

The National Strategy for the Deinstitutionalisation of Persons with Disabilities in Jordan



**Living in my community and with my
family is my right and in my interest**

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Foreword by HRH Prince Mired Raad Zeid Al-Hussein President of the Higher Council for the Rights of Persons with Disabilities

Jordan created a paradigm shift in disability rights with the enactment of the Law on the Rights of Persons with Disabilities Number 20 for the Year 2017. The process of developing this law involved thorough legislative reviews and extensive technical consultations with stakeholders in the field, ranging from individuals, organisations and families, to workers, supporters and those actively concerned with disability issues.

Articles in the Law concerning deinstitutionalisation are perhaps among the most progressive provisions that conform to global trends seeking to dismantle restrictive and marginalised environments, transforming them into surroundings that are inclusive of persons with disabilities, and enabling them to live independently with dignity, while utilising their abilities and potentials to effectively realise the principles of equality, non-discrimination and equal opportunities in their truest and finest sense.

Since the Law's enactment, the Higher Council for the Rights of Persons with Disabilities (HCD) in partnership with the Ministry of Social Development (MoSD) and relevant entities, worked diligently to complete this strategy. The document presents a road map for transforming systems of care from residential institutions into inclusive services for persons with disabilities within their families and local communities. Since then, both HCD and MoSD, and with the support of the British organisation, Lumos Foundation, began employing the initial suggestions followed by the necessary practical steps leading to the compilation of this strategy in a manner that meets the Law's objectives and intentions.

I commend all efforts that have led to the completion of this distinguished national document, and look to having its components and principles translated into realities and practices on the ground, becoming as we hope, a model example to be replicated by our neighbouring countries and friends in this world; the world in which current literature tells us that civilised nations are those that are built on principles of human rights and their inherent dignity. For those countries were, in the past, in a situation not too different than ours, with even greater socio-economic challenges. Such difficulties, however, did not stop them from creating change, and they have since managed to deinstitutionalise persons with disabilities, transforming their systems into inclusive ones, as is currently the case in Moldova, Bulgaria, Haiti and others. Therefore, it is only right for our country to want to emulate and embody this civilised and noble practice.

With the unequivocal and steadfast support of His Majesty King Abdullah II bin Al Hussein to the Kingdom's disability portfolio, we are certain that our country shall continue to serve as a beacon of light for those in search of upholding fundamental human rights, principles and values.

Mired Raad Zeid Al-Hussein

Foreword by H.E. the Minister of Social Development

Since the enactment of the Law on the Rights of Persons with Disabilities Number 20 for the Year 2017, the Ministry of Social Development (MoSD) has embarked on developing a comprehensive national plan on deinstitutionalisation, known as the National Strategy for the Deinstitutionalisation of Persons with Disabilities in Jordan. This strategy is in line with international laws and conventions of which the Hashemite Kingdom of Jordan is a signatory, as well as the Jordanian Constitution and the Jordanian Charter. This strategy also upholds the right of persons with disabilities to live with their family; their right to education, training and employment; and their right to a dignified life, within an inclusive and 'normal' setting. The Strategy reflects the Kingdom's protection and care of its citizens in preserving the rights of persons with disabilities, and facilitating their access to services in a just manner –as a standard of the nation's progress. This collective and concerted work is one of the numerous achievements realised in the reign of His Majesty King Abdullah II Ibn Al Hussein, adding, as they do, to the array of qualitative and quantitative services for persons with disabilities.

Article 27 of the Law clearly states that the MoSD will, in coordination with the Higher Council for the Rights of Persons with Disabilities (HCD), draw up a comprehensive national plan that includes temporary and permanent solutions and alternatives in order to transform governmental and privately-owned residential institutions into inclusive day-care service facilities, provided that implementation of this plan will begin no later than one year from the date on which this Law goes into effect and will be completed in ten years' time at the latest. This provision conforms to the commitments of international covenants and promotes social inclusion and equal opportunities for persons with disabilities.

Believing as the MoSD does that persons with disabilities are right-holders, who must no longer be abandoned or continue to live in segregated settings and residential institutions, away from their families, the Strategy for the Deinstitutionalisation of Persons with disabilities makes it incumbent upon us to put the best interest of persons with disabilities at the core of all we do. That is why the Strategy promotes inclusive settings and repeals all legal provisions preventing persons with disabilities from the right and freedom of choice, while also working to provide the prerequisites to independent living for persons with disabilities, on an equal basis with others.

Finally, implementing the Strategy for the Deinstitutionalisation of Persons with disabilities is an immediate national priority, which numerous countries around the world have already realised, giving persons with disabilities full legal capacity, the right to free choice and independent decision-making based on correct information.

I hereby reiterate that the successful realisation of this strategy for the benefit of all those entities working with individuals with disabilities is an urgent necessity; one which will not cause the staff in residential institutions any harm. For, they will be active participants in the process of implementing all alternatives and in transforming the services within those institutions into inclusive day-care services.

Peace, God's mercy and blessings be upon you.

Basma Mousa Ishaqat

Introduction

This strategy aims to end the institutionalisation of persons with disabilities in Jordan, to ensure that the best interests of persons with disabilities are respected, and to provide lasting and sustainable change. It takes into account existing documentation and research on institutions and other child protection issues in the Kingdom, as well as international best practices in the process of reforming systems of care (from institutions into inclusive settings). It is provided as a basis for consultation, with a view to being included, as a key component of a more detailed, realistic and applicable action plan that will be developed and implemented.

The Law on the Rights of Persons with Disabilities Number 20 for the Year 2017 (henceforth referred to as “the Law”) is the first ever anti-discrimination piece of legislation in the region, with comprehensive articles and stipulations tackling the civil, political, economic, cultural and social rights of persons with disabilities. Chief among those is the vital need for transforming the system of residential institutional services into inclusive community-based services that promote independent living, as per article 27 and the subsequent paragraphs. To this end, the Law obligates the relevant governmental entities to develop a national comprehensive action plan, within one year of the date in which the Law enters into force, which is to be implemented in 10 years. In doing so, the plan will enable the eventual re-integration of persons with disabilities into family-based surroundings and community-based environments, living as they should –and as per the Law—independently. This requires strengthening their independent living skills, and the skills of the families, relevant individuals and organisations. To effectively realise this goal, and other inter-related legislations, the Law stipulates for a number of provisions, which promote the right of persons with disabilities to (inclusive) education, employment and accessibility, amongst other rights, as the prerequisites to achieving independent living—as a meaningful and operative concept and practice.

The current status quo of residential institutions in Jordan

At the present, Jordan has 34 residential institutions that care for children, youth and adults with disabilities. The majority of institutions are privately-run, accounting for 27 of the total, whilst 5 of the remaining few are government-run and two are voluntary sector organisations. Most of the institutions are located in Amman, and research conducted on the status of these institutions indicates that 1,471 males and females are enrolled across all institutions in the country. However, 883 of the total number of persons in these institutions are non-Jordanian.

The justifications for deinstitutionalisation

Jordan relies heavily on the provision of residential institutions to provide care for persons with disabilities, and particularly those with intellectual disabilities. However, there are strong justifications calling for the urgent need to assess the current status quo, and transform the current system into an inclusive system; one that promotes independent living, and contributes to persons with disabilities being active members within their families and their local communities. Chief among those justifications are the following:

1. Institutionalisation is a clear violation of human rights, most particularly the right of a person to live independently, be included in the community, and have individual autonomy and freedom of choice.
2. Institutionalisation is harmful to the health and development of persons with disabilities, as institutions run a restrictive and marginalised regiment that prevents diversity, difference and the prerequisites needed for individual livelihood within open societies.
3. Family and community-based care for persons with disabilities have much better outcomes for persons with disabilities, enabling them to live independently on an equal basis with others, and enhancing their individual capacities.
4. Institutionalisation is expensive; in most cases it costs considerably less to support persons with disabilities to live with their families or in alternative care than it does to keep them in institutions¹.

Anticipated challenges and risks of deinstitutionalisation

1. Scarce financial resources to implement the Strategy.
2. The insufficient co-ordination between partner organisations, and the overlaps in their roles and responsibilities, or the gaps in service-delivery.
3. The dearth of required expertise and capacity needed for transforming the system of institutional services.
4. The continued turn-over in decision-making and leadership positions within the key relevant entities.
5. The political challenges posed by the fact that the majority of the residents in institutions are non-Jordanian.
6. The financial repercussions posed by the owners of the private institutions and their strong resistance to the idea and process of deinstitutionalisation, given the anticipated financial losses they claim they will incur as a result.
7. The undesirable perceptions held by some families of persons with disabilities toward accepting the latter in their homes or in their communities.
8. The differing funding priorities of donor countries.
9. Fear of the financial liability incurred from the need to transform primary and secondary education curricula into inclusive schemes and syllabi.

¹ Lumos, (2014) Ending the Institutionalisation of Children Globally – the Time is Now. Available at: <http://www.wearelumos.org/sites/default/files/Lumos%20The%20Time%20is%20Now%20April2014%20FINAL.pdf>

10. The repercussions posed by the influx of refugees into the Kingdom, given the scarce resources in Jordan's host communities.

Jordan's opportunity in deinstitutionalisation

Jordan has the opportunity become a champion of deinstitutionalisation. To do so effectively, a comprehensive plan to move away from a reliance on institutional care towards community-based services is required. This involves:

1. Developing systems and services that prevent the separation of persons with disabilities from their families and communities.
2. Actively planning and developing appropriate alternative placements for all persons with disabilities currently in institutions.
3. Actively transforming institutions into inclusive day-care services that serve children and adults with disabilities.
4. Designing and implementing a system of alternative services, which includes:
 - a. Strengthening the family to ensure that families are better able to care for their children with disabilities.
 - b. Developing the community to ensure the provision of universal services for persons with disabilities, including healthcare, inclusive education and vocational training.
 - c. Providing specialised social services, such as housing support, to ensure living arrangements are inclusive and accessible to persons with disabilities.
 - d. Providing the personal assistant service, whereby a trained individual is assigned to assist the person with a disability with their day-to-day activities as s/he chooses and in line with his or her needs.
 - e. Providing the short breaks service, whereby families can place their children in specialised day-care centres, which provide independent living services, including occupational and physiotherapy, as well as social, educational and recreational services, in line with the respective needs of the person with a disability, for no more than 48 hours at any one time.
 - f. Providing small group homes (SGHs), a residential care service where care is provided in very small units of between four and six people. The SGH must be integrated into the community (a regular house on a regular street), and with highly trained personnel in sufficient numbers, who can respond to the needs of the person with a disability, and is in the best interest of that person.
5. Transferring resources spent on institutions to community-based services, to ensure sustainability of new services and systems.

Once the pilot phase has been successfully implemented, the country will no doubt benefit from the knowledge and experience accumulated by all partners, and will therefore be in a position to lead and transfer such expertise to the region, benefiting those countries wanting to follow Jordan's trajectory in deinstitutionalisation.

Objectives of the National Strategy

The over-arching objective

To end the institutionalisation of persons with disabilities in Jordan, by ensuring that required systems and services exist to enable them to live within families, family-type placements, or supported independent living alternatives that respect their rights, meet their needs and ensure they are fully included in the life of the community and can participate to their fullest extent.

Specifically, within a ten-year period, the relevant authorities in Jordan will:

1. Build a society where all persons with disabilities are included and respected.
2. Guarantee that all universal services are fully inclusive for persons with disabilities.
3. Transition all residential institutions away from residential provision and redirect resources towards the provision of community-based solutions. This process also involves redirecting resources from institutions to fund inclusive universal services and targeted community services, ensuring the move towards community living for all persons with disabilities is a sustainable reality.

Specific objectives

1. Implement deinstitutionalisation (DI) processes in governmental, privately-run and voluntary institutions in a gradual manner, per the phases outlined in this strategy and the corresponding implementation plans.
2. Design and implement an evidenced-based awareness raising, advocacy and communications strategy to change behaviours and attitudes from a range of stakeholders – turning potential factors of resistance into agents of positive change.
3. Work with a broader group of civil society organisations and experts to effectively manage the DI transformation process.
4. Deliver training for staff working in institutions and raise awareness about the harmful effects of institutionalisation, the importance of inclusion, and the benefits of DI and family-based care.
5. Develop the legislative framework and professional capacity to manage a long-term national deinstitutionalisation programme.
6. Apply accessibility, reasonable accommodation and universal design standards within public services in the community, including accessible transportation, inclusive education schools, and leisure facilities.
7. Develop sophisticated monitoring and evaluation frameworks to ensure the support of persons with disabilities transitioning to family and community-based services.
8. Reintegrate non-Jordanians with disabilities within their biological families in their countries of origin
9. Secure the necessary funding to implement this strategy and the complete DI process.
10. Develop a system of professionalisation in the field for social workers tasked with implementing this strategy.

11. Ensure that the curricula is adapted in universities to promote inclusion, as a concept and in practice.
12. Design and implement community-based rehabilitation (CBR) programmes to support the system of alternative services.

Components of the Strategy

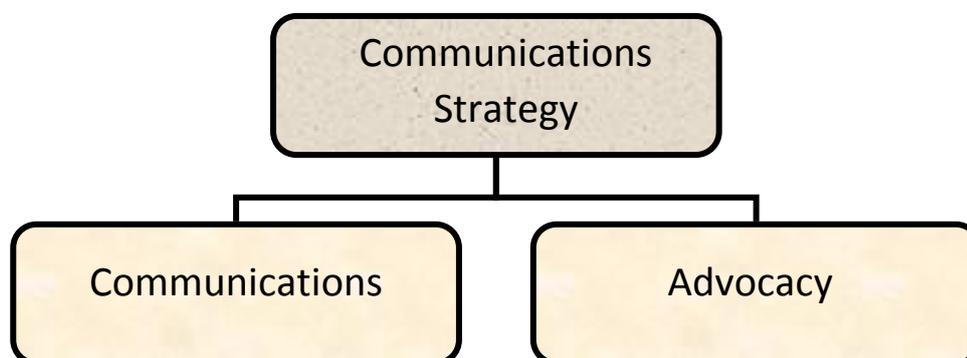
It is necessary to create the physical, logistical and technical environment that is supportive of the transition process from institutions to family and community-based services. This is illustrated within the following three components:

First component: Objective-driven processes and activities

There are two key structures required to ensure proper management of the process of reform – the Steering Committee² and the Project Management Team³—both of which will be formulated for this purpose.

1. Developing a communications strategy

Open and clear communication throughout the process of transitioning from institutions to community-based services is absolutely vital and involves a range of stakeholders. With the current strong resistance and pushback to deinstitutionalisation, it is necessary to develop a clear communications and advocacy strategy with an understanding of current awareness levels and the barriers to change for each stakeholder group and constituency to minimise resistance, highlight the benefits of alternative care services vis-à-vis the interest of persons with disabilities.



2. Reviewing the legislative framework and developing the processes for deinstitutionalisation

For implementation purposes, the Steering Committee via the Project Management Team, will co-ordinate with all relevant entities, and supervise the review and development of legislation and processes to enable the creation of a system of independent living for persons with disabilities. This will include

² The Steering Committee: This committee is established to oversee the implementation of the DI project and will be composed of representatives from the key ministries and councils and relevant civil society organisations, international organisations, as well as beneficiaries of institutions and/or their families.

³ The Project Management Team (PMT). The PMT is to be designed as an inter-sectoral, multi-agency team of experts, comprising ministries, local authorities, service managers, as well as local civil society. The overall role of the PMT is to develop and oversee the implementation of the detailed National Action Plan (NAP) and communications strategy as well as to ensure professional monitoring and evaluation of all aspects of the NAP, including processes and outcomes.

regulations for biological and foster families, short breaks, small group homes and CBR programmes.

3. Prohibiting the establishment of new residential institutions for persons with disabilities

In compliance with the Law, the Ministry of Social Development, in 2018, issued a decision to stop licensing residential institutions; a decision that will also not allow existing institutions to increase capacity, making it illegal for any organisation to set up a new institution or expand current provision of services. Notwithstanding the decision, the Ministry did not abolish the provisions relating to the licensing of residential institutions as stipulated for in the statute of centres for persons with disabilities of 2014. That is why stringent follow-up measures monitoring the extent to which this decision is applied is needed.

4. Standards and processes supportive of persons with disabilities living independently in the community

It is important to develop mechanisms that allow the redirection of resources invested in the institutional care system into the new inclusive and community-based system of services, as well as the need to review financial rules and standards for each type of existing service. Mechanisms to develop national, specific and accurate criteria for diagnosing various disabilities; standards for the detection and early intervention of disabilities, and for quality assurance of service-delivery and ease of access to these services, must also be created.

Second component: Thematic prerequisites for the process of deinstitutionalisation

There are a number of integral prerequisites necessary for this strategy to be implemented. Chief among these are the following:

1. Designing and implementing programmes that contribute to the development of model practices in the transition from institutional systems of care to inclusive ones

It is anticipated that this strategy shall be implemented in several phases, with each phase being three years. The first phase will include the following:

- a. In the first year, the Steering Committee, with advice from the Project Management Team, will select two government institutions to close and transform them into inclusive day-care organisations, as part of a pilot programme.
- b. In the second and third years, the Steering Committee will select one private institution and another voluntary-run institution. The institutions chosen must be led by individuals who are open-minded and wish to be pioneers in the process of change.

This methodology will be adopted in subsequent years, per the results of the first three years.

2. Individual and family assessments for enrolment into inclusive and alternative services

To effectively achieve deinstitutionalisation, both Jordanian and non-Jordanian persons with disabilities living in institutions and their families must be assessed thoroughly, in order to decide the best placement for them as an individual. Planning must take account of:

- a. The child or adult's wishes and the wishes of their family.
- b. The length of time the child or adult has lived away from the family.
- c. The complexity of the child or adult's needs and the ability of the family to meet those needs.
- d. The support services the child or adult will require in order to live within a family, in a family type environment, or independently.
- e. Specific behaviours and developmental delays that result from institutionalisation.
- f. The child or adult's current functioning and their potential for development.

3. Designing alternative services to residential institutions as 'model' practices

To implement deinstitutionalisation, and after the assessments have been conducted, inclusive alternative services will be designed, to become 'model' practices that can then be replicated. These include:

- a. Services for families and foster care: these include training for the families and providing them with psycho-social care and counselling; peer-to-peer support; short breaks; personal assistance; financial support; home adaptations; and other general services.
- b. Services for independent living arrangements, including small group homes for persons with disabilities⁴, which include the following:
 - Homes with the adequate living spaces
 - Supervisors and workforce personnel, including social workers
 - Independent living skills training
 - Financial support
 - Vocational training
 - Personal assistance
 - Occupational therapy, physiotherapy and other assisted support services
- c. General services for deinstitutionalisation: these depend on the accurate information compiled from individual assessments of persons with disabilities, including inclusive education; health and rehabilitation

⁴ Small group homes (SGHs) is a residential care service where care is provided in very small units of between four and six people. The SGH must be integrated into the community (a regular house on a regular street), and with highly trained personnel in sufficient numbers, who can respond to the needs of the person with the disability, and is in his or her best interest.

services; mobility/transport; vocational training and occupational support services; employment and labour/job opportunities; peer to peer support, as well as financial support.

4. Planning the transfer of resources from residential institutions to community-based services

The process of planning the transfer of resources from residential institutions to inclusive community-based services entails the following elements:

- a. Workforce development and planning for retraining and redeployment of personnel, as per their abilities, expertise and per the practical requirements of the inclusive placements. This is to include:
 - Training and awareness raising for all residential institution personnel on the deinstitutionalisation process.
 - Identifying the specific workforce required for the new services, and the development of new posts/positions (e.g. Family Support Worker, Emergency Foster Parents.).
 - Assessing current residential institution personnel regarding their suitability for redeployment.
 - Identifying personnel that can be redeployed into the various services and facilities.
 - Identifying additional funding for additional posts required.
 - Hiring new personnel, providing them with initial and continued training (in a phased manner, to be ready in time for the opening of each new service).
 - Monitoring the impact of training conducted for personnel in the inclusive, alternative services and placements.

- b. Making plans for the appropriate reuse of existing buildings and the establishment of new ones, while taking into account the following:
 - Institution buildings should never again be used as residential services or supported living arrangements or small group homes, since the latter are alternative services.
 - Existing institution buildings could well be transformed into a public health or educational facility that caters for all.
 - New buildings for alternative services and placements should be accessible and adapted to the individual requirements of persons with disabilities.
 - Developing and implementing training programmes for engineers and technocrats on accessibility standards and reasonable accommodation to ensure that the planning for new buildings and service facilities conform to these standards.

- c. Planning the ring-fencing and redirection of funding from the residential institutions to the community-based services. This will require the

development, together with the Ministry of Finance, of mechanisms to transfer funding between departmental budgets.

Third component: Additional programmes, alternative services and programme evaluation and assessments

1. Developing additional programmes and alternative services

Building upon research⁵ conducted by the Higher Council for Rights of Persons with Disabilities, further activities are required within year three of the Strategy's implementation in order to plan the phased expansion of the new community-based services as more institutions close.

2. Evaluating and learning from the demonstration programmes

It is essential that lessons learned from the four pilot deinstitutionalisation programmes inform the planning of the national roll-out. Monitoring data collected over the duration of the programmes will form the basis of a final evaluation report produced by the Project Management Team. This will assess whether demonstration programmes have delivered the intended outcomes to beneficiaries and identify any areas for improvement in the new community-based services.

⁵ A Mapping Survey of the Current Residential Care Institutions for Persons with Disabilities in Jordan 2018.

Expected outcomes at the end of year 10 of the Strategy

It is anticipated that the National Strategy on Deinstitutionalisation for Persons with Disabilities will produce a number of outcomes, chief among which are the following:

1. No children or adults with disabilities live in large-scale residential institutions.
2. All governorates have a basic range of services in place that support children and adults with disabilities to live with families or in supported independent living and enable them to participate fully in the life of the community
3. Inclusive education available at community level for all children and young persons with disabilities in Jordan, irrespective of citizenship. Vocational and lifelong learning is available to all adults with disabilities
4. All health services in Jordan are fully accessible and inclusive of persons with disabilities and supportive to their families
5. Groups of self-advocates exist across Jordan. Including and consulting self-advocates has become normal practice for all state and local authority bodies with responsibility for policies, services, and practices related to persons with disabilities
6. Jordan provides regional leadership and advice on transforming systems of care and support for persons with disabilities.