

Jordan's Deinstitutionalization Plan

The Hashimite Kingdom of Jordan, under the rule of King Abdullah II, is an Arab and predominantly Muslim country that has been an independent kingdom since 1946. Although located in the Middle East, a turbulent political region, Jordan has maintained its safety and stability over the years. Jordan is a relatively small country with a total land area of 88,794 sq KM and an estimated population of 10.6 million in 2020; it has a young population with more than one-third of the population under the age of 15. Jordan's literacy rate (percentage of people above age 15 who are literate) is high, with 96.7 % of males and 92% of females (Bickerton, 2020). Jordan is ranked as the second country with the highest number of refugees per capita (UNHCR,2020). It hosts more than 2 million Palestinian refugees, 18.5 % of whom live in refugee camps (UNRWA, n.d.), and approximately 750,195 refugees from Syria (majority) and 58 other countries, 16% of whom live in refugee camps (UNHCR,2020). Jordan's GDP for the year 2019 was an estimated 44.5 billion USD (World Bank, n.d.), and the country often relies on foreign aid to support its refugees and development in the country.

Although there are no official statistics regarding the percentage of the Jordanian population who live with disabilities, a 2018 paper by the British Institute of Development Studies stated that the Higher Council of Affairs of Persons with Disabilities in Jordan estimated that 13% of Jordanians lived with a disability in 2016. The specific statistics in the different categories of disabilities are unknown. The paper also addresses the prevalence of disabilities in the refugee community and suggests that approximately 30% of Syrian refugees in Jordan have physical or intellectual needs. (Thompson & Institute of Development Studies, 2019)

In 2007, "The higher Council for the Affairs of Persons with Disabilities" was established as part of law 31 of 2007 for the rights of persons with disabilities. In 2017, the council replaced the law with Law 20/2017, "Law on the Rights of Persons with Disabilities No.20," and the council was renamed "The Higher Council for the Rights of Persons with Disabilities (HCD) headed by His Royal Highness Prince Mired Raad Zeid Al-Hussien. The council's board is an inclusive body that includes the voices of those with various disabilities (however, it lacks the voice of an individual with an intellectual/developmental disability), the voice of parents of people with disabilities and several professionals from the field. (*Overview | Higher Council for the Rights of Persons with Disabilities*, n.d.) The 2017 law consisted of 52 articles to support the rights of individuals with disabilities in Jordan, including the development of an inclusive education system, improving employment rights and provision of reasonable accommodations, rights to individual autonomy, freedom of choice and informed consent, as well as improving accessibility and usage of universal design. Of importance to this paper is Article (27) of the law, which states that the Ministry of Social Development will work with the HCD to develop a comprehensive national deinstitutionalization plan and design alternative services for individuals

with disabilities. (*Law on the Rights of Persons with Disabilities No. 20 for the Year 2017 | Higher Council for the Rights of Persons with Disabilities, n.d.*)

As of 2018, Jordan had 34 residential institutions that housed children, youth and adults with disabilities and relied heavily on those residential institutions to care for individuals with intellectual disabilities. These institutions housed 1471 individuals, 883 of whom were non-Jordanians. (HCD document). In response to Article 27 of Law 20 for the year of 2017, the Ministry of Social Development developed a 10 Year Deinstitutionalization Plan launched on the 14th of November, 2019. Although many individuals with disabilities continue to reside in institutions, the Ministry of Social Development has made it illegal to establish new residential institutions or increase existing institutions' capacity (The Higher Council for the Rights of Persons with Disabilities & Ministry of Social Development, 2019). The plan is designed to be implemented in several three-year phases and is broken down into seven axes which are incorporated into each year and include the following:

1. Assessment

- Assessing the residents of institutions and their families to understand their needs and provide the most appropriate services
- Assessing the success of programs and services implemented in previous years

2. Alternatives

- The development of Alternative Services (e.g., reintegrating individuals with their families, developing group homes and daycare centers and creating a respite (referred to as "short breaks") program

3. Services

- Identifying and introducing other services and service providers

4. Community Rehabilitation

- Developing community rehabilitation programs and early intervention services

5. Training

- Training existing and new staff on the importance of deinstitutionalization and the implementation of new services
- Training families how to support family members with disabilities when they return home

6. Communication, Awareness and Media

- Spreading awareness into the community about the importance of the deinstitutionalization movement
- Increasing the participation and representation of individuals with disabilities in the media

7. Plan Revision

- Reviewing the plan twice during each year of implementation

The plan is currently at the beginning of its second year of phase 1. According to the official phase 1 plan provided to me by the ministry, in its first year, the MoSD and HCD have:

- Developed an administrative unit and a deinstitutionalization committee that drafted the deinstitutionalization plan, including developing evaluation and follow-up standards to ensure that goals are met.
- Begun developing an electronic system database.
- Developed assessment tools to assess individuals with disabilities and their families and trained 15 social workers to use the assessment tools.
- The ministry selected 30 residents from two institutions to reintegrate with their biological families;
 - The MoSD wrote 30 transitional plans for each of these individuals.
 - Their families began receiving training.
 - Thirty homes were adapted to meet their needs.
 - The MoSD also approved two bodies to provide monitoring and evaluation services of the individuals who reintegrated into their families, including periodic visits and reports.
- In terms of group homes, the MoSD rented two apartments to house 12 residents from one institution.
 - Designed transition plans for these residents.
 - Trained 15 staff members from the institution to support the individuals in the group homes and hired and trained five new staff members.
 - Developed a monitoring and evaluation (M&E) plan, hired four staff members to implement the M&E procedures, which would include periodic visits and reports.
 - In terms of community rehabilitation services, the MoSD trained 15 staff members from the ministry to implement community-based rehabilitation programs to enhance independent living in two of the country's governorates and trained 20 staff members from the selected governorates.
 - Two societies began implementing the community-based rehabilitation program, and M&E services, including periodic visits and reports, were set.
- The ministry established 13 early intervention units in existing daycares and provided workshops and staff training on early intervention programs.
 - A follow-up and M&E committee was also established.

- In terms of training, 446 staff from existing institutions received training on the rights of individuals with disabilities and the importance of the deinstitutionalization movement.
- The MoSD and its partners held five awareness workshops for families of individuals who are residents of institutions to inform them of alternative services and accommodations that would be made available to their families.
- In terms of media, communication and awareness, the HCD and MoSD have developed a media plan. The plan included training journalists on the rights of individuals with disabilities, developing awareness messages, conducting television and radio interviews and developing an awareness movie that would highlight the success stories of individuals with disabilities who have been included in society.

The Higher Council for the Rights of Persons with Disabilities and the Ministry of Social Development have spoken out about the deinstitutionalization plan's importance. They have justified the plan noting that keeping the institutions running is a violation of human rights and can pose health risks; they believe that individuals with disabilities have the right to be included in the community, have autonomy and freedom of choice. They state that family and community-based care result in much better outcomes for these individuals. The MoSD has included in its justification that institutionalization is expensive and serving individuals in their families and communities would cost the government less. With any major project comes challenges and risks; some of these challenges and risks that the HCD and MoSD foresee include the lack of financial resources in the country to implement the strategy and donor countries' funding priorities. Other challenges include the political challenges posed by the number of residents who are not Jordanian, training and hiring the required staff and some of the negative perceptions held by families of people with disabilities and the community. (The Higher Council for the Rights of Persons with Disabilities & Ministry of Social Development, 2019).

To better understand the challenges and risks and gain a clearer picture of what's to come from the ten-year plan, I have been given the privilege to interview members of the Ministry of Social Development, His Royal Highness Prince Mired Bin Zeid, president of the HRC, Ms. Alia Zrekiat, advisor to his royal highness and disability advocate in Jordan, Alia was diagnosed with Cerebral Palsy and at age nine had to move to London due to the lack of services in Jordan. I also spoke to Ms. Razan Al Kurdi who is the director of the independent living department at the HCD and cares for her 41 year brother with Down Syndrome. Finally, I spoke with Mr. John Black who works with Northern Ireland Cooperation Overseas (NI-CO) and leads the collaboration between the MoSD and NI-CO in Jordan. Below are the insights gained from these interviews:

The beginning:

In 2014, His Royal Highness Prince Raad bin Zeid retired as the president of the Higher Council for the Affairs of Persons of Disabilities. During his time serving as the president, the prince signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and advocated for the rights of individuals with disabilities in Jordan. Before his retirement, HRH Prince Raad had set up a committee to draft a new law regarding the rights of individuals with disabilities, which would become Law No.20 of 2017. Upon his retirement, the King appointed his son, HRH Prince Mired bin Raad, as the higher council president. The prince, who had experience working with soldiers who were disabled and at the time was the president of the Hashimite Commission for Disabled Soldiers for 15 years, was happy to follow in his father's footsteps. Soon after being appointed the HRC president, HRH Prince Mired attended the CRPD annual meeting of states parties, while at the UN for the commission meeting, the prince happened to pass by a hall where participants were talking about deinstitutionalization. At the time, deinstitutionalization was new to the prince, and he felt the need to walk into the hall and listen to the discussion. The speaker at the talk was a young man who spent most of his life at an institution in New Zealand, listening to the horrors the man experienced; the prince knew he had to return to Jordan and look into Jordanian institutions.

As soon as he returned to Jordan, the prince began his investigation and discovered the horrors and abuse in the country's institutions; 50 - 60 beds jam-packed in one room, all the men had their heads shaved, all dressed in the same set of athletic clothing and the majority of whom were given psychotropic medications and taken outside for only half an hour once a week. The prince then met with the legal team organized by his father, who was drafting the new law on the rights of people with disabilities and instructed them to add an article to the law that would cover deinstitutionalization. That was the birth of the deinstitutionalization plan in Jordan.

Early resistance:

The deinstitutionalization plan was not readily accepted by the legal team or the Minister of Social Development at the time; their main concern was financial. They anticipated resistance from the privately run centers that were charging hefty fees. At the end of the day, these were run by businessmen who had more value for the money they were making from the wealthy Saudi and Emirati people who sent their family members to Jordan. Private institutions were allowed to register under the ministry of trade and industry rather than the ministry of social development; for them, this means more profitability with fewer restrictions and accountability. The deinstitutionalization movement that places more restrictions threatens their profitability. Furthermore, the ministry was worried that closing down the government-run institutions would result in a loss of millions of dinars and thousands of jobs. The prince nonetheless persisted in his fight for the rights of peoples with disabilities and managed to get the article passed in law.

Main issues faced:

A central database for all the persons with disabilities in government and public institutions does not exist. To be able to plan for alternative services, the government needs to know how many people with disabilities are living in institutions, what are their disabilities, their needs, where did they come from, and if they have families and whether or not those families were abusive; without this information, it proves to be challenging to come up with the appropriate alternative services. A second issue they faced was confirming the diagnoses that individuals received and if the HRC could trust the diagnostic tools' integrity or whether institutions used diagnostic tools at all. One problem that will persist throughout the ten-year plan is the fact that society is not sensitized enough to the issues of deinstitutionalization, stigma and discrimination, especially towards those with an intellectual disability, are highly prevalent in Jordanian and Arab society at large. Individuals with disabilities are largely hidden from society; most people who know someone with an intellectual disability know a person sitting at home, illiterate, uneducated, and unable to look after themselves. For people who do not know someone personally, the representation of disability they see is of someone begging at the traffic light; there aren't any success stories or appropriate representation and awareness around individuals with disabilities. Another critical challenge is limited resources and lack of proper funding; while the project itself is primarily funded by international organizations, the plan's implementation will be financed by the government, which does not have enough funding. A final issue that the HCD faces and was reiterated by Mr. Black from NI-CO is the pressure to succeed which goes far beyond simply closing institutions in Jordan but about being a model for the region. In the words of HRH Prince Mired, "will countries say, look, if the Jordanians were able to do it with limited resources, we should be able to do it as well. If we don't succeed, the reverse is going to happen; all the Arab countries are going to say, they tried to do it in Jordan, and it was a total disaster, so forget about it, just continue putting persons with disabilities in institutions."

Sources of support and inspiration:

In 2015, at the conference of state parties in New York, members of the HCD met with members of the Lumos Foundation, a foundation founded by author J.K. Rowling which strives to transform care systems worldwide. In 2016 official discussions between both parties were underway, and since then, the Lumos foundation has been an integral part of the deinstitutionalization plan offering training and support to local establishments. The HCD met with members of the foundation in London and toured several service centers in London, which led to the inspiration to build services in Jordan, such as the "short break" service, similar to US respite services. In addition to the Lumos Foundation, the HCD and MoSD work closely with Northern Ireland Cooperation Overseas (NI-CO), a not-for-profit organization supporting countries in building public sector programs that are efficient and capable of managing donor aid.

Person-centred planning from the start:

Jordan's deinstitutionalization plan proves to be a person-centred plan which focuses on the needs and rights of each individual currently served in institutions. As reported by members of the HCD, John Black from NI-CO and members of the MoSD, the most crucial part of the plan is what they call the "individual evaluation & assessment." This part of the plan entails rediagnosing and verifying the initial diagnoses the individual received in the institution; it also includes a very comprehensive assessment of the individual, their physical, emotional, spiritual, psychological, medical, dietary and occupational needs to gain a better understanding of who the person is and what the person needs. After completing the individual assessments, the next step is assessing the family situation, looking at the family environment and the family's attitudes towards the individual with a disability, any abuse or neglect instances, looking at the family's criminal record and looking at the family's financial situation. These assessments focus mainly on adaptive skills rather than IQ assessments. They are conducted using culturally appropriate assessment tools that use culturally sensitive ways to ask about an individual's sexual behaviour and the family's criminal records. The cultural awareness and sensitivity extend to the design of services such as calling a service family coaching/training instead of family "counselling," which is associated with stigma and taboo in the Arab region.

Only after the comprehensive assessment is completed does the ministry begin to formulate a care and transfer plan for each resident, finding the best option based on the assessment results. In the words of Mr. John Black, "we are making sure that the services we develop and evolve are meeting the needs of the individuals, rather than pushing the individuals into the services that are available." When it comes to the design of services, Mr. Black and the MoSD are advocating for having as wide a range of services available that can support those with the capability to live with more independence to those who may need 24-hour care outside the walls of an institution.

As for the involvement of residents in the plans to leave the institutions, the government focuses on allowing them to be involved to the greatest degree they are capable of. The HCD, with support from Lumos, has established that it will take an average of 3 to 6 months to prepare an individual to move out of an institution and reintegrate into society. During those months, residents will begin to prepare by learning skills they need to live outside the facilities through initiatives such as building small domestic kitchens in the current institutions where residents can begin to practice their skills and providing the residence with more autonomy and independence within the institutions. To make the transitions easier, residents of institutions will be given the opportunity to visit the place they will move to and spend time, whether it be a few hours or a few days, to become acquainted with their new home. The MoSD will work with current staff to identify any items at the institutions that an individual may be attached to and allow them to take the item with them as a transitional object; this can be something like a piece of furniture or a specific easily movable item from the institution. When possible, residents will be given the opportunity to choose the furniture or design of their room in a group home. In terms of social connections, Mr. Black has spoken about moving friends into the same group home and moving staff with residents they have cared for for years.

Residents will also be involved in determining whether they will live independently, in a group home or return to their family homes to the greatest extent their cognitive capacity allows them to. Mr. Black gave an example of a young man who made it clear that he did not want to move back with his family; although his family have stated that they would take then man back into their home (possibly to receive the monthly allowance given by the government), the MoSD will respect the man's choice and find a group home for him.

Staff responses:

The response of the current staff at institutions has been pleasantly surprising. The majority of the staff have been sensible and realistic about the changes, they know they are happening, and they have accepted the fact that it will. They have been open to the training and understand that they may need to receive more training throughout their careers to update their skills. They understand that while they may be doing a job in the future caring for the same people, it won't necessarily be the job they are doing now. There, however, is a minority of the staff that won't be able to make the transition; Mr. Black describes these individuals as people who are more institutionalized than the residents; they come in at a specific time, do certain tasks every day in the same exact way, following the same routine and suddenly telling them that they need to be giving people options and respect the right to choose is something they find unrealistic and burdensome. What the MoSD, along with NI-CO, are working on now is identifying the staff members in the current institutions who can be part of and lead the transformation and identifying the staff members who won't be able to take part and may need to retire or move on to a different field.

Mr.Black brought up an interesting point regarding the staffing of current institutions and future services; he spoke of the importance of speaking to the domestic staff, kitchen staff and caretaking staff, highlighting that these individuals can sometimes be the best people to hire for the new services with a bit of upskilling. He also stressed the importance of speaking to these staff members to learn about what happens in the institutions and how the residents feel; he states that they often know the most because the residents feel safest with them because they don't see them as holding power over them.

Community involvement and awareness:

All parties involved stressed the importance of community awareness and involvement, starting with schools, mosques and churches. For residents of institutions to successfully reintegrate into communities, the community must be prepared. The plan involves discussions with police officers and first respondents on the appropriate ways of responding to community disputes involving an individual with a disability and having similar conversations with local shop owners. As for the residents of communities where group homes will be places, the communities

will be involved by being informed and helping them understand why this move is happening and finding ways to allow them to be a part of it so that they too can become a great resource.

Prospective jobs for the residents:

As Jordan faces an economic crisis worsened by the pandemic, finding a job is difficult for anyone, let alone someone with a disability who employers are less likely to hire. The current bodies involved in the deinstitutionalization plan believe that initially, the focus will be on community services and volunteer organizations to support individuals with disabilities. Another avenue they are working on is looking at what technical and vocational colleges can do to create programs that can enhance these individuals' job skills. There is currently a not-for-profit organization called Sana, founded by a group of mothers of individuals with various disabilities, offers, amongst other services, such as scholarships and support groups for parents, job coaching, and job shadowing individuals with disabilities. The government hopes that more services of this type are formed in the country.

My own reflections:

In my opinion, although Jordan seems far behind other countries when it comes to deinstitutionalization, I believe one benefit that comes with being behind is a wealth of information of past failures and difficulties. I think Jordan has the opportunity to learn from other countries, and I believe that this is what the experiences of organizations like Lumos and NI-CO bring to the table. Since the number of residents in all the institutions could possibly equate to the number of residents in one large institution in the US in the 60s, I think it would be doable to focus on each individual and comprehensively assess the situation as the plan intends, however, I do believe that some areas of the plan may be too optimistic and while on paper they sound wonderful and possibly doable, I think as time goes by and more residents begin to move not all plans will be possible. Furthermore, even after several interviews, I still wonder what life would look like for the large percentage of residents who are not Jordanian. The major obstacle is the inability to carry out the same assessments of the individual and family that is provided for the Jordanian resident. Additionally, the limited resources of the Jordanian government makes it unfeasible to cover the cost of group homes for non-Jordanian citizens. One option might be privately funded group homes to take care of the individuals coming from the Arabian Gulf Countries. As the plan progresses, I hope to see more focus placed on those individuals' needs.

I will end this paper with the words of His Royal Highness Prince Mired: *"Is it going to be easy? No. is it going to be a headache? Yes. Are we going to face a million problems? Definitely. Will it be a big struggle? Definitely, but we really have no other choice. We may not succeed 100%, 90% or even 80%, but we will make some lives better."*

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