

The implications of ensuring equal access and inclusion of persons with intellectual disabilities and mental health issues in disaster risk reduction and humanitarian action

A rapid literature review conducted for NAD by EENET

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1. Introduction

Situations where communities have been disrupted and destabilised are defined as emergencies by the Inter-Agency Network for Education in Emergencies.¹ Disasters involve extensive loss and impact including human, material, economic or environment. These can be as a result of a natural or man-made hazard, political instability and humanitarian emergencies. Conflict, including situations of violent and armed conflict, are another type of disaster. In a disaster, the functioning of communities is disrupted beyond the ability for them to cope within the means of their own resources.

Palestine and Lebanon are both currently in situations where their communities are disrupted and destabilised. Lebanon is situated in a region with neighbouring countries facing crisis and currently hosts the highest refugee population per capita in the world. Lebanon is faced with a humanitarian crisis as they struggle to provide the protection and assistance needed by the various populations. Palestine is characterised by recurrent conflict, blockades, military control, occupation and restricted movement presenting considerable challenges to daily life and humanitarian action. Both areas have displacement in common; Palestine with internal displacement and Lebanon with refugees.

The adverse impact of emergencies, disasters and conflict experienced by people with disabilities is widely recognised to be disproportionately more than that experienced by the general population. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides a set of rights-based principles calling on states to provide protection and safety to people with disabilities in conflict, humanitarian emergencies and natural disasters.² It is expected that people with disabilities be involved in, considered in, and benefit from all disaster management activities. The “The Sendai framework for Disaster Risk Reduction” and the “Charter on inclusion of persons with disabilities in humanitarian action” provide further guidance on the principles of disability inclusion in disaster risk reduction and humanitarian assistance.³

Guidelines and policies for disability inclusion in disaster risk reduction (DRR) and humanitarian action have been, and continue to be, developed by governments, international organisations and humanitarian agents. Despite these disability inclusion efforts, people with intellectual disabilities and mental health issues are reported to continue to face disadvantage, and to a greater extent than those identifying with other disabilities.

On the basis of these understandings, this literature review seeks to gain a better understanding of the particular challenges faced by people with intellectual disabilities and those with mental health issues in Palestine and the refugee settings in Lebanon. The review addresses the following research questions:

¹ INEE, 2010

² UN, 2007

³ UN General Assembly, 2015; World Humanitarian Summit, 2016

1. What do we know about persons with intellectual disabilities and persons with mental health issues in the context of conflict and crisis and in particular in Palestine and Lebanon? What are the factors/barriers that may contribute to disproportionate risk in the context of natural hazards and conflict?
2. What are the protection/prevention and inclusion/exclusion factors to consider in programming for DRR and humanitarian response? How does that relate to what other actors are doing in the field? Where are the gaps?
3. What are the best practices, lessons learned and/or evidence from DRR planning and humanitarian efforts (across all sectors) in the local and international contexts that can be drawn upon to inform next steps for Norwegian Association of the Disabled (NAD). How can we engage in innovative ways with refugee and internally displaced communities to draw on assets and resources to build resilience?

The literature sourced includes research articles, activity reports, statistics, government documents, country reports, international organisation and UN reports, reviews and guidelines. Where it was available, literature specific to the contexts of Palestine and Lebanon was reviewed, including Arabic language material.

With a global perspective and a focus on Palestine and Lebanon, this review is designed specifically for informing NAD's ongoing work and its disability rights programme.

- The review begins by addressing research question one and provides an overview of mental health and intellectual disability, both generally and specific to the Palestine and Lebanon contexts. This section then goes on to present key factors identified in the literature that exacerbate the risk for these populations (Section 2. Mental health and intellectual disability in situations of risk).
- In the next section, research questions two and three are addressed jointly. Organised according to the emerging themes that were identified in the literature, factors related to programming for DRR and humanitarian response are presented. Where examples from actors in the field were found, they are included. For each theme, innovative responses are then offered along with best practices, lessons learned and evidence where they were available (Section 3. Access to and inclusion in DRR and humanitarian response).
- A conclusion draws together the key findings and lessons identified in the literature.

1.1 Key concepts

Situations of risk

This review uses the terminology favoured by the Inter-Agency Network for Education in Emergencies (INEE), where situations of risk are understood to include conflict, emergency and disaster. This is also consistent with the terminology used by the “Charter on inclusion of persons with disabilities in humanitarian action” and The Sphere Handbook (Humanitarian Charter and Minimum Standards in Humanitarian Response).⁴

Mental health

According to a WHO definition, mental health includes “subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence, and self-actualization of one’s intellectual and emotional potential, among others”.⁵ The WHO further states that the well-being of an individual is encompassed in the realisation of one’s abilities, coping with normal stresses of life, productive work and contribution to our community. Furthermore, “multiple social, psychological, and biological factors determine the level of mental health of a person at any point of time”.⁶

Intellectual disability

Intellectual disability can be understood as “a group of developmental conditions characterised by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills”.⁷ This definition has been put forward for the current revision of the International Classification of Diseases, ICD (ICD-11) by a WHO working group. They place intellectual developmental disorders under a parent category of neurodevelopmental disorders and note that there are many subcategories and degrees of severity.

1.2 Overview of the Palestine and Lebanon contexts

Modern day conflict involves complex combinations of humanitarian crises, including mass displacement, political, religious, and ethnic instability, food insecurity and colossal development and reconstruction needs.⁸ Palestine and Lebanon face all of these. Climate change and seismic activity mean that Palestine is susceptible to natural disasters including floods, earthquakes, landslides, droughts and desertification.⁹ For example, the 2013 winter storm, Alexa, caused extensive flooding in Gaza and damaged hundreds of houses and schools, crops and infrastructure.¹⁰

⁴ World Humanitarian Summit, 2016; Red Cross and Red Crescent, 2011

⁵ World Health Organization, 2001, p. 5

⁶ World Health Organization, 2015

⁷ Carulla et al., 2011, p.175

⁸ Tol et al., 2011; WHO, 2013

⁹ OCHA, 2017

¹⁰ Thabet & Thabet, 2016

Lebanon is a protracted refugee setting. It has been home to Palestinian refugees for 70 years; many Palestinians living in Lebanon were born there. Refugees from other countries in the region, including Syria and Iraq, also live in Lebanon. United Nations Relief and Works Agency (UNRWA) has operated to provide basic services for Palestinian refugees since 1950, but refugees from other countries are monitored through the UNHCR, Lebanon government, and NGOs.

In Palestine, the absence of political progress towards resolving the ongoing conflict, means a long-term crisis situation.¹¹ The context here is characterised by restricted movement of people, blockades preventing trade and movement of vital supplies, and frequent military attacks on civilians.

In both contexts there is a unique set of challenges including aid-dependent populations, high unemployment, discrimination and restrictions in access to services, and an increased vulnerability to secondary risks including natural disasters.¹² In Gaza, internal political divisions have generated an energy and salary crisis. Provision of vital services, including therapies, education or other support to people with intellectual disability or mental health issues, is drastically reduced due to shortages in funding, staffing or even just the shortage of fuel to run generators.¹³

In Lebanon, the social impact of long-term aid dependency, unemployment, lack of education and apparent helplessness can contribute to mental health issues and long-term deterioration in quality of life for those with intellectual disabilities.¹⁴

In both contexts the mental health systems and disability service providers face challenges with ongoing conflict, entrenched vulnerabilities and increasing mental health needs. Despite their similarities, the Lebanon and Palestine contexts have political, economic and social differences that need to be recognised when developing differentiated DRR and humanitarian responses. Palestine is occupied territory, subject to continuous conflict and devastation and therefore continuous trauma and arrested development. Meanwhile, the refugees in Lebanon are affected more by the stresses of everyday living in adverse conditions, past trauma, tensions between host and refugee populations, and subject to restrictions placed on their rights by the host country.¹⁵ Both contexts are undergoing mental health reform in collaboration with the WHO and other agencies in response to the refugee crisis.¹⁶

¹¹ Charara et al., 2017; Llosa et al., 2014; WHO, 2013

¹² Mezan Centre for Human Rights; Palestinian Refugee News Network In Lebanon, 2017; UNISDR, 2011; WHO, 2013; World Bank, 2016

¹³ Office of High Commissioner for Human Rights, 2017

¹⁴ ARC; Klynman et al., 2007; United Nations University, 2014; WHO, 2013

¹⁵ Llosa et al., 2014

¹⁶ Marie et al., 2016; Twigg, 2015

2. Mental health and intellectual disability in situations of risk

Conflicts, emergencies and disasters do not discriminate. Everyone in the vicinity is affected. Nevertheless, the literature consistently highlights that those with disabilities, and particularly those with intellectual disabilities and mental health issues, face higher risk and are disproportionately affected.¹⁷ Available literature reveals factors that exacerbate the risk and impact for those with intellectual disabilities and mental health issues. These factors are outlined below and respond to the first research question:

What do we know about persons with intellectual disabilities and persons with mental health issues in the context of conflict and crisis, and particularly in Palestine and Lebanon? What are the factors/barriers that may contribute to disproportionate risk in the context of natural hazards and conflict?

2.1. Overview of mental health in situations of risk

Pre-existing and emerging mental health issues

People living with mental health issues in situations of risk are a marginalised group. Even prior to the conflict, emergency or disaster they already face invisibility in their settings,¹⁸ and are often rendered completely invisible in the response efforts.

In situations of risk and during the recovery period, social and psychological distress frequently results from the experienced trauma. This includes re-traumatisation of those with pre-existing mental health issues,¹⁹ and new cases of crisis-induced mental illness.²⁰ According to UNISDR, there is a 10% rise in mental illness following disaster.²¹

Mental health issues can also be a result of environmental stressors and how humanitarian responses are managed. Internal displacement as well as camp settings in host countries are characterised by overcrowded, claustrophobic conditions; social isolation and separation from family, friends and community; alienation; inadequate accommodation; loss of livelihood, unemployment, and aid dependency; lack of privacy; and lack of information about food distribution and how shelter, water and sanitation is provided. All these conditions have been seen to result in high levels of mental health issues, especially depression and post-traumatic stress disorder.²²

¹⁷ Herr, Gostin, Koh, & Gostin, 2003; Mitchell, 2014; Office of High Commissioner for Human Rights, 2017

¹⁸ UNISDR, 2011; United Nations University, 2014

¹⁹ Juen, 2016; Ronoh, Gaillard, & Marlowe, 2015

²⁰ WHO, 2013

²¹ UNISDR 2011

²² ARC; Palestinian Refugee News Network In Lebanon, 2017; UNISDR, 2011; WHO, 2013

Of the 1.9 m people living in Gaza, 1.3 m (approximately 70%) are registered refugees, with over half a million refugees living in eight recognised refugee camps with one of the highest population densities in the world. The Gaza Strip is one of the most densely populated places in the world, with 5,045 persons per square kilometer (Index Mundi, 2014). With a devastated economy, the World Bank reports an unemployment rate of 41%, despite a high level of skills and education. This is one of the highest in the world.

The West Bank is home to 809,738 refugees, with a quarter living in 19 camps and the rest in villages and towns.

In Lebanon, with over 400,000 Palestinian refugees, around 53%, live in 12 recognised camps. The rest live in rural areas or urban centres. The camps are sites of abject poverty, overcrowding, unemployment, and poor infrastructure and housing conditions (UNRWA, 2015).

Knock-on effects

People experiencing mental health issues (either newly arising or pre-existing) are at risk of developing additional long-term complications if they are unable to access appropriate medical, social and economic interventions.²³ Conflicts, emergencies and disasters severely impact formal and informal supports within communities for people with mental health issues, as social structures and community networks are disrupted.²⁴

Shehadeh highlights the corrosiveness of trauma on the protective effect of community resilience in Palestine.²⁵ With ongoing conflict and violence, the multigenerational transmission of trauma compounds the serious mental health risks within affected populations.

Mental health as a social issue

Mental health and psychosocial consequences of conflict, emergencies and disasters can be both psychological and social. Cautioning against a tendency to medicalise distress, particularly in the mass trauma of the Palestinian context, Giacaman et al. suggest a shift from the bio-medical individualised treatment approach.²⁶ Aligning with the social model of disability, they suggest the imperative to ask different questions of DRR planning and response. By recognising the social determinants of social suffering and distress in such contexts, addressing the lack of human security and human rights violations offers more in the way of alleviating the underlying causes of ongoing collective trauma.

²³ Rohwerder, 2015; Ronoh et al., 2015; Smith, 2012; United Nations University, 2014; Van Ommeren, 2014; World Bank, 2016

²⁴ UNISDR, 2011

²⁵ Shehadeh, 2015

²⁶ Giacaman et al., 2011

Mass trauma: The 2014 war on Gaza has been described as mass torture. An entire population experiencing sleep deprivation, horror, fear and helplessness placed them at great risk of complex mental health issues such as severe psychopathy, identity distortions, traumatic reactions with the intention of inflicting complex mental health issues. (Shehadeh, 2015)

The Palestine and Lebanon context

The available literature sheds some light on the situation of mental health issues in Palestine and Lebanon. On the whole, it reports the incidence to be high,²⁷ with a recent study concluding that Palestinians suffer the highest rates of mental disorders among all Eastern Mediterranean countries.²⁸ A report on refugee camp in Lebanon placed the incidence at one-third of the population.²⁹

More than 50% of Palestinian refugees in Lebanon and 85% of Palestinian refugees displaced from Syria are concerned about their inability to continue to support and protect their families. These fears were believed to potentially negatively affect their mental well-being. (Chaaban et al., 2016; UNWRA, 2016)

There are those who believe no one in Gaza is exempt from the experience of mental health issues, even humanitarian staff working there.³⁰ This position, however, is strongly criticised by Barber and Jamei who assert that, in their experience as mental health professionals in Gaza, they see a community of people who, despite dire conditions, display a collective resilience beyond that ever predicted.³¹

2.2. Overview of intellectual disability in situations of risk

The complexity of intellectual disability cannot be simplified to something one has or does not have, neither is it based entirely on an underlying medical or cognitive deficiency.³² Many people with mild intellectual disabilities prefer to regard their difficulties as socially constructed and common to all those with disabilities.³³ However, the impact of limited abstract thinking, communication difficulties and limitations in self-determination should not be overlooked. People with intellectual disabilities may rely on infrastructures and social structures for access and inclusion, and these are at risk of destruction or disruption in times of conflict, emergency or disaster. The absence of such structures could result in the acquisition of additional impairments or even be life-threatening.³⁴

Furthermore, intellectual disability is frequently (as much as 84% of the time) accompanied by additional physical disabilities or mental health issues. People with

²⁷ Palestinian Refugee News Network In Lebanon, 2017

²⁸ Charara et al., 2017

²⁹ Palestinian Refugees News Network in Lebanon, 2017

³⁰ Shani, 2017

³¹ Barber and Jamei, 2017

³² Goodley, 2016

³³ Clegg & Bigby, 2017

³⁴ Klynman, Kouppari, & Mukhier, 2007; Mitchell, 2014; Rohwerder, 2013; Ronoh et al., 2015; United Nations University, 2014

all types of disabilities have been found to face increased prevalence of mental distress when compared to the general population. The rate at which people with intellectual disability are also affected by mental health issues is double that of people without intellectual disabilities.³⁵ Even before considering the situation of risk where everyone is more vulnerable to mental health issues, people with intellectual disabilities face social, structural and financial disadvantage.³⁶ The barriers to access and inclusion that they face are exacerbated in times of conflict, emergency or disaster.

Disability overall in refugee camps in Lebanon is reported to be 22%, significantly higher than the global estimate of 15%.³⁷ Illiteracy among people with intellectual disabilities in Lebanon is said to be 78%.³⁸ In Palestine, while inclusive education activities exist, they rarely target those with intellectual disabilities.³⁹ In recent years, attitudes towards physical disability in both Palestine and Lebanon have changed, with significant resources and honour given to those who have acquired disabilities as a consequence of the conflict. However, this has increased the invisibility of those with intellectual disabilities, diverted already scant resources, and created a 'disability hierarchy' in which people with certain disabilities have access to more support and attention.⁴⁰ Attitudes towards people with intellectual disabilities remain negative and discrimination remains rife.

2.3. Disproportionate impact

Disadvantage

Even before experiencing a situation of risk or trauma, people with intellectual disabilities or mental health issues often find themselves facing social, structural and financial disadvantages in life.⁴¹ Areas of disadvantage can include access to the job market, education, political participation and cultural life, and even family and sexual rights. The impact of poverty on disability and the increased likelihood of disability being associated with poverty has been widely noted and studied,⁴² to the point where it is believed that one-in-five of the world's poor may be disabled.⁴³

An estimated 25% of people in Palestine are living in poverty; 80% receive ongoing aid and 87% of people with disabilities are unemployed.⁴⁴ With the ongoing influx of refugees in Lebanon, UNISDR, the UN Office for Disaster Risk Reduction, recognises increasing rates of unemployment and poverty.⁴⁵ Wehbi also notes the high rates of poverty among people with disabilities in Lebanon and the associated unemployment and low levels of education.⁴⁶ Amongst Palestinian households in

³⁵ Clegg & Bigby, 2017

³⁶ Klynman, Kouppari, & Mukhier, 2007

³⁷ UNICEF, 2017

³⁸ Inclusion International, 2006

³⁹ World Bank, 2016

⁴⁰ United Nations University, 2014

⁴¹ Berghs & Kabbara, 2016; Rohwerder, 2015

⁴² Braithwaite & Mont, 2009; Klynman et al., 2007

⁴³ Lansdown, 2012

⁴⁴ World Bank, 2016

⁴⁵ UNISDR, 2012

⁴⁶ Wehbi, 2011

Lebanon, one-in-ten report at least one disabled family member. Reports confirm the strong relationship between poverty and disability in these communities. Limitations on access to and availability of rehabilitation services, coupled with the limited awareness of the rights and needs of persons with disabilities, is considered to compound the effects of marginalisation.⁴⁷

When there are shortages of resources and economic difficulties, the burden of care and associated costs fall on the families of people with intellectual disabilities or mental health issues.⁴⁸ Furthermore, poverty renders people more vulnerable to environmental hazards and livelihood insecurity.⁴⁹

Intersecting challenges

Mental health issues and intellectual disability do not exist in isolation from other challenges. Some common co-occurring challenges and intersecting disadvantages have a cumulative impact.

The impact of mental health issues and intellectual disability on individuals is compounded by belonging to other marginalised or politically oppressed groups.⁵⁰ This can include, for instance, whether the person has other disabilities; their age (particularly if young or elderly);⁵¹ gender (particularly for girls and women);⁵² their 'people' group (such as whether they are from an ethnic minority, rural, or refugee community, especially in the Lebanon environment with multi-national refugee settings);⁵³ and their sexual or gender orientation.

Marginalisation

Poverty, co-occurring impairments, and intersecting groups and the associated marginalisation and discrimination places people with intellectual disabilities and mental health amongst the most affected in a disaster and the least likely to receive assistance.⁵⁴

The first level of marginalisation often takes place when people with intellectual disabilities and mental health issues are ignored in **preparedness** initiatives.⁵⁵ People with intellectual disabilities may face challenges with understanding danger, communicating with others and being understood.⁵⁶ Some people with mental health issues may be socially isolated or dependent on caregivers or ongoing medications. Their awareness of danger may also be late or absent, and they may be subject to re-traumatisation and feelings of helplessness in the face of disasters or emergencies.⁵⁷

⁴⁷ UNHCR, 2016

⁴⁸ Braithwaite & Mont, 2009

⁴⁹ Irish Aid, 2011

⁵⁰ Lansdown, 2012; Office of High Commissioner for Human Rights, 2017; UNISDR, 2011; Women's Refugee Commission, 2013

⁵¹ ADCAP, 2017; Collinson, 2015

⁵² Office of High Commissioner for Human Rights, 2017; Rohwerder, 2016, 2017b

⁵³ Rohwerder, 2015

⁵⁴ Klynman et al., 2007

⁵⁵ Klynman et al., 2007; UNISDR, 2011

⁵⁶ Rohwerder, 2013

⁵⁷ Juen, 2016

When these challenges are not carefully considered and planned for, a situation of risk is more likely to become life-threatening.⁵⁸ Indeed, the mortality rate in emergencies for people with disabilities is two to four times higher than for those without disabilities.⁵⁹ Survivors face the further risks of injury, starvation, disease, abandonment, and abuse.⁶⁰

The next level of marginalisation takes place when people are overlooked in the **response** to conflict, emergency or disaster. They can simply be ignored or be the last to access resources.⁶¹ Plans and programmes to recover and regain livelihoods often neglect the specific needs of people with intellectual disabilities and mental health issues, or are exclusionary in nature.⁶² Leaving people without the resources, medicine and appropriate interventions they need can have wide-reaching and long-term consequences. These can include deterioration of existing conditions, acquisition of additional impairment or health issues, further mental health issues, isolation, and a loss of livelihood.⁶³

It is important to note that many people with mild intellectual disabilities reject the notion that they are inherently 'vulnerable'.⁶⁴ Viewing vulnerability through the lens of the social model of disability recognises the social barriers and low value that society assigns to people with intellectual disabilities.⁶⁵ People facing mental health issues are also largely misunderstood and face stigma and associated discrimination.⁶⁶

Any marginalisation or oppression that already exists is exacerbated in situations of risk.⁶⁷ This type of discrimination can be life-threatening, can result in increased vulnerability, and as a whole, places people with intellectual disabilities and mental health issues at an extreme and disproportionate disadvantage. Conflicts, emergencies and disasters are predominately negative for all involved, but significantly more so for people with intellectual disabilities or mental health issues.⁶⁸ However, the social model draws our focus to the *disproportionate marginalisation* in situations of risk, rather than a focus on *disproportionate vulnerability* of individuals.

⁵⁸ Klynman et al., 2007; Rohwerder, 2013; Ronoh et al., 2015; UNISDR, 2011

⁵⁹ United Nations University, 2014

⁶⁰ Hemingway & Priestley, 2014; Mitchell, 2014; Rohwerder, 2013; Ronoh et al., 2015

⁶¹ Herr et al., 2003

⁶² Klynman, Kouppari, & Mukhier, 2007

⁶³ Klynman et al., 2007; Rohwerder, 2015; Ronoh et al., 2015; Smith, 2012; United Nations University, 2014; Van Ommeren, 2014; World Bank, 2016

⁶⁴ Clegg & Bigby, 2017; Rohwerder, 2013

⁶⁵ Rohwerder, 2013

⁶⁶ Rohwerder, 2015; Smith, 2012; Van Ommeren, 2014; World Bank, 2016

⁶⁷ Klynman et al., 2007; UNISDR, 2011

⁶⁸ Mitchell, 2014

3. Access to and inclusion in DRR and humanitarian response

Vast amounts of evidence exist about what to do in and after situations of conflict, emergency and disaster.⁶⁹ Numerous guidelines for disability inclusion in humanitarian response and DRR have been developed and implemented.⁷⁰ Intellectual disability and mental health issues are explicitly included in many of these, and in some cases guidelines exist specifically for mental health⁷¹ or intellectual disability.⁷² In general, the basic know-how for including people with all types of impairments is readily available. The pressing question is what barriers persist, and what measures need to be taken to ensure that people with intellectual disability and mental health issues are accessing and benefiting from this know-how.

The following sections of this literature review will consider in more detail some important factors contributing to marginalisation in DRR and humanitarian action, both at global levels and in relation to the Palestinian and Lebanon settings, where the information is available. This responds to the second research question:

What are the protection/prevention and inclusion/exclusion factors to consider in programming for DRR and humanitarian response? How does that relate to what other actors are doing in the field? Where are the gaps?

Each section will also present any findings related to the same factor with regards to best practices and lessons learned. Some of these findings are presented in text boxes where they are more detailed examples. This is in response to the third research question:

What are the best practices, lessons learned and/or evidence from DRR planning and humanitarian efforts (across all sectors) in the local and international contexts that can be drawn upon to inform next steps for NAD. How can we engage in innovative ways with refugee/internally displaced communities to draw on assets and resources to build resilience?

People with intellectual disabilities and mental health issues are diverse and complex like any other group in society. There are many issues they face that overlap with disability inclusion in general, and indeed, often with the inclusion of any marginalised group. Due to the time constraints, the focus of this review will be limited to the factors found in the literature that are significant to the inclusion needs of the specific target population.

⁶⁹ Marquez, 2016

⁷⁰ Mirza, 2011

⁷¹ WHO IASC, 2007

⁷² Inclusion Europe, 2011

3.1 Individual capacity

Beliefs surrounding individual capacity are a significant barrier to inclusion in DRR and humanitarian response for people with intellectual disabilities or mental health issues. On the whole, there is a view that some individuals are incapable and unable to live independently or contribute to society.⁷³ People with intellectual disabilities or mental health issues often have trouble expressing themselves and understanding others, and may experience unsatisfactory social relationships, and this is often assumed to be evidence of their lack of capacity.⁷⁴

Defined and judged by what they lack, rather than what they have, [children with disabilities] experience widespread violations of their rights that result not from the intrinsic nature of disability but from the social exclusion that arises from it.⁷⁵

Passive recipients

In many cases, the provision of humanitarian aid makes assumptions about people's needs, effectively disempowering individuals and denying them a voice.⁷⁶ Denying or ignoring capabilities is noted by many⁷⁷ to lead to the internalisation of these barriers. This sense of inferiority and lack of value can result in confidence being undermined and aspirations being suppressed, leading to sense of helplessness.⁷⁸ Within the culture of Palestine, the silence of children with intellectual disabilities is considered the most profound. This results from a multifaceted situation of the silence of children, the silence of people with disabilities, and the stigma associated with intellectual disability.⁷⁹

Those experiencing situations of conflict, emergency or disaster should not be considered merely passive recipients of aid. Where this is happening, it should be challenged and changed.⁸⁰ People with diverse disabilities have capabilities, experience and skills.⁸¹ Citing historical examples, Grove, Grove, and Myerscough point out that people with intellectual disabilities are not necessarily helpless in situations of risk. Examples include joining the army, and contributing to humanitarian efforts and rebuilding.⁸²

Resilience

While the importance of individual resilience is frequently mentioned in relation to DRR,⁸³ there is also increasing recognition of the social model understanding of resilience.⁸⁴ This involves a move away from individual indicators of vulnerability,

⁷³ Mitchell, 2014; Office of High Commissioner for Human Rights, 2017; Palestinian Ministry of Social Affairs, 2009

⁷⁴ Clegg & Bigby, 2017; Rohwerder, 2013; Scior et al., 2015

⁷⁵ UNICEF, 2016, p. 9

⁷⁶ Klynman et al., 2007

⁷⁷ Rohwerder, 2015; Smith, 2012; Van Ommeren, 2014; World Bank, 2016

⁷⁸ Lansdown, 2012; Office of High Commissioner for Human Rights, 2017; Palestinian Ministry of Social Affairs; Rohwerder, 2015; Smith, 2012; Van Ommeren, 2014; World Bank, 2016

⁷⁹ UNICEF, 2016

⁸⁰ Rohwerder, 2013

⁸¹ Collinson, 2015; Klynman et al., 2007

⁸² Grove, Grove, & Myerscough, 2010

⁸³ CBM, 2013; Handicap International, 2015; Höfler, 2014; Shehadeh, 2015

⁸⁴ Abed, Bermudez, & Al Far, 2010; CBM, 2013; Spurway & Griffiths, 2016

capability and resilience to a consideration of wider social and structural barriers rendering people vulnerable. Resilience then becomes a community-level concern.⁸⁵ For example, in the context of Palestine, Giacaman et al. point out the futility of providing psychological therapies without also attempting to alleviate the underlying causes of collective trauma.⁸⁶

It is apparent that within current approaches to DRR and humanitarian response there may be a perception that people with intellectual disabilities or mental health issues are less 'resilient'. This highlights the need for DRR and humanitarian actors to recognise that capability is not static. They need to be willing to identify elements of individual resilience that can be built on. And they need to approach the situation from the understanding that lack of opportunities, resources and support is hindering people from actualising their capabilities and capacities.⁸⁷

3.2 Disability inclusion

Progress on disability inclusive development and humanitarian response

A significant number of toolkits, guidelines and checklists on inclusive development are readily available.⁸⁸ Since 2003, when Herr et al. considered the international action to be "weak and intermittent", much progress has been made on disability inclusion.⁸⁹ Some of the documents leading the way include the UNCRPD,⁹⁰ The Sphere Handbook,⁹¹ and the IASC guidelines.⁹²

Many countries have adopted inclusive policy, and international organisations such as CBM,⁹³ DIFD,⁹⁴ AusAid,⁹⁵ Handicap International,⁹⁶ UNICEF,⁹⁷ and WHO⁹⁸ have well-developed disability inclusion guidance for DRR and humanitarian action. On the whole, intellectual disability and mental health issues are explicitly included in the definitions used, and often specific access needs are addressed within guidelines.⁹⁹

The UNCRPD describes people with disabilities to include "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".¹⁰⁰

⁸⁵ CBM, 2013

⁸⁶ Giacaman et al., 2011

⁸⁷ Hemingway & Priestley, 2014; Rohwerder, 2013; Spurway & Griffiths, 2016; Wessells & van Ommeren, 2008

⁸⁸ Irish Aid, 2011; Klynman et al., 2007

⁸⁹ Herr et al., 2003, p.131

⁹⁰ UN, 2006

⁹¹ Red Cross and Red Crescent, 2011

⁹² WHO IASC, 2007

⁹³ CBM, 2013

⁹⁴ DIFD, 2015

⁹⁵ AusAid, 2015

⁹⁶ Handicap International, 2015

⁹⁷ UNICEF, 2017

⁹⁸ WHO, 2011a, 2011b

⁹⁹ ie. UNICEF, 2017

¹⁰⁰ Australian Red Cross, 2014, p. 8

...Formats that are accessible for persons with intellectual disabilities include simple language and visual signs, such as pictograms, drawings, pictures and photos on printed materials. ¹⁰¹

...safe spaces for children that provide learning support, skills building and psychosocial interventions¹⁰²

Some of these also identify people with intellectual disability and mental health issues to be experiencing the most significant impact in disasters:

We recognise that some groups within the disability community are at heightened risk of marginalisation, particularly those with psychosocial and intellectual disabilities. People with these types of disability can be rendered invisible and left out of disability-inclusive development efforts. Psychosocial and intellectual disabilities are commonly less understood, leading to greater stigmatisation. We will give greater attention to people with psychosocial and intellectual disabilities by:

- encouraging partner governments to provide appropriate and accessible support services to meet people's basic needs
- supporting greater inclusion, participation and empowerment, enabling people to be contributors, leaders and decision makers in all areas of public life, such as education, health and employment
- promoting awareness of psychosocial and intellectual disabilities to reduce stigma.

A central principle of the AusAid strategy for disability inclusive development¹⁰³

There is some agreement in the literature that intellectual disability should remain considered within the broad disability grouping,¹⁰⁴ and mental health within public mental health systems.¹⁰⁵

Lesson learned

In Gaza, many international humanitarian organisations initiate important community-based psychosocial support interventions outside the health sector (e.g. child-friendly spaces, linking vulnerable people to resources) but ignore clinical intervention through health services (UNWRA, 2017). This is despite the WHO IASC (2007) guidelines recommending addressing mental health and psychological issues through inter-sectoral action.

One of the lessons learned in Afghanistan is the effectiveness of bringing mental health into the mainstream and ensuring it is a matter for all health workers and not only specialists.¹⁰⁶ Indeed, services embedded in general community provision seem appropriate to the context in Gaza, where movement is severely restricted.¹⁰⁷ Twigg reports that Lebanon has developed a forward-thinking and cooperative programme with the aim of integrating mental health care into primary health care.¹⁰⁸

¹⁰¹ UNICEF, 2017, p. 2

¹⁰² UNICEF, 2017, p. 34

¹⁰³ AusAid, 2015, p. 11

¹⁰⁴ Clegg & Bigby, 2017; Klynman et al., 2007; Rohwerder, 2013; Twigg, 2015

¹⁰⁵ Giacaman et al., 2011

¹⁰⁶ WHO, 2013

¹⁰⁷ WHO, 2011a

¹⁰⁸ Twigg, 2015

Best practice

UNRWA runs job creation programmes, distribution of food baskets, the regular assessment of refugees' poverty status and eligibility for services through social workers, in addition to a variety of skills training and capacity building mainly for women, children and youth, and sports programmes for children and adolescents especially girls. (UNWRA, 2017)

Continued side-lining of people with intellectual disability and mental health issues

However, when resources are scarce, more often than not those who are more articulate and less stigmatised tend to be better served than others in humanitarian responses.¹⁰⁹ Furthermore, there is a growing phenomenon in post-conflict countries to prioritise resources towards people with impairments (and particularly physical impairments) that have been acquired as a consequence of conflict.¹¹⁰ This is also apparent with mental health services focusing on newly acquired mental health issues. In these environments, hierarchies of impairment emerge and people with pre-existing disabilities or mental health issues and invisible impairments are further marginalised and find themselves the last in line. A number of documents suggest that those with intellectual disability and mental health issues are the last of the last.¹¹¹ Despite the important progress for the disability rights movement as a whole, the literature recognises that this has not yet proved sufficient to address the degree of discrimination perpetuated against people with intellectual disability and mental health issues.¹¹²

Given that general disability inclusion efforts are not adequately or equally including people with intellectual disability and mental health issues, the literature calls for disability inclusion to be more broad and flexible.¹¹³ The tendency for disability guidelines and subsequent programmes to amalgamate issues concerning all types of disabilities can effectively hide important differences that need to be acknowledged.¹¹⁴ Intellectual disability and mental health issues should be given a voice in all proposals, projects and evaluations through explicit mention and definitions that emphasise the diversity of disability.¹¹⁵

Best practice

Irish Aid (2011) and Herr, Gostin, Koh, and Gostin (2003) suggest an approach whereby all DRR and humanitarian response actors are required to demonstrate systematic consideration of all diversities of disability. This goes beyond simply acknowledging that people with disabilities are heterogeneous rather than a homogenous group (Herr et al., 2003), and instead requires creativity and flexibility.

¹⁰⁹ Coe, 2012

¹¹⁰ Berghs & Kabbara, 2016; Herr et al., 2003; Klynman et al., 2007

¹¹¹ Rohwerder, 2013; United Nations University, 2014; World Health Organization, 2007

¹¹² Klynman et al., 2007; Mitchell, 2014; Rohwerder, 2013

¹¹³ Clegg & Bigby, 2017; Klynman et al., 2007; Mitchell, 2014; Twigg, 2015

¹¹⁴ Herr et al., 2003; Rohwerder, 2013

¹¹⁵ Herr et al., 2003; Mitchell, 2014

General vs specialist interventions debate

Others suggest that the insufficient recognition of the needs and experiences of the most marginalised demonstrates that general DRR and humanitarian responses are inadequate and will leave many behind.¹¹⁶ Clegg and Bigby offer examples of specialist needs that require attention, such as providing skilled interpreters for people with intellectual disabilities if they are to participate meaningfully in decision-making, research, political or civil bodies.¹¹⁷ Mohanraj points out that different groups with mental health issues face different challenges requiring specialised approaches, such as the need for differentiating approaches for children and youth.¹¹⁸

The danger in specialisation, however, is the tendency for people to fall through the gaps. When it is assumed that someone needs specialised support they can find themselves being passed from one specialist group to another in search of the necessary services, and as a result access no support at all.¹¹⁹ Specialisation allows for exclusion to occur, due to the fear of what Clegg and Bigby call an “unpredictable mix of expected and unexpected abilities” and an “interactional gap”,¹²⁰ whereas in reality, as stated in the Sphere handbook, “persons with disabilities have the same basic needs as everyone else in their communities”.¹²¹

Lesson learned

Near Ramallah in the West Bank, the father of four children with intellectual disabilities reports none of them attend school. They had begun attending a public school but he'd removed them due to severe bullying. A specialist centre enrolled them, but because they made no progress their father brought them home. (UNICEF, 2016, p. 82)

A balance between mainstream and targeted responses can be found in the twin-track approach, which ensures that people with disabilities have equal access to all mainstream DRR and humanitarian response activities while also accessing some services specific to their diverse or personal needs.¹²² While the twin-track approach is not a new concept, for people with intellectual disabilities and mental health issues the focus should be on making careful rights-based decisions regarding the mix of provision they require. Specialist provision should not replace disability inclusion in the services of those already providing for basic needs.¹²³

3.3 Participation

In some countries, investing in services for people experiencing mental health issues is not a high priority, and the needs of people with intellectual disabilities is under-considered in DRR planning and humanitarian response. A global UN survey clearly

¹¹⁶ Herr et al., 2003; Irish Aid, 2011; WHO, 2011a

¹¹⁷ Clegg and Bigby, 2017

¹¹⁸ Mohanraj, 2014

¹¹⁹ Rohwerder, 2013

¹²⁰ Clegg and Bigby, 2017 p.89

¹²¹ Red Cross and Red Crescent, 2011

¹²² Australian Red Cross, 2014; CBM, 2013; Collinson, 2015; GAATES; Red Cross and Red Crescent, 2011

¹²³ Abed et al., 2010; Rohwerder, 2013

revealed that “the key reason why a disproportionate number of disabled persons suffer and die in disasters is because their needs are ignored and neglected by the official planning process in the majority of situations”.¹²⁴

Raising the profile of people with intellectual disabilities and mental health issues

A key factor hindering the recognition of needs is the lack of visibility and voice among people with intellectual disabilities and mental health issues.¹²⁵ There is a need for people with intellectual disabilities and mental health issues to raise their profile and place themselves on the political agenda.¹²⁶ Political agency – the capacity to positively influence the collective future – is lacking for people with disabilities in Palestine and Lebanon.¹²⁷ Such agency is usually found in collective action by people with disabilities who lobby and advocate for their rights and freedoms. An effective way of bringing people out of isolation and into active roles in the community is through the initiation and empowerment of disabled people’s organisations.¹²⁸ In addition to increasing visibility, this offers opportunity to self-represent, to participate and to collectively advocate. Clegg and Bigby call for solidarity among various disabled people’s groups so that this greater advocacy can happen.¹²⁹ Indeed, as UN Department for Economic and Social Affairs (UNDESA), UNISDR and the Nippon Foundation point out, there is a widespread desire among people with disabilities to be included in DRR and humanitarian response planning and to have their perspectives and concerns recognised.¹³⁰

Persons with disabilities and their representative organizations have untapped capacity and are not sufficiently consulted nor actively involved in decision-making processes concerning their lives, including in crisis preparedness and response coordination mechanisms.¹³¹

Lesson learned

In the Palestinian context, the DPOs remain fragmented and the benefits of collective action are not perceived thus placing them at the periphery of policy and DRR programming. (World Bank, 2016)

For improved representation of people with intellectual disability and mental health in disability advocacy to happen, there needs to be recognition of some barriers that are currently excluding them. One of these is the hierarchy within the disability rights movement and the higher profile of DPOs representing physical disabilities and war disabled.¹³²

¹²⁴ Margareta Wahlström as cited in UNISDR, 2013

¹²⁵ CBM, 2013; Collinson, 2015; Scior et al., 2015; WHO, 2011a, 2011b; WHO IASC, 2007

¹²⁶ Van Ommeren, 2014

¹²⁷ Rohwerder, 2015; Smith, 2012; Van Ommeren, 2014; World Bank, 2016

¹²⁸ Greskamp, 2013

¹²⁹ Clegg and Bigby, 2017

¹³⁰ UNDESA UNISDR Nippon Foundation, 2013

¹³¹ World Humanitarian Summit, 2016

¹³² CBM, 2013; Rohwerder, 2013; World Bank, 2016

Lesson learned

A World Bank report on the West bank and Gaza in 2016 noted that the Higher Council for Persons with Disabilities became functional in 2012 but DPO representation and participation remains poor, thus compromising their ability to influence or advocate for disability rights. Government recognition and cooperation remain major challenges for the DPOs. The report points to similar councils in Thailand that have been instrumental in DRR planning, management and training adding the perspectives of people with disabilities. (World Bank, 2016)

Another barrier in Palestine is the restriction on physical movement, which has particular impact on access to political decision-makers. DPOs are also centred in cities, leaving people with disabilities in other areas under- or un-represented. The absence of a common agenda further hinders cooperation between DPOs in Palestine, and this in turn affects the credibility of the DPO message.¹³³ Burton, Sayrafi, and Srour raise the concern that the fragile situation in Palestine means that any political gains made through disability advocacy can be quickly undermined.¹³⁴

Best practice

In Palestine it has been found that outreach schemes with a focus on supporting, training and engaging caregivers in their own communities are effective. Whether running support groups, offering early diagnoses or teaching families to provide disability-specific care in the home; understanding of disability in remote areas has increased through these efforts. An example of this is the mobile clinics run by the Princess Basma Rehabilitation Centre in the West Bank. (UNICEF, 2016)

Voice within the disability rights movement

Scior et al. point out that the voice of those with intellectual disabilities and mental health issues in the disability rights movement is not loud enough.¹³⁵ Those who experience difficulties with articulation and communication find that very few people are willing to take the time to listen to them. A further disadvantage is the constant and discriminatory expectation that people with intellectual disabilities and mental health issues must prove their worth or ability to contribute or represent themselves.¹³⁶ Some authors note that the silence of people with intellectual disabilities and mental health issues within the disability rights movement calls for active recognition of their access and communication needs so that they can be heard properly.¹³⁷ The interaction gap needs to be bridged; skilled interpreters must become involved and communication must not solely rely on written, web-based or automated technology.¹³⁸ Greskamp explains how participating in DPOs helps to replace a position of isolation and discrimination with an active role, focusing on capabilities rather than deficits.¹³⁹

¹³³ World Bank, 2016

¹³⁴ Burton, Sayrafi, and Srour, 2013

¹³⁵ Scior et al., 2015

¹³⁶ Rohwerder, 2013

¹³⁷ Clegg & Bigby, 2017

¹³⁸ Clegg & Bigby, 2017

¹³⁹ Greskamp, 2013

Best practice

UNICEF (2016) documents a qualitative study that captured the voices of children with disabilities in Palestine. Including children with intellectual disabilities and their families, the study developed and used innovative participatory tools, and involved researchers and staff with specific skills to ensure that diverse methods of communication were taken into account. The study is believed to have captured some of the diversity of the needs and experiences of children with disability in Palestine better than any research has done before.

3.4 Inclusive responses and services

During and after situations of risk, any number of players offer various forms of protection and assistance. This will include response, recovery, rehabilitation and reconstruction. Whether this humanitarian action is inclusive and accessible to people with intellectual disabilities and mental health issues depends on many factors, including the manner by which it is provided, the form it takes and what assistance is offered.

Exclusion from provision

People with intellectual disabilities or mental health issues can find themselves left out by DRR or humanitarian response activities. This may be due to the way the assistance is provided, which renders it inaccessible.¹⁴⁰ Sometimes people are passively left behind because the approach is suited to a general population and does not cater for certain specific needs.¹⁴¹ According to the World Bank, even when disability is considered in humanitarian response in Palestine, the focus may be primarily on physical impairment.¹⁴² People with intellectual disability or mental health issues can find their diverse needs still overlooked.

In situations of risk, humanitarian actors may be operating with limited resources. This creates circumstances where prioritisation takes place and hard choices are made. While logically it would seem that the most vulnerable should be prioritised in such instances, a common thread throughout the literature suggests that the opposite is true for people with intellectual disabilities or mental health issues.¹⁴³ Policy and practice at all levels can contribute to this exclusion, and it can sometimes be attributed to a misuse of power where humanitarian workers are making distribution choices, instead of decisions being made with the involvement of stakeholders and communities.¹⁴⁴ Again, the disability hierarchy is evident, with the war-disabled and war-traumatised attracting more resources than people with pre-existing disabilities.¹⁴⁵ Abed et al. identified the issue of under-prioritisation of men in mental health service provision in Gaza.¹⁴⁶ This raised the possibility that there is a need to target them more, especially young adult men in the context of high

¹⁴⁰ WHO, 2011

¹⁴¹ WHO, 2011a

¹⁴² World Bank, 2016

¹⁴³ Mitchell, 2014; Rohwerder, 2013; Smith, 2012; Van Ommeren, 2014; World Bank, 2016

¹⁴⁴ Klynman et al., 2007

¹⁴⁵ Burton et al., 2013

¹⁴⁶ Abed et al., 2010

unemployment and as they navigate the cultural expectations of marriage and other obligations.

Mapping the population

Marie et al. and the World Bank agree that mental health issues in Palestine are chronically under-reported and under-estimated, in addition to being under-resourced and under-funded.¹⁴⁷ Limitations of disability classification criteria can mean that people with intellectual disabilities are not adequately considered in planning and resource allocation.¹⁴⁸ The methods used can also inhibit identification. For example, if children with intellectual disabilities do not attend school, as is often the case in Palestine, they may be left out from data.¹⁴⁹

Lesson learned

“In Gaza, the volatile situation renders the educational inclusion of children and youth with disabilities even more difficult with makeshift classrooms, ad hoc solutions, and severe overcrowding with as many as 45–50 pupils per classroom. ...Enrolment rates for those with intellectual or mental disabilities are dramatically low and at the implementation level, inclusion often targets only children with mild and moderate disabilities” (World Bank, 2016, p. 29)

This has broader implications in that they are at risk not only of missing out on education opportunities and being identified in data, but may also be excluded from critical child survival initiatives, thus increasing their vulnerability in disasters.

In Lebanon, it is reported that a high percentage of people with mental health issues did not know they had these issues or that mental health treatment was available.¹⁵⁰ Invisible disabilities are often not ‘seen’, so are assumed to not exist.¹⁵¹ Further, fear and stigma may result in families ‘hiding’ people with intellectual disabilities or mental health issues from the public. There are reports of this happening in both Lebanon and Palestine.¹⁵² In a refugee camp in Lebanon it was observed that a high rate of untreated mental health issues could often be attributed to low service utilisation and low self-perceived need for services.¹⁵³

To address the various challenges of invisibility faced by people with intellectual disabilities and mental health issues in situations of risk, attention needs to be drawn to their existence and they need to be systematically identified.¹⁵⁴ Identification procedures must be designed in a way that protects individual privacy yet is rigorous enough to promote the recognition and inclusion of people with disability and disability-focused activities in humanitarian action.¹⁵⁵

“Effective identification and good data are necessary to make the political case for redistributing resource to people with intellectual disabilities, and planning new services”¹⁵⁶

¹⁴⁷ Marie et al., 2016; World Bank, 2016

¹⁴⁸ World Bank, 2016

¹⁴⁹ Ronoh et al., 2015; World Bank, 2016

¹⁵⁰ Palestinian Refugee News Network In Lebanon, 2017

¹⁵¹ CBM, 2013; Klynman et al., 2007

¹⁵² Burton et al., 2013; Commission, 2013

¹⁵³ Llosa et al., 2014

¹⁵⁴ Clegg & Bigby, 2017; Marquez, 2016

¹⁵⁵ Rohwerder, 2015

¹⁵⁶ Clegg & Bigby, 2017, p. 92

Disabling provision

Even when people with intellectual disabilities or mental health issues access services, the quality of the provision is often poor. Overlapping services, lack of training or specialisation, little common understanding between service providers, lack of locally gathered evidence and lack of contextualisation of approaches lead not only to inferior services, but to services which could be described as disabling.¹⁵⁷

Lesson learned

A review of mental health services in Gaza reported a heavy concentration of specialised services and multiplication of similar services in urban areas, resulting in over-servicing for some users and lack of support for others. The majority of service providers are non-governmental or community-based organisations. The lack of coordination and government oversight has resulted in reduced opportunities for seeking complementarities and synergies and in undertaking joint training, developing a unified approach to capacity building and establishing standards of training. Most importantly, the project-based nature of the work has meant that a variety of different approaches may be used, often unsupported by evidence or not utilising local expertise. The report was critical of low awareness of IASC guidelines amongst mental health and psychosocial support actors thus making a coordinated response problematic. (Abed, Bermudez, & Al Far, 2010)

Lesson learned

Many children with mental health issues or intellectual disabilities in Palestine have had their impairments misdiagnosed due to a lack of capacity and standardisation amongst service providers. The level of disability has been overestimated in order for children and their families to receive insurance and other financial benefits. The longer-term impact of this has been exclusion later in life from various scholarships and educational services they could have benefited from. (UNICEF, 2016, p. 82)

An inferior service for a person with a disability can be life-threatening.¹⁵⁸ If someone is prone to illness, malnutrition or abuse, and humanitarian responses are insufficient to respond to their needs, additional health issues can arise, and additional impairments could develop, as could new or additional mental health issues.¹⁵⁹

Humanitarian actors must reflect on their practice in light of the social model to identify ways in which their service delivery is not just exclusive but actively disabling people with intellectual impairments or mental health issues.¹⁶⁰ While opportunities to access differentiated services should be protected where they are available, it is best that needs be met in an integrated way only through specialist provision.¹⁶¹ As intellectual disability and mental health are cross-cutting issues, they cannot be addressed by specialist actions alone.¹⁶²

¹⁵⁷ Abed et al., 2010; Marie et al., 2016; Mezan Centre for Human Rights; World Bank, 2016

¹⁵⁸ Ronoh et al., 2015

¹⁵⁹ Ronoh et al., 2015; WHO, 2011a

¹⁶⁰ Rohwerder, 2013

¹⁶¹ Clegg & Bigby, 2017; Irish Aid, 2011

¹⁶² Marquez, 2016

Humanitarian actors in all sectors and locations should systematically review all aspects of their programmes to identify where they may be intensifying existing barriers or creating new barriers.¹⁶³ Then they should look beyond their own programmes to consider strategic cooperation and partnerships with other agencies and the community to complement or supplement their efforts. Collective and multidisciplinary action could offer more effective and efficient use of resources.¹⁶⁴

Lesson learned

“Because of the extremely fragmented way in which disability services in Palestine are delivered, with the government and UNWRA sharing space with literally hundreds of NGOs, families seeking services are effectively abandoned to their own devices to map the service landscape and arrange interventions for their children. The end result is CWDs remain largely invisible.” (UNICEF, 2016)

Consideration must also be given to synergy between short-term humanitarian response and public services for the longer-term sustainability of provision.¹⁶⁵ People with intellectual disabilities are likely to require more support than just the short-term ‘reactive’ style typical of many emergency and humanitarian responses.¹⁶⁶ In terms of mental health, the effects of trauma can extend well beyond the short term. Post-traumatic stress disorder (PTSD), for example, can manifest much later.¹⁶⁷

Lesson learned

Research conducted by Gaza Community Mental Health Program found that 30% of Gaza’s population suffer from PTSD and 10% of the population still need psychological counseling. (Gaza community health programme).

The protracted refugee situation in Lebanon, and the continued daily life stressors and ongoing conflict in Palestine, where PTSD and depression can remain elevated, point to the need for longer-term support.¹⁶⁸ This must be considered carefully in these contexts where programmes are often donor driven or dependent on short-term funding.¹⁶⁹

Community resource

Conflicts, emergencies and disasters do not happen in a vacuum; every community has its pre-existing structures, problems and capacities.¹⁷⁰ Therefore, in addition to the importance of identifying marginalised populations, existing systems, services and capacities also need to be identified. In environments like Palestine and Lebanon, where the need is dire and the resources are spread thinly, a mapping activity is valuable for identifying which of the resources needed by people with intellectual disabilities and mental health issues are still functioning and available. Such a mapping would place high value on people with disabilities, their caregivers

¹⁶³ Irish Aid, 2011

¹⁶⁴ Marie et al., 2016; Tol et al., 2011

¹⁶⁵ Van Ommeren, 2014

¹⁶⁶ Marie et al., 2016

¹⁶⁷ Mohanraj, 2014

¹⁶⁸ Llosa et al., 2014

¹⁶⁹ Mezan Centre for Human Rights

¹⁷⁰ Marquez, 2016; Van Ommeren, 2014

and their families as resources, particularly due to the often higher degree of dependence or reliance on social structures.¹⁷¹

Various community-based models have been found useful and culturally relevant for supporting mental health services, such as community centres in Lebanon¹⁷² and a social support group model described by Marie et al.¹⁷³

Best practice

Community centre model – Lebanon

With the sheer scale of the population of displaced people and their dispersion throughout Lebanon, a community centre model seeks to mobilise communities so that they can better address their own needs and the community they represent. A centre provides a physical space for identifying needs and for group-based support services and recreation. (United Nations, 2013)

Social support group model – Palestine

It is explained that exposure to trauma and violence in the Palestinian context is interpreted according to collective meanings rather than as individual experiences. Individuals in this culture prefer to seek help from friends and family members, providing an opportunity for interventions to focus on social support group models to improve the capacity of the whole community rather than on approaches based on individual treatments. (Marie, Hannigan, & Jones, 2016)

These methods recognise a preference in both Palestine and Lebanon for community-based and collective supports rather than individual treatments. Although humanitarian action is often regarded as requiring technical expertise, in reality, people who are community resources can also be offered training in some specialist skills (such as psychological first aid).¹⁷⁴

Best practice

A number of community-based groups provide community and family therapy programmes in Gaza. Palestine Trauma Centre is proactively emphasising advocacy and raising awareness around mental health issues in Gaza. (Palestine Trauma Centre UK)

3.5 Non-discrimination

A common message throughout the literature is about the power of attitudes to enable and disable, to include and exclude, to build resilience and to render vulnerable. Clearly the increased risk, lower resilience, and limited assistance experienced by people with intellectual disabilities and mental health issues has very little to do with the nature of their impairments and everything to do with the way they are perceived. Literature, both internationally and specific to Palestine and Lebanon,

¹⁷¹ Ronoh et al., 2015; World Health Organization, 2007

¹⁷² United Nations, 2013

¹⁷³ Marie et al., 2016

¹⁷⁴ Van Ommeren, 2014

demonstrates that the public perception is predominantly negative due to misconceptions, lack of knowledge or prejudice.

Misconceptions

Misconceptions identified in Palestine include the assumption that those with intellectual disabilities are incapable and not able to add much value to communities.¹⁷⁵ The World Bank also notes inaccurate concerns about the cost and difficulty of inclusion.¹⁷⁶

Misconceptions can begin from a lack of information.¹⁷⁷ Stereotyping people based on their impairment, or presuming to know what their capabilities are is a misconception when dealing with a diverse spectrum of experiences of disability intersecting with various other combinations of challenges.¹⁷⁸ Clegg and Bigby suggest that people shy away when they encounter the “unpredictable mix of expected and unexpected abilities”.¹⁷⁹ This leads to fear, avoidance and then prejudice.¹⁸⁰ Prejudice – a preconceived opinion or pre-judgement not based on reason or experience – becomes entrenched in society and manifests as stigma and discrimination.

Stigma

A number of sources confirm the high levels of stigma attached to both intellectual disability and mental health issues in Lebanon and Palestine.¹⁸¹

Best practice

“Stigma is prevalent in the [Palestine] community and in some instances even inside the home, ... yet, we witness transformational results when children benefit from appropriately tailored health care and inclusive education systems”. (UNICEF, 2016)

The stigma noted in these countries, however, is not unlike that found in other countries.¹⁸² Other authors point out that stigma and discrimination are found at all levels, including among staff of organisations, donors, aid workers and government officials.¹⁸³ As Rohwerder recognised, humanitarian workers are all still products of their societies.¹⁸⁴ Indeed, aid workers from different countries can bring with them cultural backgrounds with even more variations of discrimination than the host society.¹⁸⁵

¹⁷⁵ Palestinian Ministry of Social Affairs, 2009; UNRWA, 2017

¹⁷⁶ World Bank, 2016

¹⁷⁷ Rohwerder, 2013

¹⁷⁸ Herr et al., 2003

¹⁷⁹ Clegg and Bigby, 2017

¹⁸⁰ Mitchell, 2014

¹⁸¹ Burton et al., 2013; Mezan Centre for Human Rights, 2001; Office of High Commissioner for Human Rights, 2017; Women’s Refugee Commission, 2013

¹⁸² Burton et al., 2013

¹⁸³ Greskamp, 2013; Smith, 2012

¹⁸⁴ Rohwerder, 2013

¹⁸⁵ Greskamp, 2013

Changing attitudes

History tells us that discrimination against disability has always been evident. This, however, does not make it inevitable nor entirely resistant to change.¹⁸⁶ Some authors recognise the unique opportunity within the context of humanitarian action for new ideas, inputs and experience to be taken back into the rebuilding of communities. The “build back better” concepts can apply to social structures and attitudes just as much as to the physical environment.¹⁸⁷ The principles of universal design for building environments and products that are inherently accessible can apply to people with intellectual disabilities and mental health issues as much as they do to physical and sensory impairment. The building of societies both in the post disaster/conflict future and in the affected communities can use universal design principles for the removal of barriers in social, institutional and attitudinal structures.¹⁸⁸

Awareness-raising is the obvious tool for combating negative attitudes. Awareness and advocacy for transforming attitudes begins with visibility.¹⁸⁹ It is harder to remember to factor in a group of people who seem to be invisible.¹⁹⁰ Visibility in the community, such as in schools through inclusive education, allows for meaningful interaction.¹⁹¹ Visibility is further increased when data is collected, when people receive training about diverse disabilities, when common understandings are developed, but most of all, when people with disabilities organise themselves and raise their own profile.¹⁹² Voice and self-advocacy can be powerful and effective. DPOs can be supported to advocate and put their issues on the political and humanitarian policy agenda.¹⁹³ Klynman et al. point out that while few emergency personnel have training in disability inclusion, the people with disabilities should always be considered as the experts and asked about the best way to assist them.¹⁹⁴

Disability inclusion is not a new concept in DRR and humanitarian action. The IASC guidelines on mental support and psychological support were published in 2007.¹⁹⁵ Atlas global resource on intellectual disability was also released in 2007,¹⁹⁶ and an Oxfam training resource from 2003 clearly sets out guidelines for disability inclusion, with explicit mention of the needs of people with intellectual disabilities in times of crisis.¹⁹⁷ Following these, a growing number of resources have been developed at international, country and organisational levels.

Yet with the continuing evidence of disproportionate negative effects faced by people with intellectual disabilities and mental health issues, it is clear that no amount of guidelines will change attitudes. The inclusion of a population characterised by diversity cannot be homogenised and reduced into a set of common needs that, if

¹⁸⁶ Lansdown, 2012; McKenzie, 2013; Mitchell, 2014

¹⁸⁷ Mitchell, 2014; Rohwerder, 2013; UN General Assembly, 2015

¹⁸⁸ Rohwerder, 2013; UN General Assembly, 2015

¹⁸⁹ World Health Organization, 2007

¹⁹⁰ Rohwerder, 2013

¹⁹¹ Clegg & Bigby, 2017

¹⁹² Greskamp, 2013; Marquez, 2016

¹⁹³ Hemingway & Priestley, 2014; Rohwerder, 2013; Van Ommeren, 2014

¹⁹⁴ Klynman et al., 2007

¹⁹⁵ WHO IASC, 2007

¹⁹⁶ World Health Organization, 2007

¹⁹⁷ Harris & Enfield, 2003

met, would secure the inclusion of people with these impairments.¹⁹⁸ The central lesson to be learnt from the literature is that the road towards inclusion does not start from a focus on the impairment, but rather the reactions to impairment.

¹⁹⁸ Rohwerder, 2017a

4. Conclusion

The following bullet points summarise key issues that NAD and its partners may find useful to reflect on and discuss when planning future work:

- In Palestine in particular (and to a lesser extent in Lebanon) there appears to be already a lot of attention given to mental health problems/distress resulting from the conflict.
- Although it is not possible to map accurately from literature, it appears that this sort of psycho-social support is not an area for further urgent inputs.
- Stigma and discrimination are major barriers in Palestine and Lebanon – support and guidance need to be focused on how to change very entrenched attitudes towards people with intellectual disabilities and mental health issues.
- Disability-inclusion guidance on intellectual disability exists, but impairment-specific advice gets diluted by the time the guidance becomes action on the ground, so still the most marginalised get missed. Organisations need encouragement and help to avoid this.
- Specialist support for people with intellectual disabilities is likely to focus on the 'interaction gap'.
- DPO/disability movement is itself not inclusive or equitable and needs support to become more accessible for and representative of people with intellectual disability.
- Prioritisation of efforts in humanitarian responses is not sufficiently based on stakeholder voices, leaving the most marginalised totally deprioritised. There is a need for a strong focus on diverse stakeholder voices in decision-making to change this culture.
- Humanitarian actors bring their own discrimination into the mix, so it is not just a matter of addressing attitudes in communities and governments, but also within the NGO staff.
- When resources are limited, mapping needs to focus on understanding contextual needs, not head counts.
- Some humanitarian responses disable further, and organisations need help auditing their work with this in mind.
- Particularly in relation to mental health it seems that in these contexts there is a preference for community-centred support rather than individual support.

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