

**ARTICLE 19**

# **Lebanon: Disability and Access to Information**

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Country Report

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## Executive Summary

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The *UN Convention on the Rights of Persons with Disabilities* (CRPD) was adopted in 2006 and came into force in 2008. It represents the culmination of decades of efforts to improve the protection of the human rights of persons with disabilities, so that they can enjoy their human rights on an equal basis with others. The CRPD recognises that social and state practices which exclude people with disabilities from participation in daily life must change if persons with disabilities are to enjoy the same rights as others. It also recognises that civil and political rights, such as freedom of expression and the right to information, are a vital precondition in order for persons with disabilities to achieve their rights and overcome histories of exclusion.

Persons with disabilities continue to face attitudinal and environmental barriers to participation in many areas of life. In order to challenge these barriers, persons with disabilities need to take political action. They need to make strong arguments for change – and these arguments for change need to be based on information about their situation. If persons with disabilities and the organisations that represent them are to challenge their exclusion, they need to have information about the government policies that contribute to exclusion.

While Lebanon has not yet ratified the CRPD, Lebanon has made certain commitments in international law, under the *International Covenant on Civil and Political Rights* (ICCPR) and the *UN Convention against Corruption*, that require it to provide access to information to all its citizens, including people with disabilities.

In 2000, Lebanon adopted *Law 220 on the Rights of Disabled Persons* (Law 220/2000), several years before the adoption of the CRPD. The law is mainly built around a set of rights integrating citizens with disabilities into social and economic life, through employment, transport and housing quotas, and guarantees of health and educational services.

The law does not mention access to information. It's major contribution to political participation by persons with disabilities is its recognition of the *National Council for Disability Affairs* (the NCDA), with members elected by and from disabled persons' organisations and persons with disabilities. Unfortunately, the NCDA frequently struggles to access information from other ministries.

While Law 220/2000 makes important commitments to the rights of persons with disabilities, many of these commitments have not been fulfilled, because individuals with disabilities and Disabled Persons' Organisations do not have adequate access to information about their rights and services.

A draft law on access to information was submitted to the Lebanese parliament in April 2009, which has not yet been adopted, because of a political crisis in Lebanon - one of the main obstacles to achieving progress on access to information and disability rights in Lebanon.

The draft law includes no specific requirement to provide information in accessible or usable formats for persons with disabilities as proposed by the CRPD.

Two approaches to defining disability are sometimes represented as two opposing models: 'the medical model' and 'the social model.' Definitions are important because they lead to different understandings of the scope of the problem. Lebanon's disability prevalence rate is two percent of the total population, much lower than international rates; one reason for Lebanon's low prevalence rate is that Lebanon's official statistics body, like many others in the region, uses medical definitions of disability.

Access to information does in many cases exist – but it is based on informal social and political networks, meaning that relatively powerless people – such as many people with disabilities – do not have easy access to information that could help bring about change.

Government disclosure of information about public finances and public policy outcomes is a key element of access to information. But the Lebanese government's record often falls short of its

international commitments. Lack of disclosure makes it difficult for persons with disabilities in Lebanon to advocate effectively for their full participation in public life. Experiences from Lebanese Disabled Persons' Organisations demonstrate that they struggle to access government information on education, health and budgets.

The CRPD and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (an instrument of international law adopted in 1993) both recognise public authorities' responsibility to provide information in accessible formats and technologies and while new technologies are transforming access to information for groups with specific impairments and the money to pay for them, they are not accessible to poor people with disabilities. Other groups – such as people with learning disabilities – have no ready technological fix to overcome the particular barriers to information that they face, meaning that many persons with disabilities have no alternative but to request information through friends and relatives. People with disabilities may need to be given - and to understand - information in specific contexts in order to achieve their rights. For example, children with disabilities, who frequently live in residential institutions and persons who are considered to be lacking in legal capacity may need to have information provided to them in a way that ensures they understand it.

While access to information usually refers to information already held by a public body, the CRPD goes further than this and makes statistical reporting on disability a human rights treaty obligation. Thus, under the CRPD, states are required to generate statistics on issues relevant to the implementation of laws on disability.

Persons with disabilities face complex barriers to achieving their rights, and the CRPD represents an important attempt to overcome those barriers. The CRPD has extended and reformulated many human rights, incorporating concrete measures from existing human rights that ensure that the convention's principles – accessibility, non-discrimination, inclusion, and respect for dignity and evolving capacity – are put into practice.

Access to information is a vital element of freedom of expression, and a vital precondition for the achievement of other rights.

The CRPD develops existing international human rights law on access to information, setting out some of the political and administrative changes that are needed in order for persons with disabilities to be able to seek, receive and impart ideas and information, and use information to change their own situations and the society that they live in.

## Introduction

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Disability is a complex, multi-dimensional human experience that often resists definition and measurement, and the CRPD was an important step towards applying human rights standards to human diversity and complexity. The CRPD sets out civil, political, social, economic and cultural rights, reformulating them around key principles such as accessibility and inclusion. Access to information – the freedom to seek, receive and impart information and ideas – is guaranteed by the CRPD. It is both a vital tool for advocacy and a vital precondition for the enjoyment of other rights. Access to government information on public policy and its outcomes is crucial in order for persons with disabilities to achieve their rights.

This report looks at some of the ways that access to information can help persons with disabilities achieve their rights – and ways in which barriers to information can totally undermine their rights. It uses Lebanon as a case study. Lebanon has signed the CRPD but not yet ratified it – although its existing international commitments require it to make information accessible to persons with disabilities. Lebanon is an important case study for several reasons. First, it adopted the *Law on the Rights of Disabled Persons* in 2000, which establishes a wide range of social and economic rights. However, progress in implementing the law has been very limited – in part because persons with disabilities and the organisations representing them are not able to obtain the information they need to participate in or challenge implementation of the policy. Secondly, although Lebanon is a relatively open society, politically sensitive information generally flows within inaccessible patrimonial networks, from which powerless people are generally excluded. A law on access to information has been drafted, but not yet adopted.

Without access to information, persons with disabilities have to work harder to address their exclusion from education, employment, transport systems and healthcare. A disproportionately large number of adults and children with disabilities live in residential institutions which isolate them from daily life. Lack of access to information perpetuates a system that works against the principles of inclusion and participation that lie at the heart of international law on disability.

# Disability and Access to Information

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## The rights of persons with disabilities

One hundred and fifty-two states have ratified the CRPD. The CRPD came into being during the Arab Decade for Persons with Disabilities (2004-2013), and all but four of the 22 members of the League of Arab States have ratified it.

The CRPD recognises that social and state practices which exclude people with disabilities from participation in daily life must change if persons with disabilities are to enjoy the same rights as others. It sets out rights to health, education, welfare and labour systems, and these provide the basis for persons with disabilities to overcome discrimination and enjoy personal autonomy. It also recognises that civil and political rights are a vital precondition in order for persons with disabilities to achieve their rights and overcome histories of exclusion. The CRPD includes a detailed list of these rights, including freedom of expression, equality before the law, and political participation.

## Freedom of expression and access to information in international law

The right to freedom of expression is guaranteed in Article 19 of the *Universal Declaration of Human Rights*, which says: 'Everyone has the right to freedom of opinion and expression; this right includes the right to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers'.

In international law, access to information is an important part of freedom of expression. The right to seek, receive and impart information and ideas through any media and regardless of frontiers is sometimes also referred to as 'freedom of information', 'right to information' or 'access to information'. It is set out in more detail in Article 19 of the *International Covenant on Civil and Political Rights* (ICCPR) and in other human rights instruments.<sup>1</sup>The CRPD uses the term 'access to information' to describe the freedom to seek, receive and impart information and ideas – and in Article 21, it sets out in detail the way that this right applies to persons with disabilities:

### **Article 21: Freedom of expression and opinion, and access to information**

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- (b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- (c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- (d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- (e) Recognizing and promoting the use of sign languages.

## The key to participation in politics and public affairs

Everyone has the right to access information – the right to seek, receive and impart information and ideas of all kinds. Access to information is necessary for people to achieve many other rights, and to secure democracy. The CRPD pays special attention to access to information because it is so important for persons with

disabilities. As Article 21 of the CRPD indicates, some persons with specific impairments may need accessible formats in order to seek, receive and impart information and ideas – and they have a right to receive information in an accessible way. Article 29 of the CRPD sets out the right of persons with disabilities to participate in political and public life on an equal basis with others. Persons with disabilities need access to information if they are to take part in society, change political systems, and address long histories of political and economic exclusion.

## **A tool for persons with disabilities to advocate for their rights**

Persons with disabilities continue to face attitudinal and environmental barriers to participation in many areas of life. They are more likely to be excluded from education or employment. They are poorer than others, and this affects their access to health and other services. Sometimes, they live in residential institutions, which reinforce their exclusion from society. In order to challenge these barriers, persons with disabilities need to take political action. They need to make strong arguments for change – and these arguments for change need to be based on information about their situation.

## **Access to information from governments**

Governments and public bodies hold a great deal of information about what they do in areas such as education, health and employment. This information belongs to the public, and the public should be able to access that information easily. When people can access information freely, they can hold informed opinions and engage in full and open debate. Access to information is needed to:

- Ensure governments are scrutinised, and are thereby more open, transparent and accountable;
- Enable groups, such as persons with disabilities, to set out the barriers that they face in a clear way, and formulate policies to address these barriers;
- Enable people to expose corruption, wrongdoing and deliberate exclusion;
- Enable people to access their own personal information – part of respecting human dignity;
- Enable people to make personal decisions about things like medical treatment or finances;
- Enable economic development.

If persons with disabilities and the organisations that represent them are to challenge their exclusion, they need to have information about the government policies that contribute to exclusion. Access to information is a vital precondition for people speaking out and organising for change.

International human rights law has long recognised that governments have to change their way of working if people are to realise their right to access information. Many public authorities have traditions of secrecy and many have complicated systems of informal information exchange that work for people with privileged access to political figures, but not for everyone. For this reason, several legal authorities have written detailed accounts of the meaning of access to information – sometimes using the terms ‘freedom of information’ or ‘right to information’ to describe what the CRPD calls access to information.<sup>2</sup> ARTICLE 19’s standard-setting document *The Public’s Right to Know: Principles on Freedom of Information Legislation* sets out best practices and international standards about the right to information. They include nine key principles:

- **Maximum disclosure:** ‘Information’ includes all information held by all parts of the government and all publicly-funded bodies. Disclosure of information should be the norm, and restrictions should only apply in very limited circumstances. Anyone should be able to request information, not just a country’s citizens, and people should not have to give reasons for their request.
- **Obligation to publish:** Public bodies should be legally obliged to publish information, and should proactively publish and disseminate information, as well as responding to requests.
- **Promotion of open government:** Public bodies should actively promote open government, challenge secrecy, and spread awareness of how the public can use their right to freedom of information.
- **Limited scope of exceptions:** Public bodies can only refuse to disclose information for legitimate interests, such as personal privacy. Public bodies refusing disclosure must show that disclosure would harm that legitimate interest, and that the harm is greater than the public interest in such disclosure.



- **Processes to facilitate access:** Requests for information should be processed rapidly and fairly. An independent review of any refusals should be available.
- **Costs:** Individuals should not be deterred by excessive costs from making requests for information.
- **Open meetings:** Meetings of public bodies should be open to the public.
- **Disclosure takes precedence:** Laws which are inconsistent with the principle of maximum disclosure should be amended or repealed.
- **Protection for whistleblowers:** Individuals who release information on wrongdoing (whistleblowers) must be protected against any legal, administrative or employment-related sanctions.

These legal principles are intended to change secretive government behaviour and improve the lives of all citizens, including people from groups that are marginalised or excluded from mainstream politics. For example, for anyone seeking to improve education for persons with disabilities in Lebanon, these changes would mean they could readily analyse policies, procedures and statistics about the education system. They could use government data to help identify areas for improvement, and use their own experiences to critically examine and improve government policy and procedure where necessary.

### **Restrictions on the right to information**

All individual requests for information from public bodies should be met unless the public body can show that the information falls within the scope of the limited regime of exceptions to freedom of information. A refusal to disclose information is not justified unless the public authority can show that the information meets a strict three-part test:

- The information must relate to a legitimate aim listed in the law – like the protection of personal information or national security;
- Disclosure must threaten to cause substantial harm to that aim;
- The harm to the aim must be greater than the public interest in having the information.

### **Lebanon's international commitments on access to information**

Lebanon has made commitments in international law that require it to provide access to information to all its citizens, including people with disabilities. It has ratified the ICCPR and the *UN Convention against Corruption*, two treaties which require states to ensure that people have access to information held by the government, with very narrow exceptions. The CRPD also requires Lebanon to provide access to information. Lebanon has signed the CRPD, but it has not yet ratified it, because of a political crisis which is explained below. But Lebanon has been closely involved in the development of international law on the rights of persons with disabilities. It was among the first countries to sign the CRPD, doing so in 2007. Lebanon's *Law on Disabled Persons Rights* (Law 220/2000) recognises the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (the Standard Rules). The Standard Rules were adopted by the UN General Assembly in 1993 and they are an authoritative interpretation of international law on disability. The Standard Rules were also part of the process that led to the adoption of the CRPD. The Standard Rules recognise the importance of access to information for persons with disabilities. Standard Rule 5 requires states to 'undertake measures to provide access to information and communication'.

# Disability and Lebanese Law

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## Law 220/2000 on the Rights of Disabled Persons

In 2000, Lebanon adopted *Law 220 on the Rights of Disabled Persons* (Law 220/2000), several years before the adoption of the CRPD. Law 220/2000 represented a major step forward for disability rights in Lebanon and the wider Middle East region. It invoked the international standards of the time – the Standard Rules – adapting them into a Bill of Rights for persons with disabilities in Lebanon. Lebanon intended to implement these rights – such as the right to health, housing, education, employment and an accessible environment – through systems of special welfare entitlements for persons with disabilities, and quotas, fines or incentives for service providers and employers. The entitlements apply to people who have registered for a disability card. Only Lebanese citizens can register for a card, and they must meet a definition of disability that sees disability as a limitation resulting from impairment. Definitions developed more recently see disability as an interaction between impairments and the physical and social environment.

Social and economic rights are at the core of Law 220/2000. The law makes little provision for the civil and political rights of persons with disabilities, and makes little mention of the right of access to information. The law's major contribution to political participation by persons with disabilities is its recognition of the National Council for Disability Affairs, with members elected by and from disabled persons' organisations and persons with disabilities. The rest of the law is mainly built around a set of rights integrating citizens with disabilities into social and economic life, through employment, transport and housing quotas, and guarantees of health and educational services. Implementing decrees are needed for these norms to be translated into policies. But most of the necessary implementing decrees have not been forthcoming, because of financial austerity and a lack of political will. Many of the rights set out in the law have not been achieved – and this report argues that part of the reason is that persons with disabilities and disabled persons' organisations do not have the necessary information resources to challenge the government when it fails to live up to its commitments.

### LAW 220/2000 ON THE RIGHTS OF DISABLED PERSONS – AN OVERVIEW

**Part I. On Terms, Definitions, Classification and [disabled persons] Card:** Defines persons with disabilities as registered card holders who meet the International Classification of Impairment, Disability and Handicap (ICIDH) definition.

**Part II. On the National Council for Disability Affairs:** Establishes the National Council for Disability Affairs (NCDA) as the institution responsible for setting disability policy and supporting its implementation.

**Part III. The Right to Health, Rehabilitation and Support Services:** Establishes that persons with disabilities have the right to health care and rehabilitation at the government's expense and states that awareness campaigns about health services should be initiated.

**Part IV. The Right to Rehabilitated Environment:** Deals with the accessible built environment.

**Part V. The Right to Transport, Parking Lots and Driving Licenses:** Outlines quotas of accessible vehicles.

**Part VI. The Right to Housing: Right to housing:** Establishes quotas of accessible houses for persons with disabilities.

**Part VII. The Right to Education and Sports:** Ensures the right to education for all persons with disabilities which involves examinations in accessible formats. This section also addresses awareness raising about disability rights and accessible sports centres.

**Part VIII. The Right to Work, Employment and Social Benefits:** Outlines that public and private employers with more than 60 employees must employ a quota of three percent of workers with disabilities.

**Part IX. Fiscal Rules:** Ensures the right to limited social security payments for persons with disabilities.

**Part X. Miscellaneous Rules:** Clarifies that certain disability products are exempt from customs duty.

# Access to Information in Lebanese Law

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Lebanon's constitution protects freedom of expression.<sup>3</sup> Some legislation provides access to specific areas of information for specific sectors of the population. For example, an environment law gives citizens the right to information about the environment.<sup>4</sup> Other laws, however, restrict access to information. Public employees are prohibited from making public statements or publishing articles without their supervisor's written approval, and also from disseminating official information during and after their employment without written authorisation from their ministry.<sup>5</sup> These regulations contribute to a culture of secrecy.

## Draft law on access to information

A draft law on access to information was submitted to the Lebanese parliament in April 2009 and, although it has subsequently progressed through many parliamentary committees, it has not yet been adopted, because of a political crisis in Lebanon (see POLITICAL DEADLOCK AND ACHIEVING RIGHTS below). The draft requires public authorities and certain private authorities to provide information on request, publish information periodically, and explain decisions – with narrow exceptions such as national security and personal data. However, it includes no specific requirement to provide information in accessible or usable formats for persons with disabilities as proposed by the CPRD.<sup>6</sup>

## Activism and use of the courts

Although the draft law on access to information has not been adopted, activists have used the Lebanese courts to overturn government restrictions on information. In April 2014, the Committee of the Families of the Kidnapped and Disappeared and the organisation Support of Lebanese in Detention and Exile successfully petitioned an administrative court to order the government to release files on thousands of people who had disappeared during the 1975-1991 civil war. After three decades of pressure led by the families of the disappeared, the administrative court's verdict gave them access to transcripts of interviews with militia personnel who had been involved in the killings and opened up new possibilities for addressing the legacies of the civil war. Other activists have been working to address the issue of children who have been adopted or placed in residential institutions and denied access to information about their family origins and who are demanding information about their origins.

## OVERVIEW OF LEBANON'S DRAFT LAW ON ACCESS TO INFORMATION

### *Access to information on request*

- Public entities, and private entities that participate in the provision of a public service, are required to provide information, including financial information.
- Citizens, non-citizens and legal entities can request information from the authorities without need of explanation.
- Some information, such as national defence or personal data, is not accessible under the draft law.

### *Publication of information*

- Annual reports, laws and regulations must be published in the official gazette.

### *Explaining decisions*

- The authorities must provide legal and factual explanations for decisions that affect a person's rights.

### *The independent administrative commission*

- Persons can complain to this commission if the authorities fail to comply with the law. The commission's decisions about these complaints are binding.

# Disability in Lebanon

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## What is disability?

Disability is a complex and multi-dimensional experience which resists definition and measurement. Many people define disability in medical terms, seeing disabilities as impairments – problems in the structure, function or condition of an individual's body or mind. But over the past four or five decades, many disability activists and researchers have moved away from a focus on individuals and their impairments towards an understanding of the role of social and environmental barriers that limit the activities and participation of persons with disabilities.

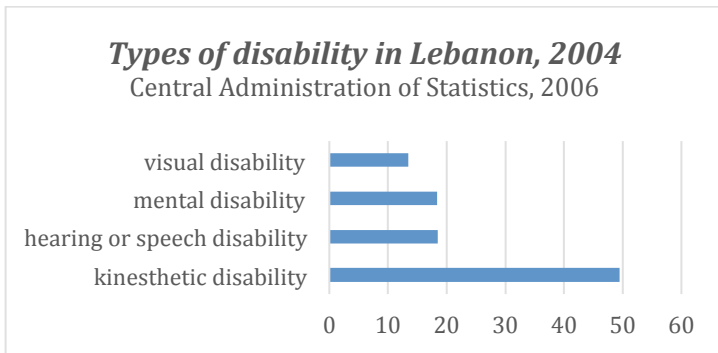
These two approaches to defining disability are sometimes represented as two opposing models: 'the medical model' and 'the social model.' The social model was a starting point for radical activism: it argued that social structures disable people, and that social structures could be changed. Activists successfully challenged definitions of disability and moved debates about disability away from medical treatment to social transformation – and to new radical understandings of how disability can shape individuals' identities in a complex society.<sup>7</sup> The CRPD reflects the debates of the past few decades, defining disability as 'an evolving concept ... disability results from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.'<sup>8</sup>

## The prevalence of disability in Lebanon

Different definitions of disability yield different understandings of the scope of the problem. Lebanon's disability prevalence rate is two percent of the total population. That is near the median for Arab countries – prevalence rates in the Arab states range from 0.5 percent to 4.9 percent of the total population.<sup>9</sup> A 59-country study conducted by the World Health Organisation between 2002 and 2004 found disability prevalence rates of 15.6 percent for adults 18 and over.<sup>10</sup>

Why are disability prevalence rates so low in a region of the world with so many wars? One reason for Lebanon's low prevalence rate is that Lebanon's official statistics body, like many others in the region, uses medical definitions of disability. In 2004, a survey of household living conditions conducted by the Central Administration of Statistics (the *Household Living Conditions Survey*) found there were 73,896 persons with disabilities in Lebanon, of whom 36 percent were female.<sup>11</sup> This survey asked household heads whether any household members had visual, mental, hearing/speech or motor impairments.<sup>12</sup> Household heads may have been reluctant to acknowledge disability – some people believe that disability is a stigma or a deviation from an imagined human norm. Studies which look at the interactions between impairments and social function are likely to yield higher prevalence rates (see *IMPAIRMENTS OR INTERACTIONS BETWEEN IMPAIRMENTS AND SOCIAL FUNCTION* below).

Sometimes medical definitions of disability are attractive to states because they lower prevalence rates. In Lebanon, as in many other countries, people with a registered disability are entitled to state benefits – and lower disability prevalence rates mean that there are fewer beneficiaries. Administrative data is another way of estimating disability prevalence, and in Lebanon administrative data also shows low prevalence rates. The Ministry of Social Affairs publishes administrative data on people registered through the disability card system, which awards welfare and other entitlements to Lebanese citizens with specific impairments.<sup>13</sup> These figures do not include non-Lebanese people with disabilities. In 2014, the ministry said there were 95,618 persons with disabilities in Lebanon. Over half – 55.1 percent – had motor (kinaesthetic) disabilities; 28.4 percent had mental disabilities; 8.7 percent had hearing or speech disabilities; and 7.8 percent had visual disabilities.<sup>14</sup>



Lebanon's *Law on the Rights of Disabled Persons (220/2000)* uses the same restrictive, medical definition of disability used in the surveys. This law recognises environmental factors but does not classify them, or try to explain how environmental factors interact with impairments. The definition of disability in Law 220/2000 is based on the 1980 *International Classification of Impairment, Disability and Handicap (ICIDH)*, which was criticised for its medical, impairment-based approach to definition. In 2001, the year after Lebanon's disability law was adopted, ICIDH was replaced in 2001 by the *International Classification of Functioning, Disability and Health (ICF)* which sees disability as an interaction between health conditions, environmental and personal factors – closer to the view of the CRPD.

#### **IMPAIRMENTS?OR INTERACTIONS BETWEEN IMPAIRMENTS AND SOCIAL FUNCTION? HOW TO DEVISE STATISTICS QUESTIONNAIRES ON DISABILITY**

The 2004 *Household Living Conditions Survey* found that the disability prevalence rate in Lebanon was around two percent. It was based on the ICIDH system, and asked respondents about types and causes of disability. The survey divided disability into four types – kinaesthetic (or motor), visual, mental, and hearing/speech. It listed ten possible causes, including genetics, war or abuse. Recently, Lebanon's statisticians have started using the alternative ICF system. The ICF system asks respondents about particular tasks such as standing for long periods; taking care of a household; joining in with community activities; concentrating for ten minutes; maintaining a friendship; walking a kilometre; or washing their whole body. It asks respondents to score these tasks across five levels of difficulty, from 'no difficulty' to 'extreme difficulty'. Both systems give a picture of disability – but the ICF's picture is richer.

#### **The experience of disability in Lebanon**

The 2004 *Household Living Conditions Survey* showed that, compared with the general population, persons with disabilities had low levels of educational attainment. 38.2 percent could not read or write, compared with 11.3 percent in the general population. Only eight percent of persons with disabilities completed secondary or tertiary education, compared with 32.1 percent in the general population. Marriage rates were also significantly lower: 37.7 percent of persons with disabilities were married, compared with 53.1 in the general population.<sup>15</sup>

**Disability and employment:** The 2004 *Household Living Conditions Survey* showed that employment rates for persons with disabilities were lower than those for the general population. Lebanese law requires larger employers to employ a quota of three percent of people registered as having disabilities (see **DISABILITY AND LEBANESE LAW** above). Despite this, there has been little progress on implementation. A 2003 study by the Lebanese Physically Handicapped Union of 200 persons with disabilities aged 14-38 found that over half of them were not in employment or education.<sup>16</sup> A 2007 study of 27,086 working-age persons with disabilities found that only 26 percent were in work.<sup>17</sup>

**Disability and the environment:** Lebanese law requires public buildings to be accessible for persons with disabilities, but a 2006 study of 612 buildings found that 95 percent were not accessible. Much of the transport infrastructure is also inaccessible (see **DISABILITY AND LEBANESE LAW** above).

**Disability and education:** Lebanese law requires educational institutions to be accessible to persons with disabilities (see **DISABILITY AND LEBANESE LAW** above). But there has been little progress on implementation: only five government schools in Lebanon have been made accessible to people with motor disabilities. Universities and technical training institutions are also inaccessible.<sup>18</sup> This lack of

access leads to low the educational attainment: in 2002, the government reported that 85 percent of children with disability did not complete primary education.<sup>19</sup>

***Disability and residential care:*** With low levels of educational attainment and low employment rates, persons with disabilities in Lebanon are more likely to be poor than the general population. This poverty is complicated by Lebanon's unique welfare system. Over 60 percent of the country's social welfare budget goes to residential institutions, mostly for children and the remainder for adults with disabilities and elderly people. About two percent of children in Lebanon – probably over 30,000 children – live in institutions, one of the highest rates in the world.<sup>20</sup> In comparison, Jordan had 1,050 children in institutions in 2006, and Syria had 3,094 in 2005, though each of these countries' populations is higher than Lebanon.<sup>21</sup>

Unlike Syria and Jordan, Lebanon has very little public provision for social welfare. Social services are delivered by non-governmental organisations, many of them linked to Lebanon's different religious groups, which play a formal role in Lebanese politics (see POLITICAL DEADLOCK AND ACHIEVING RIGHTS below). Residential institutions are an outcome of this privatised, religiously-based system: orphanages and asylums are relatively easy for smaller organisations to set up and manage compared with integrated systems. However, residential institutions achieve these cost savings by separating children and adults from their families and communities.

There are two main reasons for institutionalisation: poverty and disability. Many parents unable to afford education costs put their children in residential institutions. Parents of children with disabilities often have no educational alternatives for their children, even though the education in these institutions is of significantly lower quality, with many children not even completing primary school.

Residential institutions raise many questions about the rights of persons with disabilities in Lebanon, and about rights to accessible, intelligible information for individual children and adults who are separated from their families. For example, the CRPD requires states to ensure that residential or non-residential institutions promote the independence, full capabilities and social inclusion and participation of persons with disabilities.<sup>22</sup> Lebanon's system, however, often produces under-educated adults with disability who often end up unemployed or in low-paid, insecure jobs facing dependence and isolation. Similarly, the CRPD, along with other human rights instruments, requires states to use careful procedures when separating children from their families or adults from the community. These procedures must assess the best interests, will and preferences of the individuals at risk of separation. Such procedures require the authorities to provide children and adults at risk with a great deal of accessible and intelligible information about their rights, preferences and relationships. These procedures should also be reviewed on a regular basis.<sup>23</sup> One of the reasons for the survival of residential institutions in Lebanon is that these procedures and reviews are not regularly implemented. Disabled children, adults and their families are often not aware of these procedures or of alternatives to separation.

Lebanon has made many important commitments to the rights of persons with disabilities. But many of these commitments have not been made good, because individuals with disabilities and disabled persons' organisations do not have adequate access to information about their rights and services. The final section of this paper addresses the way that the lack of accessible information perpetuates problems (see ASSESSING LEBANON'S RECORD ON ACCESS TO INFORMATION FOR PERSONS WITH DISABILITIES below).

## Political deadlock and achieving rights

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The political deadlock in Lebanon is one of the main obstacles to achieving progress on access to information and disability rights. Lebanese president Michel Suleiman's term of office ended in May 2014. Parliament has so far failed to reach the quorum needed to vote in his successor, the second time in the past decade when political deadlock has left the presidency vacant. Parliament is divided between two alliances called 'March 8<sup>th</sup>' and 'March 14<sup>th</sup>'. These opposing alliances emerged in 2005, when the assassination of former Prime Minister Rafiq al-Hariri polarised a country emerging from civil war (1975-1990), Israeli occupation (1978-2000) and the protracted deployment of the Syrian army (1976-2005). Lebanon's political polarisation brought the country to the verge of renewed conflict in 2008. Since then, the Lebanese government has been made up of representatives of both alliances. National unity governments have averted conflict, but have not overcome political deadlock.

This political deadlock directly affects persons with disabilities. Since 2005, state budgets and public debts have been adopted by extra-constitutional means.<sup>24</sup> Legislative activity has frequently been suspended, international treaties such as the CPRD have not been ratified, and laws have not been passed. In 2003, the Lebanese Physically Handicapped Union set up a budget monitoring project that aimed to help civil society organisations, including those representing persons with disabilities, to translate their concerns about social development needs into concrete economic policies. The project aimed to bring into the public domain information about the government's fiscal policies and their social impact that was otherwise difficult for ordinary people to obtain.

Several authorities in the field of international law have set out principles for governments to adopt so that all people can achieve their right to access information – that is, to seek, receive and impart information. Governments should put government information that is of public interest into the public domain. They should make it easy for people to obtain government information quickly when they ask for it. They should adopt freedom of information laws. In Lebanon, access to information is not often based on these principles. Access exists – but it is based on informal social and political networks. AdibNehmeh, an adviser to Disabled Persons International, explains:

Formal channels [to obtain information exist but there is also] a complete, comprehensive informal network which is much more efficient than the first ... It's the way that the government prefers to do business ... You can get a friend in the ministry, he gives you information, and asks you to keep it quiet, knowing it will spread. It is a system of sharing information that is not orthodox. It gives venues to many people to get access to information in one way or another ... [although] you are not sure about the credibility of the informal information that you get. And also there's a gap between different actors getting different access to information. Any organisation can get the information that they need. But getting the information does not mean that they are enabled to use it. It doesn't give power to anyone. Transparency does not empower. Exposing corruption does nothing. You will see one minister accusing another of stealing on TV, but there is no accountability system. An informal system of information is not [suitable] for radical change. In specific contexts, it will do a lot. In other ones it will do nothing ... In the current situation, informal access to information cannot influence policy. You can get information but you can't do anything with it.<sup>25</sup>

Lebanon's political deadlock arises out of hostile political alliances that are partly configured around its religiously-based political system, where power is distributed among the various religious groups, sects and confessions. This system, known as 'Political Confessionalism', was established in 1943, just before Lebanon's independence from France, when political parties agreed on an unwritten National Covenant. The National Covenant divided government posts between Christians and Muslims by a ratio of about 6:5, and further subdivided them amongst most of the country's 18 recognised religious sects or confessions. In 1990, after the civil war ended, a revised constitution gave Christians and Muslims equal representation and called for the abolition of political confessionalism.<sup>26</sup> But parliament has not yet abolished the system, perhaps because the interests of many of those involved, both Lebanese and regional, have had an investment in maintaining it. Political confessionalism affects persons with disabilities too. One reason for this is that social services for persons with disabilities are mostly managed by private religious organisations. Nearly all Lebanese medical,

educational and welfare services are privately run. The state covers some of the costs for people who cannot afford them, but most of these are delivered by the privatised, fragmented and confessionalised social welfare system that is interwoven with the confessionalised political system. This system is responsible for implementing many of the social and economic rights for people with disabilities that are set out in Law 220/2000. The system resists both radical change and transparency. People wanting to find out more about the situation of persons with disabilities in Lebanon need to receive information not only from the government but also from private, mainly confessional, social welfare associations.

So Lebanon's political system does not allow relatively powerless people – such as many people with disabilities – easy access to information that can help bring about change. Recent events have made it harder to advocate for the kind of radical changes that disabled people need in order to realise the rights set out in the CRPD. Since 2011, civil war in Syria has intensified Lebanon's polarisation. Over a million Syrians have taken refuge in Lebanon. Inter-confessional tensions in Syria have sent sparks flying across its borders. The Syrian conflict has depressed Lebanon's economic growth, saturated its labour markets and strained public finances.<sup>27</sup> As a result, Lebanon faces political, security and economic obstacles to implementing its commitments to the human rights of its population. Regrettably, these obstacles are often invoked to explain and justify the lack of progress in the implementation of the rights of people with disabilities.



# Accessing Lebanon's record on access to information for Persons with Disabilities

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Access to information about public finances and the outcomes of public policy is a key element of the broader right to seek, receive and impart information and ideas of all kinds. Information held by public bodies belongs to the public, and it should be disclosed, subject only to a narrow set of exceptions. It is a vital precondition for advocacy and for the achievement of other rights for and by persons with disabilities. This section looks at Lebanon's record on making such information accessible.

## The National Council for Disabled Persons' Affairs and access to information

Lebanon's Law 220/2000 includes few provisions for the fundamental freedoms of persons with disabilities, such as freedom of expression and access to information, that are preconditions for their full participation and inclusion in daily life. Instead, Law 220/2000 emphasises social, economic and environmental rights, such as education, health, employment and access to the transport system and the built environment.

But Law 220/2000 includes an important provision enabling persons with disabilities and the organisations representing them to influence disability policy: the National Council for Disability Affairs (NCDA). The council has 18 members:

- Four officials from the Ministry of Social Affairs, including the minister
- Four people elected from disabled persons organisations
- Four people from organisations providing services to persons with disabilities
- Four people with disabilities elected by disabled card holders
- Two ministerial appointees.

Under Law 220/2000, the NCDA is responsible for setting disability policy, in coordination with other branches of government and NGOs. It is also responsible for supporting policy implementation.<sup>28</sup> The NCDA was set up in 1993, and its major achievements include the drafting of Law 220/2000, and the development of the disability card system, which has made Lebanon's privatised welfare system more accessible for people with disabilities who meet the registration requirements.

The provisions for the NCDA in Law 220/2000 do not set out the rights to access information that their policy coordination role implies. Given this law's lack of attention to civil and political freedoms of persons with disabilities, however, the right to access information for the elected representatives of registered persons with disabilities and organisations invites scrutiny.

The NCDA is chaired by the Minister of Social Affairs, and its decisions are implemented by the Ministry of Social Affairs. The minister presides over the NCDA and also over the office of the NCDA, and he or she 'represents the NCDA to all other national and state authorities'.<sup>29</sup> In practice, this means that information requests to other ministries have to go through the Minister of Social Affairs. Ministers change fairly frequently, often every year or two, and over the past decade government operations have frequently been part-suspended because of Lebanon's prolonged political crisis. In practice, the NCDA has become an advisory body to the ministry. If the NCDA itself needs information, the only way to get it is through the minister. The council has no formal access to other ministries. One member of the NCDA said:

The NCDA has access to all the information in the Ministry of Social Affairs. But with other ministries there are sometimes problems. We can get published information. But we can't get hold of internal information, even if it's necessary for determining policies ... Most ministries don't respond. They haven't got used to the existence of the NCDA yet. We usually get information from their websites.<sup>30</sup>

The NCDA can face even more barriers in accessing information on disability held by private welfare associations. Residential institutions run by private associations receive nearly all the disability budget of the Ministry of Social Affairs. Nearly all disability programmes are implemented by these private associations, using state funds. Officials are not entirely sure of the truth of the information that such

private associations might provide: “[The ministry] can ask for information, but [they] might not get true information,” said one.<sup>31</sup>

## **Disabled Persons’ Organisations and access to information**

Full and effective participation by persons with disabilities is one of the principles of the CPRD, and the convention requires states to consult closely with and actively involve persons with disabilities when developing and implementing disability policy and other decision-making processes.<sup>32</sup> Lebanon has not yet ratified the convention, but Law 220/2000 invokes the Standard Rules in its preamble. The Standard Rules call for consultation with persons with disabilities and with disabled persons' organisations in a wide range of areas, including access to information.<sup>33</sup> Information sharing and consultation are an important part of access to information, particularly with groups who are affected by government decision-making. However, if the NCDA's experience is a guide, it seems that Lebanon has taken few steps to make access to information a reality.

**Access to information about education services:** Law 220/2000 requires schools to be accessible, but in 2013, the Ministry of Education and Higher Education had only provided the funds for adaptations to five schools, one in each governorate. The Ministry of Education adopted a *National Educational Plan for Persons with Disabilities* in 2012, but there has been little progress on its implementation.<sup>34</sup> In 2014, the Youth Association for the Blind (YAB) requested information from three ministries, including the Ministry of Education, about policies and programmes for persons with disabilities, wanting to use the information as the basis for proposals for more inclusive policies. In September of that year, YAB submitted a letter asking staff in the Ministry of Education to nominate a person to coordinate with a YAB researcher, or to collect the relevant information on YAB's behalf. One month later, the ministry responded saying that YAB could not conduct such research as the ministry's research department was responsible for such research. YAB was not able to obtain the information that it needed to monitor the implementation of the law.

**Access to information about state budgets:** Many authoritative interpretations of international law require states to include information about disability in state budgets. The Standard Rules say that ‘States should include disability matters in the regular budgets of all national, regional and local government bodies’.<sup>35</sup> In addition, authoritative interpretations of the International Covenant on Economic, Social and Cultural Rights (ICESCR) say that states are required to make budgetary provision for persons with disabilities.<sup>36</sup> The NCDA is not readily able to access budgetary information for a number of reasons, not least Lebanon's extra-constitutional budgeting system that is a consequence of its deadlocked parliament (see POLITICAL DEADLOCK AND ACHIEVING RIGHTS above). Neither state budgets nor public debts are adopted in a constitutional way, and many important budget documents, such as audits, are not published.<sup>37</sup> This gives ministries considerable latitude in transferring resources between budget lines. Powerful ministries and others who are involved can persuade the government to adopt extraordinary budget measures and access national reserves without clear lines of accountability. “All parties have an interest in financial non-transparency because they are spending without control,” said AdibNehmeh, an adviser to Disabled Persons International.<sup>38</sup>

The Lebanese Physically Handicapped Union (LPHU) set up a budget-monitoring programme in 2003. In part, this was to address the fact that ministry budgets did not make clear what resources were allocated for disability. Law 220/2000 requires a number of ministries, including the ministries of education, health, public works and transport, to implement the law, and it is not always possible to find out if funds have been allocated to that purpose.

The LPHU budget-monitoring programme accessed information through informal and personal networks. However, even this is no longer working, and it is not possible to get budgetary information through official channels.

Lack of budgetary transparency undermined other efforts by the disability movement to promote participation and inclusion. For example, Law 220/2000 requires that public buildings, along with any private buildings used for public purposes such as schools, should be made accessible.<sup>39</sup> In 2012, the LPHU advocated for schools to be made accessible. An education minister promised that the Ministry of Education would allocate four million US dollars to the programme. When the budget was drafted, the

education ministry said that the allocation had been rejected by the finance ministry. The LPHU went to the prime minister's office and successfully asked for prime ministerial support for the programme. However, the finance ministry said that still they could not make the allocation because of the complications of managing an extra-constitutional budget.

In informal meetings with senior officials, the LPHU was assured that the minister could make the allocation if he wanted to – an example of the way that ministers can access reserves extra-constitutionally in response to political pressures. The LPHU managed to obtain a leaked letter from the education ministry to the finance ministry, which indicated that the education ministry had lowered its allocation from four million dollars to less than 150,000 dollars. In collaboration with a TV station, the LPHU staged an occupation of the education minister's office to challenge the minister. The minister promised to hold another meeting, but he left office a few days later. The exercise showed the stark limitations of using Lebanon's informal access-to-information systems to bring about radical change.

***Access to information about health:*** Law 220/2000 has very few provisions requiring the authorities to make information accessible to persons with disabilities. But there is an explicit requirement in the case of health care, made in Article 31 – echoing requirements in the Standard Rules and the CRPD. It requires the ministries of public health and social affairs to conduct awareness campaigns and publish information on available services and the duties of health agencies and disease prevention.<sup>40</sup> Information about healthcare cost coverage is very important, because although Law 220/2000 provides for free healthcare for registered persons with disabilities healthcare is largely privatized in Lebanon. For example, in 2011, three quarters of all health spending was in the private sector.<sup>41</sup> In 2013, UNESCO estimated that the Lebanese Ministry of Public Health covered the treatment costs for about 1,700 persons with disabilities at a cost of about four million US dollars.<sup>42</sup>

The legal provision for awareness about the health rights of persons with disabilities and the responsibilities of health agencies does not seem to have improved information flows and proactive dissemination of health-related information has been limited. In one case, immediately after Law 220/2000 was enacted in 2000, government ministries organised an awareness campaign about the disability card system. Another example is when the government of Prime Minister Najib Mikati allocated funds for the hospitalisation of persons with disabilities - the ministries of public health and social welfare announced the changes in a press conference.

## Making information accessible

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Access to information – the right to seek, receive and impart information and ideas of all kinds – is a fundamental freedom established in many instruments of international law. This report has so far discussed ‘access to information’ in terms of the duty of public bodies to disclose any information and records which they hold subject to a narrow set of exceptions. Access to information, however, covers all sorts of information – not just that held by governments. For persons with disabilities to enjoy their right to access information on an equal basis with others, the processes of seeking, receiving and imparting information must be accessible. Standard Rule 5 and Article 21 of the CRPD explain some of the ways in which these processes can be accessible, requiring states to provide information in formats and modes – such as braille or sign language – that can be used by people with specific impairments. They also require governments to encourage the mass media and others to provide information and cultural materials in accessible formats (see also Article 30).

Accessibility is one of the eight general principles of the CRPD set out in Article 3. Article 9 sets out the way this general principle is applied, and General Comment 2 of the Committee on the Rights of Persons with Disabilities provides further elaboration of the principle. A legal principle is, among other things, a guide to interpretation: each of the rights in the CRPD ought to be interpreted in the light of the principle of accessibility: processes like seeking, receiving and imparting information need to be accessible.

The CRPD frequently requires information to be made available to persons with disabilities so that they can achieve other rights on an equal basis with others. For example, states must provide persons with disabilities with information about assistive technologies and on reproductive health.<sup>43</sup> They are also required to provide information on how to avoid, recognise and report violence, exploitation and abuse.<sup>44</sup> In each of these cases, the principle of accessibility means that information – all types of information – must be presented in an accessible way.

### **Lebanon’s record on making information accessible**

The CRPD and the Standard Rules both recognise public authorities’ responsibility to provide information in accessible formats and technologies. Although Law 220/2000 invokes the Standard Rules in its preamble, it does not make systematic provision for accessible formats for information. The only requirement for the government to use accessible formats is the requirement to make public examinations available in accessible formats, such as braille.<sup>45</sup> According to the Ministry of Social Welfare, school examinations are indeed provided in braille. However, the government has taken few other steps to provide official information in accessible formats.

Some public and private bodies expect blind people to use new technologies such as screen readers. For example, when the Youth Association for the Blind asked private companies where they announced job vacancies, many directed them to company websites. Screen readers, software programs that allow blind or visually impaired users to read text displayed on a computer screen with a speech synthesiser or brailledisplay, are a transformative technology, but a relatively expensive one. The software may cost over a thousand US dollars, and a cheap computer in Lebanon costs about six hundred US dollars. An internet subscription costs about 15 US dollars a month. Visually impaired people have to buy these for themselves, although the government may support municipalities so that they provide free internet access locally. However, not all websites are compatible with screen readers: the main government information portal, dawlati.gov.lb, is not designed to be compatible with screen readers. The Office of the Minister of State for Administrative Reform (OMSAR) which runs the website is open to the possibility of developing a compatible website, but has not yet taken steps to do so.

New technologies are transforming access to information for groups with specific impairments and the money to pay for them. However, new technologies are not accessible to poor people with disabilities. Other groups – such as people with learning disabilities – have no ready technological fix to overcome the particular barriers to information that they face. Many persons with disabilities have no alternative but to request information through friends and relatives. The director of the Youth Association for the Blind said: “If I want to buy an apartment, how much tax do I have to pay to register it in my name? I have to contact someone who knows how to ask because the information is not accessible. People are not really complaining about this. They are used to

it. It is normal for them.”

The CRPD envisages wide access to information of all kinds for persons with disabilities – recognising that lack of access to information is a factor inhibiting the ability of persons with disabilities to participate in everyday life. States are required to encourage private bodies – such as media organisations – to make information and cultural material accessible.<sup>46</sup> One head teacher explained how important this was. Dr Hussein Ismail runs Lebanon’s only school providing deaf education beyond the ninth grade. An English teacher in the school had asked secondary age children to write about AIDS and no student in the class knew what it was. “Ninety percent of what children learn comes from their environment,” said Dr Ismail.

## **Making information intelligible**

The CRPD also recognises that people with disabilities may need to be given - and to understand -information in specific contexts in order to achieve their rights. Two such contexts are considered here, situations where persons with disabilities are disproportionately likely to face a serious threat to their rights, and need accessible and intelligible information to deal with that threat. Many persons with disabilities have their rights undermined by legal or quasi-legal procedures such as the denial of legal capacity or placement in residential institutions. These procedures often undermine people’s rights because the authorities involved do not provide information that is intelligible to the people with disabilities who are involved, and do not give them adequate opportunity to express their own views, will and preferences.

Children with disabilities are disproportionately likely to be separated from their families and brought up in a residential institution. The decision to separate children is often taken by someone acting on behalf of the child, in a way that harms the child’s autonomy.

Sometimes social workers, judges and medical personnel take decisions on behalf of persons with disabilities. Adults with psychosocial, cognitive and communications impairments are disproportionately affected by measures which deny them a say in decisions affecting them, or deny their legal capacity.

In cases like these, the rights to freedom of expression and access to information are fundamentally important. The CRPD stipulates several requirements. It requires states to take exceptional efforts to make sure that persons with disabilities in these situations are able to understand their situation by ensuring they are given clear information and enabled to express their opinions. It requires children with disabilities to be given disability- and age-appropriate assistance so as to achieve their right to express their views on all matters affecting them.<sup>47</sup> It requires states and other authorities to respect the autonomy of persons with disabilities at all times, and ensure they have accurate information that allows them to make decisions regarding their own bodies and lives.<sup>48</sup> It requires periodic review of decisions such as placement in residential care or denial of legal capacity, which are often taken with insufficient attention to the fundamental freedoms of persons with disability.<sup>49</sup> It also requires ‘procedural and age-appropriate accommodations’ for persons with disabilities in court proceedings.<sup>50</sup>

### **Children and adults in residential institutions**

A disproportionately large number of children with disabilities and many adults with disabilities in Lebanon live in residential institutions that separate them from families, and isolate them from participation in everyday life. Disability is often the cause of these separations. International law prohibits unnecessary separation of children from families.<sup>51</sup> The CRPD recognises the right of persons with disabilities to live in the community, and states that persons with disabilities should not be obliged to live in a particular living arrangement.<sup>52</sup> Likewise, the Standard Rules require rehabilitation services to be provided in the community, and require that any residential rehabilitation services be time-limited.<sup>53</sup>

These international rules evolved in response to long histories of abuse in residential institutions for children and for people with disabilities. International law also provides a safeguard for children in institutions – the right of periodic review of placement.<sup>54</sup> This right means that the authorities must regularly review the progress of children in residential care and the appropriateness of their placement. Disabled people who are subject to measures that restrict their legal capacity likewise have a right to have these measures reviewed regularly, and reviews must ascertain and respect their rights, will and

preferences.<sup>55</sup> These procedures require authorities to make accessible and intelligible a great deal of sensitive information to people whose ability to communicate and learn may be impaired: reviews of placement require great skill. The CRPD's notion of 'reasonable accommodation' is relevant here: it means that in particular cases, states and other authorities need to make special efforts to ensure that persons with disabilities enjoy their rights in the same way as others. This notion has implications for access to information: when dealing with periodic review, consent to treatment, or explanations of involuntary treatment, the state needs to ensure that people have disability-, gender- and age-appropriate assistance to achieve their rights.

International law is clear about the need for these administrative and judicial safeguards against abuse in residential settings, but in many countries the administrative procedures for these reviews are not well developed. This means that children and adults with disabilities can be denied access to crucial information just at the point when they are most exposed to the decisions of powerful authorities.

Lebanese institutions do not have well-developed systems for periodic review of placement in residential care. The decree setting out the internal structure of the Ministry of Social Affairs requires the staff of the specialised care department to 'follow up the case of the disabled [person] in the institution and suggest the ending of the period of care and rehabilitation'.<sup>56</sup> In 2004, Lebanon reported to the Committee on the Rights of the Child, a UN mechanism for monitoring implementation of the *UN Convention on the Rights of the Child* (CRC), that there were no statistics on methods of review implemented in residential care institutions.<sup>57</sup> In 2014, the Ministry of Social Affairs said that it sends inspectors to institutions, but that there were eight thousand persons with disabilities in institutions, and that they only checked a sample of them.<sup>58</sup> A legal review conducted for this study found that elderly people going into care may have their views taken into consideration<sup>59</sup> but that there is no civil law regulating the separation of children from parents, and no legal texts dealing with the right of people in residential care to know the reasons for their placement.

NGOs working on these issues highlight some critical gaps in access to information, which deepen the dependence and isolation of people in institutions. According to Legal Agenda, a Lebanese NGO, children in residential care who have lost contact are not given the right to information about their original families or access to their personal files.. According to one LPHU staff member, disabled children and adults in residential institutions cannot access their case files: "Institutions will give some information to people who persist. But usually they give any excuse not to give information."

An example of this difficulty is the experience of the Disability Monitor, an initiative of disabled persons' organisations and the Ministry of Social Affairs to study the implementation of Law 220/2000. The initiative installed boxes for citizens to post comments and complaints about the implementation of the law in municipalities, ministry centres and institutions for persons with disabilities. In 2013, the Disability Monitor reviewed 197 comments about the implementation of the law.<sup>60</sup> However, many residential institutions for children with disabilities refused to allow complaints boxes in their institutions, unless their staff were given the key, allowing them to read children's complaints and potentially identify complainants.

#### Denial of legal capacity and access to information

The situation is worse for people who are deemed lacking in legal capacity. The CRPD emphatically asserts that all persons with disabilities have equality before the law, and stresses the importance of safeguards to prevent abuse relating to the exercise of legal capacity. Legal capacity includes the ability to hold rights and duties and to have those rights protected by the legal system; the ability to use legal systems to carry out legal transactions and to start and end legal relationships. Lebanese law, like legal systems in many other countries, conflates legal capacity with mental capacity, a culturally-inflected, difficult-to-define category related to an individual's decision-making skills. Many legal systems assume that someone with a cognitive or psychosocial problem cannot make decisions for themselves, often on the basis of their having an impairment.<sup>61</sup> An example of this is the Lebanese disability card. People with visual or motor disabilities have the right to hold a disability card. The cards of people with mental disabilities are held by their guardians. The cards of people with hearing disabilities may be held by the person with a disability or by their guardian.<sup>62</sup> Commenting on the way that legal status and impairment have been entangled in this way, a disability rights activist said he

believed that people with motor and visual disabilities had been given clearer rights because both groups were better organised.<sup>63</sup>

The situation for people with mental health conditions in Lebanon is complicated by legal traditions shaped by its patriarchal society, which stress wardship and welfare. Under a 1983 law, people with mental health conditions can be given medical treatment without their consent.<sup>64</sup> The law does not give people subjected to involuntary treatment a right to know about the decisions that are taken on their behalf. A 2004 patients' rights law sets high standards for doctors to obtain the informed consent of all patients, but it does not have clear guidance on information and consent for those people deemed to lack legal capacity.<sup>65</sup> A draft law from 2009 gives information rights to patients subjected to involuntary treatment.<sup>66</sup> If passed, this would help bring Lebanese law in line with international law. Mental healthcare principles adopted by the UN General Assembly in 1991 state that 'A patient (which term in the present Principle includes a former patient) shall be entitled to have access to the information concerning the patient in his or her health and personal records maintained by a mental health facility'.<sup>67</sup>

## Generating Information

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Access to information usually refers to information generated and held by a public body. Most authoritative interpretations of Article 19 of the ICCPR, which sets out the right to seek, receive and impart information, say that the authorities are not required to generate information just because someone would like to have it: 'The right to seek information in any event relates to all *generally accessible information*'.<sup>68</sup> Ghassan Moukheiber, a Lebanese parliamentarian who played a leading role in drafting Lebanon's access to information bill that is now before its deadlocked parliament, agrees with that view. "The authorities are not required to provide information that does not exist."<sup>69</sup>

Like many countries, Lebanon has relatively little information on the situation of persons with disabilities. Many states have little inclination to describe in detail the scope of the problems that they face. Generating information on a section of the population with special needs and special entitlements is a process that is likely to lead to more claims on the state. Because of this, some international legal authorities have argued that states have obligations to generate certain kinds of statistics. The UN Committee on Economic, Social and Cultural Rights says that states need to monitor the extent to which such rights are being enjoyed by all individuals within its territory or under its jurisdiction, and that national statistics are needed to do this. Furthermore, special attention needs to be given to any worse-off regions and to particularly disadvantaged groups.<sup>70</sup>

The CRPD makes statistical reporting on disability a human rights treaty obligation: 'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies that give effect to the present Convention ... States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.'<sup>71</sup> Even though Lebanon has not yet ratified the CRPD, it is bound by its existing obligations to generate statistics and other kinds of information that allows it to monitor its commitments to the rights of persons with disabilities (Lebanon ratified the ICESCR in 1972).

Lebanon's statistics body faces some unique challenges. Lebanon has not had a census since 1932. The 1932 census, based on a deliberately restrictive understanding of Lebanese nationality, found that the country had a Christian majority. This demographic finding then became part of the National Covenant of 1943, which allocated the majority of government posts to Christians. The census became entangled in power sharing, and as a result, no censuses have been conducted for over 80 years. The lack of census data – which in most countries is used by statisticians as a sample frame – also contributes to low prevalence rates. Instead of a population census, the Central Administration of Statistics (CAS) uses a census of dwellings, and it conducts household surveys based on the dwellings census. However, residential institutions are not included in dwellings, so the large disabled population in institutions is not included.

In addition, Lebanon has historically used medical, impairment-based definitions of disability drawn from the World Health Organisation's 1980 *International Classification of Impairments, Disabilities and Handicaps* (ICIDH).<sup>72</sup> Such impairment-based definitions of disability are likely to decrease disability prevalence rates. A definition that looks beyond impairment, to the effects of disability on social function, is likely to yield more accurate prevalence rates. Lebanon's Central Administration of Statistics (CAS) has taken part in the international discussions on the new *International Classification of Functioning, Disability and Health* (ICF), which has been adopted by the World Health Organisation and which sees disability as an interaction between health conditions, environmental and personal factors.<sup>73</sup> The CAS is planning a national disability survey in 2015/2016, with support from the League of Arab States, and it will use the ICF definitions in the survey.

## Conclusion

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Access to information is vital for persons with disabilities to achieve their rights. The CRPD develops existing international human rights law on access to information, setting out some of the political and administrative changes that are needed for persons with disabilities to be able to seek, receive and impart ideas and information, and to use information to change their own situations and the society that they live in.

Many persons with disabilities, and many of the organizations that represent them, do not have easy access to the information that they need to make changes to their lives. Often information is not accessible either. Accessible information is information that is presented in formats that are intelligible to people with specific impairments. But accessibility means more than that: accessible information is information that can be used by people in extraordinary situations where their rights are at stake. Children at risk of separation from their families, or people with cognitive, mental or other disorders whose legal capacity is subject to legal interference need a lot of intelligible information to have their rights, will and preferences respected by others. The CRPD emphasises that disabilities must never constitute barriers to equal rights. For that to happen, information needs to be presented in accessible, intelligible formats – even in the most complex situations.

Sometimes, persons with disabilities and the organisations representing them cannot get information about the situation of persons with disabilities because it does not exist. In many countries, statistics bureaus and ministries do not collect the kind of information on persons with disabilities that allows for inclusive, positive disability policies to be formulated and implemented. Disabled persons' organisations face a lengthy struggle just to get the information that they need to advocate for change. The CRPD and other elements of international law stress the importance of changing this – requiring states to develop adequate statistics relating to disabilities.

This report has assessed how access to information for persons with disabilities in the specific context of Lebanon. Unusually for the region, Lebanon has yet not ratified the CRPD – although it was one of the first countries to sign it, and although its commitment to international law on disability is clear in Law 220/2000 on the Rights of Disabled Persons. The report has shown that Lebanon's existing commitments in international law require it to ensure that persons with disabilities and the organizations representing them have access to information; that the information they use is accessible; and that the government generates adequate statistics on persons with disabilities.

Lebanon's record is very mixed. There is plenty of information about how the government works in Lebanon – but it often flows through inaccessible informal networks. Ensuring access to information for persons with disabilities would help transform the government's relationship with a group of people who are often excluded from decisions that affect them – it would help make Lebanon a more inclusive place for persons with disabilities and for everybody. Often, information is not accessible for persons with disabilities – it cannot be used by people with specific impairments, or with people in difficult social or legal situations. Investing in information accessibility would make Lebanon a more inclusive, democratic place, and help persons with disabilities make the best of systems of service provision that have long excluded them from everyday life.

Lebanon's record on generating statistics about disability is mixed too – but the Central Administration of Statistics is gearing up for a new set of studies that will be based on international best practice, and will help Lebanon's disability movement to work harder for the changes that are needed to realise what the preamble of



Law 220/2000 says: 'The entire world has come to believe that every person, whatever his physical or intellectual capacities has the right to enjoy life on an equal basis with others'.

# Recommendations

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Everyone has the right to freedom of expression, which includes the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, orally, in print, in the form of art, through print, broadcast or digital media, or through any other media of their choice.

States must adopt all appropriate measures to ensure that persons with disabilities can exercise the same rights to freedom of expression and information as other people and through all forms of communication of their choice. The term 'communication' should include languages, display of text, Braille, tactile communication, large print and accessible multimedia, as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology. We therefore make the following recommendations to the Lebanese government:

## **Consultation**

Carry out comprehensive consultations with National Council of Disability Affairs, disabled persons' organisations and all relevant ministries on reforms and policies to ensure the rights of persons with disabilities.

## **Legal Framework**

Ensure that the rights to freedom of expression and information of persons with disabilities and the right to equality and non-discrimination are protected in Lebanon's domestic legal system.

Reform Law 220/2000 in consultation with all relevant stakeholders.

Adopt legislation ensuring the right to information for patients subjected to involuntary medical treatment.

## **Budgets**

Ensure that government budgets give a clear account of expenditure on disability.

## **Accessible formats**

Ensure that government information is accessible in a range of formats responding to the diverse needs of people with disabilities, including sign language, Braille, audio, electronic and easy-to-read and understand versions. Ensure that other authorities remove obstacles to access which prevent persons with disabilities from participating fully in everyday life.

## **Proactive dissemination**

Ensure that persons with disabilities and the public have access to reliable and accurate information about all matters relevant for the achievement of their rights, and that this is provided on the basis of pro-active disclosure.

## **Information needs in specific circumstances and reasonable accommodation**

Reform the system of residential institutions to ensure proper safeguards, such as the right to periodic review. Ensure proper reviews and inspections of residential facilities.

Ensure that reviews are conducted regularly and that information is provided so that the individual concerned can understand the reason for their placement in an institution and can challenge it.

Provide information about alternatives to residential care.

Ensure that the information provided is accessible and, in cases of persons with intellectual impairments, ensure that reasonable accommodation is made so that the individuals concerned can fully understand the information provided to them.

## **Statistics and Data**

Ensure that accurate, reliable and comprehensive information and data relating to both disabilities and the full achievement of human rights by people with disabilities are collected on a regular basis and maintained in an organised and systematic manner.

Ensure that this information is open and accessible and disaggregated according to underserved areas, urban and rural disparities and upper and lower income quintiles.

Develop indicators and benchmarks that monitor Lebanon's progress towards people with disabilities achieving their rights in full, following guidance from relevant international global agencies with experience in producing indicators on different aspects of human development, and in consultation with experts and Disabled Persons' Organisations.

## Endnotes

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<sup>1</sup>For example, *UN Convention on the Rights of the Child* (Article 13); *Arab Charter on Human Rights* (Article 32); *European Convention on Human Rights* (Article 10), *American Convention on Human Rights* (Article 13); *African Charter on Human and Peoples' Rights* (Article 19).

<sup>2</sup> See *Report of the Special Rapporteur, Promotion and protection of the right to freedom of opinion and expression*, UN Doc. E/CN.4/2000/63, 18 January 2000, para 42; or the 2004 [Joint Declaration on Access to Information](#) of three special mandates on freedom of expression at the UN, OSCE and OAS.

<sup>3</sup> The Lebanese Constitution (1995), Article 13

<sup>4</sup> *Law 444/2002 on the Protection of the Environment*

<sup>5</sup> *Legislative Decree No. 112/59* (1959) Public Sector Staff Regulation, Article 15

<sup>6</sup> CRPD Articles 9, 21

<sup>7</sup> Bill Hughes and Kevin Paterson (1997) 'The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment', *Disability and Society* 12:3

<sup>8</sup> CRPD, Preamble (e)

<sup>9</sup> ESCWA/League of Arab States (2014) *Disability in the Arab Region: an overview*, Beirut, page 10

<sup>10</sup> WHO/World Bank (2011) *World Report on Disability*, Geneva/Washington D.C., page 27

<sup>11</sup> ESCWA/League of Arab States (2014) *Disability in the Arab Region: an overview*, Beirut, page 57

<sup>12</sup> Central Administration of Statistics and UNDP (2006) *Living Conditions of Households: the National Survey of Household Living Conditions 2004*, Beirut, page 72

<sup>13</sup> The term 'administrative data' refers to information collected by government departments and other organisations such as registration and transaction records, usually during the delivery of a service.

<sup>14</sup> Print-out of administrative data from the Ministry of Social Affairs, dated 27 Oct 2014.

<sup>15</sup> Central Administration of Statistics and UNDP (2006) *Living Conditions of Households: the National Survey of Household Living Conditions 2004*, Beirut, page 72

<sup>16</sup> SylvanaLakkis and Edward Thomas (2003) *Disability and livelihoods in Lebanon*, available at <http://r4d.dfid.gov.uk/Output/174965/>

<sup>17</sup> ILO (2013) *Emerging good practices related to the training and job placement of persons with disabilities in Lebanon*, Beirut

<sup>18</sup> UNESCO (2013) *Social inclusion of young persons with disabilities in Lebanon: where do we stand and what should be done to promote their rights?* Beirut (LB/2014/SS/RP/69, page 14)

<sup>19</sup> UN Committee on the Rights of the Child (2005) *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Third Periodic Reports of States Parties Due in 2003, Lebanon*, CRC/C/129/Add.7, Geneva, para 304

<sup>20</sup> Lebanon's 2004 state report to the Committee on the Rights of the Child said there were 32,484 children in residential care institutions for newborns, orphans and social cases, vocational and delinquency.<sup>20</sup> A non-attributable 2006 study found there were 23,458 children in residential care, excluding institutions for children with disabilities. A non-attributable 2001 study found that there were 4,631 children with disabilities in 64 institutions, not all of them long-stay. An official of the Ministry of Social Affairs stated that there were 8,000 people in [adult and child] institutions for disability.

<sup>21</sup> UNICEF and Syrian Commission for Family Affairs (2008) *Situation Analysis of Childhood Status in Syria*, Damascus, page 138; UNICEF and National Council for Family Affairs (2007) *Children in Jordan, Situation Analysis 2006-2007*, Amman, page 99

<sup>22</sup> CRPD Article 26.1

<sup>23</sup> Committee on the Rights of the Child (2013) *General comment No. 14 on the right of the child to have his or her best interests taken as a primary consideration* (Art. 3, para. 1), paras 58-70; CRPD Articles 12.4, 23.4

<sup>24</sup> Jean Aziz (2014) 'Lebanese officials file lawsuit against the state', *AlMonitor*, available at <http://www.al-monitor.com/pulse/originals/2014/11/lebanon-lawsuit-against-state-budget-expenditure.html#>, accessed on 19 Jan 2015

<sup>25</sup> Interview with AdibNehmeh, December 2014

<sup>26</sup> Lebanese constitution (1995) Preamble, para h; Art 95

<sup>27</sup> World Bank (2013) *Lebanon: Economic and Social Impact Assessment of the Syrian Conflict*, Washington D.C., pages 1-6

<sup>28</sup> *Law 220/2000 on the Rights of Disabled Persons*, Articles 6-26

<sup>29</sup> *Law 220/2000 on the Rights of Disabled Persons*, Articles 12.1

<sup>30</sup> Interview, December 2014

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- <sup>31</sup> Interview, December 2014
- <sup>32</sup> CRPD Articles 2, 4.3
- <sup>33</sup> Standard Rules, Rule 5
- <sup>34</sup> UNESCO (2013) *Social Inclusion of Young Persons with Disabilities in Lebanon: Where do we stand and what should be done to promote their rights*, Beirut, page 15
- <sup>35</sup> Standard Rules 16.1
- <sup>36</sup> Committee on Economic, Social and Cultural Rights (1981) *General Comment No. 1, Reporting by States Parties*, E/1989/22 paras 2 and 4; (1994) *General Comment No. 5: Persons with Disabilities*, E/1995/22, para 13
- <sup>37</sup> See Lebanon's *Open Budget Survey 2012*, available at <http://internationalbudget.org/wp-content/uploads/OBI2012-LebanonCS-English.pdf> (accessed 6 March 2015)
- <sup>38</sup> Interview with Disabled Persons International adviser, December 2014
- <sup>39</sup> *Law 220/2000 on the Rights of Disabled Persons*, Articles 36 and 37
- <sup>40</sup> The other references to information and awareness raising in *Law 220/2000 on the Rights of Disabled Persons* relate to training for transport staff and police on the needs of passengers with disabilities (Article 51) and awareness of disability rights in the civic education syllabus (Article 64)
- <sup>41</sup> Data available at <http://apps.who.int/nha/database/DataExplorerRegime.aspx>
- <sup>42</sup> UNESCO (2013) *Social inclusion of young persons with disabilities in Lebanon: where do we stand and what should be done to promote their rights?* Beirut (LB/2014/SS/RP/69, page 14)
- <sup>43</sup> CRPD Articles 4.1.h, 23.1, 26.3
- <sup>44</sup> CRPD Article 12.4
- <sup>45</sup> *Law 220/2000 on the Rights of Disabled Persons*, Article 62.a
- <sup>46</sup> CRPD Articles 21 and 30
- <sup>47</sup> CRPD Article 7.3
- <sup>48</sup> Committee on the Rights of Persons with Disabilities (2014) *General comment No. 1, Article 12, Equal recognition before the law*, CRPD/C/GC/1, para 42
- <sup>49</sup> CRPD Articles 12.4 and 23.2
- <sup>50</sup> CRPD Article 13.1
- <sup>51</sup> CRC Article 9, CRPD Article 23.4
- <sup>52</sup> CRPD Article 19
- <sup>53</sup> Standard Rules, Rule 4
- <sup>54</sup> CRC Article 25, CRPD Article 23.4
- <sup>55</sup> CRPD, Article 12.4
- <sup>56</sup> Decree 5734 (1994) on the organisation of the Ministry of Social Affairs, Article 25.e
- <sup>57</sup> UN Committee on the Rights of the Child (2006) *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Third Periodic Reports of States Parties Due in 2003, Lebanon*, CRC/C/129/Add.7, Geneva, October 25, page 63
- <sup>58</sup> Interview, December 2014
- <sup>59</sup> Decision 1/121 (2004) on the organisation and definition of groups of beneficiaries of social care in institutions contracted to the Ministry of Social Affairs, Article 19
- <sup>60</sup> LPHU (2013) *٢٠١٣ تقرير الرصد الثاني، مرصد حقوق الأشخاص المعوقين*, Beirut
- <sup>61</sup> UN Committee on the Rights of Persons with disabilities (2014) *General Comment No. 1: Article 12, Equal recognition before the law*, para 12
- <sup>62</sup> *Law 220/2000 on the Rights of Disabled Persons*, Article 1.d
- <sup>63</sup> Interview, December 2014
- <sup>64</sup> *Legislative Decree 72/1983* relating to the care and treatment of the mentally ill.
- <sup>65</sup> *Law 288/2004 on medical ethics*
- <sup>66</sup> The draft law, entitled '*Care, treatment and protection for those affected with mental or psychological illnesses*,' was presented by the Idrak organisation.
- <sup>67</sup> UN General Assembly Resolution 46/119 (1991) *The protection of persons with mental illness and the improvement of mental health care*, A/RES/46/119, para 19
- <sup>68</sup> Manfred Nowak (2005) *UN Covenant on Civil and Political Rights. CCPR Commentary*, Kehl am Rhein: Engel, page 446, para 18
- <sup>69</sup> Interview, November 2014
- <sup>70</sup> Committee on Economic, Social and Cultural Rights (1981) *General Comment 1, Reporting by States Parties*, E/1989/22 para 11. Other international legal instruments echo this emerging obligation to collect statistics about specific groups. For example, the 1946 Constitution of the World Health Organisation requires statistical reporting on

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health (Article 64). UN General Assembly Resolution 63/150 (2009) '*Realizing the Millennium Development Goals for persons with disabilities through the implementation of the World Programme of Action concerning Disabled Persons and the CPRD*' encourages state to collect and analyse statistics and other data on the situation of persons with disabilities (A/RES/63/150, para 5). UN General Assembly Resolution 65/186 (2011) '*Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond*' calls on governments to strengthen national data on disability (A/RES/65/186 para 13).

<sup>71</sup> CPRD, Article 31

<sup>72</sup> David B. Gray, Gerry E. Hendershot (2000) 'The ICDH-2: Developments for a new era of outcomes research' *Archives of Physical Medicine and Rehabilitation*, 81, page S11

<sup>73</sup> Interview with CAS official, December 2014