Economic and Social Commission for Western Asia (ESCWA)

Barriers to Implementing Article 19:

A Study on the Institutionalization of Persons with Disabilities in Select Arab Countries

United Nations

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The views expressed in this report are those of the authors and do not necessarily reflect the views of the United Nations or its officials or Member States.

Table of Contents

Tables

Acronyms

CLS	Centre for Lebanese Studies
CRPD	Convention on the Rights of Persons with Disabilities
EGM	Expert Group Meeting
ESCWA	Economic and Social Commission for Western Asia
HCD	Higher Council for the Affairs of Persons with Disabilities
ISDS	Inclusive Social Development Section
ISG	International Solutions Group
MoSA	Ministry of Social Affairs
NGO	Non-governmental organization
SDD	Social Development Division
UN	United Nations
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
UNOHCHR	United Nations Office of the High Commissioner for Human Rights
USD	United States Dollar

Glossary

Deinstitutionalization	The process of transitioning from residential care for Persons with Disabilities to independent living and their inclusion in the community.
Elderly Persons	Persons aged 65 and older.
Institutionalization	The practice of relying on residential institutions to provide care for Persons with Disabilities. According to the Convention on the Rights of Persons with Disabilities, it is crucial to "find alternatives that will lead people with disabilities to independent living".
Institutionalization rate	The proportion of institutionalized persons within a population
Persons with Disabilities	Persons with long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others, as defined in the Convention on the Rights of Persons with Disabilities.
Residential Institutions	Public or private entities providing care for adults or children with disabilities who stay there as residents. These entities usually provide food, shelter and sometimes, specialized care for the Persons with Disabilities residing there.
Social Protection	National policies to ensure income security and access to basic health care. Such programmes can be contributory, such as social insurance and social health insurance, or non-contributory, such as social assistance and health care services provided for free or at reduced costs.
Social Protection Floor	A nationally defined set of basic social security guarantees which secure protection aimed at preventing or alleviating poverty, vulnerability and social exclusion.
Working age population / workforce	Population aged 15-64

Executive Summary

Under Article 19 of the Convention on the Rights of Persons with Disabilities (UN CRPD), individuals with disabilities are entitled to live independently and be included in their communities. Throughout the world, the practice of placing children and adults with disabilities into residential institutions (institutionalization) presents a significant barrier to the realization of these rights. Residential institutions often operate in isolation from local environments, restricting the autonomy of those they are intended to serve. Article 19 of the UN CRPD imagines a radically different way of supporting persons with disabilities, calling for the provision of personalized assistance within communities, and for existing local facilities and services to be made universally accessible. Most importantly, Article 19 states persons with disabilities should be able to choose where and with whom they live, just like everyone else.

Residential institutionalization is not the only practice that stands against the implementation of Article 19, but it is one of the most prevalent. In the Arab region, as in the rest of the world, a range of residential institutions have been established. To date, there has been little collective examination of the residential institutions that currently operate in in Arab states. On a regional level, the services available in institutions, the living conditions experienced by residents of institutions, and the regulation and monitoring of institutions by governments have remained largely unexplored.

This report examines these and other topics selectively across 18 Arab countries through the lens of state commitments under Article 19. Though limited in scope, through interviews with public officials and directors of institutions, as well as persons with disabilities living in institutions, their caregivers, and family members, the report provides insight into existing institutionalization practices, as well as reflects on future pathways to deinstitutionalization.

Overall, the report finds that few of the institutions studied are providing the kind of care and services required to facilitate the integration and independent living of persons with disabilities in their communities. It also finds that that in many Arab states, families often turn to institutionalization due to a lack of alternative care options and the inaccessibility of many public spaces, services and facilities. With these two pieces of information in mind, the report identifies the immediate need for deinstitutionalization strategies that address the creation of

new local support services, the improvement of accessibility in all areas of society, and the eventual closure of residential institutions.

As a regional study, albeit a qualitative one on a modest scale, this report seeks to assist Arab governments that have signed the Convention in developing new insights on the implementation of Article 19. It also strives to inform a variety of actors concerned with monitoring the implementation of the Convention on the progress states are making in implementing Article 19, and to provide guidance for any organizations or groups wishing to promote the inclusion and independent living of persons with disabilities.

Please note that the findings of this study mainly relate to the sample of institutions interviewed and shall not be taken as a general statement about other institutions in the region.

MAIN FINDINGS

Causes of institutionalization
The study found that institutionalization is often a result of the inability of families to care for relatives with disabilities for reasons that include a lack of local services, inadequate access to transportation, limited financial resources, and difficulties providing appropriate care in the home environment. Residential institutions in the region accommodate a significant number of orphaned and abandoned persons with disabilities, as well as many children of divorced parents, children from families that have more than one family member with disabilities and children with multiple disabilities. For some interviewed families, social stigma and the fear of harassment or abuse also played a role in the decision to place their relatives with disabilities in residential institutions.

Types of institutions
Most countries in the region have public residential institutions, except Lebanon, whose institutions are all run by civil society organizations and funded by the government. Private institutions were more likely to have high staff turnover due to job dissatisfaction and low wages. Various governmental and non-governmental bodies, individuals and/or families covered residency costs for persons with disabilities, depending on the type of institution (i.e., public, private for-profit or private non-profit).

Types of care provided

Care provided in institutions varies in quality and scope. While some institutions provide only food and shelter alongside basic medical services, others offer specialized services, such as rehabilitative medical care, formal, informal and vocational education, employment support, psychosocial support, transportation assistance, and activities outside the institution. Only six out of 19 institutions interviewed provide in-house formal education following national curricula, though others offer non-standardized educational programming, such as literacy classes.

Monitoring of institutions

All directors of institutions reported that their institutions were regularly inspected by government bodies but given the often poor living conditions within some institutions, standards and procedures for such monitoring were unclear. Additionally, reporting and monitoring processes frequently varied between public and private institutions, and at times, government officials expressed lacking influence over institutions in the private sector. Morocco's Act No. 65-15 of 2018 on the governance and monitoring of residential institutions, which requires institutions to create internal monitoring committees, is a notable example of progress in this area.

Obstacles to independence

In interviews, the majority of directors of institutions stated that institutionalized persons with disabilities had limited prospects for independence or integration into formal school systems, the labour market and/or society at large. According to these interviews, the majority of institutionalized persons with disabilities were illiterate. Those who received formal education outside the institution accounted for less than five per cent of the total number of residents in all 19 institutions. In case studies of two institutions, more than 80 per cent of interviewed residents were reportedly either never offered an opportunity to go to school or had dropped out of school.

The study found only a few instances of residents employed inside or outside institutions: many worked for low wages, and in some instances their parents received their remunerations. For residents with access to education or employment, decisions on what they should study or where they should work were often made by caregivers or parents.

The study revealed a complex relationship between the staff of institutions and the families of persons with disabilities: a lack of successful communication between these two parties appeared to create additional challenges for residents. While staff referenced a lack of familial involvement in the lives of institutionalized persons, interviewed parents mentioned that they felt they did not have the skills necessary to adequately support their children. Case studies showed that disconnect between family members and staff regarding care plans occasionally resulted in difficult and emotionally taxing situations for persons with disabilities, particularly when transitioning back and forth between their communities and the institution.

In 10 of 19 institutions, staff perceived residents as likely to stay permanently, and described social stigma as the main barrier to integration. Persons with disabilities, however, viewed the lack of employment and education opportunities as the central barriers to their independence.

Strategies for deinstitutionalization, integration and inclusion
While the majority of the 13 public officials interviewed for this report supported deinstitutionalization, few disclosed any specific plans and timelines. A key exception is Jordan, which has a ten-year plan mandated by law to close institutions for persons with disabilities by 2027. Jordan's plan intends to replace residential institutions with alternative community-based facilities such as group homes and independent living centers, in addition to providing training and financial support to families to help them accommodate residents with disabilities at home.

While Jordan was the only country surveyed that possessed a concrete plan to close residential institutions, public officials from other countries mentioned strategies intended to increase the inclusion of persons with disabilities in communities and thus lessen the use of residential institutions. The public official from the State of Palestine described plans to create new accessible housing units for persons with disabilities, and to provide medical equipment and financial support to persons with disabilities and their families. In Morocco and Lebanon, efforts to increase social inclusion have prioritized improving persons with disabilities' access to formal and informal education. Saudi Arabia intends to promote deinstitutionalization through expanding care subsidies and providing training to families. While the majority of interviewed public officials affirmed the importance of increasing the inclusion of persons with disabilities in public life, throughout the region, there was little evidence of state-led plans with the end goal of closing residential institutions.

Gaps in data

Officials and representatives from 14 Arab States (Bahrain, Iraq, Jordan, Lebanon, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Sudan, Syria, Tunisia and Yemen) provided basic numerical data on institutions offering residential services for persons with disabilities and/or the total number of institutionalized persons with disabilities in their respective countries. However, the research team often encountered a lack of distinction between residential and non-residential institutions, as well as an absence of data on private institutions. The research team also identified a significant lack of disaggregated data regarding the age, sex, and disability types of persons with disabilities living in institutions. A notable exception was Jordan, which made available current and detailed official statistics on persons with disabilities, including institutionalization rates disaggregated by gender and country of origin. Without proper data on institutions, it is difficult for governments and other interested parties to fully monitor the implementation of Article 19.

RECOMMENDATIONS

Based on its findings and guided by the provisions of Article 19, the report makes the following recommendations.

Deinstitutionalization plans with concrete timelines, budgets and sources of alternative should be adopted. The guidance of the UN Committee on the Rights of Persons with Disabilities recognizes that while the implementation of Article 19 is an urgent human rights priority, its full realization requires structural shifts that may need to be taken in stages.[1] This concept of progressive achievement is particularly relevant to countries in the Arab region, in which the immediate and complete closure of all institutions may not be feasible for reasons related to war and conflict, poverty, inaccessible infrastructure and weak social protection systems. However, to meet the requirements of Article 19, even states facing these challenges must actively plan for deinstitutionalization through increasing the accessibility of community services and creating new systems of local personal assistance, with the end goal of ending the use of residential institutions. The exact pathways taken by States to achieve this final result may differ, but according to the CRPD maintaining the status quo of institutionalized care is not an option. At every stage of the deinstitutionalization planning process, States should

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[1] CRPD, 2017d, p.2.

actively consult with civil society, seeking the opinions of persons with disabilities and their representative organizations. Especially countries coming out of violent conflict should design reconstruction in a way that facilitates the inclusion of persons with disabilities in their local communities.

Our understanding of the extent and scope of institutionalization needs to improve. Further in-depth research and data collection are needed to concretely identify the numbers and types of residential institutions in the Arab world, as well the profiles of institutionalized persons with disabilities and the quality of care they receive. In many cases, the available data does not allow for a solid understanding on which strategies can be built. The available information on Lebanon indicates that almost half of the children receiving free education or vocational training at the residential schools are formally registered as "residential" although they return to their families in the evening.[2] Robust and reliable statistics on institutionalization are needed to fully evaluate progress made by Arab States in their implementation of Article 19, and to inform deinstitutionalization plans and policies.

Throughout transitions to community-based services, improved monitoring and regulation are necessary to ensure existing residential institutions provide high quality care. While states plan for and implement alternatives to residential institutions, steps must be taken to ensure persons with disabilities currently living in institutions are protected, supported, and listened to. Governments must actively monitor and regulate all operational institutions, identifying barriers to residents' autonomy and facilitating necessary improvements in the provision of care and services while keeping larger goals of independent living in mind.

More inclusive, better-quality and individualized support services for persons with disabilities are needed at the local level. In addition to ensuring hospitals, schools, recreational and commercial spaces, transport, employment support, etc. are accessible to people with disabilities, home and community-based support services can make caring for individuals with disabilities less costly and lessen the pressure on families to send family members to institutions, which are often located in bigger cities. This can include subsidized personal assistance and assisted living programs, medical equipment, adaptation of the home environment and individualized rehabilitative care.

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[2] USJ, 2012.

Governments should redirect state resources away from institutions to directly supporting persons with disabilities and their families. Currently, many Arab countries provide financial support to public and non-profit institutions, and some subsidize care in private residential centers. Individuals with disabilities from disadvantaged socioeconomic backgrounds are more likely to end up spending their lives in residential institutions since support services maybe be expensive, difficult to obtain or far from home. This study recommends that as part of deinstitutionalization plans, governments redirect their financial support away from residential institutions and to persons with disabilities and their families or caregivers, in addition to improving the provision of necessary facilities and services within communities. Additionally, making the provision of community-based services for persons with disabilities an identifiable budget item also contributes to the coordination of Article 19's implementation.

Education and employment are two essential means to ensure the inclusion of individuals with disabilities in society. Inclusion in the mainstream education system and workforce are important ingredients for inclusion in the community. Investing in inclusive education and implementing/upholding inclusive labour laws, policies and programmes will boost the intellectual and financial independence of persons with disabilities, thus reducing isolation and promoting independent living and participation in society. The existing numbers in the case of Lebanon suggest that most of the children holding a Personal Disability Card do not attend integrated public schools. [3]This raises serious concerns about the whereabouts of children who hold a Personal Disability Card and their access to education and their future participation in the labour market.

Accessible transportation can help individuals remain in their communities. Even when institutions offer non-residential programs, inaccessible transport services, high transportation costs and logistical difficulties force many families to place their relatives in institutions full time. In addition to establishing more facilities and services at the local level, ensuring access to accessible, affordable and efficient transportation will allow individuals to seek specialized care, education and employment outside of their communities while maintaining their residence of choice.

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[3] CERD, 2014.

Mitigating stigma surrounding disability will help support social inclusion. Negative depictions of individuals with disabilities in public culture reinforces the separation and exclusion of persons with disabilities from society. Public education campaigns can help fight stereotypes and portray positive images that fight the stigma and shame surrounding disability. Governments can enlist the help of civil society organizations and media groups to identify discriminatory stereotypes and reinforce more equitable norms that advance social inclusion.

Finally, the study found that the majority of public officials were pro-deinstitutionalization while directors of institutions often maintained that their role was to protect persons with disabilities from society. **Further dialogue is needed between government officials and institutions on how institutions can support the transition away from segregated residential care and become establishments that continue to provide specialized services while fostering independent and community living.** In many instances, residential institutions are the only entities available to persons with disabilities that have the capacity to provide specialized services, so rather than simply shuttering them, they could be redesigned in a way which replaces institutionalized care with day-service facilities that support the principles outlined in Article 19.

This report comprises five chapters. The first chapter presents an introduction to the study in addition to some recommendations. The second chapter describes the methodology deployed in this study and its limitations. The third chapter presents the empirical findings of the interviews with public officials and heads of institutions. The fourth chapter presents the findings of the case studies. Finally, the fifth chapter presents a conclusion of the study and recommendations for the way forward.

Chapter 1: Introduction

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

b) *Persons with disabilities have access to a range of in-home residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

c) *Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

—UN Convention on the Rights of Persons with Disabilities (Article 19)

There is no single set definition for disability, though recent years have seen a confluence of several analytic models that have informed how disability is understood in society. For a long time, a dominant model was the medical model of disability, which assumes that disabilities and impairments must be "fixed" through rehabilitation and medical treatment.[4] By presenting disability as an ailment to be cured, the medical model positions life with disability as outside the norms of human functioning, ultimately dividing persons with disabilities from persons without disabilities.

Today, a transition away from the medical model of disability has opened the door for reflection on the practice of institutionalization. In general, institutions for people with disabilities often operate by restricting residents from participating in the outside community and giving them little to no choice about their activities and how they are treated.[5] Even

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[4] Rohwerder, 2015.
[5] Chow and Priebe, 2013.

institutions that are well-monitored and regulated can lead to exclusion and deprive people with disabilities of their freedom and ability to interact with society an equal basis with others.

The institutionalization and the time people with disabilities spend in institutions are often strong indicators of negative psychosocial impact. If persons with disabilities must conform with a pre-planned, non-individualized schedule, and are subjected to prolonged periods of isolation, they may suffer psychosocial distress and deterioration: institutionalization can diminish autonomy and self-confidence, worsen mental health conditions, provoke negative and self-damaging behaviors, and cause attachment problems and distorted relationships, making it more difficult to live in society.[6]

Deinstitutionalization movements globally have stemmed from negative perceptions of the effects of institutions on the physical and psychosocial condition of persons with disabilities, as well as from baseline objections to the practice of excluding persons with disabilities from society. Within the deinstitutionalization movement, two main camps have emerged. Some countries, such as the United States, have chosen to transform existing residential institutions into community health centers.[7] Civil society has long been critical of this strategy, calling instead for the complete closure of institutions and the creation of new structures for providing personal assistance and services.

Regardless of the chosen approach, many countries have advanced in supporting community-based models of individualized care. Yet only modest progress has been made on this front in many Arab countries, despite 21 out of 22 having signed and/or ratified the Convention on the Rights of Persons with Disabilities.[8][9] Much more needs to be done to integrate persons with disabilities into society, challenge cultural stigmas surrounding disability, and expand the services needed to allow persons with disabilities to live and actively participate in their communities.

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[6] Kaur & Vinnetoka, 2018; Bos, Fox, Drury, McLaughlin, Nelson & Zeanah, 2011; Ratoskan & Tanga, 2009.
[7] Dumont, 2008.
[8] Only Somalia has not signed the Convention.
[9] United Nations Treaty Collection, 2018.

Persons with disabilities in the Arab region face substantial disadvantages in key areas of human development, creating further barriers to integration and inclusion. They have lower rates of literacy, educational attainment, school attendance and economic participation and continue to be marginalized from the education system and the labour market.[10] For example, most schools in Lebanon still exclude children with disabilities, including through inaccessible school premises, and inappropriate school curricula and teaching methods.[11] Some progress, however has been achieved by including children with learning difficulties in about 30 schools in Lebanon.

When considering the issue of deinstitutionalization in the Arab region, it is important to note that the social inclusion of persons with disabilities has not been mainstreamed in most Arab countries – cities are not accessible, schools are not inclusive and specialized services for persons with disabilities are often available only in institutions. Without options available at the local level, persons with disabilities and their families often have no other choice but to turn to institutions to meet their needs.

An international framework for rights and services

A landmark change in the concept of disability, now grounded firmly in human rights, occurred in 2006 with the adoption of the Convention on the Rights of Persons with Disabilities. The Convention codified a shifting in mentality away from an approach to disability that assumes impairments exist within an individual and require medical treatment or rehabilitation, to the view that the interaction between impairments and the barriers that exist in society result in disability, so action must be taken to reduce these barriers. Through its detailed framework of economic, social and cultural rights, the Convention positions persons with disabilities as rights-bearers entitled to and capable of exercising key freedoms in society. The Convention outlines the way States Parties should provide environments conducive to exercising such freedoms, alleviating the burden for individuals and highlighting the shared responsibilities of communities and Governments.

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[10] ESCWA, 2018; Musawi, Ali and Ramadan, 2015.
[11] Human Rights Watch, 2018.

Twelve Arab countries have reported to the UN Committee on the Rights of Persons with Disabilities, to which States Parties are expected to report on the measures they have taken to fulfil their obligations under the Convention. Comoros, Egypt, Libya,[12] the State of Palestine, Syria and Yemen have not yet submitted their first reports to the Committee.[13] However, those reports which have been submitted have rarely addressed institutionalization, with States Parties focusing instead on improvements in rehabilitation, education, employment and accessibility to public spaces, as well as on raising public awareness to counteract cultural stigma and discrimination.

Monitoring the implementation of Article 19 poses a distinct challenge, as the article is closely tied to civil and political rights, which must be protected immediately, as well as economic, social, and cultural rights, which can be progressively realized. The principle of progressive realization, stated in Article 4 of the Convention, acknowledges that due to context-specific challenges, State parties may need time to generate action plans and strategies. This is affirmed by Committee guidance that acknowledges implementing Article 19 may require lengthy structural transitions.[14] As stated prior, this is relevant to many Arab countries, in which the immediate closure of institutions may be unrealistic due to armed conflicts, poor infrastructure, or a lack of resources. Such circumstances do not exempt Governments from action, but rather call attention to the need of State Parties to actively create plans addressing the inclusion of persons with disabilities in society, of which deinstitutionalization should be a component.

The issue of institutionalization is closely related to several of the Convention's other articles. The practice of institutionalization and the provision of isolated care denies persons with disabilities the ability to participate in many key elements of society, such as in family life (Article 23), the workforce (Article 27) and political systems (Article 29).

Article 19 also shares strong links with Article 12 on equal recognition before the law. Both prior to and throughout the institutionalization process, many individuals with disabilities are denied legal capacity, or the ability to exercise their rights through making substantive decisions about their own lives.[15] This is particularly true for persons with psychosocial

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[12] Libya only ratified the Convention in February 2018.
[13] UNOHCHR, n.d.
[14] CRPD, 2017d.
[15] Mental Health Europe, 2012.

disabilities living in institutions, as mental health legislation often contains provisions allowing for decisions to be made on their behalf, including decisions about the length of stay in institutions and the type of treatment received. A denial of legal capacity also often bars persons with disabilities from owning property, opening bank accounts, and voting, all critical modes of community participation.

Broadly, the practice of institutionalization is discrimination, stigma, and inaccessibility. Negative views of disability contribute to assumptions that persons with disabilities cannot or should not live in communities on an equal basis to others, contributing to the provision of institutionalized care and the failure to make public spaces and facilities universally accessible. In this sense, Article 19 seeks to address issues also touched upon by Article 5 on non-discrimination, Article 8 on awareness raising, and Article 9 on accessibility.

National actions: Where countries in the Arab region stand on disability and inclusion

As a starting point for considering the issues of institutionalization of persons with disabilities, some general insights can be gleaned from national documents, as available, including state reports filed under the Convention. This section will give a brief regional overview of the actions countries have taken in relation to Article 19, based on information gleaned from the desk review as well as supplementary data provided by government officials during the course of the study.

The Gulf

Bahrain's 2017 report to the Committee did not refer to deinstitutionalization but indicated considerable progress in including persons with disabilities in society in terms of education, health care, employment and accessibility.[16] In 2007, Bahrain's Ministry of Labour and Social Development established the Center for Services for People with Disabilities. According to the report, while the center does provide accommodation to persons with disabilities, it also offers a variety of non-residential services, such as vocational training and physiotherapy programs,

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[16] CRPD, 2017.

and provides counseling to families. Bahrain's reporting on Article 19 also focused on ensuring the independence of persons with disabilities through inclusive housing measures.

The **Kuwait** 2015 report outlined plans for a new social integration scheme for persons with disabilities: this scheme includes plans to clarify obstacles to integration, develop procedural mechanisms for each stage of the integration process, and introduce an awareness campaign to reduce stigma and foster social cohesion.[17] Article 28 of Kuwait's Constitution guarantees the right of all individuals, including persons with disabilities, to mobility and free choice of location and type of accommodation. Kuwait's report did not mention deinstitutionalization, instead presenting housing policy as a means to ensure community integration. Persons with disabilities receive priority in the housing welfare application process, as well as stipends for domestic help, including drivers for those with "moderate or severe" disabilities.[18]

The report from the **Kingdom of Saudi Arabia** 2015 stated that 15 per cent of all students with disabilities live in boarding facilities, where they receive a monthly personal allowance. While individuals with disabilities have the right to home care and support services under Decision No. 24 of Saudi Arabia's 1980 Social Rehabilitation Regulations, the country's more recent Disability Care Act of 2000 guarantees care through a variety of state-run institutions, and perhaps encourages the use of these institutions by providing stipends to those who use their services.[19]

The **United Arab Emirates'** 2013 report to the Convention referenced to the country's Federal Act No. 14 of 2009, which "guarantees the right of persons with disabilities to enjoy an enabling environment in conditions conducive to an independent life".[20]The act prohibits the accommodation of persons with disabilities "in such a way to isolate and exclude them from their family milieu," and stipulates rehabilitation programs should be primarily concerned with facilitating community integration. The initial report stated that the Ministry of Social Affairs had signed memorandums of understanding with the Sheikh Zayed Housing Programme and the Ministry of Public Works with the purpose of encouraging these bodies to provide an

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[17] CRPD, 2015.
[18] CRPD, 2015.
[19] CRPD, 2015c.
[20] CRPD, 2013.

"enabling environment" for persons with disabilities.[21] Following the United Arab Emirates's 2013 submission, the Committee urged the State party to further develop community-based services to promote the inclusion of persons with disabilities.[22] Rehabilitation centers and other facilities are currently run jointly through the Ministry of Community Development, the Zayed Higher Organization for Humanitarian Care, and the Sharjah City for Humanitarian Services .[23] Notably, the Zayed Organization provides opportunities for in-home treatment. Certain vocational training programs for young adults in the United Arab Emirates include an assisted transition to independent living at age 18.[24]

Qatar's 2012 report addressed social integration primarily through inclusive housing and accommodation policies.[25]Referring to children whose parents are unable to care for them, the report noted measures to avoid institutionalization through placing the child with extended family or another family within a community. In 2016, Qatar opened its first community-based mental health center, offering outpatient treatments for children and teenagers in a "home-like" environment: this center and others like it are meant to provide holistic alternatives to hospitalization.[26]

The **Sultanate of Oman's** 2014 report focused on the creation of awareness campaigns concerning the rights of persons with disabilities and the construction of accessible public spaces and community facilities. The report also referenced Article 11 of Oman's 2008 Care and Rehabilitation of the Disabled Act, which addresses social integration through requiring "agencies concerned with social, athletic and cultural activities to accommodate the participation of individuals with disabilities".[27] The report named eight private and public institutions that provide care for persons with disabilities but did not stipulate whether or not these institutions offer residential services.[28]According to a state official from Oman, the Government is in the process of creating new disability legislation in accordance with the

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[21] CRPD, 2013.
[22] CRPD, 2016a.
[23] CRPD, 2016.
[24] CRPD, 2016.
[25] CRPD, 2012.
[26] Doha News, 2016.
[27] CRPD, 2014, p.26.
[28] CRPD, 2014.

Convention. Oman is also currently working in cooperation with UNICEF to identify mechanisms for disability detection and to promote the inclusion of children with disabilities in the country's educational system.[29]

Yemen signed the Convention in 2007 but has not yet submitted a CRPD report. Yemen's general disability Law No. 2 on establishing the Disabled Care and Rehabilitation Fund, was passed in 2002. The country also has a National Disability Strategy, brought into force in 2010. More than 300 organizations that previously provided specialized services to persons with disabilities have been forced to close as a result of coalition-led airstrikes in Yemen beginning in 2015.[30] UNOHCHR's 2015 report noted that monitoring the rights of Yemen's growing population of persons with disabilities is a distinct challenge in the ongoing conflict.

The Levant

In **Iraq**, the right to independent living is guaranteed under Article 17 of the Constitution. According to the country's 2015 report to the Committee, the majority of persons with disabilities live in "family settings".[31] Iraq's Child Protection Bill, proposed in 2013 and referenced in the country's report, contains articles relevant to the institutionalization of children with disabilities. Specifically, two chapters of the bill are dedicated to "the right of the child to reside in nurseries and state houses (alternative care institutions)" and "the right of the children with special needs to receive care and rehabilitation; especially because the State guarantees the protection of the child in any condition or action that impedes his/her learning, health, physical, or mental development" .[32] While the intended purpose of the bill is to secure the rights of children throughout Iraq, articles within these chapters may potentially encourage the institutionalization of children with disabilities if community support services are not available. The British council is working with the Ministry of Education in Iraq on an inclusive education policy.

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[29] UNICEF, 2016.
[30] UNOHCHR, 2015.
[31] CRPD, 2015d, p.17.
[32] CRPD, 2015d.

Over the last decade, **Jordan** has become a regional leader in its support of the rights of persons with disabilities to self-determination and independent living. Since 2008, disability programmes have aimed at integrating students with intellectual or visual disabilities into the standard education system.[33] In response to Jordan's submission of its initial report to the Committee in 2012, the Committee criticized the country's involuntary institutionalization of persons with disabilities and advised allocating necessary resources for a deinstitutionalization strategy.[34] Jordan has since introduced a revised law on disability that stresses the intersection of disability with the surrounding environment (Law No. 20 of 2017), as well as a new national disability strategy, including specific action plans for inclusive education, accessibility and deinstitutionalization. Informed by Law No. 20, Jordan's current action plan on deinstitutionalization aims to replace all residential institutions with community-based care centers over a period of ten years. Law No. 20, which replaced Law No. 31 of 2007, prohibits institutionalization of persons with disabilities except with their informed consent.

In 2007, the Government established the Higher Council for the Affairs of Persons with Disabilities (HCD), which was renamed to the Higher Council for the Rights of Persons with Disabilities in 2017 in accordance with the new law.[35] In line with the Convention and its role in supporting deinstitutionalization, the HCD in 2017[36] has emphasized the right of all people with disabilities to live independently and participate in their communities on par with other citizens. In accordance with Articles 27 and 29 of Law No. 20, the HCD has committed to taking the lead "to find alternatives that will lead people with disabilities to independent living [...] and terminate institutionalization on the basis of disability" by 2027.[37]

Lebanon signed both the Convention and its Optional Protocol in 2007, but its Parliament has not yet ratified them. Lebanon has a separate law on the rights of persons with disabilities (Law No. 220) and its national disability strategy is under development.[38] Lebanon has also established a National Committee for the Affairs of the Disabled. Throughout Lebanon, non-governmental organizations (NGOs) are the main providers of specialized services for persons

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[33] Peters, 2009.
[34] CRPD, 2017b.
[35] ESCWA, 2018.
[36] 2017.
[37] CRPD, 2017b.
[38] ESCWA, 2018.

with disabilities, rather than the governmental agencies.[39] Though the government supports several NGO-managed centers monetarily, as of 2013, no governmental medical institutions in Lebanon were equipped to provide specialized medical services to persons with disabilities.[40] Progress has been made specifically in the realm of psychosocial disability through Lebanon's 2015-2020 Mental Health Strategy, which placed an emphasis on funding community-based mental health services.[41]UNICEF is also currently working with the Ministry of Education to support the inclusion of children with learning disabilities in 30 public schools throughout Lebanon.[42]

Palestine ratified the Convention in 2014 but has not submitted a report to the Committee. The State's national disability legislation, Law No. 4 on the Rights of the Disabled, has not been updated since 1999, though Palestine adopted its National Strategic Plan for the Disability Sector in 2012.[43]A key policy goal of the plan is "the provision of all basic and vital services for persons with disabilities".[44] Palestine's Ministry of Health's 2016-2018 strategy also includes new disability related interventions, including the development of community-based mental health services.[45]

Syria has ratified the Convention but has not yet submitted its report to the Committee. In 2009, prior to the outbreak of the conflict, Syria established the National Plan for the Care and Rehabilitation of People with Disabilities.[46]The interviewed public official from Syria also reported the existence of a 2018-2020 plan to expand and improved disability-related services. Several international organizations are currently working in Syria to protect persons with disabilities. In 2016, UNICEF's Syria Country Office introduced the first cash transfer scheme to support the families of children with disabilities.[47]In evaluating the implementation of

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[39] UNESCO, 2013.
[40] UNESCO, 2013.
[41] Ministry of Public Health, 2015.
[42] UNICEF, 2018.
[43] ESCWA, 2016.
[44] World Bank, 2016, p.21.
[45] World Bank, 2016.
[46] ESCWA, 2018.
[47] UNICEF, 2017.

Article 19 in Syria, it is necessary to consider that over the course of the conflict, the majority of Syria's health infrastructure has collapsed .[48]

North Africa

Algeria's 2015 report under the Convention states that the Government signed an agreement with Handicap International (now known as Humanity & Inclusion) in 2011 to ensure the quality of care and services for persons with disabilities, and to further deinstitutionalization processes, specifically for children .[49]As of 2016, current projects from this partnership with Humanity and Inclusion include efforts to support inclusive education in the districts of Setif and Tizi Ouzou and to improve access to community-based rehabilitation services for children and adults in Western Saharan camps .[50]Algeria's CRPD report also mentions the deployment of local solidarity units by Algeria's Social Development Agency to monitor the implementation of Article 19.

Djibouti's 2016 report stated that due to the cultural importance of family ties, there are currently no residential care facilities for persons with disabilities in the country.[51] In the early 1990s, in response to internal armed conflict, the State created a rehabilitation center to provide treatment to persons who had acquired disabilities in the war, though this center has now closed. According to its report, Djibouti has since allocated two districts of subsidized housing to war veterans with disabilities.

Egypt signed the Convention in 2008 but has not yet submitted its first report to the Committee. In 2018, Egypt passed Law No. 10 on the Rights of Persons with Disabilities, the first update to the country's disability legislation since 1975.[52] The law notably supports inclusion through prohibiting educational institutions from rejecting students on the basis of disability. UNICEF has worked with Egypt to support inclusive education for children with disabilities, providing technical assistance to 120 schools throughout 2015.[53]

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[48] Handicap International, 2016a.
[49] CRPD, 2015b.
[50] Handicap International, 2016.
[51] CRPD, 2017c.
[52] Salabi, 2018.
[53] UNICEF, 2017.

Libya ratified the Convention in 2018 but it has not yet reported to the Committee. The country's national disability legislation, Law No. 5 on Disabled Persons, has not been updated since 1987.[54]The law suggests that persons with disabilities should reside with their families and only be provided with accommodation when necessary: the National Libyan Organization for the Development of Disabilities has criticized this aspect of the law as limiting the autonomy of persons with disabilities.[55] In late 2018, Libya's Ministry of Labour and UNDP brought together public officials and organizations of persons with disabilities to discuss a variety of issues, including community integration, through an initiative called "No One Left Behind.".[56]

Mauritania's 2017 report to the Committee does not mention any measures taken to protect independent living under Article 19. The country's overarching law on the Protection and Promotion of Persons with Disabilities was adopted in 2006, though the country's constitution does not contain articles on disability.[57]

According to its 2015 state report to the Committee, in 2006 **Morocco** adopted Act No. 14-05 to regulate the establishment and operation of social care institutions to ensure service quality. The Ministry of Family, Solidary, Equality and Social Development was tasked with licensing, monitoring, inspecting and evaluating institutions that cater to the needs of persons with disabilities .[58]Act 14-05 was replaced by Act No. 65-15 of 2018 which further strengthened the governance and monitoring of institutions. Several past reports have called attention to the specific challenges faced by children with disabilities in Morocco's institutions, particularly children who have been orphaned or abandoned.[59] Human Rights Watch [60]has urged the Committee to question the Moroccan Government on its efforts to collect data on, support and deinstitutionalize abandoned children with disabilities. A field visit conducted by the International Solutions Group revealed that childhood integration in Morocco varies widely

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[54] ESCWA, 2018.
[55] National Libyan Organization for the Development of Disabilities, 2014.
[56] UNDP, 2018.
[57] ESCWA, 2018.
[58] CRPD, 2015a.
[59] UNICEF, 2010; Handicap International, 2015; Human Rights Watch, 2017.
[60] 2017.

according to disability type. For example, children and adolescents with mobility issues were generally included in mainstream classroom environments, while young people with psychosocial disabilities were frequently placed in specialized centers.[61] The Committee's concluding observations for Morocco recommended that the State party adopt a deinstitutionalization strategy that includes provisions for collecting data on abandoned children living in institutions.[62]

Sudan's 2014 report under the Convention states that independent living and community inclusion are protected through the country's 2009 Disability Care Act, under which persons with disabilities have the right to obtain residential land .[63] However, the report also mentions that the Disability Care Act contains provisions for the sheltered housing of persons with disabilities. In their concluding remarks to Sudan, the Committee urged the State Party to adopt a strategy to ensure independent living.[64]

Tunisia's report from 2010 stated that the Government recognizes the right of persons with disabilities to live in the community and to choose their place of residence. While the report does not directly reference any established laws ensuring deinstitutionalization, Tunisia's Law No. 83 (2005) contains articles relevant to independent living and social inclusion. Many of these articles are related to housing policy, such as Article 13, requiring accessible residential units in all public housing blocks, and educational inclusion, such as Article 19, which stipulates that all Tunisian schools must admit students regardless of disability status .[65] Following Tunisia's submission, the Committee did not directly comment on Article 19 implementation. However, the Committee's observations on Article 14 on liberty and security of the person included a recommendation that the State party repeal all legislation that allows for the deprivation of liberty on the basis of impairment, and in doing so review all cases of persons with disabilities who may be deprived of their liberty in "hospitals and specialized institutions".[66]

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[61] ISG, 2016.
[62] CRPD 2017e.
[63] CRPD, 2015f.
[64] CRPD, 2018.
[65] CRPD, 2010.
[66] CRPD, 2011, p.4.

The adoption of the Convention has provided a valuable global framework for monitoring actions taken by countries to protect the rights of persons with disabilities. Most reports submitted by Arab States indicate the use of institutions to provide care and services to persons with disabilities, but the majority do not distinguish between residential and non-residential centers. This lack of differentiation inhibits a full understanding of the extent of institutionalization in the region. Tracking all centers that provide services to persons with disabilities is a beneficial first step, but in their efforts to implement Article 19, Governments should separately collect data on spaces that specifically house persons with disabilities in residential accommodations. In its guidance and feedback, the Committee has also recognized the gap in data in many Arab States and called on them to provide statistical information on policies and programmes implemented in line with the Convention, along with robust and disaggregated statistical data on persons with disabilities and violations of their rights.

A start towards addressing the information gap

As discussed, there is a significant lack of information on the living conditions of institutionalized persons with disabilities in the Arab world and efforts to promote deinstitutionalization and integration. None of the reports submitted by Arab States under the Convention thus far have distinguished statistically between institutionalized persons with disabilities and persons with disabilities who live independently or with their families, nor have the majority of the reports provided country-wide data on residential institutions housing persons with disabilities.

This report therefore explores the following questions:

- How many people with disabilities live in institutions in Arab countries?
- What services and facilities are offered in institutions?
- What are the living conditions present in institutions?
- How do persons with disabilities perceive their experiences in institutions?
- How, if at all, do persons with disabilities in institutions interact with members of the community outside institutions
- How do institutions facilitate integration into society?

Chapter 2: Methodology

The study adopted a qualitative research design comprised of two phases. Phase one of the study sought to examine government policies and data on institutionalized persons with disabilities using the following research methods: (1) a desk review, (2) structured telephone interviews with public officials from 18 Arab countries (Appendix 1), and (3) structured telephone interviews with directors of two residential institutions in each country (Appendix 2). The second phase of the study aimed to investigate the living conditions in institutions through case studies of two residential centers for persons with disabilities, one in Jordan and another in Lebanon. In each case study, the research team conducted the following research activities: (1) individual face-to-face interviews with five residents, (2) individual face-to-face interviews with the heads of the institutions, (3) individual face-to-face interviews with three parents, (4) two focus group discussions with caregivers, and (5) an hour-long non-participatory semi-structured observation in each institution. The following section contains a more detailed description of the instruments and research activities carried out in the two phases of the study.

Phase 1 Instruments

Desk review: The desk review drew on official reports, academic articles, official statistics, unpublished government reports and studies by international agencies.

Structured telephone interviews with public officials: Though the study targeted institutions and public officials in 18 countries, the research team was only able to successfully reach and conduct interviews with officials in 13 countries (Bahrain, Iraq, Jordan, Lebanon, Mauritania, Morocco, the Sultanate of Oman, the State of Palestine, Qatar, Saudi Arabia, Syria, Tunisia, and Yemen). Through these interviews, the research team sought to identify the number of residential institutions currently operating in each country, their regional distribution, the type and level of government support provided to institutions, and current governmental policies regarding institutionalization. The research team also inquired about the rates of institutionalization, including trends related to age, nationalities and disability types.

Structured telephone interviews with heads of institutions: The research team was able to conduct telephone interviews with the directors of 19 institutions in 11 countries (Egypt, Iraq,

Jordan, Lebanon, Libya, the Sultanate of Oman, State of Palestine, Saudi Arabia, Tunisia, United Arab Emirates, and Yemen). Directors were selected to include a variety of institutions across sectors (i.e., private for-profit, private non-profit, public) and accommodation of persons with different types of disabilities (e.g., physical, intellectual, etc.). These interviews aimed to provide insight into the living conditions within residential institutions, with a focus on available services, opportunities for education and employment, and community integration measures.

Phase Two Instruments: Case Studies

Two case studies were carried out in Jordan and Lebanon. The criteria for selecting the institution in each of the two countries included: residence provision, the hosting of foreign nationals, coverage of a range of disability types, and inclusion of males and females of all ages. Fieldwork in each institution involved observation (Appendix 3), and interviews with persons with disabilities (Appendix 4), parents and families (Appendix 5), caregivers and specialists (Appendix 6), and the heads of the institutions (Appendix 2). The desk review informed the development of the interview questionnaires for persons with disabilities, caregivers, and parents of persons with disabilities in the two country case studies.

Persons with disabilities were selected randomly for interviews, across sex, age and disability types, provided they were 18 years of age or older and were receiving residential disability-related services. Interviews took place in private spaces to ensure participants could express their perceptions without any outside influence. The research team took measures to ensure that no one was coerced to participate. The interviewer clarified to participants that participation was not mandatory, and then took consent orally. Participants were reminded that the purpose of the interview was not to scrutinize the institutions, but rather to identify areas in which services could be improved.

The research team was able to interview only those with physical impairments, mild and moderate intellectual disabilities, autism spectrum disorder and sensory disabilities. In a few cases where it was possible to carry out interviews with persons with severe disabilities, the resident was joined by his/her caregiver or an interpreter for people with hearing and speech impairments. The team selected residents with different durations of stay in order to better

understand the impact of institutionalization on their overall condition, attitudes and expectations.

Interviewed parents were selected by institutions based on the length of residency and severity (mild, moderate or severe) of disability of their resident family member. Caregivers were selected based on the type and duration of stay of the resident they care for. See Table 1 for a more detailed overview of the case study interviews.

Table 1 – Research activities conducted at case study institutions and criteria for sample selection

	INTERVIEWS WITH RESIDENTS (Total of 10 interviews)			INTERVIEWS WITH PARENTS (Total of 6 interviews)			FOCUS GROUPS WITH CAREGIVERS (Total of 4 focus groups)	INTERVIEW WITH THE HEAD OF THE INSTITUTION (Total of 2 interviews)	OBSERVATION (Total of 2 observations)
Institution in Jordan		Duration of stay at the institution	Type of disability (-ies)		Duration of stay at the institution	Type of disability (-ies)	Two focus group discussions with caregivers at the institution	One interview with the director of the institution	One hour of general observation
	Resident 1	4 years	Moderate physical & mild intellectual impairments	**Parent 1**	0.5 year	Moderate intellectual & sensory impairments			
	Resident 2	7 months	Moderate sensory & mild intellectual impairments	**Parent 2**	> 15 years	Severe physical impairments			
	Resident 3	1 year	Moderate intellectual impairment						
	Resident 4	1.5 years	Moderate physical & mild intellectual impairments	**Parent 3**	> 10 years	Mixed intellectual impairments			
	Resident 5	0.5 year	Mild intellectual impairment						
Institution in Lebanon		Duration of stay at the institution	Type of disability (-ies)		Duration of stay at the institution	Type of disability (-ies)	Two focus group discussions with caregivers at the institution	One interview with the director of the institution	One hour of general observation
	Resident 1	12 years	Mild intellectual impairment	**Parent 1**	14 years	Moderate sensory impairment			
	Resident 2	9 years	Mild intellectual impairment						
	Resident 3	14 years	Mild sensory impairment	**Parent 2**	6 years	Moderate physical impairment			
	Resident 4	6 years	Moderate physical impairment						
	Resident 5	14 years	Severe intellectual disability	**Parent 3**	14 years	Severe intellectual disability			

Expert group meeting

Following the completion of the first draft of the study, the Social Development Division at the Economic and Social Commission for Western Asia (ESCWA) invited representatives of government ministries and national disability councils,[67] international experts, and civil society

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[67] From Egypt, Jordan, Lebanon, Mauritania, Morocco, Oman, Palestine, Qatar, the Syrian Arab Republic, Tunisia, and Yemen.

leaders to an Expert Group Meeting (EGM) to review the initial results and seek missing information or clarify discrepant data prior to the finalization of the report. The discussions and feedback provided at the EGM, as well as the additional information given to the research team following the meeting, have been incorporated into the report.

Limitations

Apart from the very limited number of institutions that could be interviewed for this study, it also faced a number of limitations that inhibit the generalization of its findings. First, resource and capacity constraints meant that only two in-depth case studies of residential institutions could be conducted, and these institutions may not be representative of institutions throughout the region. There is also potential bias in the selection of participants who were interviewed in the two case studies, as many were identified by the institution's administrators. For example, interviewed parents may have been selected due to their good relations with the institution or active involvement in their children's' lives, which may or may not be characteristic of most parents. Moreover, residents with disabilities and their parents are dependent on the services of the institutions, thus they may have been reluctant to express criticism. Because the institutions in the two case studies primarily housed persons with physical, sensory, and intellectual disabilities, the research team had limited access to persons with psychosocial disabilities, who face unique challenges in residential institutions, particularly over-medicalization, and their experiences should be explored through further research.

In interviews with directors of institutions and public officials, the study did not explore all types of institutions that accommodate persons with disabilities, such as psychiatric institutions, prisons, or elderly homes. The limited number of institutions examined in this section also inhibits the generalization of findings. Finally, at times, data collected in interviews with public officials did not align with data from other sources, including information provided in the EGM.

Chapter 3: Findings – A Survey of Institutions

This chapter addresses institutions and institutionalized persons with disabilities based on interviews with public officials and directors of residential institutions across 16 Arab countries.[68] Numerical data was limited: only Jordan, Syria, and Sultanate of Oman had recently compiled statistics about the numbers and types of residential institutions, and the number of institutionalized persons with disabilities. Based on information provided in interviews, this section will discuss the various types of institutions currently operating in the region and the residents they serve, as well as existing policies regulating institutions and future deinstitutionalization plans

Types of institutions and the people in them

Based on information shared by public officials, Lebanon had the largest number of residential institutions (at least 102), followed by Saudi Arabia (at least 51)[69], Jordan (34), Palestine (6), Yemen (6), Iraq (4), Syria (2)[70], Qatar (2), Oman (1) and Bahrain (1). The public official from Morocco said the country had "five or six" residential institutions but noted that these institutions were for abandoned persons generally, not specifically for persons with disabilities.

In the EGM, Sudan's representative stated that residential institutions were not an accepted concept in Sudan; rather, they had foster families who adopted children under 15. Similar to Sudan, the representative from Mauritania confirmed that there were no residential institutions in Mauritania; however, the public official reported a total of 25 institutions that provided teaching and day-care services for persons with disabilities. The number of residential institutions in Tunisia was inconclusive: the public official provided a total count of institutions of 323 but did not differentiate between residential and non-residential institutions.

Institution types

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[68] Bahrain, Egypt, Iraq, Jordan, Lebanon, Libya, Mauritania, Morocco, the Sultanate of Oman, the State of Palestine, Qatar, Saudi Arabia, Syria, Tunisia, United Arab Emirates and Yemen.

[69] This is likely a low estimate as the public official interviewed in Saudi Arabia did not provide data on private institutions.

[70] While Syria currently has two active residential institutions, three educational institutions with residential sections were suspended due to the war.

According to interviews with public officials, non-state-run residential institutions (including private non-profit institutions, private for-profit institutions, and institutions run by NGOs) outnumber state-run residential institutions in Jordan, Lebanon, Palestine and Yemen. In contrast, officials from Bahrain, Qatar and Oman reported that their countries exclusively had state-run residential institutions, though it is notable that these states reported low numbers of residential institutions generally. Of Iraq's four reported residential institutions, two were state-run and two were non-state run. Of Saudi Arabia's 51 reported residential institutions, 50 were state-run and one was non-profit, though the public official lacked data on private institutions. According to information provided by Jordan's HCD, there are currently 27 private and 5 governmental and nongovernmental (volunteer) institutions for persons with disabilities in Jordan.

In Jordan, all public institutions serve persons with a range of different disabilities, though two boarding schools exist for blind and deaf persons. In the State of Palestine, two reported institutions were for persons with visual impairments and the remaining four catered to persons with various types of disabilities. According to the public official from Morocco, there are five public institutions that provide residential accommodation for persons with disabilities, though these institutions are not exclusively for persons with disabilities, but for orphans and abandoned persons of all abilities. One of these institutions in Morocco provided specialized care for persons with visual impairments. The Yemeni official reported two institutions for persons with visual impairments, two institutions for persons with physical impairments, one institution for persons with visual and physical impairments, and one "mixed" institution. Five of these six institutions are boarding schools designed for school-age children with disabilities.

Institutions were of varying sizes: according to interviews with the directors of institutions, the total number of residents in institutions ranged from 5 to 100 residents in private institutions, and from 30 and 300 residents in public institutions.

Institutionalized persons with disabilities

Reported numbers of institutionalized persons with disabilities country-wide were as follows: Saudi Arabia (7,815), Lebanon (1,842), Jordan (1,471), Iraq (360), Yemen (282), the Sultanate

of Oman (69), Syria (23) and Bahrain (22) (see table 2). Other countries did not have data on the total number of persons with disabilities living in institutions.

Persons living in institutions had different types of disabilities. Cases of intellectual and cognitive disabilities were predominant at institutions in Jordan, Morocco, Qatar, Tunisia, and Syria. Physical disabilities were predominant in institutions in Iraq.

Table 2 – Numbers of reported residential institutions and institutionalized persons with disabilities in select countries

Country	Number of residential institutions	Number of institutionalized persons
Bahrain	1	22
Iraq	4	360
Jordan	34	1,471
Lebanon	≥ 102	1,842
Mauritania	0	0
Oman	1	69
Palestine	6	Data not available
Qatar	2	Data not available
Saudi Arabia	≥ 51	7,815
Syria	2	23
Yemen	6	282

Gender

In Iraq, Jordan, Oman, and Tunisia the number of institutionalized males was higher than that of females. While the majority of directors of institutions reported a higher number of males in mixed institutions, and there were more male-only institutions overall, Saudi Arabia, the State of Palestine and Yemen had more females in institutions. In Jordan, as of 2018, the total number of institutionalized persons with disabilities in Jordan comprised 1,045 (71 per cent) males and 426 (29 per cent) females. Other countries did not have statistics pertaining to sex.

Marital status

Interviews indicated that few persons with disabilities living in institutions were married or in a relationship. Directors from four private and public institutions said that a maximum of 15 per cent of resident persons with disabilities were either married or divorced.

Nationality

Only heads of institutions in Jordan, Lebanon, Saudi Arabia and Tunisia reported hosting non-nationals, although most directors did not report restrictions on nationality for admission to their institutions. Institutions in Jordan were the only ones that reported hosting large numbers of non-nationals. 51 per cent were Jordanians and the rest were from Saudi Arabia (34 per cent), Libya (6 per cent), Syria (2 per cent), Palestine (2 per cent), Iraq (1 per cent), Kuwait (1 per cent), or others (3 per cent). At the institution in Saudi Arabia, 10 per cent of residents were Syrians and Yemenis. Two institutions in Lebanon hosted a relatively small number of Syrians and Palestinians. One of the institutions in Tunisia hosted Syrians with disabilities as well.

Age

Many persons with disabilities were admitted before the age of four and had spent between 30 and 55 years at the institution. At five institutions, persons with disabilities were only admitted at or above the age of three and were expected to leave at 18 to 20 years old. Public officials from Bahrain, Iraq, Saudi Arabia, Syria and Yemen noted that residential homes for the elderly accommodate elderly persons with disabilities.

Orphans and abandoned persons

Many directors reported a significant number of orphaned and abandoned persons with disabilities. At institutions in Egypt and Iraq, the majority of residents with disabilities were orphaned or abandoned. A director of an institution in the State of Palestine reported that 16 out of 22 persons with disabilities living at the center were orphaned, abandoned or had unknown parents. An average of 10 to 15 per cent of persons with disabilities in institutions in Jordan and Lebanon were orphaned or abandoned. Directors of institutions in the United Arab Emirates and Yemen also reported a large number of orphans and abandoned persons. In Tunisia, "persons with no families," accounted for 43 per cent of institutionalized persons with disabilities. Very few institutions had no orphans or abandoned persons with disabilities.

Socio-economic status

The majority of other institutions reported that families came primarily from poor socio-economic backgrounds. Directors of private non-profit and for-profit institutions in Jordan noted that families of persons with disabilities were relatively well off. Institutions that cared for a high number of orphans with disabilities, such as Egypt and Iraq, lacked information on the socio-economic status of their residents' families.

Causes of institutionalization

The reasons for institutionalization ranged from personal to policy-related ones.

Iraq is the only Arab country that institutionalizes persons only when they have severe disabilities. Morocco, the State of Palestine, Tunisia and Yemen institutionalize persons with mild disabilities, including mild sensory ones.

Most public officials attributed institutionalization in their countries to challenges faced by families in caring for their relatives with disabilities. Jordanian and Moroccan officials reported that persons with disabilities were primarily institutionalized for reasons relating to orphanhood and abandonment. The official from Qatar described institutionalization as driven by a lack of parental knowledge and skills surrounding the specific needs of persons with disabilities, a view that was echoed by officials from Oman, Saudi Arabia and Yemen. The official from Yemen also referenced the lack of services outside major cities as a reason behind institutionalization. The Syrian official reported that persons with disabilities reside in institutions mainly due to poverty and internal displacement, but also because of high unemployment, emigration and the heavy 'burden' they put on their families.

In Lebanon, the lack of coordination between the Ministry of Social Affairs and the ministries of transportation and education was described as delaying the integration process and given as a reason for institutionalization. The Lebanese public official noted that the Ministry of Social Affairs has no power over other ministries to advance integration, as there is no law in Lebanon that supports independent living of persons with disabilities. According to one report, poverty and education were the two main reasons for institutionalization in Lebanon .[71]

Directors of institutions, particularly private, for-profit ones, reported that parents and families admit their children with disabilities so that they can obtain disability-specific medical assistance, education, vocational training and other services. Directors of institutions also

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[71] MoSA & UNICEF, 2007.

reported admission due to orphanhood, abandonment, parents' inability to take care of their children, social stigma, and court decisions requiring institutionalization,

Services in residential institutions

The 19 residential institutions surveyed provided various kinds of services for persons with disabilities, falling into three groups. The first group, the majority, provided food, shelter, and basic medical and disability-specific assistance. The second group provided self-care education as well as basic literacy and informal education programmes aimed at transferring persons with disabilities to external formal schooling. The third group were formal schools certified by ministries of education and designed to both educate and provide care for persons with disabilities.

Directors of institutions in the third group reported offering additional services including speech therapy, sports, arts and crafts, and entertainment activities. A few directors reported providing occupational therapy. Less than half of the institutions offered computer training and services, and in many cases, the use of devices such as phones and laptops was not permitted.

The majority of institutions provided services for a wide range of disabilities. An institution in Oman provided specialized residential care for deaf persons, and institutions in Palestine, Tunisia and Yemen were schools for the blind. These four institutions offered specialized and focused support services tailored to specific types of disabilities.

Accommodation

The majority of directors stated that the available space at their institutions was suitable for the number of residents. Accommodation was mostly in group rooms separated by sex and with shared bathrooms, but the number of residents per room and users per bathroom varied. In some cases, persons with specific types of disabilities, such as quadriplegia, were assigned a private bathroom to accommodate their needs. Most group rooms accommodated between two to eight persons sharing one or two bathrooms.

Despite no directors outwardly describing living conditions of their institutions as inadequate or inhumane, interviews did reveal instances of overcrowding and other troubling phenomena.

At one public institution, the director reported that large beds were shared by five persons with disabilities. In some cases, group rooms accommodated up to 45 persons, and bathrooms were shared by up to 10 persons. When asked about bathrooms, the director of one institution commented "there are more than enough, because the majority wear diapers so they don't even need bathrooms."

Health care

Health care was primarily provided through government hospitals and nearby health clinics. Only two directors, in the State of Palestine and Yemen, reported having a health-care system that involved carrying out regular medical check-ups and examinations at the institution. More than a third of the institutions did not have resident nurses, and more than half did not have a resident doctor.

The majority of directors reported that many residents showed signs of depression or aggression. A few directors reported having nurses, a neurologist, psychiatrist or special educators available to provide psycho-social support. Very few said that their institutions conducted regular assessments that included a psychological element. Some institutions consulted external psychiatrists on a case-by-case basis, and sometimes referred these cases to specialized psychiatric hospitals or NGOs.

Directors in the State of Palestine and Yemen stated that their institutions had hired professionals to study cases of depression or aggression. A director in the United Arab Emirates stated that the institution addressed cases of depression and aggression by means of "behavioral modification […] and drugs given to them by the psychiatrist." A director of a public institution with no personnel qualified to treat such conditions stated that "they [the institution] have around three (…) children who break everything and push people around. We [the staff] don't do anything to them because they're sick and will not understand anyway."

While all institutions had some system through which residents could receive medical care, a significant number of directors reported recent deaths of residents. The director of one institution reported five resident deaths due to sickness, including two residents who passed away while at home. Another director of an institution where the majority of residents were

bedridden reported that one resident per year usually died from choking. A third reported that 2-3 residents a year die from strokes.

Education

Despite high levels of illiteracy among persons with disabilities, the majority of institutions reviewed in the study did not provide in-house education, and few persons with disabilities were reported to have attended outside formal schooling. A few institutions prepared persons with disabilities for outside formal schooling or special education facilities through informal catch-up classes and remedial support, and through securing their admission in nearby public and private schools. Persons with disabilities who were integrated into schools outside the institution accounted for less than five per cent of the residents of the institutions; few were reported to have made it to university.

On the other hand, six[72] out of the 19 surveyed institutions were essentially educational institutions (certified public schools) for persons with disabilities. They provided specific levels of formal education (including vocational education) following the national curriculum. Still, some persons living in educational institutions remained illiterate, often those who were older.

Directors in Iraq and Jordan reported persons with disabilities being refused admission in nearby schools due to their disability. Dropout rates were particularly high among persons with autism spectrum disorder. Directors reported that some persons with disabilities dropped out of outside formal schools and special education facilities because other students made fun of them.

Decisions regarding the education of persons with disabilities were either made by directors or by teachers, speech therapists, social workers, physiotherapists or the family. In some cases, these decisions were made by a joint committee comprised of social workers, teachers, and institution staff working together with the parents of the resident. A few institutions followed up on residents' educational profile and helped them devise an educational plan upon completion of ninth grade or high school.

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[72] Institutions in Lebanon, the Sultanate of Oman, the State of Palestine, Tunisia and Yemen

Employment

Only six[73] institutions, four of which were private and two public, reported that some of their residents were working, most often inside the institution. Their salaries ranged from USD 50 per month to USD 500 per month.

Persons with disabilities who were externally employed tended to work in the service industry and in administrative positions, as well as in carpentry, tailoring and other crafts. A few worked as teachers. Directors reported that decisions related to employment and financial independence were often made by the directors themselves with the team at the institution, or by the resident's family. Some institutions in Jordan and Lebanon gave salaries earned by working persons with disabilities to their parents for fear of them losing or squandering the money.

Participation in institutional decisions

The vast majority of directors reported that there were no residents' councils in their institutions. Some directors claimed that residents were either too young or too severely disabled to participate in institutional decision-making. A director of one public institution commented, "What would the children say, anyway? They can't even talk.". Only two institutions, in Lebanon and Tunisia, reported having councils of residents.

Freedom of movement

In the majority of cases, persons with disabilities were not allowed to move freely in and out of institutions. A few directors reported permitting residents to go out only after they had submitted a permission request stating the reason for and agenda of their trip. Only one director of a public institution in Tunisia reported that all residents could go out unescorted every day with prior permission.

Duration of stay

The majority of institutions did not have an age criterion for admittance or limits on the duration of residence. Persons with disabilities staying in the institution for long periods or

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[73] Jordan, Lebanon, the State of Palestine, Tunisia and Yemen

their entire lives (25 years or more) were likely to be orphans or abandoned as children. This suggests that many institutions have no clear deinstitutionalization or integration goals, but rather provide shelter services indefinitely. When asked about the longest duration of stay, a director at one institution explained that it had no authority to release residents without families from care. Another director explained that persons with disabilities stay at the institution "until they die." One other stated that persons with disabilities "never leave the institution, they love the place."

The exceptions were institutions that focused on the integration of persons with disabilities in both the formal (six institutions in Lebanon, the Sultanate of Oman, the State of Palestine, Tunisia and Yemen) and non-formal (three institutions in Jordan and Tunisia) education systems. The duration of residence in these institutions, which were more likely to be private, was generally between three and 15 years, after which residents were transferred to a formal school or sent home to their families.

Quality of caregiving

The ratio of caregivers to care recipients diverged considerably. While the majority of institutions had an average of one caregiver or nurse for every six persons with disabilities, in other institutions, this ratio was up to one caregiver or nurse for 17 residents.

Nearly half of the institutions lacked qualified or specialized personnel, such as nurses, physiotherapists, speech and language therapists, occupational therapists or teachers. While the majority of direct helpers (caregivers and nurses) did not hold university degrees, most directors claimed that the medical and educational staff were qualified and held at a least a bachelor's degree in the field of their work.

Three directors reported that volunteers support persons with disabilities alongside paid staff. One director at a public institution reported that all staff members were nuns, and responsible for providing the majority of services to residents, including medical diagnoses and pharmaceutical prescriptions. Some directors at private institutions expressed the belief that employing qualified and educated nurses and caregivers for direct assistance was unnecessary. As one director explained, caregivers and nurses are "mothers, not educators".

More than a third of the directors reported that they monitor and evaluate their staff (particularly nurses and caregivers) by camera surveillance. Another group of directors reported evaluating caregivers based on achievement of pre-determined programmes designed by the institution. A third group described evaluating staff performance with appraisal and assessment tools including questionnaires with measurable objectives developed by directors, supervisors, doctors or other specialists.

Directors rarely stated that they required their caregivers and nurses to submit reports, though some conducted observation periods followed by individual interviews or staff meetings to monitor performance. Only one director claimed that no monitoring and evaluation assessments were needed because "we [the staff] trust each other over here."

The majority of directors of both public and private institutions reported that they support their caregivers by means of professional and educational development, health insurance, salary raises, promotions, bonuses, motivation plans and gifts. Some institutions lacking qualified caregivers had conducted training workshops.

Directors reported noticeably higher personnel turnover rates in private institutions compared to public ones. Some directors, particularly of private institutions in the State of Palestine, explained that the main reasons were low salaries and job dissatisfaction. Directors of private institutions in Jordan expressed a strong dissatisfaction with the high staff turnover rates, considering it a waste of their efforts to invest in and train their staff.

The majority of institutions allowed caregivers only limited participation in overall planning and decision-making; directors generally designed a rigid programme for caregivers to follow. Institutions with qualified staff, particularly those that provided education, were more likely to rely on caregivers to participate in the design and adaptation of programmes.

Policies, regulations and management

Registration and certification procedures

In Jordan, Libya, the State of Palestine, Saudi Arabia and Yemen, public institutions hosting persons with disabilities are not required to go through an official registration process because they are established and funded by the government.

For private institutions, registration procedures vary. In Lebanon and the State of Palestine, registration is approved by their interior ministries, while in Iraq, Jordan, Saudi Arabia and Yemen, licenses are granted by their social/labour ministries. In Jordan, the approval of the Civil Defense Department is also needed while in Saudi Arabia the approval of the Ministry of Health is also required. Yemen also requires the approval of the Welfare and Rehabilitation Fund for the Disabled for registration, and the private institutions are required to submit reports regularly in order to maintain certification.

Morocco requires all institutions to follow specific registration steps in order to get a permit. In 2018, Morocco adopted Law 65-15, updating previous legislation regulating the management of social welfare institutions, which requires directors of institutions to submit annual budgets and action plans to maintain certification.

Reporting and inspection procedures

All institutions in Bahrain, Iraq, Jordan, Lebanon, Morocco, Oman, Saudi Arabia, the State of Palestine, Tunisia, Yemen, and Syria are required to submit reports to the government about different aspects of their development. In Bahrain, Morocco and the State of Palestine, institutions are funded by their respective governments on the basis of these progress reports. In Iraq, Jordan and the State of Palestine, public and private institutions send reports about their activities to ministries, typically of social affairs. Syria's institutions are expected to report on a monthly basis to directorates of labour/social affairs in governorates and quarterly to the ministry.

In Iraq, activity reports are sent on a yearly basis, and in case of any irregular finding or a violation in the normal flow of procedures, the institution is closely observed and will be asked to submit monthly reports while under review. In Morocco, under Law 65-15, institutions are also required to report on their activities on a yearly basis and create internal "surveillance committees" to facilitate their inspection. At least two residents of the institution (or

beneficiaries of services in the case of non-residential centers) are required to sit on the committee.

In Jordan, institutions are expected to send monthly reports on their activities and certain demographic data pertaining to beneficiaries (e.g., number of residents, types of activities, programmes followed). In the State of Palestine, the Sultanate of Oman, Saudi Arabia, Tunisia and Yemen, public institutions must file a quarterly report to concerned ministries.

All directors reported that their institutions were officially registered and regularly inspected, though few clarified specific standards for inspection. The majority of directors stated that their institutions were registered and certified by the local government, primarily the local branches of social/labour ministries.

Both private and public institutions were inspected by government agencies at frequencies ranging from weekly to annually. Commonly, inspections were conducted by representatives from ministries of social affairs and ministries of health. A director in Libya mentioned his public institution audited by the Libyan Audit Bureau. The director of an institution in Yemen stated that in addition to inspections by the Ministry of Social Affairs and the Ministry of Health, her institution was inspected by Yemen's Higher Council for the Rights of Persons with Disabilities.

While the majority of the directors stated that they regularly report on their programmes and activities to the government, some in Egypt and Iraq stated that they do not report to the government.

Support and funding

In Bahrain, Iraq, Morocco, Qatar, Saudi Arabia, Syria and Tunisia, all public institutions for people with disabilities are funded by national ministries. In Lebanon, the State of Palestine and Yemen, all non-profit institutions are funded by national ministries. Lebanon has no public residential institutions for persons with disabilities, so the Government supports its private, non-profit institutions with allocations that depend on the type of disability. According to one report, 60 per cent of the budget from the child protection programme of the Ministry of Social

Affairs is allocated to support residential institutions .[74]While private, for-profit institutions in Jordan are not funded by the public budget, they have signed agreements with the Government to accommodate persons referred to them by public institutions: if an individual comes from a disadvantaged socio-economic background and state-run centers are at capacity, the Government will cover the cost of private institutionalization at a lower monthly rate. In Iraq and Saudi Arabia, the Government does not support private institutions.

The criteria for public institutions to receive government funding include a number of factors. The governments of Bahrain, Lebanon and Tunisia generally fund institutions for persons with all types of disabilities. Iraq, Saudi Arabia, and the Sultanate of Oman tend to fund institutions catering to the needs of persons with severe or multiple disabilities. Yemen prefers to support institutions that deal with physical impairments, and Jordan those supporting persons with cognitive or intellectual disabilities. Saudi Arabia and Yemen consider the number of enrolled residents, the age group, the services provided and the size of the institution in allocating funding.

The cost of stay at an institution and the amount of government funding provided varied depending on the type of the institution (private or public) and the level of assistance required. Public institutions were free of charge. The cost of stay at private, non-profit institutions was covered by donations only, except in Lebanon and the State of Palestine, where the government and donations cover costs. The majority of directors expressed dissatisfaction with amount of government support they received. For example, a director of a private institution in Jordan stated that they were not able to secure enough money to carry out an urgent surgery for one resident.

Payment for most private, for-profit institutions came from a combination of family contributions and charities. The majority of directors of for-profit institutions reported that without assistance, many families were unable to keep up with costs, which can be very high. For example, in Jordan, the majority of families default on their payments to for-profit/private institutions, which can be as high as US $3,000 per month.

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[74] MoSA & UNICEF, 2007.

Challenges in managing institutions

Government officials and institution directors mentioned different challenges in managing institutions. In the State of Palestine, Syria and Yemen, the demand for institutionalization is higher than what institutions can accommodate. In the case of Yemen, this demand is mainly for the purpose of education.

In the State of Palestine and Tunisia, financial challenges were among institutions' reported problems. Saudi Arabia was the only country to report challenges pertaining to health issues, such as the spread of infections and epidemics amongst residents. In Libya, Syria and Yemen, safety and security due to conflict were major concerns. In Syria, reported challenges also included a lack of trained staff, outdated infrastructure and curricula, and having to relocate institutions to unsuitable temporary facilities.

In Iraq, Lebanon, the State of Palestine, Syria and Yemen, officials stated that there had been no reports of abuse in institutions. The Yemeni official elabourated by stating that there have been no reports of abuse because staff are professionals employed by the Ministry of Social Affairs and the Ministry of Education. Bahrain and Saudi Arabia each had a single incidence of abuse referred to court. In Bahrain, the institution's services were suspended. In Saudi Arabia, criminal charges were filed.

Transitioning to deinstitutionalization

Plans and steps forward

When asked about government positions regarding deinstitutionalization, interviewed public officials tended to take a pro-deinstitutionalization stance, although to varying extents. Despite outward support of independent living, interviews revealed a lack of the concrete deinstitutionalization policies needed to progressively realize Article 19. Instead, public officials cited programs intended to improve service provision and increase inclusion in schools and the workforce. Only Jordan provided a detailed, time-constrained action plan that outlined the closure of residential institutions.

The Bahraini and Iraqi public officials reported that their governments support independent living by providing long-term social support services, such as educational opportunities, psychosocial support and rehabilitation services. Without disclosing a specific strategy, the Bahraini official stated that the Government is trying to eliminate obstacles to deinstitutionalization. When asked about de-institutionalization, the Iraqi official reported that there are new policies being created to address inclusion, including laws to combat discrimination and programs to ensure inclusion in the labour market.

The State of Palestine incorporated independent living in its Sustainable Development Goals strategy for 2030. The Palestinian official reported that the Government is equipping persons with disabilities with necessary medical equipment, redesigning their houses to make them more inclusive, and providing their families with funding for care at home.

The Lebanese public official, while expressing pessimism regarding the integration of persons with disabilities into society, reported that the Government aims to keep persons with disabilities living within their families and communities. She focused on the educational aspect of integration and expressed a need to integrate persons with disabilities into public and private educational institutions. The official in Morocco also discussed educational inclusion and stated that the Government intends to address inclusion by making all public and private education facilities accessible to persons with disabilities. In Morocco's 2016 Decree on the Rights of Persons with Disabilities, educational institutions for persons with disabilities are considered part of the country's national educational system, and subject to the same regulations, though the official from Morocco stated that the country hopes to make separate facilities the exception, rather than the norm.

The Saudi Arabian official reported that while the number of institutions is increasing, the government has a short-term, two-part project to initiate deinstitutionalization. The official's comments reflected a pattern of apparent misconceptions about actions that constitute deinstitutionalization: the described plan entails privatizing public institutions, followed by the creation of a national "day-care service," in which teams throughout the country visit the homes persons with disabilities to provide medical assistance and training to families. The official did not clarify how the privatization stage will help further deinstitutionalization goals. (Similar ambiguity was seen in comments from the Tunisian public official, who, when asked about deinstitutionalization, cited the upcoming creation of five new institutions for persons with

disabilities.) Persons with disabilities in Saudi Arabia currently also have the ability to stay with their families and receive a monthly allowance that varies according to the degree or severity of their disability, in addition to other factors. According to the Saudi Arabian official, in 2017, the Government of Saudi Arabia spent approximately 5 billion Saudi Arabian riyals (US $1.3 billion) per month on contributions for 400,000 citizens with disabilities.

The Yemeni official reported that the Government encourages deinstitutionalization and believes that persons with disabilities, particularly children, should stay with their families. Policies of residential institutions mandate that residents visit their homes on weekends and official holidays. To keep persons with disabilities with their families, the Government plans to provide day-care centres outside cities.

According to its government official, the Sultanate of Oman is currently working on an alternative to institutionalization that is focused on the provision of rehabilitative services in home environments and day centers. It is important to note that Oman only has a single, state-owned residential institution that accommodates 69 residents. When asked about Oman's medium-term deinstitutionalization plan, the public official stated that the Government does not intend to issue licenses for any new residential institutions.

Jordan has made perhaps the most significant progress toward deinstitutionalization in the region, specifically through the release of new action plans on deinstitutionalization, educational inclusion and accessibility. The Jordanian official stated that, based on Articles 27 and 29 of Law No. 20 of 2017, in 10 years there will no longer be any residential institutions in Jordan. According to the action plan on deinstitutionalization, all existing residential institutions will be converted to community care centers that provide rehabilitative and educational services. The public official also commented that independent living will be supported by training families on how to assist their children with disabilities and by offering technical and material support through trained and specialized personnel certified by both the Ministry of Social Development and Jordan's Higher Council for the Rights of Persons with Disabilities. Jordan also intends to launch the "Alternative Family Programme" for institutionalized individuals who have no biological families and are less than 18 years of age. They will be provided with a home offered by volunteer families until they turn 18. The Government will launch additional programmes to develop day-care or independent living centres for different age groups and disability types. The centres will provide vocational

rehabilitation and training to enhance the employability of persons with disabilities. The Jordanian Government also intends to focus on early diagnosis and intervention, which will help people with disabilities manage their lives and explore their options at an earlier stage in life. The governmental plan for deinstitutionalization entails creating group homes that consist of four to five persons with disabilities living with a supervisor or foster families.

Attitudes towards inclusion

Interviews with directors reflected two different interpretations of inclusion that would influence the course of deinstitutionalization. Some directors asserted that the role of institutions was to provide necessary rehabilitation to facilitate the inclusion of persons with disabilities in society. Others contended that the role of institutions was to protect persons with disabilities from society.

Most directors, particularly those who believed in inclusion, emphasized the role of governments in creating a physical and cultural environment that accommodates persons with disabilities, including to participate in social institutions and navigate public spaces without external help. Directors of private institutions, particularly those providing educational services, stressed participation in education and employment as key elements of inclusion. For example, a director in Yemen highlighted that the national education curriculum is not inclusive and does not cater to the needs of persons with disabilities. Some directors also expressed the view that inclusion is more successful among persons with mild and moderate disabilities.

The majority of directors also emphasized the role of the government in promoting a culture free from stigmatization and shame. A director in the State of Palestine explained that "families of persons with disabilities refused to disclose their children out of shame". This issue was also raised by a director of a private institution in Lebanon, who stated, "Society should stop shaming and bullying persons with disabilities. We [the institutions] cannot make a difference on our own." According to the majority of directors, parents also need help and support in understanding and accepting their family members' disability.

Directors who were less optimistic about inclusion tended to stress the importance of controlled contacts between residents and people outside the institution, such as through receiving

visitors, short visits outside the institution, weekend family visits, outdoor walks, strolls in the mall and lunch at restaurants. A director in Lebanon, however, stated that visits were not effectively helping persons with disabilities integrate into formal schooling and the community at large. Some directors interpreted integration as the comingling of sexes and of persons with various types of disabilities in prearranged schedules.

In contrast to perceptions of persons with disabilities as helpless people who need institutional protection, a director of a public institution in Tunisia stated that the will of persons with disabilities to improve their lives is crucial for their inclusion in society. This director argued that persons with disabilities have "to strive for getting an education, be it mainstream or vocational education." This institution was the only one that allowed its residents to go in and out of the institution freely each day. The director added that institutions for persons with disabilities should mainly focus on providing quality education so residents can develop their strengths and work towards leading independent lives.

Obstacles to deinstitutionalization

According to many directors, the two main obstacles to deinstitutionalization were the community's negligence and stigma against persons with disabilities, and the families' inability to help because of their misunderstanding of disability. "To protect persons with severe disabilities from the cruelty of the community, we should keep them in institutions," a director of a public institution in Iraq asserted, a comment echoed by several other directors, mainly at private institutions. They argued that persons with disabilities cannot live in society because no one will help them.

Directors from Jordan, Lebanon, the State of Palestine and Tunisia expressed dissatisfaction with families and parents' unwillingness to take their children out of the institution. In Jordan, a director of a private for-profit institution also reported domestic violence and abuse by parents and family members and stated that some persons with disabilities had not seen their parents for at least three years. The majority of directors in all countries noted that parents rarely visit their children or take them out over the weekend. Staff members cited cases of parents keeping their children out of their communities and isolated in the house or institutions. In contrast, some institutions also discouraged parents from visiting or taking residents out: the director of

a private institution argued that doing so raised the likelihood that "children would want to leave the institutions".

At the Expert Group Meeting, multiple participants described the absence of community-based alternatives as a major barrier to deinstitutionalization, specifically highlighting the lack of financial and social support available to the families of persons with disabilities. Representatives from Egypt and Lebanon mentioned the financial burden in-home care places on family members, though several participants noted that financing institutions is far costlier for governments than directly providing funds to families. Stigma surrounding disability was also frequently listed as a barrier to social inclusion and community integration in Arab countries.

Representatives from Jordan and Lebanon noted the specific challenges of providing care for refugees, foreign nationals and displaced persons with disabilities. The representative from Jordan noted the difficulty of facilitating the transitions of foreign nationals living in institutions into communities without family support. The representative from Lebanon described the need for greater assistance for Palestinians with disabilities living in Lebanon.

Jordan's representative additionally stated that the prevalence of private for-profit residential institutions presented a significant obstacle to the country's deinstitutionalization goals, as these institutions lack an incentive to actively integrate residents into communities. Similar obstacles were noted by the representative from Lebanon, who mentioned the challenges of coordinating services within the country's large number of private residential institutions, and by the representative from Palestine, who described the region-wide challenge of regulating private sector institutions that provide social services.

Finally, multiple participants mentioned the challenge posed by discriminatory legislation, particularly personal status laws that deny persons with disabilities the legal capacity to make autonomous decisions.

As seen in this chapter, the characteristics and regulation of institutions in Arab countries varies greatly, as do the persons living within them and the kind of services and care they receive. Aside from in Jordan, deinstitutionalization plans are mostly vague, though other methods to support independent living are being formulated, such as creating group homes and

independent living centres; using awareness campaigns to promote independent living; passing governmental initiatives to make public spaces more inclusive; ensuring that national education curricula and exams are accessible to persons with disabilities; and allocating more money to the families of persons with disabilities to help them cover the fees of needed care services, including medical equipment. Unfortunately, stigma remains high and attitudes towards inclusion are discouraging. Moreover, the barriers to deinstitutionalization remain significant. However, in order to obtain a more informed assessment of life inside institutions in the Arab region, the researchers conducted case studies of two institutions, seeking substantive feedback of both staff, residents of institutions and their parents about life inside the institutions, as will be outlined in the following chapter.

Chapter 4: Case Studies on Jordan and Lebanon

Two case studies of institutions were conducted, one in Jordan and one in Lebanon. For each case study, researchers interviewed five residents, three family members, and the head of the institution. The field research team also conducted two focus group discussions with caregivers and one hour-long observation in the residents' common spaces.

Selection criteria for the two institutions included providing full-time residence; hosting foreign nationals; covering the widest range of disability types, including physical and intellectual disabilities; and accommodating both male and female residents of varying ages. This chapter presents results from each case study.

The Case of Jordan

The Jordanian institution was a state-owned centre offering services for persons with severe and multiple disabilities that also operated as a training center for university students studying health-related fields. The institution accepted persons between the ages of 16 and 70, aiming to provide guidance to their families as well, especially those with other members who were elderly, sick or had a disability.

There were 227 residents living in the institution, divided into groups by their type of disability and age. Almost 70 per cent of the residents were bedridden and needed full-time assistance; the rest were able to move on their own or use wheelchairs. The institution tried to group the

residents by age as much as possible. The majority of residents were Jordanian citizens, though the institution had one resident each from Iraq, Lebanon and the State of Palestine.

Monthly fees for each resident were around 850 Jordanian Dinars (US $1,200) but varied according to disability type. Residence costs for Jordanian nationals were entirely covered by the Government.

Reasons for institutionalization and admittance procedures

Residents reported being institutionalized because they were orphans, abandoned or did not have families that could support them. Other family-related issues, such as the death of a family member, the divorce of parents or the imprisonment of a guardian, were also given as reasons for institutionalization.

A number of current residents had previously lived at other similar institutions. Some used to live with their families. Some residents were enrolled in mainstream schools before dropping out in middle or high school. Other residents had attended literacy centres that focused on improving reading and writing skills, while some were not previously enrolled in any type of educational program. An interviewed parent said his child had been rejected from both public and private schools.

In general, residents were admitted to the institution by the Ministry of Social Development at the request of families. Prior to institutionalization, disability assessments were carried out by a medical committee and a report was sent to the Ministry of Social Development, which assigned people to the most convenient institution based on their disability and area of residency. If the assessment results show mental illness instead of a disability, the person was transferred to a mental hospital.

Instances of incorrect assessments were reported by staff. Some persons were admitted to the institution because their disability was classified as severe, but later tests showed their disability was actually mild and they were sent home. There were other cases where the centre had a different assessment outcome from the Ministry but were unable to change the Ministry's original report (though the support given was based on their own assessment). There were other instances where people with mild disabilities were admitted to the center "through a higher

authority" despite not having a severe disability. According to the head of the institution, the centre has no say in accepting or rejecting cases.

Only one resident out of five reported having been admitted to the institution against his will. All interviewed family members reported that their institutionalized relatives did not initially want to enter the institution, and later changed their minds. One family member of a resident commented that she hoped her relative would stay at the institution forever, because of the quality of the rehabilitative care he was receiving there. According to the head of the institution, residents were rarely ever deinstitutionalized; there was no age criterion for termination of residency.

Services and facilities

The head of the institution noted that the centre is classified as a training facility and not as an educational one, meaning instruction focused on teaching basic life skills. Only one parent reported that her daughter was not involved in any activities, noting that it was because of her physical condition; "she cannot move, eat, or even swallow."

While none of the residents interviewed were enrolled in academic classes, some expressed hope of getting an education. One resident said, "I wanted to continue my education before coming to this centre, but the ministry did not help." Residents had specific career goals, but vocational education was discontinued following the institution's recent re-classification as a training center for university students in 2017. A resident commented, "They teach us how to brush our teeth and wash our hands [but] I [would] like to become an agricultural engineer." Another resident said, "I've never tried this but I would like to become a carpenter… I never told them this at the centre."

None of the residents interviewed reported having access to a medical doctor, though the director of the institution stated that an average of six residents per day were sent to a nearby hospital because of medical complications.

Parents interviewed expressed their satisfaction with the institution's services in terms of their children's conduct and discipline. One parent stated that their son "became disciplined, he listens to us, he can rely more on himself, he has better understanding." Parents appreciated newly developed skills and the provision of basic human needs. One parent assessed the

institution positively due to the availability of the director at any time of the day she chose to visit.

Accommodations

The centre consisted of two similar three-story buildings (one for males and one for females) connected by a corridor and a small garden. There were three classrooms, one music room and two recreational rooms. Each classroom had one large table with some chairs and materials such as colouring books and pens. None of the classrooms had any sensory tables or other tools suitable for teaching persons with visual impairments. No computers or any special education technology instruments were available.

Each residential floor had a supervisors' office, a nurses' unit, bedrooms, common rooms, and shared bathrooms and showers that were not structurally well equipped for persons with disabilities. The supervisor explained that most residents used diapers and were not able to use the bathroom on their own. The floors had enough space to move around even with wheelchairs; those on wheelchairs used the elevators to move between floors. Rooms were organized by severity of disability, and rooms for individuals unable to move from their beds had at least eight beds per room.

Staffing

The head of the institution described having a large and proficient team of staff that took good care of the residents. The team consisted of 80 caregivers, of whom there were 15 lower-skilled helpers and 65 higher-skilled staff including 34 nurses, 18 special educators, three occupational therapists, seven physiotherapists, one dietitian, one psychologist and one social worker.

The head of the institution reported always being present in assisting caregivers with their work. Two heads for any department alternated between day and night shifts, observing different areas.

Caregivers complained of overly demanding work and low wages but acknowledged that the head of the institution allowed for flexible scheduling. In focus groups, staff reported challenges with the large number of residents, the unwillingness of family members to

communicate with the institution, and residents' aggressive and depressive behaviours, which caregivers described as a result of missing their family members.

Participation in decisions

The head of the institution stated that there was no council for residents to take part in decision-making because the only decisions they were capable of making were related to their life at the institution, such as food choices or where to go on outings.

When asked if they had autonomy in managing their time and space, the interviewed residents, all of whom were over 18, unanimously answered by saying that they felt free to make their own decisions. Multiple residents referenced being able to sleep and go outside as they wished. One of the residents stated that she could leave the institution provided she had the permission of a family member. A resident with mobility difficulties reported feeling confined to his room when the elevator was out of service.

Some of the interviewed residents reported feeling overpowered and coerced by the institution and their parents to act in certain ways, or to make decisions that affected their personal lives. One resident felt coerced when his family moved him from one centre to another without his consent or prior knowledge.

Relationships and interactions

According to the interviewed caregivers and the director of the institution, residents were likely to suffer from depression because they either felt abandoned (those who did not have contact with family members) or missed their family members (those who have very little contact with their families). In cases where depression became severe, caregivers reported trying to reach out to residents' family members, many of whom visited the center infrequently, despite being allowed to do so on a weekly basis. Most family members who contacted their relatives in the institution did so over the phone, although residents reported preferring in-person visits.

One caregiver suggested that parents did not visit because of the social stigma surrounding disability. Staff mentioned an extreme case in which a resident passed away and the institution had to bury her because her parents refused to come to the center. Some interviewed parents

and family members expressed hesitancy about bringing their children home because they did not know how to complete tasks related to their care, such as changing their diapers. Most reasons for not bringing institutionalized children home were related to physiological or other disability-related issues. The majority of parents reported that they were usually contacted by the institution only in emergencies.

Most families had difficult social and financial conditions. Some families had more than one child with a disability, which exacerbated their limited capacities to provide financial and other forms of support. When it came to financial support, almost all parents stated that they had not applied for or requested any financial aid from the Government. Of those who applied, their requests were rejected because they only had one child with a disability.

Parental educational levels varied. When asked whether or not the family's role was affected by their educational and socio-economic background, the staff gave the opinion that religious families and those with higher levels of educational attainment tended to integrate their children more within their social circles (i.e. did not keep their child away from their family and friends, accepted his/her disability, showed more support to their child), while families with lower levels of educational attainment were less likely to integrate their children with disabilities into their social lives.

Observation of interactions between caregivers and residents suggested that residents were comfortable around and dependent on their caregivers. The setting was not suitable for persons with disabilities to move around on their own, so they were always assisted by a caregiver. Caregivers were constantly encouraging residents, talking to them with a soft and friendly tone. The head of the institution was present during the time of observation, and residents were constantly joking with him and calling him by his first name. Caregivers were seen providing physical therapy. Most residents were able to communicate with the caregivers and director with minimal difficulty.

Although caregivers and residents reported cases of aggression, no incidents occurred during the time of observation. In one earlier case, a caregiver reported that she suffered a miscarriage following an altercation with a resident, and in another case, a resident broke a caregiver's jaw. Caregivers described occasions where residents would fight each other over a toy or a blanket,

but no interviewed residents reported experiences with bullying, harassment and/or discrimination from their peers.

Inclusion and deinstitutionalization

The head of the institution maintained that based on Jordan's Law on the Rights of Persons with Disabilities No. 20 of 2017, the institution was supposed to reject people beyond age 50, but has refrained from doing so "out of humanitarian support." The only formal channel for deinstitutionalization was through the Ministry of Social Development, a decision it determined by evaluating the family's capability to care for their institutionalized relative. Caregivers stated that relatives made decisions on behalf of their institutionalized family members without taking their preferences into consideration. They also reported that most residents preferred to live at home and looked forward to vacations when they could leave the institution and be with their families. However, when asked whether they would like to leave the institution or stay in it, the majority of the interviewed residents made it clear that they preferred to stay, or were indifferent or undecided. One resident expressed a desire to leave the institution, commenting, "I do not know what I need [to be fully independent] but [I] would like to live a normal life, like everybody else. Maybe if I can get a job, it will be possible."

When caregivers were asked about the kind of support persons with disabilities needed to live autonomously, they stressed the importance of family assistance and cooperation. They also reported potential risks related to domestic violence, attempts at abandonment, and sometimes a family's ignorance in dealing with their family member.

Primary findings

Despite providing beneficial services to persons with disabilities, this state-owned residential center in Jordan did not support the meaningful participation of residents in the local environment or assist in transitions to independent living. Regardless of the quality of facilities and care provided, it is necessary to recognize that residential institutions do not advance the right to community life, and thus stand against the implementation of Article 19.

The observation of this center shed light on the complex role of the families of persons with disabilities throughout institutionalization process. The necessity of familial involvement was reiterated by caregivers, who felt a lack of communication between families and staff

negatively impacted the lives of residents in the institution. While caregivers spoke of feeling unsupported by families, parents of residents mentioned feeling ill-equipped to adequately attend to the needs of their children with disabilities. A father of a female resident who had been institutionalized for 15 years spoke of wanting to bring his daughter home so she could live with her siblings, but lacking both the financial resources and knowledge of her care routine (such as diaper changing and preparing certain foods) necessary to do so. Parents also mentioned fearing that their children would be mocked and ridiculed outside the institution, reiterating social stigma as a central barrier to deinstitutionalization.

This case study provided additional insight into the relationship between public residential institutions and the Jordan's Ministry of Social Development. Costs were entirely covered by the Government, and the Ministry oversaw disability assessment and admittance procedures, though staff members claimed incorrect determinations were common. According to the director of the institution, the only pathway to deinstitutionalization was through a Ministry assessment of the resident and their family.

Persons with disabilities in the institution consistently mentioned a desire to gain autonomy through employment. Vocational education had previously been offered in the institution, but was discontinued following a Ministry reclassification of the institution as a training center for university students in 2017. While residents generally expressed an appreciation of the institution, these statements were occasionally followed by references to a lack of other options. As one resident put it, "I like to stay at the center. I have no place else to go."

The Case of Lebanon

The institution examined in Lebanon was a private, non-profit centre for persons with cognitive, sensory and physical disabilities in addition to those with learning difficulties, provided that they could respond to rehabilitation. The centre had a day-care section and a residential one; the research team examined only the latter. The residential section hosted 165 persons with disabilities, aiming to rehabilitate and integrate them into society as independent citizens. The institution accepted people between the ages of two and a half and 35 years. The institution supported both Lebanese and non-Lebanese nationals, including from the State of

Palestine and Syria, though all those currently living within the residential section were Lebanese.

The Ministry of Social Affairs covered 70 per cent of tuition fees, and the institution covered the remaining 30 per cent. Families did not bear any expenses except those pertaining to transportation. Non-Lebanese paid a minimal amount of money, around $100 per year, with the rest covered by the institution.

Reasons for institutionalization and admittance procedures

Physical disabilities were the most prominent disability type in this institution, followed by hearing impairments. The least prevalent type of disability was visual impairment. Though not considered persons with disabilities, the centre also had residents with learning difficulties coming from distant villages where specialized education was not available. Residents were welcome as long as they were receiving some form of education; individuals were not permitted to stay if they were not enrolled in an educational programme.

The majority of the interviewed persons with disabilities reported their disabilities as the main reason for their institutionalization, stating that they were at the institution for education and treatment. According to one resident, his parents preferred that he stays at the institution because it was more convenient for them since they did not have to worry about transportation. Another resident reported that her school referred her because of her hearing impairment. Parents reported that their children's disabilities, the long distance to and from the institution, and its good reputation encouraged them to admit their family members.

Some residents had lived in other residential institutions prior to their time at the centre. A number were previously day students at the same or different institutions. Interviewed residents who had been enrolled in public, vocational or specialized schools reported having faced difficulties prior to dropping out. One parent reported that he used to send his child to a public school, but that his child struggled because the school lacked specialized services. Some parents reported removing their children from both public and private schools due to grade retention and bullying.

Prior to institutionalization, the type of disability each person had was determined by the Ministry of Social Affairs. Staff members stated that the Ministry of Social Affairs frequently made incorrect determinations. The institution was required to abide by the Ministry's decision, but when it was time for health card renewals, if necessary, the institution would send a report with a request for a new determination attached to it. Usually, the institution reassessed each case every six months unless there was an urgent case that required immediate intervention.

Residents as young as two and a half years were admitted by members of their families or the Government. Those who were admitted could spend anywhere between nine months (the time needed to finish vocational training) and 20 years (university degree level) at the institution. According to the director of the institution, if the resident does not adapt to his/her new environment, the institution calls the parent or guardian and asks them to take him/her home.

Caregivers reported that residents never came in voluntarily but learned to accept their situation. When asked, "Are you staying in this institution out of your free will?" all of the interviewed residents said "yes". What was notable, however, were their elabourations on how they perceive their freedom of mobility. One resident said, "Yes, the situation is good here, but I do not know who can decide whether I should stay or not." Another resident noted that their stay is of their free will because they have no other place to go. A third resident answered, "Yes, [it is my free will] somehow, […] I sleep here now, for example, but I [would] like to live on my own. I would like to leave, I do not like staying here but it is fine." Another preferred to leave because she wanted to work to provide for her family, but had her family had money, she would rather remain in the institution. Other residents made it clear that they cared for their friends at the institution and wished to stay with them. Only one resident reported that she would like to leave the institution so that she could "live outside and breathe".

One out of the five interviewed residents reported having been admitted to the institution against her will. She was convinced by the institution's "integration officer" to move in, although the officer is reportedly employed to facilitate the integration of residents into society. Another caregiver shared that a resident asked her to lie to her parents and tell them that the institution did not want her to stay anymore so that she could be sent back home.

The head of the institution stated that residents ideally stayed until they completed their education. In reality, some remained in the institution because their parents or guardians did not approve of them leaving, or because they had nowhere else to go. One caregiver commented that some residents "do not know what they like to study or to do in life, so the institution helps them figure that out by meeting up with them and their families." Such meetings were particularly important when children have "unrealistic life expectations," one caregiver said.

The interviewed parents of residents had clear expectations regarding the duration of their children's stay at the centre. One parent expected his child to remain at the institution for approximately seven years for educational purposes. Another expected their child to stay at the institution until he finished university, and a third expected his child to stay until he was employed.

Services and facilities

The institution provides vocational training and formal schooling up to ninth grade. The curriculum is the Lebanese curriculum adapted to the children's needs. Children are taught both English and Arabic. After completing ninth grade, students enroll in other schools or attempt to find work. The head of the institution reported that 41 per cent of the centre's residents received education outside the institution, through public high schools, technical schools, and universities.

Facilities included rooms for occupational therapy, physiotherapy and psychotherapy. Classrooms were not separated based on disability type but by the type of education (vocational or formal) and age. For those not able to engage in regular or formal education (kindergarten through brevet/middle school), the institution provided workshops on computers, handicrafts, music, and drama.

All five interviewed residents were involved in educational activities in formal or vocational school systems. Of those who attended regular schools, some were baccalaureate candidates. Others had graduated and were engaged in trainings. All interviewed residents expressed satisfaction with the education they had received.

Aside from educational activities, interviewed residents reported being involved in activities such as writing and sports. One parent reported that his son liked educational events and conferences that discuss themes related to the lives of persons with disabilities.

Early childhood educators provided a "morning orientation", in which children learned how to take care of their bodies, clean themselves, not open the door for strangers, etc. They also taught residents about expressing themselves.

Other services include speech therapy, physiotherapy and ergotherapy, the use of productive or creative activities in treating and rehabilitating people with physical disabilities and emotional instabilities. The interviewed parents unanimously praised the services provided by the institution.

Parents generally appeared satisfied with the care their children received. In one case, a parent said that his child had been at the institution for 14 years, and had they not been satisfied, they would have taken him home. Another parent used his child's educational level as an indicator of his satisfaction with the institution, mentioning that his son was a first-year biochemistry student at a Lebanese university.

Accommodations

Persons with intellectual disabilities and those with other types of disabilities (i.e., physical or sensory, and/or autism spectrum disorder) resided in two different buildings. The complex accommodating persons with other disabilities had three floors: the ground floor for general services, the first floor for daytime education (formal and vocational), and the second and third floors for residence. Each floor had three divisions for people with visual impairments, physical disabilities and/or autism spectrum disorder, and hearing impairments, with further sections based on disability type, sex and age. Each division was designed taking specific disabilities into account. For the physical disabilities division, there were ramps to facilitate movement, for example, and chairs and handles inside the showers.

The majority of bedrooms accommodated six residents; a few accommodated four residents (usually with visual impairments). In each room, there was one closet per resident, beds with linens and blankets (younger children had a few plush toys), a couple of ceiling fans, and a

desk or two for studying. Every division had its own common room with one television. There were two or three shared bathrooms per division. An exception was the section for women over age 15 with hearing impairments. These residents had a private bathroom for each bedroom because they are perceived by caregivers as more independent and in need of less help.

Staffing

The caregiving team was comprised of 16 resident caregivers (all females), three psychologists, two social assistants, two occupational therapists, one speech therapist, one general doctor (who comes to the institution three days per week), one neurologist (who comes to the institution once a week), one therapist (coordinates with social workers), one medical helper and one arts teacher. According to the head of the institution, the minimum level of education required for staff is a baccalaureate technique, equivalent to a high school diploma. Special educators, social workers and other professionals all met the minimum required levels of education. Staff attended regular trainings and workshops, most recently on sex education and the right to play.

The head of the institution monitored the center through floor supervisors. Caregivers were assessed based on the institution's constitution, and promoted or punished based on performance, evaluated in part through the completion of task charts.

All interviewed caregivers agreed that the salary was insufficient for the physical effort and energy that their job required. As one caregiver put it, "[What we need are] fewer working hours; [the work schedule is] very long." One caregiver who used to earn a higher salary in her previous job was only satisfied with her current one because of the spiritual benefits that she felt came with it. Many interviewed caregivers described their job as "paid volunteerism".

Other concerns included being away from their own families, which drained them emotionally and psychologically. One staff member said that verbal encouragement would make her feel more valued and motivated to continue doing her job, while another said that what employees needed was not words but money. Some caregivers stated they needed more breaks and days off. Others felt that the working conditions were fine because they were provided with food, drinks, and, for those living at the institution, a place to sleep. They also stated that they needed more breaks and days off.

The head of the institution stated that the main reason for staff turnover was marriage, as many employees come from villages and returned home after they married.

Participation in decisions

The institution had a children's convention and a child-to-child conference to help children express their opinions on the services and activities at the centre. The head of the institution stated that residents of all ages were taught about their rights and were encouraged to reach out to staff members with issues or complaints.

When asked whether they had autonomy in managing their time and space, all of the interviewed residents reported having tight, pre-planned schedules. One individual said that while there was a fixed schedule, residents still had the freedom to choose how they would like to end their day: playing cards, watching television, resting in the bedroom or the common room, praying, etc.

Relationships and interactions

Caregivers reported infrequent family visits and low response rates when contacted by staff. One employee said that caregivers worried when residents left the institution over the weekend and wondered whether they would return. Staff members reported that when residents came back from visits home, they often showed signs of physical and emotional abuse. Staff members also stated parents did not abide by suggested care plans when their children visited home, and that many residents returned to the institution having forgotten skills they had learned. One staff member commented, "Children come back to the institution after the weekend as if they were new residents who need to be taught everything all over again." Caregivers described a higher level of aggression among residents who returned from visiting their homes over the weekends, stating that parents modeled "bad behavior". Caregivers also reported instances of children refusing to return home because their parents forced them to work.

None of the interviewed parents reported receiving any form of counselling or training from social workers or other specialized personnel on how to care for their children with disabilities when they were visiting home. All three of the interviewed parents reported that their children

came home every weekend. The interviewed parents all cited the importance of the education their children were getting at the institution, and one mentioned not wanting to interfere with the institution's educational system as a reason for not visiting more.

Caregivers said that they were trying to form a parents' council to enable parents to share success stories and tips with each other. They described how some parents had poor communication with their children, while others were always in contact and frequently asked questions about their children. On average, active parents communicated with the caregivers every week or two; inactive parents did not contact them and only visited the institution when it provided transportation.

Inclusion and deinstitutionalization

The head of the institution reported working on a new "reverse integration" programme, whereby more than 2,500 school students and a number of non-governmental organizations visited the institution yearly. As part of the programme, students and volunteers participated in activities with the residents and learned about the Braille system with them. Reverse integration, however, assumes that inclusion involves preparing society to tolerate persons with disabilities, irrespective of whether or not persons with disabilities move out of institutions to live within communities. Given that these interactions (i.e., volunteering and visiting) are inside the institution and temporary, reverse integration is not necessarily related to inclusion or deinstitutionalization.

Interviewed residents revealed a variety of ideas about the kind of support they needed for independence. The majority of interviewed residents described employment and financial independence as necessary to achieve autonomy. Some residents also listed marriage as an indicator of independence. Three residents were ambivalent when asked to describe their futures outside the institution. One resident said that she liked the center and would prefer to remain there. Another resident said stated that he was not comfortable around people outside the institution, while a third said that he could not assimilate into the community because he needed people around him who were able to understand his special needs.

Caregivers considered the individual's self-acceptance, realistic life expectations, mobility (i.e., the ability and freedom to move independently) and physical appearance as equally

important factors for the independence and inclusion of a person with disability into society outside the institution. According to one caregiver, persons with hearing impairments had a higher level of mobility and capacity for independence. Another caregiver stated that "the most important criterion for independent living is for the person with disability to accept himself/herself." A third caregiver argued that sometimes residents have unrealistic life aspirations that hinder the achievement of the autonomous lives they envision.

According to the head of the institution, underage residents could not leave without a parent, but those who are above 18 could receive permission from the institution to go out. One resident expressed his dissatisfaction with that routine because he wanted to have a busy life full of outings, not necessarily revolving around trips home. He stated that he liked to go out to different places without a guardian or a companion, but that he was not allowed to do so unless his mother gave her consent. The director maintained that "what applies at home, applies in the institution. Even if you are living at home, you inform your parents when you are going out." Her insistence on the family metaphor reinforces the idea that residents are at home and not at an institution.

When residents were asked how easy it was for them to move in and out of the institution, all reported not being allowed to exit the institution unless they had obtained a spoken and, in some cases, written or signed permission of their parent or guardian. When describing persons with disabilities' autonomy, one of the caregivers stated that "Persons with disabilities are autonomous inside of the institution and not outside of it. They cannot handle the outside world."

Caregivers stressed the role of parents in supporting the independence of persons with disabilities. In interviews, staff stated that residents needed to feel valued because they were marginalized individuals. Only one caregiver suggested that public spaces should be made more inclusive and that medical support could be of use.

When family members were asked about the support that they needed, they generally focused on vocational, medical and financial support. The majority said that they could only feel secure about their relative's future once they knew that he/she had a stable job. They also requested help in terms of specialized equipment, such as hearing aids.

Among residents with moderate medical cases, the majority typically stayed for at least 20 years. According to one caregiver, institutionalization ends in two ways: if the resident obtains employment or if the resident's case can no longer be managed by the institution. The latter occurs when the institution has exhausted all rehabilitative options and the resident has not shown any signs of improvement, or if their case has grown worse.

Primary findings

Despite offering a number of important health and education services, the institution did not have a specific system for integrating residents into their communities or supporting their deinstitutionalization. In the institution, the needs of residents appeared to be met, and some residents reported enjoying their time at the centre, but interviews highlighted the residents' isolation from the community and inability to live with autonomy. As one resident put it, "I am free to do what I want, but I can't go out for a walk." Their exclusion was likely compounded by paternalistic attitudes demonstrated by some staff members, who appeared to believe residents were not capable of making important decisions about their own lives.

The institution affirmed that institutionalization often stems from a lack of other options for care. Some residents stated that they had nowhere else to go. Interviews with parents and residents revealed the relationship between transportation and institutionalization, as parents described the lack of affordable transportation options as a primary factor in their decisions to send their children to live at the center. This was perhaps most clearly seen in the case of a resident who was formerly a day student at the center and was subsequently institutionalized when transportation costs to and from the institution became prohibitive for his family. It is evident that affordable and reliable transportation is central to the deinstitutionalization process: with adequate access to transportation, persons with disabilities can receive services from centers while living independently or with their families.

Like the Jordanian institution, the center revealed a complicated relationship between staff members and the family members of persons with disabilities. In this case, such tension became apparent in discussions of residents' visits home. In focus groups, staff claimed parents did not know how to adequately care for their children when they left the institution; however, none of the interviewed parents reported receiving counselling or training from staff.

Together, these two case studies highlight the varying services, facilities and lifestyles of the residents living in institutions. In contrast with the case of Jordan, where a recent Ministry reclassification of the institution as a training center for university students resulted in the removal of the institution's vocational education program, the institution in Lebanon required all students to be enrolled in an educational progamme, thus better preparing residents for a life outside the institution. However, contrary to Article 19, both institutions showed similar responses from residents in relation to their freedom of choice where and with whom to live, as well as their isolation from the community. Thus, the case studies further strengthen the findings from the regional study of institutions that more work is needed to support the inclusion and independence of persons with disabilities residing in institutions, who often turn to these centres because there are no other options available. There are many steps that both governments and institutions can take to advance the implementation of Article 19, as will be outlined in the final chapter.

Chapter 5: Conclusion

While some Governments in the Arab region are moving towards mitigating the use of residential institutions through not accrediting or opening new institutions, supporting personal assistance and improving the accessibility of public services, many countries continue to rely on residential institutions to provide care for persons with disabilities. Many barriers remain to the fulfilment of Article 19's goals of community inclusion and independent living. This study highlights the urgency of addressing institutionalization as a primary concern for Governments seeking to implement the Convention and affirm the rights of persons with disabilities throughout the Arab region.

Interviews revealed poor conditions in residential institutions, including unhygienic and overcrowded environments. In the majority of institutions covered in this study, residents were not free to move between the institution and the local community. Eventual pathways to integration in society were at times unclear or nonexistent. There is therefore an immediate need for States to improve conditions within existing institutions while simultaneously developing deinstitutionalization strategies.

Even in cases where institutions provide high quality services to persons with disabilities, the defining characteristics of institutionalized settings—a rigid routine, exclusion from social life in the community, and a lack of choice regarding whom one lives with or receives care from—stand against the principles of Article 19. If residents are impeded from making substantive decisions about their own lives based on personal preferences, this constitutes a failure to protect their rights to autonomy, liberty, and independence. In accordance with the UN CRPD, institutions should not be improved to provide residents with a larger degree of freedom, but rather be replaced by new systems of care. Through creating strategies that address the creation of alternative, independent living facilities, the improvement of accessibility across society, and the provision of direct support to persons with disabilities and their families and communities, States would aim to progressively realize Article 19 and move toward the end of institutionalization

Planning for the end of the use of residential institutions is necessary not only for the progressive realization of Article 19, but also Article 12 on legal capacity, Article 14 on liberty and security of the person, Article 23 on respect for home and the family. Enabling independent

living has positive implications for the participation of persons with disabilities in the workforce, as called for in Article 27, and political systems, as called for in Article 29. Article 19's implementation is also central to the New Urban Agenda's goals of accessible cities, as well as the 2030 Agenda and its Sustainable Development Goals, specifically target 10.2 to promote the social, economic and political inclusion of all.

Transitions away from institutionalization and toward socially inclusive modes of care and service provision will be complex and at times difficult, particularly in Arab countries facing poverty, armed conflict, infrastructural challenges and weak social protection floors. Cooperation across ministries and between governmental and non-governmental actors will be necessary throughout this process. While deinstitutionalization is critical to the implementation of Article 19, the closure of institutions must be accompanied by structural changes that increase accessibility across all areas of society.

The following recommendations seek to highlight specific actions countries throughout the region can take to uphold their commitments under Article 19 to support the independence and inclusion of persons with disabilities.

Adopt deinstitutionalization plans with concrete timelines, budgets, and sources of alternative care: CRPD Committee guidance has stressed that all states that have ratified the Convention must commit to ending the practice of institutionalization. However, the realization of this commitment may need to be taken in stages and the timeline of this process can vary. This is particularly relevant to countries in the Arab region, where the immediate and complete closure of all institutions may not be feasible due to war and conflict, poverty, inaccessible infrastructure, and weak or nonexistent social protection systems. But even when facing these challenges, countries must plan for the future transition to community-based care and the end of institutionalization practices. States that have existing inclusive care models in place should consider strengthening these systems and adopt policies that phase out residential institutions, including the commitment not to open any new residential institutions (Oman). States that do not currently possess alternatives to residential institutions may wish to immediately consult with experts to develop strategies for supporting independent living and community-based care and to seek assistance in creating deinstitutionalization plans tailored to country-specific needs and resources. An example of deliberate and time-scaled strategic planning can be found in Jordan's action plan on deinstitutionalization, which will replace the country's residential

institutions with community care centers over a period of ten years. Alternatives to residential institutions can include subsidized in-home care, assisted living programs, and the provision of individualized support services. At all stages of planning processes, States Parties should actively consult persons with disabilities and their representative organizations.

Contribute to an increased understanding of the extent and scope of institutionalization in the region: Arab Governments are advised to conduct their own in-depth research that probes the use of and conditions in residential institutions in their respective countries, with specific attention paid to the role of institutions in facilitating or impeding independent living. Amassing and publishing disaggregated statistics on currently operational institutions, both public and private, and the number and profiles of persons they accommodate is critical to the monitoring and evaluation process, and a necessary first step in promoting and supporting independent living and formulating deinstitutionalization plans and policies.

Improve monitoring and regulation of existing residential institutions throughout transition processes to community-based care: While states create and implement deinstitutionalization strategies, steps must be taken to ensure persons with disabilities currently living in institutions are protected, supported and listened to and that the institutions themselves are providing high quality care. Governments must actively monitor and regulate all operational institutions, identifying barriers to residents' autonomy, reducing guardianship, and facilitating improvements in the provision of care and services while keeping larger goals of independent living in mind. Morocco has recently made progress in the area of monitoring through the passage of Law 65-15, which requires all residential institutions to create committees to facilitate the monitoring and inspection process.

Improve the accessibility and inclusivity of existing community-based services and facilities: To fully support the independent lives of persons with disabilities, wide-ranging accessibility improvements must be enacted throughout the Arab region. Ensuring persons with disabilities have equal and unimpeded access to hospitals, schools, transportation systems, workplaces, commercial areas, and leisure spaces will reduce the need for the provision of services through institutions.

Develop individualized support services at the local level: In addition to improving the accessibility of public facilities and services, Arab countries must work to ensure persons with

disabilities have access to personalized support in their homes and communities. This can take the form of subsidized personal assistance, community-based rehabilitation programs, housing adaptations, and/or the provision appropriate medical equipment. Community-based support services must be tailored to meet the diverse needs of persons with sensory, psychosocial, physical and intellectual disabilities. Providing training and technical support to the families of persons with disabilities may also be helpful, as interviewed families were often reluctant to remove their relatives from institutions because they did not know how to best assist them. Promisingly, the public official from Palestine described a forthcoming plan to provide medical equipment directly to persons with disabilities to promote independent living, and the public official from Saudi Arabia stated that the Government would soon roll out a programme to train the families of persons with disabilities on providing care within home environments. In all cases, new programmes should be widely publicized, so persons with disabilities can make informed decisions about the assistance they wish to receive.

Redirect state resources away from institutions to directly benefit persons with disabilities and their families: Currently, many Arab countries provide financial support to public and non-profit institutions, and subsidize care in private institutions. Interviewed public officials, directors of institutions and caregivers associated institutionalization primarily with the socio-economic conditions of families of people with disabilities, and to a lesser extent with disability itself. Individuals with disabilities from disadvantaged socioeconomic backgrounds are more likely to end up spending their lives in residential institutions since support services maybe be expensive, difficult to obtain or far from home. If money that is currently directed towards institutions instead goes to persons with disabilities and families themselves, this money could be used to pay for needed care, support services, assistive technologies, adjustments to their home environment, etc. and therefore reduce and even eliminate the need for residential institutions. This study therefore recommends that as part of deinstitutionalization plans, governments shift their financial support away from institutions and toward directly assisting persons with disabilities and their families/caregivers, in addition to improving the provision of necessary facilities and services within communities.

Improve the inclusivity of national education systems: Interviewed persons with disabilities living in institutions frequently cited a lack of educational opportunities as a barrier to community participation. Rather than creating separate educational centers for persons with

disabilities, governments should take steps to promote the inclusion of persons with learning disabilities in state-run schools. Lebanon has recently made progress in this area through the roll-out of a joint program with UNICEF intended to increase the enrollment of children with learning disabilities in 30 public schools throughout the country. This will be achieved through deploying special educators to each school, providing training to teachers on curriculum adjustment, and creating five mobile teams consisting of psychologists, psychomotor therapists, and speech therapists that will travel between schools.[75]The British Council supports Iraq in developing an inclusive education strategy.

Support the participation of persons with disabilities in the labour market: Alongside exclusion from educational systems, a lack of employment opportunities was often mentioned as a barrier to independent living. In addition to creating or enforcing quota systems for the employment of persons with disabilities, Governments would be advised to create or support programmes that encourage employers to hire persons with disabilities and support them in the workplace. A shift in the mentality of employers can be assisted by providing them with Disability Equality Trainings, technical assistance and financial support to help them make the necessary adaptations to their facilities. Vocational training programs and schemes that help with transport to work will also facilitate integration into the workforce. Plans like Saudi Arabia's Tawafuq programme that combine measures to improve workplace inclusivity with vocational training and employment support are particularly effective.[76]

Invest in affordable and accessible transport: While improving accessibility across all sectors is necessary, case studies indicated that improving or creating accessible transportation systems should be a priority in the efforts of Arab States to protect the right to community living and social inclusion. Interviews with families showed that inaccessible transport services, high transportation costs and logistical difficulties forced many parents to place their relatives in institutions full-time, even when non-residential options were available. When support services are not provided at the local level, affordable and accessible transportation is necessary to ensure persons with disabilities can travel to receive care, education and employment outside of their communities while maintaining their residence of choice.

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[75] MoSA & UNICEF, 2007.
[76] See https://www.hrdf.org.sa/Page/Tawafuq_EN for more information

Combat the stigma attached to disability: Negative depictions of individuals with disabilities in public culture, on television, in newspapers, school textbooks, novels and children's stories and other media outlets feed prejudiced attitudes that reside in the conscious and unconscious minds of the general public. Such representations can enforce the exclusion of persons with disabilities from communities, presenting a significant barrier to deinstitutionalisation and independent living. Public education campaigns play an important role in combating stereotypes and reducing stigma surrounding disability. Under Article 8 of the Convention, Governments have an obligation to actively initiate and maintain awareness campaigns to build receptiveness to the rights of persons with disabilities. In doing so, civil society organizations and media groups can help identify discriminatory stereotypes and reinforce more equitable norms that advance the inclusion of persons with disabilities in their communities.

Engage in dialogue on how institutions can support the transition away from segregated residential care: The study found that the majority of public officials were pro-deinstitutionalisation while directors of institutions often maintained that their role was to protect persons with disabilities from society. Further dialogue is needed between government officials and institutions on how institutions can support the transition away from segregated residential care and become establishments that continue to provide specialized services while fostering independent and community living. In many instances, residential institutions are the only entities available to persons with disabilities that have the capacity to provide specialized services, so rather than simply shuttering them, they could be redesigned in a way which replaces institutionalized care with day-service facilities that support the principles outlined in Article 19. These redesigned facilities can also work together with the government, civil society and the media to combat discriminatory stereotypes which result in the exclusion of persons with disabilities from society.

At its core, Article 19 of the Convention on the Rights of Persons with Disabilities stipulates that persons with disabilities, like all others, have the right to choose how to engage in society. They are entitled to actively participate in communities as students, employees, friends, and neighbors, and to enjoy the benefits of leisure spaces, home environments, and family life. Unfortunately, the practice of institutionalisation excludes persons with disabilities from making these choices. Even the most basic acts of personal autonomy, such as deciding what

to eat, when to go to sleep, and who to interact with, are difficult in an institutionalized environment.

21 out of 22 Arab States have signed or ratified the Convention, yet there remains a significant gap between these commitments and the reality of the Convention's implementation in the region. This extends to Article 19, as many Arab States and societies rely on residential institutions to provide care and services to persons with disabilities, despite the resulting deprivation of rights to independent living and community participation. In the region, there is a clear need to advance the implementation of Article 19 through new national strategies for inclusion. The closure of residential institutions will be a necessary component of these future plans, but it alone does not ensure the full integration of persons with disabilities. Despite many regional constraints and various domestic and local challenges, the Governments of Arab States must address inclusion and independent living expansively and holistically, removing social, cultural, physical, economic and legal barriers to ensure persons with disabilities can participate in all aspects of society on a basis equal with others.

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Appendices

Appendix 1 – Questionnaire for Public Officials

Information about institutions housing disabled individuals

1. What is the total number of institutions that accommodate persons with disabilities?
2. How many are public / private / non-profit? (Distribution)
3. What is their distribution across the country? (e.g., rural / urban areas)
4. What are the types of disabilities that institutions mostly host?
   a. How many institutions exist for each type of disability? (for persons with visual impairments? For Down syndrome? Etc.) (numbers)
   b. How many are mixed?
5. What is the total number of persons with disabilities living in institutions? Do you have the distribution by age, sex, type of disability, orphans, abandoned, presence of parents and nationality?
6. What is the process of registration and certification for institutions housing disabled individuals? Is it the same for public and private?
7. Do these institutions send regular reports about their development and activities? To whom? What is the periodicity?
8. What is the process of quality control? Are these institutions regularly inspected? What is the periodicity?
   a. What were the main problems discovered during inspections?
   b. Do you have reports about abuse?
9. Are you aware of homes for elderly that may also host persons with disabilities? Do you know how many?
   a. If yes, where are they located? Are they public or private? Is the number increasing or decreasing?
   b. Do they undergo the same registration, certification and quality control process? How are they supervised?
10. Do you have information about persons with disabilities in the population in prisons?
    a. Do you have any statistics? What do they say?
11. Do you have information of children with disabilities in orphanages?
    a. Do you have any statistics? What do they say?

12. Are there institutions that mostly serve persons with disabilities from affluent families? How many?

13. Are there institutions who serve mainly poor? How many? Where? Public or private?

Ministries' support of institutions housing disabled

14. Does the ministry support the cost of caring for children in private (profit or nonprofit making) institutions? If yes, how much does the ministry pay per child?

15. Can you describe the process in which an institution housing children with disabilities has to undergo to receive funding from the ministry?

   a. Are there criteria for these institutions in order to receive funding (size, qualification of staff, type of work etc.)?

   b. Are there criteria for the types of disabilities which the ministry supports in institutions housing disabled persons?

   c. Are these institutions inspected by the ministry prior to receiving the funding? If yes what do you inspect?

   d. Are they inspected after they receive funds? If yes, how frequently are they inspected?

   e. What kind of information do you collect from these institutions during inspection? Do you interview the cared for? their parents?

Database and information on disabled persons living in institutions

16. Do you have a database of disabled individuals in institutions? If yes, what are the most predominant disabilities? How severe? Age? Gender? Nationality? Temporarily residence or permanent?

17. Other useful statistics on persons with disabilities in institutions?

Government policies towards institutions for disabled?

18. What is the government position concerning the de-institutionalization of disabled people? Do you think there is a need to decrease or increase the number of such institutions?

19. What is the medium-term government policy for the institutions?

20. What do you think are the main reasons why disabled individuals live in institutions?

21. What could help reduce the number of disabled individuals living in institutions?

22. Does the government have a plan for de-institutionalization?

23. Additional useful information.

Appendix 2 – Questionnaire for Heads of Residential Institutions

General questions

1. Name of institution

2. Type of institution: residential, daycare, both?

3. Year of establishment

4. Location (capital, small town, rural area)

5. Mission of institution

6. Is your institution state owned, private for profit, or private not for profit?

7. If private how much is the monthly fee?

8. What are the types of disabilities that your institution hosts? What are the most prevalent types?

9. From how many countries do the inhabitants come? Which countries?

10. Is there a council of inhabitants? On which questions is it consulted? How does it participate in decision making?

Statistical information

11. How many PWD are hosted in your institutions? What is the distribution of inhabitants by age, gender, nationality, type of disability, duration of residence and marital status? (Any documents representing this data?)

12. At which age are the inhabitants normally admitted to your institution? At which age do they leave (if at all)?

13. How long do they stay on average? What is the longest and what is the shortest duration of their stay?

14. Through which channel are they normally registered in the institution? How many come out of own choice? How many are registered by their parents or other parties? How many are orphans or abandoned? How many have been admitted involuntary or against their choice?

15. Through which channels and why persons with disabilities leave the institution

16. How many inhabitants need regular assistance in their daily routine (once per day, 3 times per day, more often)

17. How many need full-time medical care? (24/7)

18. Do you have information about the social status of the family of your inhabitants (e.g., poor, middle class, well off, elite family)? What is the distribution?

19. Are there cases of death among residents in your institution? How many per year? Reasons?

Education and employment

20. What is the distribution by level of education, broken down by gender, age, type of disability and nationality?

21. How many of the inhabitants are literate / illiterate, broken down by sex, age, type of disability and nationality?

22. Is any education provided in-house by your institution? How?

23. How many inhabitants are visiting special education facilities outside of the institution (distribution)

24. How many of them are attending public schools? Private schools? Formal? Non-formal? (distribution)

25. How many PWD in your institution are working? How many are paid for their work? How much?

26. Who receives the remuneration? Distribution by gender, age, type of disability and nationality.

27. How many of those who work are working inside the institution (distribution) How many of the PWD in the institution are employed outside (distribution)? What kind of jobs do they do? How many are employed in skilled / unskilled employment? (distribution)

28. How is the transport to outside work and education organized?

Services and facilities in institutions

29. Has your institution been registered and certified by an official body as being qualified for taking care of persons with disabilities? By whom?

30. Is your institution inspected regularly? By whom? How often? Annually?

31. Do you regularly provide reports about your institution and activities? To whom?

32. Is the available space at the institution suitable for the number of residents?

33. Who are the caretakers? How many of them are regularly employed by the institution? How many male / female?

34. What is the fluctuation in full-time personnel?

35. How many of these have certified qualification to provide care (nurse, specialized teacher, special needs education)? What kind of education/professionalism they have? Insist on asking for formal education.

36. How many of them don't have a relevant qualification?

37. What is the staff/inhabitant ratio?

38. How many caretakers come on one inhabitant. How many inhabitants come on one skilled caretaker?

39. Do caregivers take part in the overall planning of the institutions' strategy? How?

40. Do you monitor caregivers' work process? How? How do you assess their work?

41. How do you support caregivers' work?

42. How many inhabitants live in single rooms? Do these single rooms have private bathrooms?

43. How many share rooms? How many people per room?

44. If showers and bathrooms are shared, how many people have to share one shower? How many one bathroom?

45. Do you have a mechanism for dealing with complaints? (from who? PWD? Caregivers? Parents?) Is it used? What is the procedure for dealing with complaints? Who deals with it?

46. How is the health care of the inhabitants organized? (By resident doctors in the institution? By family doctors from outside? By nearby hospitals?)

47. Is there a resident doctor in the institution? If not, how often does the doctor visit you? In what cases?

48. Are there counsellors or psychologists who assess mental health of inhabitants?

49. Do any of the disabled inhabitants manifest signs of depression, aggression or other symptoms of mental health problems? What are the main causes of these conditions? How frequent are these cases? What happens in these cases? What kind of support do they receive? How many of them improve?

50. Is there a resident nurse(s) in the institution? If not, how often does the nurse visit you? And in what cases?

51. Do residents receive any other services including rehabilitation, physiotherapy, speech therapy, etc.? from who? Your institutions? Other institutions? Names?

52. What other services and facilities are offered by the institution for the PWD? (e.g., sport, cultural events)?

53. Are there IT and internet facilities in the institution? Are they used (distribution)?

54. Do PWD take part in decision making regarding the services and arrangements in the institution? How?

55. What are the main challenges that your institution face in caring for the disabled inhabitants?

56. What type of support would help you provide better care for these individuals?

Costs

57. How much does a place in the institution cost per inhabitant per month? Is it different for different types of disabilities or inhabitants?

58. Who bears the costs? (Government? Families? Charity?)

59. Do many families default on payments? What happens in this case?

60. How prohibitive / affordable are these costs for persons with disabilities from low income families?

61. Are there possibilities for obtaining subsidies (e.g., government, health insurance, charity)?

Relationship with the outside community

62. How often do the hosted PWD get out of the institution to visit their homes or anywhere else?

63. Are they free to move in and out at their choice?

64. How many visits do they receive a week?

65. Who visits them? Family members, state officials, NGOs, schools?

66. How often do the PWD see their immediate family members?

67. What are the main reasons families mention behind admitting their relatives to institutions?

68. Do family members participate in any of the institution activities? Do they participate in the decision made for PWD?

69. Does the institution have a strategy to facilitate the inclusion of PWD in the community?

70. How does integration happen? Does the institution have a strategy to facilitate the inclusion of PWD in the community?

71. What do you think about attempts to integrate disabled individuals in the society instead of housing them in institutions?

72. Does the institution offer IT training for integration into virtual communities and networks?

Additional useful information?

Website:

Appendix 3 – Observation Guidelines

1. Overall environment and quality of the common spaces and facilities (including ramps, equipment, and others). Look for changes or traces in physical spaces and objects (for e.g., is the board new-clean? Are the books or chairs wrapped in nylon? Does the computer lab look like it's being used regularly?).

2. Individual non-social activity/condition (the extent and nature of the person's involvement in constructive activity)

   a. doing nothing
   b. self-stimulation
   c. self-injury, aggression
   d. engaging in non-complex activities that are non-functional or age inappropriate
   e. leisure
   f. engaging in more complex activities such as self-care, using equipment
   g. other?

3. Interaction between caregivers and PWD (the contact they receive from and give to other people)

   a. abuse
   b. poor practice and neglect
   c. reprimanding or preventing someone from doing something
   d. neutral conversation, praise and affection
   e. incentivising someone to act autonomously and/or embark on more complex tasks with bigger responsibilities such as self-care activities, using equipment's, other good practices

4. Interaction between PWDs themselves (i.e. type of conversations, communication, aggression, etc.)

5. The extent and nature of any challenging behaviour they show

Appendix 4 – Questionnaire for Persons with Disabilities

Experience in and perception of the institution

1. For how long have you been living in this institution?
2. What was the reason for coming to an institution?
3. Whose decision was it for you to come to an institution?
4. For how long do you anticipate to stay at this institution? What factors would determine this?
5. Are you staying in this institution out of your free will? Why?
6. What do you think of the quality of services you receive at this institution?
7. How would you describe your relationship with your caregivers? Do they treat you well?
8. How would you describe your relationship with other residents?
9. Do you get the autonomy you need in managing your time and space, and to make priorities the way you see fit?
10. How easy for you is it to move in and out of the institution? How often you do that per month?
11. Would you like to leave this institution? Why? What do you need to be able to leave and live outside? What is stopping you from doing so?
12. Where would you like to live and with who?
13. Do you have any friends inside the institution?
14. Are you bullied or violated by anyone inside the institution? By who? And how?
15. Please select which of the following facilities isn't available at your institution: internet, phone, private bathrooms, garden, physiotherapy, counselling, speech therapy, sports, pool, TV in each room, common areas).
16. How would you describe the quality of services provided in this institution? – including food, shelter, cleanliness, privacy, attention by caregivers, healthcare, education, opportunity for employment, access to nearby community, etc. - (each can be evaluated as good, fair, or bad).
17. Is there a daily doctor in the institution? is he/she helpful when you need them?

Relationship with family and community

18. Are you in contact with your family members? Friends? Colleagues? Outside the institutions? How frequently? By phone? Do they come and visit you here? How often?

19. Do any of your family members come and visit you?

Who? How often?

20. Do you visit them at their place?

How often?

21. How would you describe your relationship with your parents?

22. Do you experience any discrimination when you are outside the institution? Where? What type of discrimination or harassment?

23. Are you bullied or violated by anyone outside the institution? By who? And how?

Attitude and expectations / Education and work

24. Were you at school before coming to this institution? Was it a special school or mainstream?
    a. If yes, what was the highest certification you attained? **Did you have any learning difficulties?**
    b. If not, why weren't you enrolled?

25. Did you drop out at any point before finishing the program/degree? If yes, why?

26. What kind of activities are you involved in at this time? (Job, school, religious activities, family events, sports and recreation, etc.) PLEASE SPECIFY.

27. Are you currently receiving any kind of education? please specify grade/degree, formal/informal, vocational/academic, etc.
    a. Are you facing any learning difficulties?
    b. Describe your relationship to your teacher.
    c. Are you intending to continue your higher education?

28. Have you ever worked before? What type of work was it?
    a. Why did you leave your work?
    b. How would you describe your previous work conditions?

29. Do you currently work?
    a. Inside or outside the institution?
    b. How would you describe your work conditions?

30. **If they don't work**, are you willing to work in the future?

    a. If yes, are you doing anything in the meantime to reach this end?

    b. If not, why not?

Autonomy and self-determination

31. Where do you see yourself 5 years from now? where would you be living? Career life? Family life? Community life?

32. To what extent are you actively making decisions with regards to your own life (accommodation, marriage, education, work)? Why? Why not?

33. Do you at any point feel overpowered or coerced by an individual or a group to act in certain ways or make certain decisions? If yes, by who? and how

34. What do you need to be able to be fully independent and to manage your own life?

Any other thoughts or experience you would like to share?

Appendix 5 – Questionnaire for Parents and Families

Background information

1. Is your institutionalized relative receiving in-house care (resident) from this institution? (Interviewees must be family of a disabled person receiving in-house services)

2. Age of interviewee:

3. Gender:

4. What is your relationship to the resident? (Mother, father, sibling, …)

5. Do you work?

    a. Full time/ part-time

    b. Nature of work

6. During the past 12 months, has there been a time when you or your household did not meet all of your essential expenses? (e.g., mortgage, rent, utility bills, medical care, food or groceries.

7. Do your caregiving financial responsibilities make it difficult to meet your essential household expenses?

8. What is the type of disability of your family member who is in the institution (cognitive impairment, developmental/physical impairment, sensory impairment, Autism, others). How old is he/she?

9. What type of care does your relative need? How independent is he/she? Can they go to the bathroom, transfer, feed themselves, etc.

10. Was he/she able to attend school? If yes to extent if not, why not?

Received services
11. Do you receive, on behalf of your family member, any state-funded financial assistance? Is it enough to support your disability-related expenses?

12. Does your family member receive any state-funded education or rehabilitation services? Please specify.

13. Have you received help/counselling/training from a social worker, psychologist, counsellor, therapist, or physician because of your caregiving responsibilities? Useful?

14. What kind of support do you and your family member need to be able to help him/her live outside the institution?

Relationship with family member
15. How do you usually support your family member at the institution?

16. Are you often in touch with his/her close caregivers at the institutions? How do you communicate and what do you often talk about?

17. How often do you visit your family member at the institution?

18. Do you take them to visit home?
   a. If yes, how often? What do you do? And how does it affect your disabled family member?
   b. If no, why not?

Perceptions of the institution
19. What was the main reason why your family member was admitted to a residential institution?

20. Was he/she admitted voluntarily and with their informed consent?

21. Did he/she attend day-care institutions before being institutionalised?
   a. If yes, was it helpful? Why did he/she need be institutionalised afterwards?
   b. If no, why not?

22. Were they in other residential institutions before?

23. How did you feel about putting them in an institution?

24. How much does the institutionalization of your family member cost? How do you cover the costs? (Pay yourself, paid by the institutions itself, state-funded, charity, etc.)

25. What do you think of the quality of services received by your disabled family member at the institution?

26. Did you realize any improvement since your family member was first institutionalized? How did he/she improve?

27. Are you regularly informed of your family member's condition and progress? How often? Helpful?

28. Do you think that institutionalization can help persons with disabilities improve their health and live an autonomous life in the future?
    a. If yes, how?
    b. If no, why not? And what can be helpful for deinstitutionalization?

Expectations and planning towards the future

29. How long do you think he/she will stay in the institution?

30. What kinds of activities are your disabled family member involved in at this time? (Job, school, religious activities, family events, sports and recreation, etc.)

31. What kinds of activities you hope your family member to engage one year from now? What do you think can make this possible?

32. Where do you think your family member will be in 5 years?

33. What are the barriers to integrating persons with disability back in the society? (theoretical)

Appendix 6 – Questionnaire for Caregivers and Specialists

Background
1. Job title

2. Qualifications/highest degree obtained

3. Do you work full time in this institution? How many days per week? How many hours per day?

4. For how long have you been providing care for people with disabilities?

5. Are you paid? How would you describe your work conditions? (Pay, working hours, holiday, etc.)

Responsibilities

6. How many persons with disabilities are you responsible for assisting?

7. What is the age range of the majority of individuals you provide care for?

8. Can you tell us about the exact activities you provide/conduct with people with disabilities in the institution? (Managing medication, bathing, eating, getting in and out of bed or chair, using toilet, shopping, managing money, using telephone and texting, helping to participate in social events, speech therapy, physiotherapy, occupation therapy).

Needs of persons with disabilities

9. What is the primary condition of the persons you support and provide assistance to? (cognitive impairment, developmental/physical impairment, sensory impairment, Autism, others) please specify.

10. Do you diagnose residents when they are first admitted to the institution? Who diagnoses people with disabilities and assess their needs? Do you often repeat the diagnosis? When? How often?

11. Thinking about the care and assistance you provide, what parts have been challenging most for you?

12. Do you think that disability inevitably debilitates individuals and prevent them from living autonomously and from making their own decisions? Why? /Why not?

13. What kind of support (family, medical, social, governmental, institutional) can help persons with disabilities to lead an autonomous life?

14. On average how many years/months do residents stay in the institution?

Relationship with family

15. How would you describe people with disabilities' relationship with their family members?

    a. Are they often in touch with their family members? Who?

    b. How often do families visit their disabled family member at the institution?

    c. Do they often take them to visit their home? How long do they usually stay there?

16. Tell us about the parents' role in the development of persons with disabilities' condition? **(actual role and how it ideally can be).**

17. Can you describe the socio-economic background of the majority of residents' families? Is the family's role affected by their educational and socio-economic background? Why? Why not?

18. How would you describe your relationship to people with disabilities' parents/guardians?

    a. Do you meet with all parents?

    b. How often do you meet with them?

    c. What do you usually discuss?

Role of the institution

19. What is the main reason why they are usually institutionalised? (general question). **AND WHO** usually admits persons with disabilities to the institution?

20. Are they usually admitted voluntarily and with their informed consent? Are they asked to sign an informed consent? If not who signs it?

21. Do they stay in the institution voluntarily?

22. Did persons with disabilities attend day-care institutions before being institutionalised? Were they residents in other institutions?

23. Are you the only caregiver responsible for people with disabilities?

    a. **IF YES,** is your assistance covering all persons with disabilities' individual needs? do you need other professional's help to provide all the support they need? If yes, what kind of support and professionals can help you with your work?

    b. **IF NO,** who is supporting you? Is it enough to cover all persons with disabilities' individual needs? If no, why not?

24. Do you receive training from the institution? If yes what was it? How useful?

25. Can you describe a typical day at the institution? What would you be doing? What would most residents be doing?

26. Do any of them exhibit psychological or intellectual illness symptoms? If yes What would be the percentage? Have they been officially diagnosed? Are they receiving support? By whom?

27. Do you know if any of the residents' experiences bullying or harassment? If yes by whom?

Expectations and planning towards the future

28. Do you think that institutionalisation can help persons with disabilities improve their health and live an autonomous life in the future?

    c. If yes, how?

    d. If no, why not? And what can be helpful for deinstitutionalisation?

29. Where do most persons with disabilities end up in 5 years?

30. What could help persons with disabilities plan and own their lives in the future?

31. Any other thoughts/experience you'd like share?