen, I. (2017). Commodification of healthcare and its consequences. *World Review of Political Economy*, 8(1): 82-103. DOI: 10.13169/worlrevipoliecon.8.1.0082
- Clare, S. (2009). Agency, Signification, and Temporality. *Hypatia*, 24, 50–62.
- Clear, M., and Gleeson, B. (2002). Disability and materialist embodiment. *Journal of Australian Political Economy*, The, (49), 34-55.
- Colatrella, S. (2011). Nothing Exceptional: Against Agamben. *Journal for Critical Education Policy Studies (JCEPS)*, 9(1).
- Collins, P. H. (1999). Reflections on the Outsider Within. *Journal of Career Development*, 26(1), 85-88. <https://doi.org/10.1177/089484539902600107>
- Collinson, S. (2016). Constructive deconstruction: making sense of the international humanitarian system. *Overseas Development Institute: London*.
- Colombo, S. (2022). Are death and suffering in Ukraine different than in Yemen, Afghanistan or Ethiopia? Double standards in humanitarian assistance. *Epidemiologia&Prevenzione*, <https://epiprev.it/5928>
- Combaz, E. (2018). Situation of persons with disabilities in Lebanon. *Brighton, UK: Institute of Development Studies*.
- Cone, D. (2010). Shifting community views: reducing stigma in Dadaab. *Forced Migration Review*, (35), 19.
- Cook, R. J., and Dickens, B. M. (2000). Voluntary and involuntary sterilization: denials and abuses of rights. *International Journal of Gynecology & Obstetrics*, 68(1), 61-67.

Cooley, A. and Ron, J. (2002). The NGO Scramble: Organizational Insecurity and the Political Economy of Transnational Action. *International Security* 27(1), 5–39.

Cooley, A. and Ron, J. (2002). Organizational Insecurity and the Political Economy of Transnational Action. *International Security*, 27.

Corker, M., and French, S. (1999). *Disability discourse*. McGraw-Hill Education (UK).

Costantini, G. and El-Serafy, Y. (*forthcoming*). Exacerbating Exclusion?: How the logics of refugee education perpetuate the exclusion of refugees with disabilities. *International Review of Education, Journal of Lifelong Learning*.

Crawley, H., & Skleparis, D. (2018). Refugees, migrants, neither, both: Categorical fetishism and the politics of bounding in Europe's 'migration crisis'. *Journal of ethnic and migration studies*, 44(1), 48-64.

Crea, T. M.; Klein, E., K.; Okunoren, O.; Jimenez, M., P., (...) and Bruni, D. (2022). Inclusive education in a refugee camp for children with disabilities: How are school setting and children's behavioral functioning related? *Conflict and Health*, 16:53.

Crea, T. M., Evans, K., Hasson III, R. G., Neville, S., Werner, K., Wanjiku, E., ... and Bruni, D. (2023). Inclusive education for children with disabilities in a refugee camp. *Disasters*, 47(1), 99-113.

Crenshaw, K. (1989). *Demarginalizing the Intersection of Race and Sex: a black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics*. University of Chicago: Legal Forum.

Creswell, J. W. and Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). SAGE Publications.

Crock, M., Smith-Khan, L., McCallum, R., & Saul, B. (2017). *The legal protection of refugees with disabilities: Forgotten and invisible?* Edward Elgar Publishing.

Crotty, M. (2010). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: SAGE Publications.

Crul, M., Lelie, F., Biner, Ö., Bunar, N., Keskiner, E., Kokkali, I., ... and Shuayb, M. (2019). How the different policies and school systems affect the inclusion of Syrian refugee children in Sweden, Germany, Greece, Lebanon and Turkey. *Comparative Migration Studies*, 7(1), 1-20.

Dalal, Y. (2020). Lebanon's Invisible: Refugees, COVID-19, and the Beirut Port Explosion. *Middle East Institute*. DOI: <https://www.mei.edu/publications/lebanons-invisible-refugees-covid-19-and-beirut-port-explosion>

Das, M. (2021). Lebanon faces critical shortage of drugs. *The Lancet Oncology*, 22(8), 1063.

Davey, E., Borton, J. and Foley, M. (2013). A history of the humanitarian system: Western origins and foundations. *HPG Working Paper*. DOI: <http://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/8439.pdf>

Davis, L., J. (1997). *The Disability Studies Reader*. New York & London: Routledge.

Davitti, D. (2018). Biopolitical borders and the state of exception in the European migration 'crisis'. *European Journal of International Law*, 29(4), 1173-1196.

DeJong, J., Sbeity, F., Schlecht, J., Harfouche, M., Yamout, R., Fouad, F. M., ... and Robinson, C. (2017). Young lives disrupted: gender and well-being among adolescent Syrian refugees in Lebanon. *Conflict and health*, 11, 25-34.

Delanty, G. (2020). Six Political Philosophies in Search of a Virus: Critical Perspectives on the Coronavirus Pandemic. LEQS Paper No. 156/2020.

Demetriou, O. M. (2018). *Refugeehood and the Postconflict Subject: Reconsidering Minor Losses*. Suny Press.

Desai, M. (2020). Children in specific emergency situations and need for child protection services. In Rights-based integrated child protection service delivery systems (pp. 439–462). Springer. DOI: https://doi.org/10.1007/978-981-13-8534-6_15

De Sousa Santos, B. (2016). *Epistemologies of the South: Justice against Epistemicide*. Routledge: USA.

Dhaybi, J. (2020). Report Alleges Gross Misuse of Donor Funds for Refugee Education in Lebanon. *Al-Fanar Media*. DOI: <https://www.al-fanarmedia.org/2020/06/report-alleges-gross-misuse-of-donor-funds-for-refugee-education-in-lebanon/?lbsf=true&id=42371>.

Diab, J. L. (2020). A Budding “Good Practice”: Access to Quality, Non-Formal Education for Syrian Refugees in Lebanon. *IJRDO-Journal of Educational Research*, 5(1), 01-10.

Diab, J., L. (2023). Safe Return and Voluntary Repatriation for Syrian Refugees from Lebanon: What Needs to Happen Next? Discussion Paper. United Nation University. DOI: [file:///Users/giadacostantini/Downloads/RepatriationSyrianRefugees_FINAL%20\(2\).pdf](file:///Users/giadacostantini/Downloads/RepatriationSyrianRefugees_FINAL%20(2).pdf)

Diab, J., L. (2023). On Prosecution, Persecution and Protection: Unpacking Anti-Refugee Narratives, Kinopolitics and Selective Outrage in Lebanon. *Refugee Law Blog on Refugee Law and Forced Migration*. DOI: <https://rli.blogs.sas.ac.uk/2023/05/16/on-prosecution-persecution-and-protection-unpacking-anti-refugee-narratives-kinopolitics-and-selective-outrage-in-lebanon/#:~:text=The%202014%20decision%20would%20see,Syrians%20already%20inside%20the%20country>

Diekema, D. S. (2003). Involuntary sterilization of persons with mental retardation: an ethical analysis. *Mental retardation and developmental disabilities research reviews*, 9(1), 21-26.

Di Nicola, V. (2020). The Global South: An emergent epistemology for social psychiatry. *World Social Psychiatry*, 2(1), 20-26.

Dionigi, F. (2016). The Syrian Refugee Crisis in Lebanon: State Fragility and Social Resilience (LSE Middle East Centre Paper Series; No. 15). London: Middle East Centre, The London School of Economics and Political Science.

Dieumegard, G., Nogry, S., Ollagnier-Beldame, M., & Perrin, N. (2021). Lived experience as a unit of analysis for the study of learning. *Learning, Culture and Social Interaction*, 31, 100345.

Defence Language Institute Foreign Language Center (DLIFLC) (2019). Cultural Orientation Arabic-Levantine. DOI: https://fieldsupport.dliflc.edu/products/lebanese/aq_co/website/arabic-levantine.pdf

Donini, A. (2014). Humanitarianism, perceptions, and power. In Acuto, M. ed., *Negotiating Relief: The Dialectics of Humanitarian Space*, p.39-47. Hurst.

Donohue, C. R. (2023). “The Bare Replacement”: Geneticists’ and Bioethicists Support of Eugenics, from after the Second World War to the Human Genome Project. *Revista Brasileira de História*, 43, 225-252.

Dryden-Peterson, S. (2017). Refugee education: Education for an unknowable future. *Curriculum Inquiry*, 47(1), 14-24.

Duda-Mikulin, E., Scullion, L., and Currie, R. (2019). Wasted lives in scapegoat Britain: Overlaps and departures between migration studies and disability studies. *Disability & Society*, 0(0), 1–25. <https://doi.org/10.1080/09687599.2019.1690428>

Dunn, D. S., and Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists’ cultural competence using disability language. *American Psychologist*, 70(3), 255.

Düvell, F., & Lapshyna, I. (2022). On war in Ukraine, double standards and the epistemological ignoring of the global east. *International Migration*, 60(4), 209-212.

ECW (Education Cannot Wait). (2019). The Humanitarian-Development Nexus Modelling Education in Crisis. DOI: <https://www.educationcannotwait.org/sites/default/files/2022-01/HLSG%20Humanitarian%20Development%20Nexus%20Paper%20April%202019.pdf>

Edwards, R. (1998). A critical examination of the use of interpreters in the qualitative research process. *Journal of Ethnic and Migration Studies*, 24 (2), 197-208.

Eid, C. (2023). Barriers to Education for Syrian refugee children in Lebanon. DOI: <https://globalhistorydialogues.org/projects/barriers-to-education-for-syrian-refugee-children-in-lebanon/>

Ek, R. (2006). Giorgio Agamben and the spatialities of the camp: an introduction. *Geografiska Annaler: Series B, Human Geography*, 88(4), 363-386.

Elder, B. C. (2015). Stories from the margins: Refugees with disabilities rebuilding lives.

El-Ghali, H., A., Ghalayini, N. and Ismail, G. (2016). Responding to crisis: Syrian refugee education in Lebanon. Policy Brief #7. DOI:https://www.aub.edu.lb/ifi/Documents/publications/policy_briefs/20152016/20160406_responding_to_crisis.pdf

England, K. V. (1994). Getting personal: Reflexivity, positionality, and feminist research. *The professional geographer*, 46(1), 80-89.

Erevelles, N. (2014). Thinking with disability studies. *Disability Studies Quarterly*, 34(2).

Erevelles, N. (2011). *Disability and Difference in Global Context: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan.

Erevelles, N., and Nguyen, X. T. (2016). Disability, girlhood, and vulnerability in transnational contexts. *Girlhood Studies*, 9(1), 3-20.

ESCWA (United Nations Economic and Social Commission for Western Asia). (2021). ESCWA's Multidimensional Poverty in Lebanon, 2019-2020: Painful Reality and Uncertain Prospects. DOI: <https://blog.blominvestbank.com/41484/escwas-multidimensional-poverty-in-lebanon-2019-2020-painful-reality-and-uncertain-prospects/#:~:text=As%20stated%20by%20ESCWA's%20report,%25%20of%20Lebanese%2Dnational%20households.>

Estriani, H. N. (2019). The Syrian refugees in Lebanon: Moving towards securitization. *Jurnal Hubungan Internasional*, 7(2), 178-188.

EuroMed Rights. (2023). Economic difficulties spare nobody in Lebanon, certainly not Syrian refugees. DOI: <https://euromedrights.org/publication/economic-difficulties-spare-nobody-in-lebanon-certainly-not-syrian-refugees/>

Fakhoury, T., and Ozkul, D. (2019). Syrian refugees' return from Lebanon. *Forced Migration Review*, (62).

Fakhoury, T., and Abi Raad, L. (2017). Refugees as minorities: Displaced Syrians as a “new minority” in Lebanon’s sectarian power-sharing system. *Maghreb-Machrek*, (4), 43-53.

Fanon, F. (1963). The Wretched of the. *Earth (New York: Grover, 2004)*, 62.

Fassin, D. (2007). Humanitarianism as a Politics of Life. *Public culture*, 19(3), 499-520.

Fassin, D. (2011). Policing borders, producing boundaries. The governmentality of immigration in dark times. *Annual Review of anthropology*, 40, 213-226.

Fassin, D. (2013). The predicament of humanitarianism. *Qui Parle: Critical Humanities and Social Sciences*, 22(1), 33-48.

Fiddian-Qasmiyeh, E. (2024). Recentring the South in Studies of Migration in Crawley, H., & Teye, J. K. (2024). *The Palgrave Handbook of South–South Migration and Inequality* (p. 749). Springer Nature.

Fieldhouse, D. K. (2008). Lebanon and the French, 1918–1946'. *Western Imperialism in the Middle East 1914-1958* (Oxford, 2008; online edn). DOI: <https://doi.org/10.1093/acprof:oso/9780199540839.003.0008>, accessed 30 July 2023.

Finkelstein, V. (1980). *Attitudes and Disabled People: Issues for Discussion*. New York: World Rehabilitation Fund.

Finlay, L. (2000). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12, 531-554.

Fleck, L. (1979). *Genesis and Development of a Scientific Fact*. Chicago: University of Chicago Press. [first published in 1935]

Fontana, A., and Frey, J. H. (2005). The Interview: From Neutral Stance to Political Involvement. In N. K. Denzin and Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 695–727).

Fontana, G. and Costantini, G. (2024). "Disability in Intra-State War-to-Peace Transitions: Understandings, Policies, and Challenges to Implementation". *Disability and Society*. <https://doi.org/10.1080/09687599.2024.2412276>

Foucault, M. (2007). *Security, territory, population: lectures at the Collège de France, 1977-78*. Springer.

Frangieh, B. (2017). Analyse de l'activité des enseignants face à la diversité des élèves dans une école inclusive au Liban. *Revue d'éducation comparée*, (18), 173-192.

Frangieh, B., and Ramel, S. (2019). Inclusive education in the Lebanese educational system. *Journal of Studies in Language, Culture and Society*, 2(2), 8-15.

Fregonese, S. (2012). Beyond the "weak state": Hybrid sovereignties in Beirut. *Environment and Planning D: Society and Space*, 30 (4): 655–74.

Fresia, M., and Von Känel, A. (2016). Beyond space of exception? Reflections on the camp through the prism of refugee schools. *Journal of refugee studies*, 29(2), 250-272.

Friese, H. (2017). Representations of gendered mobility and the tragic border regime in the Mediterranean. *Journal of Balkan and near eastern studies*, 19(5), 541-556.

Fylan, F. (2005). Semi-structured interviewing. In *A handbook of research methods for clinical and health psychology* (pp. 65–77). New York: Oxford University Press.

Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative research*, 2(2), 209-230.

Gaad, E. and Khan, L. (2007) Primary mainstream teachers' attitudes towards inclusion of students with Special Educational Needs in the private sector: a perspective from Dubai. *International Journal of Special Education*, 22 (2), 95-109.

Gaibazzi, P., Dünwald, S., and Bellagamba, A. (Eds.). (2016). *EurAfrican borders and migration management: Political cultures, contested spaces, and ordinary lives*. Springer.

Gallagher, C. and Laqueur, T. (1987) (eds) *The Making of the Modern Body: Sexuality and Society in the Nineteenth Century*. Berkeley: University of California Press

Gambill, G., C. (2001). Syrian and the Politics of Arbitrary Detention in Lebanon. *Middle East Intelligence Bulletin*, 3(1). DOI: https://www.meforum.org/meib/articles/0101_11.htm

Garratt, L. (2017). Doubly estranged: racism, the body and reflection. *Ethnic and Racial Studies*, 40:4, 617-635, DOI: [10.1080/01419870.2016.1206589](https://doi.org/10.1080/01419870.2016.1206589)

Geisser, V. (2013). La question des réfugiés syriens au Liban: le réveil des fantômes du passé. *Confluences Méditerranée*, 87(4), 67–84.

GEM (Global Education Monitoring Report Team). (2020). *Global education monitoring report, 2020: Inclusion and education: all means all*. UNESCO Publishing. DOI: <https://en.unesco.org/gem-report/report/2020/inclusion>.

Ghai, A. (2012). Engaging with disability with postcolonial theory. In *Disability and social theory: New developments and directions* (pp. 270-286). London: Palgrave Macmillan UK.

Ghosn, F., and Khoury, A. (2011). Lebanon after the civil war: peace or the illusion of peace?. *The Middle East Journal*, 65(3), 381-397.

Gibon, C. (2022). Lives at risk in Lebanon as medicine availability plummets. Al-Arabiya News. DOI: <https://english.alarabiya.net/life-style/2022/08/31/Lives-at-risk-in-Lebanon-as-medication-availability-plummets>

Giddens, A. and Griffiths, S. (2006). *Sociology*. Polity.

Gilens, Martin, 2014, *Affluence and Influence: Economic Inequality and Political Power in America*, Princeton, NJ: Princeton University Press.

Gill, C. J. (1995). A psychological view of disability culture. *Disability Studies Quarterly*, 15, 15–19.

Giroux, H. A. (2006). Reading Hurricane Katrina: Race, class, and the biopolitics of disposability. *College Literature*, 171-196.

Glaser, B. G., Strauss, A. L. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine

Gleeson, B. J. (1997). Disability studies: A historical materialist view. *Disability & Society*, 12(2), 179-202.

GoL (Government of Lebanon), UNDP, and UNHCR (2022). Lebanon Crisis Response Plan (LCRP) 2022-2023. DOI: <https://reliefweb.int/report/lebanon/lebanon-crisis-response-plan-lcrp-2022-2023>

- Gonzalez-Gorman, S. (2022). Underlying push and pull factors in undocumented immigration in the United States. *Policy Studies*, 43(5), 920-942.
- González Maldonado, R. (2017). *Non-formal education: a way out: the realisation of the right to education of refugees through non-formal education activities in Greece* (Doctoral dissertation).
- Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction*. London: Sage.
- Goodley, D. (2014). *Dis/Ability Studies: Theorising Disablism and Ableism*. London: Routledge.
- Goodley, D. (2016). *Disability Studies: An Interdisciplinary Introduction*. 2nd ed. London: Sage.
- Goodley, D., Lawthom, R., Liddiard, K., and Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, 34(6), 972-997.
- Government of Lebanon, UNDP, and UNHCR (2022). Lebanon Crisis Response Plan 2022-2023. DOI: file:///Users/giadacostantini/Downloads/LCRP_2022_Final.pdf
- Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global South. *International Journal of Inclusive Education*, 15:1, 87-100. DOI: 10.1080/13603116.2010.496198
- Grech, S. (2015). Decolonising Eurocentric disability studies: why colonialism matters in the disability and global South debate, *Social Identities*, 21:1, 6-21. DOI: 10.1080/13504630.2014.995347
- Grech, S., and Soldatic, K. (2015). Disability and colonialism:(dis) encounters and anxious intersectionalities. *Social Identities*, 21(1), 1-5.
- Grech, S. (2017). Disability, poverty and education: Perceived barriers and (dis) connections in rural Guatemala. *Disability and the Global South*, 1(1), 128-152.
- Grech, S., and Pisani, M. (2022). Disability and forced migration: Critical connections and the global South debate. In *Disability law and human rights: Theory and policy* (pp. 199-220). Cham: Springer International Publishing.
- Groce, N., and Kett, M. (2014). Youth with disabilities. *Youth with Disabilities (2014) Working Paper*, 23.
- Guba, E. G. (1990). The paradigm dialog. In *Alternative paradigms conference, mar, 1989, indianapolis, school of education, san francisco, ca, us*. Sage Publications, Inc.
- Guba, E., Lincoln, Y. (2005). Paradigmatic controversies, contradictions, and, emerging confluences. In Denzin, N. and Lincoln, Y. (Eds.), *The Sage Handbook of Qualitative Research*. 3rd Ed., Thousand Oakes, California: Sage, (p. 191-216).
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications, Inc.

Haddad, E. 2004. Who is (not) a Refugee? EUI Working Paper SPS No. 2004/6. *European University Institute, Italy*.

Haddad, S. (2004). The origins of popular opposition to Palestinian resettlement in Lebanon. *International Migration Review*, 38(2), 470-492.

Haddad, S., and Jamali, D. (2003). The politics of refugees' non integration: the dilemma of Palestinians in Lebanon. *Journal of International Migration and Integration/Revue de L'integration et de la Migration Internationale*, 4, 1-22.

Hakim, C. (2019). The French Mandate in Lebanon, *The American Historical Review*, Volume 124, Issue 5, December 2019, Pages 1689–1693, <https://doi.org/10.1093/ahr/rhz1024>

Halawi, Al Sabri, R. (2022). Religio-Crimmigration: The Intertwinement of Religion, Crime, and Migration in Lebanon. *International Criminal Justice Review*, 32(4), 410-428.

Hall, M. C., "Critical Disability Theory", *The Stanford Encyclopedia of Philosophy* (Winter 2019 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/win2019/entries/disability-critical/>.

Hamadeh, S. (2019). A critical analysis of the Syrian refugee education policies in Lebanon using a policy analysis framework. *Journal of Education Policy*, 34(3), 374-393.

Harvey, D. 2005. *A Brief History of Neoliberalism*. Oxford: Oxford University Press.

Hattar-Pollara, M. (2019). Barriers to education of Syrian refugee girls in Jordan: Gender-based threats and challenges. *Journal of nursing scholarship*, 51(3), 241-251.

Healy, S., and Tiller, S. (2016). Be near a road: Humanitarian practice and displaced persons in North Kivu. *Refugee Survey Quarterly*, 35(2), 56-78.

Heins, V. (2005). 'Giorgio Agamben and the current state of affairs in humanitarian law and human rights policy'. *German Law Journal*, 6(5): 845–860.

Held, D. (1980). *Introduction to critical theory: Horkheimer to Habermas* (Vol. 261). Univ of California Press.

Hertz, R. (1997). Introduction: Reflexivity and voice. In R. Hertz (Ed.), *Reflexivity & voice* (pp. vii-xviii). Thousand Oaks, CA: Sage.

Heupel, M. et al. (2021). Emergency Politics After Globalization . *International Studies Review*, 23:1959-1987. DOI: 10.1093/isr/viab021.

Hiranandani, V. (2014). Disability in Humanitarian Emergencies in India: Towards an Inclusive Approach. In *Disability, Human Rights and the Limits of Humanitarianism*, edited by Gill, M and Schlund-Vials, C., J. UK: Ashgate Publishing Limited.

Hoffmann, S. (2020). "Sovereignty". In *Humanitarianism*. Leiden, The Netherlands: Brill. https://doi.org/10.1163/9789004431140_094.

Hosking, D. L. (2008). *Critical Disability Theory*. A paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK, Sept. 2-4, 2008.

Hoyer, A. (2016). Spanish news framing of the Syrian refugee crisis. DOI: https://cedar.wvu.edu/cgi/viewcontent.cgi?article=1025&context=wwu_honors.

Human Rights Watch. (2016). Lebanon: 250,000 Syrian Children Out of School. DOI: <https://www.refworld.org/docid/578e2d8a4.html>

Human Rights Watch (2021). “‘Our Lives are Like Death’: Syrian Refugee Returns from Lebanon and Jordan.” DOI: <https://www.hrw.org/report/2021/10/20/our-lives-are-death/syrian-refugee-returns-lebanon-and-jordan>.

Human Rights Watch (2018). ‘I Would Like to Go to School’: Barriers to Education for Children with Disabilities in Lebanon. DOI: https://www.hrw.org/sites/default/files/report_pdf/lebanon0318_web.pdf.

Human Rights Watch (2017). Following the Money: Lack of Transparency in Donor Funding for Syrian Refugee Education. DOI: <https://www.hrw.org/report/2017/09/14/following-money/lack-transparency-donor-funding-syrian-refugee-education>.

Human Rights Watch (2017). Lebanon: Syrian refugee Children Blocked from School. DOI: <https://www.hrw.org/news/2021/12/03/lebanon-syrian-refugee-children-blocked-school>.

Humanity and Inclusion (HI) (2015). Humanitarian aid is leaving people with disabilities behind. DOI: <https://www.humanity-inclusion.org.uk/en/news/humanitarian-aid-is-leaving-people-with-disabilities-behind>.

Humanity and Inclusion (HI) (2022). The real lives behind the data: Children with disabilities in education across Egypt, Jordan, Lebanon and the occupied Palestinian territory. DOI: https://www.hi.org/sn_uploads/document/Factsheet-InclusiveEducation-RealLives-EN-2022-2.pdf.

Hutchinson, D. L. (1999). Ignoring the Sexualization of Race: Heteronormativity, Critical Race Theory, and Anti-Racist Politics, 47 BUFF. L. REV. 1.

Hutchinson, D. L. (2001). Identity Crisis: “Intersectionality,” “Multidimensionality,” and the Development of an Adequate Theory of Subordination. 6 Mich. J. Race & L. 285 (2001). DOI: <http://scholarship.law.ufl.edu/facultypub/387>

Huysmans, J. (2006). *The politics of insecurity: Fear, migration and asylum in the EU*. Routledge.

ICJ (International Commission of Jurists) (2020). Unrecognized and Unprotected: The treatment of Refugees and Migrants in Lebanon. DOI: <https://www.icj.org/wp-content/uploads/2020/11/Lebanon-Migrant-rights-Publications-Reports-Thematic-reports-2020-ENG.pdf>.

ILO (International Labor organization) (2016). ILOand disability inclusion. DOI: https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_407645.pdf.

INEE (Inter-Agency Network for Education in Emergency) (2023). Disability-Inclusive Education in Emergencies: Key concepts, approaches and principles for practice. DOI: <https://inee.org/resources/disability-inclusive-education-emergencies-key-concepts-approaches-and-principles>.

Inter-agency Network for Education in Emergencies (INEE) (2021). *Mind the gap: The state of girls' education in crisis and conflict*. New York, NY. DOI: <https://inee.org/resources/mind-gapstate-girls-education-crisis-and-conflict>.

Iversen, E. and Oestergaard, E. (2019). Gender Equality in education and emergencies. *Forced Migration Review*. DOI: <https://www.fmreview.org/education-displacement/iversen-oestergaard>.

Jalbout, M. (2015). *Reaching all children with education in Lebanon*. Brookings: World.

Janmyr, M. (2016). *The Legal Status of Syrian Refugees in Lebanon*. Issam Fares Institute for Public Policy and International Affairs, American University of Beirut.

Janmyr, M. (2016). Precarity in Exile: The Legal Status of Syrian Refugees in Lebanon. *Refugee Survey Quarterly*, 35(4): 58–78.

Janmyr, M. (2016). Spaces of legal ambiguity: Refugee camps and humanitarian power. *Humanity: An International Journal of Human Rights, Humanitarianism, and Development*, 7(3), 413-427.

Janmyr, M. (2017). No Country of Asylum: 'Legitimizing' Lebanon's Rejection of the 1951 Refugee Convention, *International Journal of Refugee Law*, Volume 29(3), 438–465. DOI: <https://doi.org/10.1093/ijrl/eex026>.

Jasbir K. Puar (2012) Coda: The Cost of Getting Better: Suicide, Sensation, Switchpoints. *GLQ* 1; 18 (1), 149–158. DOI: <https://doi.org/10.1215/10642684-1422179>.

Jasser, M. Z. (2014). Sectarian Conflict in Syria. *PRISM*, 4: 58-67. DOI: <https://www.jstor.org/stable/26469777>.

Jawad, A. S., Chamoun, N., and Merashli, M. (2023). Disastrous decline of the healthcare system in Lebanon. *Journal of the Royal Society of Medicine*, 116(1), 27-30.

Jayawickrama, J. (2018). Humanitarian aid system is a continuation of the colonial project. DOI: <https://www.aljazeera.com/opinions/2018/2/24/humanitarian-aid-system-is-a-continuation-of-the-colonial-project>.

Jureidini, P.A., and McLaurin, R.D. (1984). Lebanon after the war of 1982. In E.Azar (Ed.), *The emergence of a new Lebanon: Fantasy or reality?*

Kagan, M. (2011). “We live in a country of UNHCR”: The UN surrogate state and refugee policy in the Middle East. Las Vegas, NV: UNLV William S. Boyd School of Law. DOI: <http://ssrn.com/abstractD1957371>.

Kagawa, F. (2005). Emergency education: A critical review of the field. *Comparative Education*, 41, 487–503. DOI:10.1080/03050060500317620.

Kannike, E. M. (2018). The Ethnic and Religious Groups in Syria. Accessed on 13 September 2024. DOI: <https://syriancivilwarmap.com/ethnic-and-religious-groups-of-syria>.

Karam, F. J., Monaghan, C., and Yoder, P. J. (2017). ‘The students do not know why they are here’: education decision-making for Syrian refugees. *Globalisation, Societies and Education*, 15(4), 448-463.

Karpinska, Z. (Ed.). (2012). *Education, aid, and aid agencies*. New York, NY: Continuum International.

Katz, I. (2017). Between bare life and everyday life: Spatializing Europe’s migrant camps. *Architecture MPS*, 12(2), 1-20.

Keerepaibool, S., and Worland, S. (2021). Life in Limbo: The Forgotten Refugee Children in the Realization of Their Human Rights. In *The Palgrave Handbook of Global Social Problems* (pp. 1-22). Cham: Springer International Publishing.

Kelcey, J., and Chatila, S. (2020). Increasing inclusion or expanding exclusion? How the global strategy to include refugees in national education systems has been implemented in Lebanon. *Refuge*, 36(2), 9-19.

Kikano, F., Fauveaud, G., and Lizarralde, G. (2021). Policies of exclusion: The case of Syrian refugees in Lebanon. *Journal of Refugee Studies*, 34(1), 422-452.

Kim, E. (2014). The Spectre of Vulnerability and Disabled Bodies in Protest. Pp. 137–154 in *Disability, Human Rights and the Limits of Humanitarianism*, ed. Michael Gill and Cathy Schlund-Vials. Farnham: Ashgate.

Kisirwani, M. (1997). The rehabilitation and reconstruction of Lebanon. In P. J. Logan, *Remaking the Middle East*. Berg Publisher.

Kiwan, D. (2010). ‘Highly skilled guest-workers in the UK’, Special Issue of *Policy and Society*. DOI: <http://dx.doi.org/10.1016/j.polsoc.2010.09.003>

Kiwan, D. (2021) Inclusion and citizenship: Syrian and Palestinian refugees in Lebanon. *International Journal of Inclusive Education*, 25:2, 283-297, DOI: 10.1080/13603116.2019.1707308

Kiwan, D. (2022). ‘Dis/abled decolonial human and citizen futures’, *Citizenship Studies*, 25th Anniversary Special Issue Edition, <https://www.tandfonline.com/doi/full/10.1080/13621025.2022.2091236>

Klehr, A. (2018). *How effective is the education response for displaced Syrian children in Lebanon?: Non-formal education programming in a fragile context* (Bachelor's thesis, University of Twente).

Krause, M. (2014) *The Good Project: Humanitarian Relief NGOs and the Fragmentation of Reason*. Chicago, IL and London: University of Chicago Press.

Krzyżanowski, M., Triandafyllidou, A., and Wodak, R. (2018). The mediatization and the politicization of the “refugee crisis” in Europe. *Journal of Immigrant & Refugee Studies*, 16(1-2), 1-14.

Kurtulus, E. N. (2009). ‘The Cedar Revolution’: Lebanese independence and the question of collective self-determination. *British Journal of Middle Eastern Studies*, 36(2), 195-214.

Lakkis, N. A., and Issa, G. M. (2020). A pilot intervention to promote positive parenting in refugees from Syria in Lebanon and Jordan. *Frontiers in Psychiatry*, 11, 510034.

Larkin, P., De Casterlé, B., and Schotsmans, P. (2007). Multilingual translation issues in qualitative research: Reflections on a metaphorical process. *Qualitative Health Research*, 17, 468476.

Lather, P. (1991). *Getting smart: feminist research and pedagogy with/in the postmodern*. New York: Routledge.

Laughlin, S. and Speetjens, P. (2022). High-stake blaming: Lebanon scapegoating Syrian refugees for economic crisis. DOI: <https://thebadil.com/in-depth/lebanon-scapegoating-syrian-refugees/>

Laurie, E. W. (2015). Who lives, who dies, who cares? Valuing life through the disability-adjusted life year measurement. *Transactions of the Institute of British Geographers*, 40(1), 75-87.

Lawlor, L., and Nale, J. (Eds.). (2014). *The Cambridge Foucault Lexicon*. Cambridge University Press.

Lazzarato, M. (2015). Neoliberalism, the Financial Crisis and the End of the Liberal State. *Theory, Culture & Society*, 32(7-8), 67-83. DOI: <https://doi.org/10.1177/0263276415600037>

LCRP (2021). Lebanon Crisis Response Plan 2017 – 2021, 2021 update. DOI: https://reliefweb.int/sites/reliefweb.int/files/resources/LCRP_2021FINAL_v1.pdf

Lee, M. (2022). The externalization of border control in the global South: The cases of Malaysia and Indonesia. *Theoretical Criminology*, 26(4), 537-556. DOI: <https://doi.org/10.1177/13624806221104867>

Lemberg-Pedersen, M. (2019). Manufacturing Displacement: Externalization and Postcoloniality in European Migration Control. *Global Affairs*, 5(3), 247-271. Article 3. DOI: <https://doi.org/10.1080/23340460.2019.1683463>

Lester, A., and Dussart, F. (2014). Colonization and humanitarianism: Histories, geographies and biographies. In *Colonization and the Origins of Humanitarian Governance: Protecting Aborigines*

across the 19th century British Empire (Critical Perspectives on Empire, pp. 1.36). Cambridge: Cambridge University Press. DOI: 10.1017/CBO978113901102001.

Liebel, M. (2023). *Childhoods of the Global South: Children's Rights and Resistance*. Policy Press.

Liguori, A. (2019). *Migration law and the externalization of border controls: European state responsibility*. Routledge.

Lilja, M., and Vinthagen, S. (2014). Sovereign power, disciplinary power and biopower: resisting what power with what resistance?. *Journal of political power*, 7(1), 107-126.

Loeb M. (2013). Disability statistics: an integral but missing (and misunderstood) component of development work. *Nord J Hum Rights*, 31(3):306-324.

Loescher, G., & Milner, J. (2005). Security implications of protracted refugee situations. *The Adelphi Papers*, 45(375), 23-34.

Lombardo, P. A. (2008). Disability, eugenics, and the culture wars. . *Louis UJ Health L. & Pol'y*, 2, 57.

Lough, O., Barbelet, V. and Njeri, S. (2022). Inclusion and Exclusion in humanitarian action: findings from a three-year study. HPG report. London: ODI. DOI: www.odi.org/en/publications/inclusion-and-exclusion-in-humanitarian-action-findings-from-a-three-year-study

Lutz, C. (1986). Emotion, Thought, and Estrangement: Emotion as a Cultural Category. *Cultural Anthropology*, 1(3), 287–309. DOI: <http://www.jstor.org/stable/656193>

Lynch, R. T., and Thomas, K. R. (1994). People with disabilities as victims: Changing an ill-advised paradigm. *Journal of Rehabilitation-Washington*, 60, 8-8.

Machel, G. (2001). *The Impact of War on Children: A Review of Progress Since the 1996 United Nations Report on the Impact of Armed Conflict on Children*. United Nations Children's Fund, 3 UN Plaza, New York, NY 10017.

MacQueen, B., and Baxter, K. (2014). Refugees and Political Stability in Lebanon. *Middle Eastern Studies/ Ortadoğu Etütleri* 6(1).

Madhok, S. (2013). Action, agency, coercion: Reformatting agency for oppressive contexts. In *Gender, agency, and coercion* (pp. 102-121). London: Palgrave Macmillan UK.

Madhok, S.; Phillips, A.; Wilson, K.; Hemmings, C. (2013). *Gender, Agency, and Coercion*. Palgrave Macmillan: London, UK.

Mahfouz, J., El-Mehtar, N., Osman, E. and Kotok, S. (2020). Challenges and agency: principals responding to the Syrian refugee crisis in Lebanese public school. *International Journal of Leadership in Education*, 23:1.

Mahmood, S. (2001). Feminist theory, embodiment, and the docile agent: Some reflections on the Egyptian Islamic revival. *Cultural anthropology*, 16(2), 202-236.

- Mahmood, S. (2012). *Politics of Piety: The Islamic Revival and the Feminist Subject*. Princeton University Press: Princeton, NJ, USA.
- Malaspina, A. (2008). *Creation of the Modern Middle East: Lebanon*. New York: Chelsea House Publications.
- Malaeb, B. (2018). State fragility in Lebanon: Proximate causes and sources of resilience. *International Growth Centre's Commission on State Fragility, Growth and Development; IGC: London, UK*.
- Malik, H. (2000). Between Damascus and Jerusalem: Lebanon and the Middle East peace. Policy Paper no.45. *Washington, DC: Washington Institute for Near East Policy*.
- Malik, H. C. (1997). Is There Still a Lebanon? *Middle East Quarterly*.
- Malkki, L. H. (1995). Refugee and Exile: From 'Refugee Studies' to the National Order of Things. *Annual Review of Anthropology*, 24:495-523.
- Malkki, L. H. (1996). Speechless Emissaries: Refugees, humanitarianism, and dehistoricization. *Cultural anthropology*, 11(3): 377-404.
- Massari, A. (2021). *Visual securitization: Humanitarian representations and migration governance* (p. 204). Springer Nature.
- Mauthner, N. S., and Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431.
- May, T. (2011). *Social Research: Issues, Methods and Process* (4th edition). Maidenhead: Open University Press.
- Mazur, R. (1986). Linking Popular Initiatives and Aid Agencies: The Case of Refugees. *Refugee Issues*, 3(2), 1-16, Refugee Studies Programme, University of Oxford.
- Mbembe, Achille. (2003). Necropolitics. *Public Culture* 15(1), 11–40. DOI: <https://doi.org/10.1215/08992363-15-1-11>
- McClearn, J., Jensen, R. B., & Talhouk, R. (2023). Othered, Silenced and Scapegoated: Understanding the Situated Security of Marginalised Populations in Lebanon. *arXiv preprint arXiv:2306.10149*.
- McGuire, A. (2010). Disability, Non-disability and the Politics of Mourning: Re-conceiving the 'we'. *Disability Studies Quarterly*, 30(3/4).
- McFalls, L. (2010). Benevolent Dictatorship: The Formal Logic of Humanitarian Government, in D. Fassin and M. Pandolfi (eds), *Contemporary States of Emergency*. New York: Zone.
- McIntosh, I., & Wright, S. (2019). Exploring what the notion of 'lived experience' offers for social policy analysis. *Journal of social policy*, 48(3), 449-467

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York: New York University Press.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, 26(6), 667-682.

Meekosha, H., and Shuttleworth, R. (2009). What's so 'critical' about critical disability studies?. *Australian Journal of Human Rights*, 15(1), 47-75.

Meekosha, H., and Soldatic, K. (2011). Human Rights and the Global South: the case of disability. *Third World Quarterly*, 32(8), 1383-1397.

Meekosha, H., Shuttleworth, R., and Soldatic, K. (2013). Disability and critical sociology: Expanding the boundaries of critical social inquiry. *Critical Sociology*, 39(3), 319-323.

Mencütek, Z., Ş. (2019). *Refugee Governance, State and Politics in the Middle East*. Oxon: Routledge.

Merhej, R. (2021). *Case Study on the Inclusive Education Pilot Project in Lebanese Public Schools*. UNICEF, MEHE, and Haigazian University

Miggiano, L. (2009). States of Exception: securitisation and irregular migration in the Mediterranean. *New Issues in refugee Research*, Research Paper 177.

Migliarini, V. (2017). *Intersectionality and the education of dis/abled asylum-seeking and refugee children in Rome: Criticism and discrepancies of "integration-style inclusion" models*. Doctoral Dissertation, Roma Tre University.

Mignolo, W. (2012). Decolonizing western epistemology/building decolonial epistemologies. *Decolonizing epistemologies: Latina/o theology and philosophy*, 19-43.

Mignolo, W. (2013). Geopolitics of sensing and knowing: On (de) coloniality, border thinking, and epistemic disobedience. *Confero: Essays on education, philosophy and politics*, 1(1), 129-150.

Mignolo, W. D. (2017). Coloniality is far from over, and so must be decoloniality. *Afterall: A journal of art, context and enquiry*, 43(1), 38-45.

Miles, S. (2000). Overcoming resource barriers: the challenge of implementing inclusive education in rural areas. In *Children with Disabilities and the Convention on the Rights of the Child*.

Miles, S., and Singal, N. (2010). The education for all and inclusive education debate: Conflict, contradiction or opportunity? *International journal of inclusive education*, 14(1), 1-15.

Miles, S. (2013). Education in times of conflict and the invisibility of disability: a focus on Iraq?. *Disability & Society*, 28(6), 798-811.

Minca, C. (2023). Of werewolves, jungles, and refugees: more-than-human figures along the Balkan route. *Geopolitics*, 28(2), 550-569.

Minow, M. (1990). *Making All the Difference: Inclusion, Exclusion, and American Law*. Cornell University Press,

Mirza, M. (2019). The Legal Protection of Refugees with Disabilities: Forgotten and Invisible? *International Migration Review* 53 (1), 311–313. DOI: <https://doi.org/10.1177/0197918318798578>

Mohanty, C. T., and Torres, L. (Eds.). (1991). *Third world women and the politics of feminism* (Vol. 632). Indiana University Press.

Mooney, E., and French, C. (2005). Barriers and bridges: access to education for internally displaced children. *The Brookings Institution-University of Bern*.

Moraña, M., E. Dussel, and C.A. Jáuregui. (2008). Colonialism and its replicants. In *Coloniality at large: Latin America and the postcolonial debate*, ed. M. Moraña, M.E. Dussel, and C.A Jáuregui, 1–20. Durham/London: Duke University Press.

Morris, J. (1991). 'Us' and 'them'? Feminist research, community care and disability. *Critical Social Policy*, 11(33), 22-39.

Moser-Mercer, B., Hayba, E., and Goldsmith, J. (2018). Higher education spaces and protracted displacement: How learner-centered pedagogies and human-centered design can unleash refugee innovation. In *Technologies for development: from innovation to social impact* (pp. 41-52). Springer International Publishing.

Mouvement franco-libanais SOLIDA (Soutien aux Libanais Détenus Arbitrairement). (2005). URGENT Lebanese prisoners detained in Syria: A priority question to raise before the Syrian authorities. DOI: https://www.fidh.org/IMG/pdf/Rapport_alternatif_Solida_Syrie_2005_ENG_.pdf

Nair, S. (2010). Sovereignty, Security, and Migrants: Making Bare Life, in S. Biwas, and S. Nair (eds.) *International Relations and States of Exception: Margins, Peripheries and Excluded Bodies*, London and New York: Routledge

Naufal, H. (2012). Syrian Refugees in Lebanon, the Humanitarian Approach under Political Divisions. *Migration Policy Center Research*, DOI: <http://cadmus.eui.eu/handle/1814/24835>

Nayel, M. A. (2013). Palestinian refugees are not at your service. *The Electronic Intifada*, DOI: <https://electronicintifada.net/content/palestinian-refugees-are-not-your-service/12464>

Neuman, W. L. (2003). *Social Research Methods: Qualitative and Quantitative Approaches*. Boston: Allyn and Bacon

Nguyen, X. T. (2018). Critical disability studies at the edge of global development: Why do we need to engage with southern theory?. *Canadian Journal of Disability Studies*, 7(1), 1-25.

Nisan, M. (2000). The Syrian Occupation of Lebanon. *Coalition for Responsible Peace in the Middle East*.

- Nisan, M. (2015). *Politics and War in Lebanon: Unraveling the enigma*. New York: Routledge.
- Norozi, S. A., and Moen, T. (2016). Childhood as a social construction. *Journal of Educational and Social Research*, 6.
- Norwegian Refugee Council (NRC) (2020). The Obstacles Course: Barriers to Education for Syrian Refugee Children in Lebanon. DOI: https://www.nrc.no/globalassets/pdf/reports/the-obstacle-course-barriers-to-education/executive-summary---the-obstacle-course_barriers-to-education.pdf
- Novelli, M. (2010). The new geopolitics of educational aid: From cold wars to holy wars? *International Journal of Educational Development*, 30, 453–459. DOI:10.1016/j.ijedudev.2010.03.012
- Novelli, M., and Cardozo, M. T. L. (2008). Conflict, education and the global south: New critical directions. *International Journal of Educational Development*, 28(4), 473-488.
- Novelli, M., and Kutan, B. (2023). The imperial entanglements of ‘Education in Emergencies’: from saving souls to saving schools?. *Globalisation, Societies and Education*, 1-15.
- NRC (Norwegian Refugee Council). (2020). The Obstacle Course: Barriers to Education for Syrian Refugee Children in Lebanon. DOI: https://www.nrc.no/globalassets/pdf/reports/the-obstacle-course-barriers-to-education/executive-summary---the-obstacle-course_barriers-to-education.pdf
- Nyers, P. (1998). Refugees, humanitarian emergencies, and the politicization of life. *Refuge: Canada's Journal on Refugees/Refuge: Revue canadienne sur les réfugiés*, 17(6), 16-21.
- Oglesby C. (1969). *Vietnamism has Failed. The Revolution can only be Mauled, not Defeated*. Commonweal, p. 90.
- Oliver, M. (1996). *Understanding Disability: From Theory to Practice*. Basingstoke, UK: Macmillan.
- Oliver, M. . (2004). Capitalism, disability, and ideology. *Special Educational Needs and Inclusive Education: Systems and contexts*, 1, 82.
- Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.
- Olkin, R., and Pledger, C. (2003). Can disability studies and psychology join hands?. *American Psychologist*, 58(4), 296.
- Overboe, J. (2007). Disability and genetics: Affirming the bare life (the state of exception). *The Canadian Review of Sociology*, 44(2), 219.
- Papageorgiou, V. (2018). The externalization of European borders. *Center for International Strategic Analyses (KEDISA)*, 23.
- Paris, R. (2004). *At war's end: Building peace after civil conflict*. Cambridge, England: Cambridge University Press.

Patton, M. Q. (2015). *Qualitative research and evaluation methods: integrating theory and practice*. 4 edn. Los Angeles: SAGE.

Pearce, E. (2015). "I See That It Is Possible" Building Capacity for Disability Inclusion in GenderBased Violence Programming in Humanitarian Settings. WRC & IRC. DOI: <https://www.womensrefugeecommission.org/resources/document/945-building-capacity-fordisability-inclusion-in-gender-based-violence-gbv-programming-in-humanitarian-settingsoverview>

Pedwell, C., & Whitehead, A. (2012). Affecting feminism: Questions of feeling in feminist theory. *Feminist theory*, 13(2), 115-129.

Peoples, C., & Vaughan-Williams, N. (2020). *Critical Security Studies: An Introduction* (3rd ed.). Routledge. <https://doi.org/10.4324/9780429274794>

Perkowski, N. (2018). Frontex and the convergence of humanitarianism, human rights and security. *Security Dialogue*, 49(6), 457-475.

Pfeiffer, D. (2006). Eugenics and disability discrimination. In *Overcoming disabling barriers* (pp. 80-100). Routledge.

Pherali, T., and Abu Moghli, M. (2021). Higher education in the context of mass displacement: Towards sustainable solutions for refugees. *Journal of Refugee Studies*, 34(2), 2159-2179.

Pierce, M. (2020). Sovereignty, discipline, security: Foucault and the governmentality of US border enforcement. *Critique: A Worldwide Student Journal of Politics*. Spring.

Piketty, Thomas, 2014, *Capital in the Twenty-First Century*, Cambridge, MA: Harvard University Press.

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education*, 16(2), 175-196.

Pinnock, H., and Hodgkin, M. (2010). Education Access for All. *Forced Migration Review*, 35, 2.

Pipes, D. (1990). *Greater Syria: The History of an Ambition*. New York & Oxford: Oxford University Press.

Pisani, M., and Grech, S. (2015). Disability and forced migration: Critical intersectionalities. *Disability and the Global South*, 2(1), 421-441.

Pisani, M. (2016). 'Illegal bodies' on the move: a critical look at forced migration towards social justice for young asylum seekers. *Perspectives on youth*, 3, 83-98.

Pothier, D. and Devlin, R. (eds), (2006). *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*. Vancouver, Canada: UBC Press.

- Presler-Marshall, E., Abu Hamad, B., Youssef, S., Jones, N., Baird, S., and Małachowska, A. (2021). Adolescents in protracted displacement: exploring risks of age-and gender-based violence among Palestine refugees in Jordan, Lebanon and the State of Palestine. DOI: <https://www.gage.odi.org/wp-content/uploads/2021/10/Adolescents-in-protracted-displacement-exploring-risks-of-age-and-gender-based-violence-among-Palestine-refugees-in-Jordan-Lebanon-and-the-State-of-Palestine.pdf>
- Preston, R. (1991). The Provision of Education to Refugees in Places of Temporary Asylum: some implications for development. *Comparative Education*, 27(1), 61-81.
- Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Duke University Press.
- Quijano, A. (2007). Coloniality and modernity/rationality. *Cultural studies*, 21(2-3), 168-178.
- Rabin, N. (2020). Legal Limbo as Subordination: Immigrants, Caste, and the Precarity of Liminal Status in the Trump Era. *Geo. Immigr. LJ*, 35, 567.
- Rajaram, P., K. (2002). Humanitarianism and Representation of the Refugee. *Journal of Refugee Studies*, 15(3): 247-264.
- Rajaram, P. K., & Grundy-Warr, C. (Eds.). (2007). *Borderscapes: hidden geographies and politics at territory's edge* (Vol. 29). U of Minnesota Press.
- Ramadan, A. and Fregonese, S. (2017). Hybrid Sovereignty and the State of Exception in the Palestinian Refugee Camps in Lebanon. *Annals of the American Association of Geographers*, 107:4, 949-963, DOI: 10.1080/24694452.2016.1270189
- Ramalingam, B. and Barnett, M. (2010). The Humanitarian's Dilemma: collective action or inaction in international relief? *Overseas Development Institute*. DOI: <https://dlc.dlib.indiana.edu/dlc/bitstream/handle/10535/6622/ODI-The-Humanitarian%27s-Dilemma-2010.pdf?sequence=1&isAllowed=y>
- Ravaud, J.-F. and Stiker, H.-J. (2001). Inclusion/exclusion: an analysis of historical and cultural meanings. In Albrecht, G., K. Seelman and Bury, M. (eds), *Handbook of Disability*. Thousand Oaks, CA: Sage, 490-514.
- Renkens, J., Rommes, E., and van den Muijsenbergh, M. (2022). Refugees' agency: On resistance, resilience, and resources. *International Journal of Environmental Research and Public Health*, 19(2), 806.
- Retamal, G.; Aedo-Richmond, R. (1998). (eds.) *Education as a humanitarian response*. London: Cassell; Geneva: UNESCO International Bureau of Education.
- Retief, M., & Letšosa, R. (2018). Models of disability: A brief overview. *HTS Teologiese Studies/Theological Studies*, 74(1).
- Riggirozzi, P. et al. (2023). Securitization, humanitarian responses and the erosion of everyday rights of displaced Venezuelan women in Brazil. *Journal of Ethnic and Migration Studies*. DOI:

<https://www.tandfonline.com/doi/epdf/10.1080/1369183X.2023.2191160?needAccess=true&role=button>

Rioux, M., & Carbert, A. (2003). Human rights and disability: The international context.

Rohwerder, B. (2016). Women and girls in forced and protracted displacement. *Governance and Social Development Resource Center*.

Rohwerder, B. (2017). Disability Inclusive Humanitarian Response. *Brighton: Institute of Development Studies*.

Rohwerder, B. (2017). Women and girls with disabilities in conflict and crises. Knowledge, evidence and learning for development, K4D. DOI: https://assets.publishing.service.gov.uk/media/5b9a458540f0b67866ffbd56/032-Women_and_girls_with_disabilities_in_crisis_and_conflict.pdf

Rossiter, C. L. (1949). Constitutional dictatorship in the atomic age. *The Review of Politics*, 11(4), 395-418.

Roth, S.; Purkayashta, B. and Denskus, T. (2024). Handbook on Humanitarianism and Inequalities. Edward Elgar Publishing: Cheltenham, UK.

Roth, S. (2012). 'Professionalisation trends and inequality: Experiences and practices in aid relationships.' *Third World Quarterly* 33(8): 1459–74.

Roth, S. (2015). *The Paradoxes of Aid Work: Passionate Professionals*. Florence, GB: Routledge.

Rothberg, M. (2019). *The implicated subject: Beyond victims and perpetrators*. Stanford University Press.

Russell Hochschild, A. (2009). Introduction: An Emotions Lens on the World. In *Theorizing Emotion: Sociological Exploration and Applications* by Hopkins, D.; Kleres, J.; Flam, H. and Kuzmics, H. (eds.) 29-38.

Russel, M. (2019). Capitalism & Disability. Ed. Keith Rosenthal. E-book. Chicago: Haymarket. Saebones, A., Bieler, R. B., Baboo, N., Banham, L., Singal, N., Howgego, C., and Dansie, G. (2015). Towards a disability inclusive education: Background paper for the Oslo Summit on Education for Development. DOI: https://www.usaid.gov/sites/default/files/documents/1865/Oslo_Ed_Summit_DisabilityInclusive_Ed.pdf

Şahin-Mencütek, Z., and Tsourapas, G. (2023). When Do States Repatriate Refugees? Evidence from the Middle East. *Journal of Global Security Studies*, 8(1), ogac031.

Saia, T., Yaghmaian, R., Cuesta, R., Mueller, C., and Pebdani, R. N. (2024). A call to action for disability and rehabilitation research using a DisCrit and Disability Justice framework. *Disability and Rehabilitation*, 46(14), 3189-3195.

Sakr, E. (2005). The politics and liberation of Lebanon. *Middle East*, 9(4), 87.

Saleem, A., M. (2023). 'Decolonising the international development sector requires a disruption (part 1): A focus on the past can mask the colonial present'. DOI:<https://religioninpublic.leeds.ac.uk/2023/07/05/decolonising-the-international-development-sector-requires-a-disruption-part-1/>

Saltes, N. (2013). 'Abnormal'bodies on the borders of inclusion: Biopolitics and the paradox of disability surveillance. *Surveillance & Society*, 11(1/2), 55-73.

Salti, N., Chaaban, J., Moussa, W., Irani, A., Al Mokdad, R., Jamaluddine, Z., and Ghattas, H. (2022). The impact of cash transfers on Syrian refugees in Lebanon: Evidence from a multidimensional regression discontinuity design. *Journal of Development Economics*, 155, 102803.

Sayer, A. (1999). Long live post-disciplinary studies! Sociology and the curse of disciplinary parochialism/imperialism. Paper presented at the British Sociological Association Conference, April 1999, in Glasgow, Scotland.

Schalk, S. (2017). Critical disability studies as methodology. *Lateral*, 6(1).

Schutz, A. (1962). Collected papers, Vol. I. The Hague: Nijhoff.

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118–137). Sage Publications, Inc.

Selden, S. (2000). Eugenics and the social construction of merit, race and disability. *Journal of Curriculum Studies*, 32(2), 235-252.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2(3), 197-204.

Shivji, A. (2010). Disability in Displacement. *Forced Migration Review*, 35. DOI: <https://www.fmreview.org/sites/default/files/FMRdownloads/en/disability/shivji.pdf>

Shklarov, S. (2007). Double vision uncertainty: The bilingual researcher and the ethics of crosslanguage research. *Qualitative Health Research*, 17, 529-538. Quoted in Berman, B., C. and Tyysk , V. (2011). "A Critical Reflection on the Use of Translator/Interpreters in a Qualitative Cross-Language Research Project". *International Journal of Qualitative Methods*, 10(1).

Shuayb, M. (2019). A Critique of Education in Emergency and Humanitarian Contexts: Observation from the field. In C. Kyriakides and R. Torres (2019), *Borders of Mass Destruction: Racialization, National Belonging and the Refugee*. Routledge (US).

Shuayb, M., Makkouk, N. and Tuttunji, S. (2014) *Widening access to quality education for Syrian refugees: The role of private and NGO sectors in Lebanon*. Centre for Lebanese Studies.

Shuayb, M., Al Maghlouth, N., Held, K., Ahmad, N., Badran, T. and Al Qantar, S. (2016). An education for the future: the schooling experience of Syrian refugee children in Lebanon and

Germany. DOI: <https://www.lebanesestudies.com/wp-content/uploads/2017/01/An-Education-for-the-Future.pdf>

Shuayb, M. and Hammoud, M. (2022). Children in Lebanon Cannot Afford to Lose Another Academic year. Center for Lebanese Studies. DOI: <https://lebanesestudies.com/publications/children-in-lebanon-cannot-afford-to-lose-another-academic-year/>

Shuayb, M., and Ahmad, N. (2021). The psychosocial condition of Syrian children facing a precarious future. *Refuge*, 37(1), 27-37.

Shuayb, M., Hammoud, M., Nehme, N., Antoun, S., Al Samhoury, O., Maalouf, M., Brun, C., Shuayb, I., Tutunji, S., and Sayed. Y. (2024). Education Under Fire: A Rapid Study of Parents' and Teachers' Readiness for School Amidst Israeli Attacks on Lebanon. Beirut and Cambridge: Centre for Lebanese Studies and REAL Centre, University of Cambridge.

Silvers, A. (2009). Off! A diverse theory of justice for disability. *Disability and disadvantage*, 163.

Sinclair, M. (2001). Learning for a future: Refugee education in developing countries. In M. Sinclair (Ed.), *Education in emergencies* (pp. 1–84). Geneva, Switzerland: UNHCR.

Skeggs, B. (2014). Values beyond value? Is anything beyond the logic of capital? *British Journal of Sociology*, 65(1), 1-20.

Skorzak, J. (2019). Resisting Necropolitics: Reconceptualizing Agency in Mbembe and Agamben. DOI: <https://www.e-ir.info/2019/08/21/resisting-necropolitics-reconceptualizing-agency-in-mbembe-and-agamben/>

Skoufias, E., and Di Maro, V. (2008). Conditional cash transfers, adult work incentives, and poverty. *The Journal of Development Studies*, 44(7), 935-960.

Sleeter, C. (2010). Building Counter-Theory about Disability. *Disability Studies Quarterly*, 30(2). doi:10.18061/dsq.v30i2.1244

Slim, H. (2003). Is Humanitarianism Being Politicised? A Reply to David Rieff. *The Durruti Cross Symposium on Ethics in Aid*. DOI: <https://hdcentre.org/wp-content/uploads/2016/07/Is-Humanitarianism-Being-Politicised-October-2003.pdf>

Smillie, I. and Minear, L. (2004). *The Charity of Nations: Humanitarian Action in a Calculating World*. Sterling, VA: Kumarian Press.

Smith-Khan, L. and Crock, M. (2018). Making rights to education real for refugees with disabilities. DOI: <https://unesdoc.unesco.org/ark:/48223/pf0000266058>

Soguk, N. (1999). *States and Strangers: Refugees and Displacements of Statecraft*. Minneapolis: University of Minnesota Press.

Soldatic, K., and Meekosha, H. (2012). Moving the boundaries of feminist social work education with disabled people in the neoliberal era. *Social Work Education*, 31(2), 246-252.

- Sözer, H. (2020). Humanitarianism with a neo-liberal face: Vulnerability intervention as vulnerability redistribution. *Journal of Ethnic and Migration Studies*, 46(11), 2163-2180.
- Snounu, Y. (2019). Apartheid, disability, and the triple Matrix of Maiming in Palestine. *Peace Review*, 31(4), 459-470.
- Spradley, J. P. (1979). *The ethnographic interview*. New York, London: Holt, Rinehart and Winston.
- Squire, V. (2015). The Securitisation of Migration: An Absent Presence?. In *The Securitisation of Migration in the EU. The European Union in International Affairs*, edited by Gabriela Lazaridis and Khursheed Wadia, pp. 19–36. London: Palgrave Macmillan.
- Stein, M. A. (2017). Disability human rights. In *Nussbaum and law* (pp. 3-49). Routledge.
- Stevens, D. (2014). Shifting conceptions of refugee identity and protection: European and Middle Eastern approaches. In *Refugee Protection and the Role of Law* (pp. 73-97). Routledge.
- Stiker, H.-J. (1999). *A history of disability*. Ann Arbor: University of Michigan Press.
- Stock, I., Üstübeci, A., and Schultz, S. U. (2019). Externalization at work: responses to migration policies from the Global South. *Comparative Migration Studies*, 7(1), 1-9.
- Stoddard, A. (2004). You say you want a devolution prospects for remodeling humanitarian assistance. *Journal of Humanitarian assistance*, 1.
- Strand, M. (2013). In the Round: Supporting Teachers' Authentic Professional Learning. DOI: https://mountainscholar.org/bitstream/handle/10217/80980/Strand_colostate_0053A_12107.pdf?sequence=1
- Suleiman, J. (2006). 'Marginalised Community: The Case of Palestinian Refugees in Lebanon' (University of Sussex Development Research Centre of Migration, Globalisation, and Poverty 2006) 6.
- Tarricone, P., Mestan, K., and Teo, I. (2021). Building resilient education systems: A rapid review of the education in emergencies literature. DOI: https://research.acer.edu.au/int_research/4/
- Taşkale, A. R. (2022). The biopolitical economy of the COVID-19 pandemic and the possibilities for an affirmative biopolitics. *Distinktion: Journal of Social Theory*, 23(2-3), 274-287.
- Teh, H. (2022). Books Saving Lives? Critiquing the Conceptualisation of Education as Humanitarian Aid. *Cambridge Educational Research e-Journal*, 9, 310-325. DOI. <https://doi.org/10.17863/CAM.90570>
- Terry, S. (2011). The International Committee of the Red Cross in Afghanistan: reasserting the neutrality of humanitarian action. *International Review of the Red Cross*, 93(881), 173–188.

Thorleifsson, C. (2016). The limits of hospitality: coping strategies among displaced Syrians in Lebanon. *Third World Quarterly*, 37(6), 1071-1082.

Tilley, E., Walmsley, J., Earle, S., and Atkinson, D. (2012). 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, 27(3), 413-426.

Tinas, M. (2020). Syrians in Lebanon from the perspectives of the Lebanese government and Lebanese Society. *Turkish Journal Of Middle Eastern Studies*, 7(2), 19.

Tisdall, E. K. M., and Punch, S. (2012). Not so 'new'? Looking critically at childhood studies. *Children's geographies*, 10(3), 249-264.

Titchkosky, T. (2014). Monitoring disability: the question of the 'human' in human rights projects. *Disability, human rights and the limits of humanitarianism*, 119-35.

Titchkosky, T. (2003). *Disability, self, and society*. University of Toronto Press.

Titchkosky, T. (2003). Governing embodiment: Technologies of constituting citizens with disabilities. *Canadian Journal of Sociology/Cahiers canadiens de sociologie*, 517-542.

Titchkosky, T., and Michalko, R. (2017). The body as a problem of individuality: A phenomenological disability studies approach. In *Disability, space, architecture: A reader* (pp. 67-294). Routledge.

Tlostanova, M., and Mignolo, W. (2009). Global coloniality and the decolonial option. *Kult*, 6(Special Issue), 130-147.

Trani, J., F., Bakhshi, P and Nandipati, A. (2012). 'Delivering' Education; Maintaining Inequality. *The case of children with disabilities in Afghanistan*. Brown School Faculty Publications, 38. DOI: https://openscholarship.wustl.edu/brown_facpubs/38

TRANSTEC (2015). *Beyond Humanitarian Assistance? UNHCR and the Response to Syrian Refugees in Jordan and Lebanon*. Brussels: TRANSTEC.

Turner, L. (2015). Explaining the (Non-)Encampment of Syrian Refugees: security, Class and the Labour Market in Lebanon and Jordan. *Mediterranean Politics*, 20(3): 386-404.

Tuzi, I. (2023). Educational Challenges of Syrian Children in Lebanon: The Role of Non-formal Education in Enhancing School Attainment. *Transnational Education Review*, 1(1), 29-42.

Twum-Danso Imoh, A., Rabello de Castro, L., and Naftali, O. (2022). Studies of childhoods in the Global South: towards an epistemic turn in transnational childhood research? *Third World Thematics: A TWQ Journal*, 7(1-3), 1-16.

UNESCO (2018). Towards a disability inclusive education. Background Paper for the Oslo Summit on Education for Development (Http://Unesdoc. Unesco. Org/Images/0023/002338/233897e. Pdf).

UNESCO (2019) The intersections between education, migration and displacement are not gender-neutral. DOI: <https://en.unesco.org/gem-report/node/2866>

UNCRC (United Nation Convention on the Rights of the Child). (1989). DOI: <https://www.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf>

UNHCR. (2011). *Working with Persons with Disabilities in Forced Displacement*. United Nations High Commissioner for Refugees Geneva.

UNHCR. (2016). Missing Out: Refugee education in crisis. UNHCR. DOI: <https://www.unhcr.org/missing-out-state-of-education-for-the-worlds-refugees.html>

UNHCR (2023). Lebanon Fact Sheet. DOI: <https://reporting.unhcr.org/document/4773>

UNHCR (2023). Lebanon Inter-Agency Coordination – In Focus: Women, Girls, Men and Boys with Disabilities in Lebanon. DOI: <https://reliefweb.int/report/lebanon/lebanon-inter-agency-coordination-focus-women-girls-men-and-boys-disabilities-lebanon#:~:text=Lebanon%20signed%20the%20Convention%20on,in%20line%20with%20the%20Convention.>

UNICEF (2023). UNICEF Disability Inclusion Policy and Strategy (DIPAS) 2022-2030. DOI: <https://www.unicef.org/unicef-disability-inclusion-policy-and-strategy-dipas-2022-2030>

UNICEF. (2023). UNICEF remains committed to children's right to education in Lebanon and urges national investment to ensure livable wages for teachers and education staff to guarantee uninterrupted learning for all children. DOI: <https://reliefweb.int/report/lebanon/unicef-remains-committed-childrens-right-education-lebanon-and-urges-national-investment-ensure-livable-wages-teachers-and-education-staff-guarantee-uninterrupted-learning-all-children-enar>

UNICEF Lebanon (2018). The Ministry of Education and UNICEF promote inclusive education. DOI: <https://www.unicef.org/lebanon/press-releases/ministry-education-and-unicef-promote-inclusive-education>

UNICEF, Dreesen, T., Kamei, A., Karamperidou, D., Abou Fakher, S., Marji, L., AND Santiago Ortiz Correa, J. (2021). *Unlocking Learning: The Implementation and Effectiveness of Digital Learning for Syrian Refugees in Lebanon*. UNICEF.

Valdes, F. (1995). Sex and Race in Queer Legal Culture: Ruminations on Identities and Inter-Connectivities. 5 S. CAL. REV. L. & WOMEN'S STUD. 25.

Vaughn, J. (2009). The Unlikely Securitizer: Humanitarian Organizations and the Securitization of Indistinctiveness. *Security Dialogue*, 40(3):263-285.

Wacquant, L. (2005). Race as civic felony. *International Social Science Journal*, 57(183), 127-142.

Walsh, J. (2014). The Hidden Point of Intersection: Bio-politics in Foucault and Agamben. DOI: <https://soundideas.pugetsound.edu/cgi/viewcontent.cgi?article=1006&context=psupc>

Walton, E., McIntyre, J., Awidi, S. J., De Wet-Billings, N., Dixon, K., Madziva, R., ... and Wedekind, V. (2020). Compounded exclusion: Education for disabled refugees in Sub-Saharan Africa. In *Frontiers in Education*, 5, 47. Frontiers Media SA.

Ward, J. L. (2021). *Narratives of Disability and Displacement: Oral Histories of the Lived Experiences of Disabled Refugees*. University of San Francisco.

Ward, P. and Bian, J. (2024). Class matters in humanitarianism. In *Handbook on Humanitarianism and Inequality*. Edited by Roth, S.; Purkayashta, B. and Denskus, T. (2024). Edward Elgar Publishing: Cheltenham, UK.

Warner, J. (2013). The politics of ‘catastrophization’. *Disaster, conflict and society in crises: Everyday politics of crisis response*, 92-110.

Watson, S. (2011). The ‘human’ as referent object? Humanitarianism as securitization. *Security Dialogue*, 42(1):3-20.

Weber, M. (1949). *The methodology of the social sciences*. Free Press.

Weiss, T. G. (2013). *Humanitarian business*. John Wiley & Sons.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York: Routledge.

White, J. (2019). *Politics of Last Resort: Governing by Emergency in the European Union*. Oxford: Oxford University Press.

Williamson, R. L., and Çetin, B. (2019). The Participation of Refugee Children with Disabilities in Educational Options in Turkey: A Systematic Review. *International Journal of Educational and Pedagogical Sciences*, 13(6), 899–904.

Wilson, B. K., Burnstan, A., Calderon, C., & Csordas, T. J. (2023). “Letting die” by design: Asylum seekers’ lived experience of postcolonial necropolitics. *Social Science & Medicine*, 320, 115714.

Winthrop, R., and Matsui, E. (2013). A new agenda for education in fragile states. Center for Universal Education at Brookings. DOI:<https://www.brookings.edu/wp-content/uploads/2016/06/08-education-agenda-fragile-states-winthrop.pdf>

Wolfe, P. (2006). Settler Colonialism and the Elimination of the Native. *Journal of genocide research*, 8(4), 387-409.

Wright, B. A. (1983). *Physical disability: A psychosocial approach*. New York, NY: Harper & Row

Wu, W.-Y. (2021). *Waiting, Hopes and Futures : Higher Education for the Displaced Students from Syrian in Lebanon and Jordan*. Doctoral dissertation, University of Birmingham

VASyR 2022 (Vulnerability Assessment of Syian Refugees in Lebanon). (2023). DOI: https://reliefweb.int/report/lebanon/vasyr-2022-vulnerability-assessment-syrian-refugees-lebanon?gad_source=1&gclid=EAIaIQobChMI0_30gNiehQMV149QBh09jQLDEAAAYASAAEgJknvD_BwE

- Veracini, L. (2015). What can settler colonial studies offer to an interpretation of the conflict in Israel–Palestine? *Settler Colonial Studies*, 5(3), 268-271.
- Yanary, V. N. and Abidi, C. B. (2018). “‘We’ the Refugees: Reflection on Refugee Labels and Identities.” *Refuge: Canada’s Journal on Refugees* 34(2): 52-60.
- Yeo, R. A. (2019). Disability and Forced Migration. *Social Work with Asylum Seekers, Refugees and Migrants: Theory and Skills for Practice*, 77-94.
- Young, K. (2023). Exclusive humanitarianism: Policy recommendations for genuine inclusion of persons with disabilities in humanitarian action. *International Review of the Red Cross*, 105(922), 396-415.
- Zaccara, L., & Gonçalves, M. D. C. D. S. (2022). Migrants, Refugees, and Displaced Persons in the Middle East and North Africa: An approach from the Global South. *REMHU: Revista Interdisciplinar da Mobilidade Humana*, 29, 13-20.
- Zetter, R. (1991). Labelling Refugees: Forming and Transforming a Bureaucratic Identity. *Journal of Refugee Studies*, 4(1): 39-62.
- Zeveleva, O. (2017). Biopolitics, borders, and refugee camps: exercising sovereign power over nonmembers of the state. *Nationalities Papers*, 45(1), 41-60.

APPENDICES

Appendix I: Flyer (English and Arabic)



Participants needed for Research Project

My name is Giada Costantini, I am a post-graduate researcher at the University of Birmingham, and I am looking for opportunities to collaborate with refugee children with disabilities and their families to better understand their life experiences and access to learning opportunities.

What the study is about:

This project is about the lived experiences of disabled Syrian refugee children, who are out of school, and their parents, in accessing educational opportunities and learning spaces in Lebanon. Moreover, the study will also explore parents' views and experiences in navigating the Lebanese context, focusing on their networks, and strategies in accessing help and opportunities, as well as disability organizations and NGOs' responses to disabled Syrian refugees' needs, especially regarding to the educational needs of disabled refugee children.

This research is confidential, and you can withdraw.

I will be very careful never to collect nor to write down any identifiable information that could harm you and your family. A system of withdrawal is in place, and there will be no repercussion if you decide to withdraw from the project.

If you are interested in taking part in this project,

or are seeking further information about the project, please contact me via whatsapp (Giada [redacted]) or send me an email [redacted]. You can also reach my supervisors Dr. Dina Kiwan [redacted] or Dr. Maha Shuayb [redacted] who both speak Arabic.





يحتاج المشاركون لمشروع بحث

اسمي جادا كوستانتيني، باحثة دراسات عليا في جامعة بيرمينغهام. أبحث عن فرص للتعاون مع الأطفال اللاجئين ذوي الإعاقة وعائلاتهم، لفهم تجارب حياتهم وامكانية وصولهم إلى فرص التعلم بشكل أفضل.

موضوع الدراسة:

يدور هذا المشروع على التجارب المعيشية في الوصول الى فرص التعليم وأماكن التعلم من قبل الأطفال اللاجئين السوريين ذوي الإعاقة، غير الملتحقين في المدرسة، وأولياء أمورهم في لبنان. علاوة على ذلك، ستكشف الدراسة أيضاً وجهات نظر أولياء الأمور وتجاربهم في التنقل في السياق اللبناني، مع التركيز على شبكات التواصل والاستراتيجيات التي يتبعونها للحصول على الدعم والفرص. بالإضافة إلى البحث في استجابات منظمات الإعاقة والمنظمات غير الحكومية لاحتياجات اللاجئين السوريين ذوي الإعاقة، وبالأخص فيما يتعلق بالاحتياجات التعليمية للأطفال اللاجئين ذوي الإعاقة.

هذه دراسة بحثية سرية، ولديك حرية الانسحاب من المشروع.

سأحرص على عدم جمع أو تدوين أي معلومات التي من شأنها إلحاق الضرر بك أو بعائلتك. إذا قررت الانسحاب من المشروع، سيكون لديك حرية القرار دون أي تداعيات.

إذا اردت المشاركة في مشروع البحث،

أو تسعى للحصول على مزيد من المعلومات حول المشروع،

يرجى الاتصال بي عبر الواتساب:

أو عبر البريد الإلكتروني الخاص بي

يمكنك أيضاً التواصل مع مشرفتي المشروع (اللواتي يتحدثن اللغة العربية) :

الدكتورة دينا كيوان:

أو الدكتورة مها شعيب:

Appendix II: Parents' consent form (English and Arabic)



UNIVERSITY OF
BIRMINGHAM

Consent Form for parents

The following document gives an outline of the research study to which you are being invited to participate. Please feel free to ask for any clarification and/or additional questions you might have.

This project is a doctoral student research project, that is affiliated to the Disability Under Siege Programme (please visit this link to more about Disability Under Siege Programme: <https://disabilityundersiege.org/>). This project is about the lived experiences of disabled Syrian refugee children, who are out of school, and their parents, in accessing educational opportunities and learning spaces in Lebanon. Moreover, the study will also explore parents' views and experiences in navigating the Lebanese context, focusing on their networks, and strategies in accessing help and opportunities, as well as disability organizations and NGOs' responses to disabled Syrian refugees' needs, especially regarding to the educational needs of disabled refugee.

You have no obligation to participate in this study. If you consent to be interviewed, you can decide which questions you want to answer, and how much you want to say concerning the specific topic discussed. You can also withdraw from the study after the interview took place up until the 15 of October 2022. There will be no negative consequences if you decide to withdraw. Furthermore, please note that your data will be fully anonymised and always kept confidential. You will not be identified in any reports and/or papers, and nothing that you say will be shared if you do not want to.

There will be no direct benefit to you, as I am conducting this research as part of my university degree. However, I hope that this research can offer new knowledge that, with other studies, would be able to improve the situation for disabled refugees in the society. There are no risks involved in this study. The findings of this research will be used for academic research purposes including conference papers and journals articles. Please note: all the data gathered will be uploaded on the university storage system and locked on my password protected laptop. The audio recorder and notebooks will be stored in my locked desk drawer. Only my professors and I will have access to them. The data collected will be kept for 10 years after the end of the study and be deleted afterwards.

Please feel free to contact me: Giada Costantini, Whatsapp [REDACTED], email: [REDACTED]

Should you have any additional questions, please contact Dr. Dina Kiwan [REDACTED] Dr. Valentina Migliarini [REDACTED] or Dr. Maha Shuayb [REDACTED] Please note, Professor Kiwan and Professor Shuayb speak Arabic.

Consent to interview your child:

☐ Yes

☐ No

Consent to interview you and your family:

☐ Yes

☐ No

Consent to audio record:

☐ Yes

☐ No

Signature:

(participant)

Date of Interview:

Anonymized Archival #:

Thanks for your participation!!!



نموذج موافقة أولياء الأمور

يقدم المستند التالي مخططاً للدراسة البحثية التي تتم دعوتك للمشاركة فيها. لا تتردد في طرح أي توضيح و/ أو أسئلة إضافية قد تكون لديك.

هذا المشروع هو مشروع بحثي لطلاب الدكتوراه، تابع لبرنامج الإعاقة تحت الحصار. قم بزيارة هذا الرابط لمعرفة المزيد: <https://disabilityundersiege.org>. يدور المشروع على التجارب المعيشية في الوصول إلى فرص التعليم وأماكن التعلم من قبل الأطفال اللاجئين السوريين ذوي الإعاقة، غير الملتحقين في المدرسة، وأولياء أمورهم في لبنان. علاوة على ذلك، ستكشف الدراسة أيضاً وجهات نظر أولياء الأمور وتجاربهم في التنقل في السياق اللبناني، مع التركيز على شبكات التواصل والاستراتيجيات التي يتبعونها للحصول على الدعم والفرص. بالإضافة إلى البحث في استجابات منظمات الإعاقة والمنظمات غير الحكومية لاحتياجات اللاجئين السوريين ذوي الإعاقة، وبالأخص فيما يتعلق بالاحتياجات التعليمية للأطفال اللاجئين ذوي الإعاقة.

أنت غير ملزم بالمشاركة في هذه الدراسة. إذا وافقت على إجراء المقابلة، يمكنك تحديد الأسئلة التي تريد الإجابة عليها وكمية المعلومات التي تريد مشاركتها. لن يكون أي عواقب سلبية إذا قررت الانسحاب من الدراسة. حيث يمكنك الانسحاب أي وقت بعد إجراء المقابلة حتى تاريخ 15 أكتوبر/تشرين الأول 2022. علاوة على ذلك، يرجى الملاحظة أن بياناتك ستكون مجهولة المصدر تماماً وستظل سرية دائماً. لن يتم تحديد هويتك في أي تقارير و/ أو أوراق، ولن تتم مشاركة أي شيء نقوله إذا كنت لا ترغب في ذلك.

لن تكون هناك فائدة مباشرة لك، حيث سيتم إجراء هذا البحث كجزء من شهادتي الجامعية. ومع ذلك، أمل أن يقدم هذا البحث معرفة جديدة التي من شأنها، إلى جانب الدراسات الأخرى، أن تكون قادرة على تحسين وضع اللاجئين ذوي الإعاقة في المجتمع. سيتم استخدام نتائج هذا البحث لأغراض البحث الأكاديمي بما في ذلك أوراق المؤتمرات ومقالات المجلات. يرجى الملاحظة: سيتم تحميل جميع البيانات التي تم جمعها على نظام التخزين بالجامعة وإبقائها على جهاز الحاسوب المحمول المحمي بكلمة مرور. سيتم تخزين مسجل الصوت ودفاتر التدوين في درج مكتبي المقفل. الوصول إليهم سيكون ممكناً فقط من قبلي و من قبل مشرفتي البحث. سيتم الاحتفاظ بالبيانات التي تم جمعها لمدة 10 سنوات بعد انتهاء الدراسة وسيتم حذفها بعد ذلك.

الرجاء عدم التردد في الاتصال بي: جادا كوستانتيني

رقم الهاتف: [REDACTED]

البريد الإلكتروني الخاص بي: [REDACTED]

إذا كان لديك أسئلة إضافية، يمكنك أيضاً التواصل مع مشرفتي المشروع (اللواتي يتحدثن اللغة العربية) :

الدكتورة دينا كيوان: [REDACTED]

أو الدكتورة مها شعيب: [REDACTED]

الموافقة على مقابلة طفلك: ☐ نعم ☐ لا

الموافقة على مقابلتك و مقابلة عائلتك: ☐ نعم ☐ لا

الموافقة على التسجيل: ☐ نعم ☐ لا

التوقيع (المشارك): _____

تاريخ عقد المقابلة: _____ رقم البيانات المحفوظة بالارشيف المجهول: _____

شكراً جزيلاً

Appendix III: Interview questions with parents (English and Arabic)

Below, the topics addressed during the semi-structured interviews are presented in bullet points.

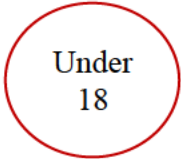
- Family composition
- Current economic situation
- Prior socio-economic status before the Syrian war
- How life changed after arriving in Lebanon
- Current housing conditions – whether accessible for their disabled child
- Relationship with neighbours both refugees and hosting communities
- Services available in-home country for their disabled kid if he/she was already born
- Their views and understanding of disability in general
- Type and severity of their kid's disability
- Whether acquired or congenital
- Thoughts about differences between disabled children based on sex
- Services and provisions available for disabled Syrian refugee children in Lebanon
- Way of accessing these services
- What it can be done to make people more aware and knowledgeable about disability
- Their opinions on education
- Educational opportunities available for their kids
- How they came to know about these educational opportunities
- Their opinions on NGOs' educational services for disabled refugee children
- Their local network – how they build it, benefits of having it, collaboration with other parents of disabled refugee children
- Views on the role of community in providing spaces for disabled refugee children
- Thoughts about the level of inclusion in the society
- Thoughts about the main struggles they face daily, and how disability is perceived influencing their daily life
- Which are the daily needs of their disabled child
- Thoughts about whether disabled children need are considered and addressed by humanitarian provisions and/or other organizations
- Information on their potential contacts with disability NGOs and/or organizations
- Relationship with hosting community (any contact with parents of disabled Lebanese children? any form of cooperation?)

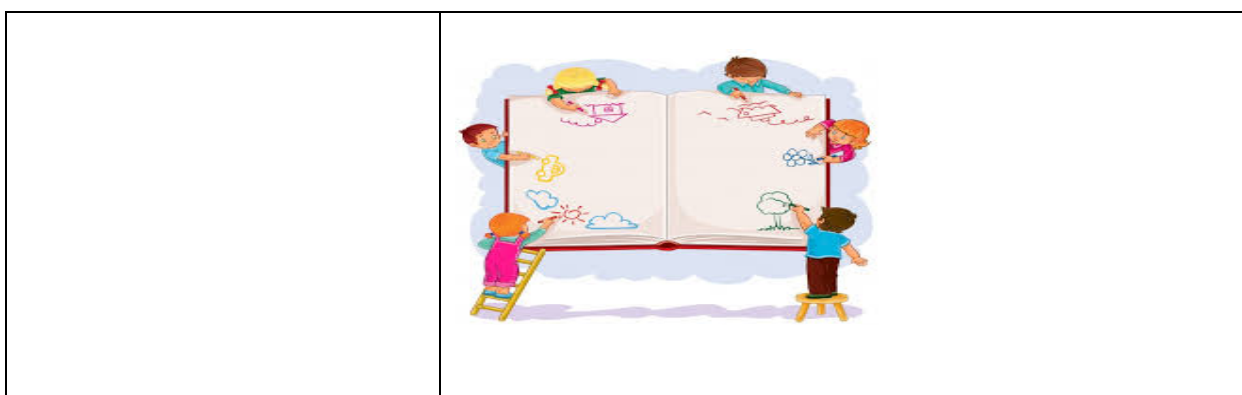
مقابلات مع أسر الأطفال المعوقين

- تكوين الأسرة
- الوضع الاقتصادي الحالي
- الوضع الاجتماعي والاقتصادي السابق قبل الحرب السورية
- كيف تغيرت الحياة بعد وصولنا إلى لبنان
- ظروف السكن الحالية - سواء كان الوصول إليها متاحًا لطفلهم المعاق
- العلاقة مع الجيران على حد سواء اللاجئين والمجتمعات المضيفة
- الخدمات المتاحة في الوطن للطفل المعاق إذا كان قد ولد بالفعل
- وجهات نظرهم وفهمهم للإعاقة بشكل عام
- نوع وشدة إعاقة أطفالهم
- سواء كانت مكتسبة أو خلقية
- خواطر حول الفروق بين الأطفال المعوقين على أساس الجنس
- الخدمات والمؤن المتاحة للأطفال اللاجئين السوريين المعوقين في لبنان
- طريقة الوصول إلى هذه الخدمات
- ما الذي يمكن فعله لجعل الناس أكثر وعيًا ودراية بالإعاقة
- آرائهم في التعليم
- الفرص التعليمية المتاحة لأطفالهم
- كيف تعرفوا على هذه الفرص التعليمية
- آرائهم حول الخدمات التعليمية التي تقدمها المنظمات غير الحكومية للأطفال اللاجئين المعوقين
- شبكةهم المحلية - كيف يبنونها ، فوائد الحصول عليها ، التعاون مع آباء آخرين للأطفال اللاجئين المعوقين
- وجهات نظر حول دور المجتمع في توفير مساحات للأطفال اللاجئين المعوقين
- أفكار حول مستوى الاندماج في المجتمع
- أفكار حول النضالات الرئيسية التي يواجهونها يوميًا ، وكيف يُنظر إلى الإعاقة على أنها تؤثر على حياتهم اليومية.
- ما هي الاحتياجات اليومية لطفلهم المعاق
- الأفكار حول ما إذا كان الأطفال المعوقين بحاجة إلى أخذها في الاعتبار ومعالجتها من خلال الأحكام الإنسانية و / أو المنظمات الأخرى
- معلومات عن اتصالاتهم المحتملة مع المنظمات غير الحكومية و / أو المنظمات المعنية بالإعاقة
- العلاقة مع المجتمع المضيف (أي اتصال مع أولياء أمور الأطفال اللبنانيين المعاقين؟ أي شكل من أشكال التعاون؟

Appendix IV: Easy-to-read form (English and Arabic)

Topic of the research

Hi my name is: Giada Costantini		
I am a researcher at the University of Birmingham, UK		
I also work with the Lebanese American University, in Lebanon		
I am researching about Syrian refugee children with disabilities in Lebanon		
And their access to learning spaces		
Children age under 18		
I would like to work with you to ask what your life experience is and what is important for you		



The purpose of this research

The purpose of this research is to listen to the experiences of Syrian children with disabilities in Lebanon

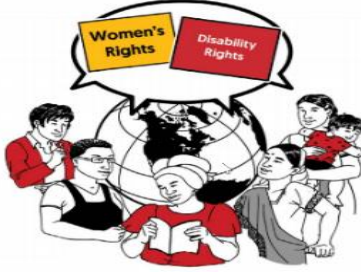


This research is conducted with you! You are the main actor!

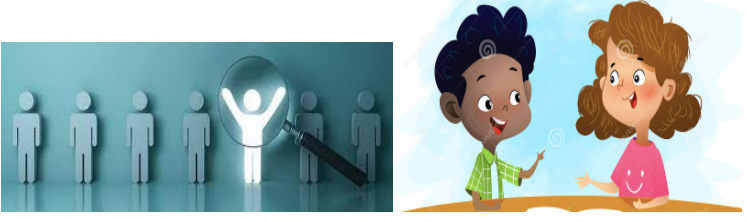


This research will be guided by the principles of the UN Convention on the Rights of Persons with Disabilities and on the Convention on the Rights of the Child



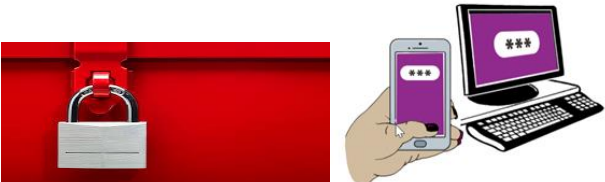
These principles respect all people with disabilities as equals with equal rights	
We believe that doing research together is important to support change for the better	
An interpreter will be with me to help me understand Arabic	

If you decide to join the research, we will:

Talk and discuss together	
You can choose a member of your family to stay with you during our conversation	

You can decide what you want to share with us	
You can give us your feedback	
All the information we have will be discussed and agreed together	

How I will keep all the information if you decide to join the research:

I will keep notes of our discussion on my laptop and notebook	
I will need to record our discussion so that I can remember it later	
All the information will be kept safe and confidential with a password	

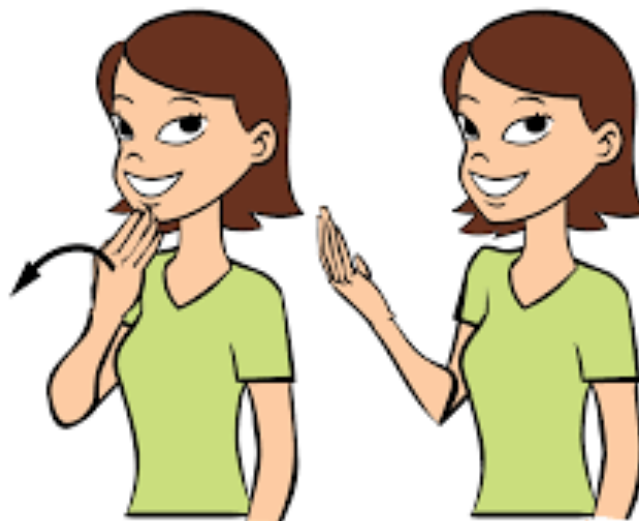
Confidential means that I will not share your information with other people	
---	--

All information will be kept anonymous

Anonymous means that when I write up notes on my laptop and notebook, I will not write your name	
No one will know that I am writing about you	
I will keep all the information safe and secure at the University of Birmingham	
If you change your mind at any time, you can decide to have your information deleted	
Your data will be kept safely in line with the rules of the University of Birmingham	

Would you like to participate?	 
Yes	
No	

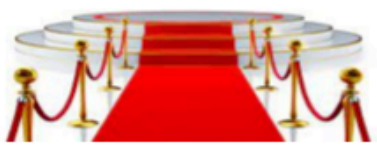
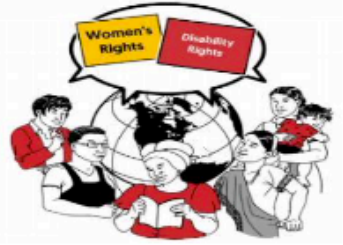
Thanks a lot for your time!!!



مرحباً، اسمي جادا كوستانتيني	
أنا باحثة في جامعة بيرمينغهام بالمملكة المتحدة	  
أعمل أيضاً مع الجامعة اللبنانية الأمريكية في لبنان	  
أبحث في موضوع الأطفال السوريين اللاجئين ذوي الإعاقة في لبنان	  
إمكانية وصولهم إلى أماكن التعلم	 
الأطفال التي تقل أعمارهم عن 18 عامًا	 
أود أن أعمل معك لأسانلك عن تجربتك الحياتية وما هو مهم بالنسبة لك	 

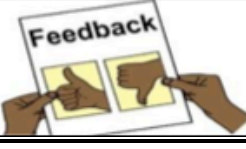


هدف البحث

هدف هذا البحث هو الاستماع إلى تجارب الأطفال السوريين ذوي الإعاقة في لبنان	   
سيتم إجراء هذا البحث معك! أنت الممثل الرئيسي!	 
سيتم توجيه هذا البحث بموجب مبادئ اتفاقية الأمم المتحدة لحقوق الأشخاص ذوي الإعاقة واتفاقية حقوق الطفل	  
تحتزم هذه المبادئ جميع الأشخاص ذوي الإعاقة وتعتبرهم متساوون، ولديهم حقوق متساوية	

نؤمن أن إجراء البحث معاً أمر مهم لدعم التغيير نحو الأفضل	
سيرافقني مترجم ليساعدني على فهم اللغة العربية	

إذا قررت الانضمام إلى البحث، فسنقوم بما يلي

سنحدث و نناقش سويا	
يمكنك اختيار أحد أفراد عائلتك للبقاء معك أثناء محادثتنا	
يمكنك تحديد ما تريد مشاركته معنا	
يمكنك أن تعطينا ملاحظاتك	

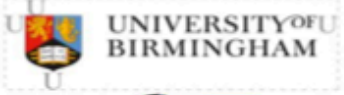
ستتم مناقشة جميع المعلومات التي لدينا والاتفاق عليها معك	
--	--

يف ساحتفظ بجميع المعلومات إذا قررت الانضمام إلى البحث

سأحتفظ بملاحظات مناقشتنا على جهاز الحاسوب المحمول ودفتر التدوين	 
سأحتاج إلى تسجيل مناقشتنا حتى أتمكن من تذكرها لاحقًا	
ستبقى جميع المعلومات آمنة وسرية ومحمية بكلمة مرور	 
تعني كلمة سرية أنني لن أشارك معلوماتك مع أشخاص آخرين	 

يتم الاحتفاظ بجميع المعلومات على أنها مجهولة المصدر

يقصد بمجهولة المصدر أنه عندما أكتب ملاحظات على جهاز الحاسوب المحمول أو دفتر التدوين، فلن أكتب اسمك	 
لن يعرف أحد أنني أكتب عنك	 

سأحافظ على أمان جميع المعلومات في جامعة بيرمينغهام.	  
إذا غيرت رأيك في أي وقت، يمكنك حذف معلوماتك	 
سيتم الاحتفاظ ببياناتك بأمان بما يتماشى مع قوانين جامعة بيرمينغهام	  

هل ترغب في المشاركة؟	 
نعم	
لا	

Appendix V: Interview questions with children (English and Arabic)

- His name, age, things he likes, and he dislikes, and everything he would like to share when asked to present himself.
- Talk about his family and friends
- His/her relationship with family members and siblings
- His/her relationship with other children and teachers (in the educational space accessed, previous and current experiences)
- Description of a good day and a bad day
- How he/she would like to be supported
- What is important for him/her
- Questions on what he/she would like to do when growing up
- Thoughts about learning/education
- Information on education opportunities, if any, attended by the child
- Ways in which they access educational spaces
- Favourite subject
- Does he/she like these learning spaces or he/she would rather prefer to go to another school?
- Does he/she like learning?
- His/her relationship with the physical and attitudinal environment in which he/she lives.
- His/her experience in Lebanon
- His/her understanding of disability
- His/her view on inequalities

مقابلات مع أطفال اللاجئين المعوقين

- اسمه / اسمها وعمره وما يعجبه وما يكره وكل ما يود مشاركته عندما يُطلب منه تقديم نفسه / بنفسها
- تحدث عن العائلة والأصدقاء
- علاقته بأفراد أسرته وإخوته
- علاقته / علاقتها مع الأطفال والمعلمين الآخرين
- وصف ليوم جيد ويوم سيئ
- كيف يود أن يتم دعمه
- ما هو مهم بالنسبة له / لها
- أسئلة حول ما يود أن يفعله عندما يكبر
- خواطر حول التعلم / التعليم
- معلومات عن فرص التعليم، إن وجدت، التي حضرها الطفل
- طرق وصولهم إلى الأماكن التعليمية
- الموضوع المفضل
- هل يحب مساحات التعلم هذه أم يفضل الذهاب إلى مدرسة أخرى؟
- هل يحب التعلم؟
- علاقته بالبيئة المادية والسلوكية التي يعيش فيه
- تجربته في لبنان
- فهمه / فهمها للإعاقة
- وجهة نظره في عدم المساواة

Appendix VI: Organizations' representatives consent form (English and Arabic)



UNIVERSITY OF
BIRMINGHAM

Consent Form for disability organizations

The following document gives an outline of the research study to which you are being invited to participate. Please feel free to ask for any clarification and/or additional questions you might have.

This project is a doctoral student research project, that is affiliated to the Disability Under Siege Programme (please visit this link to more about Disability Under Siege Programme: <https://disabilityundersiege.org/>). This project is about the lived experiences of disabled Syrian refugee children, who are out of school, and their parents in accessing educational opportunities and learning spaces in Lebanon. Moreover, the study will also explore parents' views and experiences in navigating the Lebanese context, focusing on their networks, and strategies in accessing help and opportunities, as well as disability organizations and NGOs' responses to disabled Syrian refugees' needs, especially regarding to the educational needs of disabled refugee.

You have no obligation to participate in this study. If you consent to be interviewed, you can decide which questions you want to answer, and how much you want to say concerning the specific topic discussed. You can also withdraw from the study after the interview took place up until the 15 of October 2022. There will be no negative consequences if you decide to withdraw. Furthermore, please note that your data will be fully anonymised and always kept confidential. You will not be identified in any reports and/or papers, and nothing that you say will be shared if you do not want to.

There will be no direct benefit to you, as I am conducting this research as part of my university degree. However, I hope that this research can offer new knowledge that, with other studies, would be able to improve the situation for disabled refugees in the society. There are no risks involved in this study. The findings of this research will be used for academic research purposes including conference papers and journals articles. Please note: all the data gathered will be uploaded on the university storage system and locked on my password protected laptop. The audio recorder and notebooks will be stored in my locked desk drawer. Only my professors and I will have access to them. The data collected will be kept for 10 years after the end of the study and be deleted afterwards.

Please feel free to contact me: Giada Costantini, Whatsapp

email:

Should you have any additional questions, please contact Dr. Dina Kiwan, Dr.

Valentina Migliarini, or Dr. Maha Shuayb

Please note, Professor Kiwan and Professor Shuayb speak Arabic.

Consent to interview: ☐ Yes ☐ No

Consent to record: ☐ Yes ☐ No

Signature: _____

(participant)

Date of Interview: _____ **Anonymized Archival #:** _____

Thanks for your participation!!!



نموذج موافقة أولياء الأمور

يقدم المستند التالي مخططاً للدراسة البحثية التي تتم دعوتك للمشاركة فيها. لا تتردد في طرح أي توضيح و/ أو أسئلة إضافية قد تكون لديك.

هذا المشروع هو مشروع بحثي لطلاب الدكتوراه، تابع لبرنامج الإعاقة تحت الحصار رقم بزيارة هذا الرابط لمعرفة المزيد: <https://disabilityundersiege.org>. يدور المشروع على التجارب المعيشية في الوصول إلى فرص التعليم وأماكن التعلم من قبل الأطفال اللاجئين السوريين ذوي الإعاقة، غير الملتحقين في المدرسة، وأولياء أمورهم في لبنان. علاوة على ذلك، ستكشف الدراسة أيضاً وجهات نظر أولياء الأمور وتجاربهم في التنقل في السياق اللبناني، مع التركيز على شبكات التواصل والاستراتيجيات التي يتبعونها للحصول على الدعم والفرص. بالإضافة إلى البحث في استجابات منظمات الإعاقة والمنظمات غير الحكومية لاحتياجات اللاجئين السوريين ذوي الإعاقة، وبالأخص فيما يتعلق بالاحتياجات التعليمية للأطفال اللاجئين ذوي الإعاقة.

أنت غير ملزم بالمشاركة في هذه الدراسة. إذا وافقت على إجراء المقابلة، يمكنك تحديد الأسئلة التي تريد الإجابة عليها وكمية المعلومات التي تريد مشاركتها. لن يكون أي عواقب سلبية إذا قررت الانسحاب من الدراسة. حيث يمكنك الانسحاب أي وقت بعد إجراء المقابلة حتى تاريخ 15 أكتوبر/تشرين الأول 2022. علاوة على ذلك، يرجى الملاحظة أن بياناتك ستكون مجهولة المصدر تماماً وستظل سرية دائماً. لن يتم تحديد هويتك في أي تقارير و/ أو أوراق، ولن تتم مشاركة أي شيء تقوله إذا كنت لا ترغب في ذلك.

لن تكون هناك فائدة مباشرة لك، حيث سيتم إجراء هذا البحث كجزء من شهادتي الجامعية. ومع ذلك، أمل أن يقدم هذا البحث معرفة جديدة التي من شأنها، إلى جانب الدراسات الأخرى، أن تكون قادرة على تحسين وضع اللاجئين ذوي الإعاقة في المجتمع. سيتم استخدام نتائج هذا البحث لأغراض البحث الأكاديمي بما في ذلك أوراق المؤتمرات ومقالات المجلات. يرجى الملاحظة: سيتم تحميل جميع البيانات التي تم جمعها على نظام التخزين بالجامعة وإبقائها على جهاز الحاسوب المحمول المحمي بكلمة مرور. سيتم تخزين مسجل الصوت ودفاتر التكوين في درج مكتبي المغفل. الوصول اليهم سيكون ممكناً فقط من قبلي و من قبل مشرفتي البحث. سيتم الاحتفاظ بالبيانات التي تم جمعها لمدة 10 سنوات بعد انتهاء الدراسة وسيتم حذفها بعد ذلك.

الرجاء عدم التردد في الاتصال بي: جادا كوستانتيني

رقم الهاتف: [Redacted]

البريد الإلكتروني الخاص بي: [Redacted]

إذا كان لديك أسئلة إضافية، يمكنك أيضاً التواصل مع مشرفتي المشروع (اللواتي يتحدثن اللغة العربية) :

الدكتورة دينا كيوان: [Redacted]

أو الدكتورة مها شعيب: [Redacted]

الموافقة على مقابلتك و مقابلة عائلتك : ☐ نعم ☐ لا

الموافقة على التسجيل: ☐ نعم ☐ لا

التوقيع (المشارك) : _____

تاريخ عقد المقابلة: _____ رقم البيانات المحفوظة بالارشيف المجهول : _____

شكراً جزيلاً

Appendix VII: Interview questions with organizations' representatives (English and Arabic)

- Their experiences as actors in disability organizations and NGOs
- Thoughts about the role played by disability organizations and NGOs in Lebanon
- Role they are playing to ensure human rights for disabled refugees
- Thoughts about inclusion
- Conceptualization and understanding of disability
- Their approach to disabled Syrian refugees' needs
- Their engagement with education services for disabled children, whether refugees or not
- Ways in which they are supporting refugee families with disabled family members
- Thoughts about current policies and provisions supplied by national and international actors targeting disabled population
- Their involvement in designing and/or contributing to the provisions and policies framework
- Major challenges for disabled Syrian refugees

المقابلات ومجموعات التركيز مع منظمات الإعاقة والمنظمات غير الحكومية

- خبراتهم كجهات فاعلة في منظمات الإعاقة والمنظمات غير الحكومية
- أفكار حول الدور الذي تلعبه منظمات الإعاقة والمنظمات غير الحكومية في لبنان
- الدور الذي يلعبونه لضمان حقوق الإنسان للاجئين المعوقين
- أفكار حول تضمين تصور وفهم الإعاقة
- نهجهم في تلبية احتياجات اللاجئين السوريين المعوقين
- مشاركتهم في خدمات التعليم للأطفال المعوقين، سواء كانوا لاجئين أم لا
- الطرق التي يدعمون بها عائلات اللاجئين مع أفراد الأسرة ذوي الإعاقة
- أفكار حول السياسات والأحكام الحالية التي قدمتها الجهات الفاعلة الوطنية والدولية التي تستهدف السكان ذوي الإعاقة
- مشاركتهم في تصميم و / أو المساهمة في إطار الأحكام والسياسات
- تحديات كبيرة للاجئين السوريين المعاقين

Appendix VIII: Oral consent form



UNIVERSITY OF
BIRMINGHAM

Researcher record of oral consent template

Interviewee Pseudonym and Archival Number:

Date:

Location (City / Region):

Project Explained (Yes/No):

Interview recorded or Notes Taken:

Participant agreed to direct quotes? (Yes / No)/ not sure how to translate it:

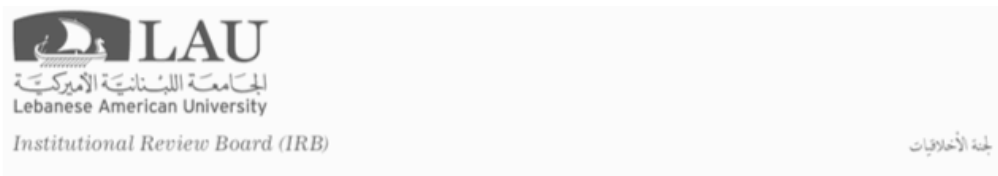
Participant agreed to quotes which would not identify them? (Yes/No)/ not sure:

Participant is not to be quoted at all (Yes/No)/ not sure:

Signature of Researcher : Giada Costantini

**(Signed in the presence of the
interviewee to confirm oral consent):**

Appendix IX: Notice of IRB approval



NOTICE OF IRB APPROVAL

To: Dr. Maha Shuayb
Centre for Lebanese Studies

APPROVAL ISSUED: 15 July 2022
EXPIRATION DATE: 15 July 2023
REVIEW TYPE: EXPEDITED – INITIAL

Date: July 15, 2022

RE: **IRB #:** LAU.STF.MS5.15/Jul/2022

Protocol Title: *The lived experiences of disabled refugee children in accessing education and learning spaces in Lebanon*

The above referenced research project has been approved by the Lebanese American University, Institutional Review Board (LAU IRB). This approval is limited to the activities described in the Approved Research Protocol and all submitted documents listed on page 2 of this letter. **Enclosed with this letter are the stamped approved documents that must be used.**

APPROVAL CONDITIONS FOR ALL LAU APPROVED HUMAN RESEARCH PROTOCOLS

LAU RESEARCH POLICIES & PROCEDURES: All individuals engaged in the research project must adhere to the approved protocol and all applicable LAU IRB Research Policies & Procedures. **PARTICIPANTS** must **NOT** be involved in any research related activity prior to IRB notice date or after the expiration date.

PROTOCOL EXPIRATION: The LAU IRB approval expiry date is listed above. The IRB Office will send an email at least 45 days prior to protocol approval expiry - Request for Continuing Review - in order to avoid any temporary hold on the initial protocol approval. It is your responsibility to apply for continuing review and receive continuing approval for the duration of the research project. Failure to send Request for Continuation before the expiry date will result in suspension of the approval of this research project on the expiration date.

MODIFICATIONS AND AMENDMENTS: All protocol modifications must be approved by the IRB prior to implementation.

NOTIFICATION OF PROJECT COMPLETION: A notification of research project closure and a summary of findings must be sent to the IRB office upon completion. Study files must be retained for a period of 3 years from the date of notification of project completion.

IN THE EVENT OF NON-COMPLIANCE WITH ABOVE CONDITIONS, THE PRINCIPAL INVESTIGATOR SHOULD MEET WITH THE IRB ADMINISTRATORS IN ORDER TO RESOLVE SUCH CONDITIONS. IRB APPROVAL CANNOT BE GRANTED UNTIL NON-COMPLIANT ISSUES HAVE BEEN RESOLVED.

If you have any questions concerning this information, please contact the IRB office by email at irb@lau.edu.lb



The IRB operates in compliance with the national regulations pertaining to research under the Lebanese Minister of Public Health's Decision No.141 dated 27/1/2016 under LAU IRB Authorization reference 2016/3708, the international guidelines for Good Clinical Practice, the US Office of Human Research Protection (45CFR46) and the Food and Drug Administration (21CFR56). LAU IRB U.S. Identifier as an international institution: FWA00014723 and IRB Registration # IRB00006954 LAUIRB#1

Dr. Joseph Stephan
Chair, Institutional Review Board



DOCUMENTS SUBMITTED:

LAU IRB Initial Protocol Application	Received 14 March 2022
Research Protocol	Received 14 March 2022, amended 5 July 2022
Flyer – English Arabic	Received 14 March 2022, amended 5 July 2022
Informed Consent Forms for Parents– English Arabic	Received 14 March 2022, amended 5 July 2022
Informed Consent Forms for Disability Organization – English Arabic	Received 14 March 2022, amended 5 July 2022
Assents English Arabic	Received 14 March 2022
Interviews and focus groups guideline questions	Received 14 March 2022
Ethical approval University of Birmingham	Received 1 June 2022
Letter to OPDs	Received 5 July 2022
IRB Comments sent: 24 May 2022 6 July 2022	PI response to IRB's comments dated: 5 July 2022
CITI Training - Maha Shuayb	Cert.# 25808746 Dated (16 January 2018)
CITI Training – Giada Costantini	Cert.# 50160053 Dated (15 July 2022)

