

# Women with Disabilities' Encounters with the Medical and Health Systems in Israel

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# **Research Summary**



This study was carried out by the leadership group of women with disabilities from the Leadership Center at Beit Issie Shapiro, in collaboration with the Disability Rights Clinic, Faculty of Law, Bar-Ilan University.

For the past few years, a group of women with disabilities has been active within the Leadership Center at Beit Issie Shapiro. Among the many challenges these women experience, is having to cope with dual discrimination - being a woman and having a disability. Based on their very negative personal experiences, the group decided to research women with disabilities' situation in the health and medical systems. The ultimate goal is to change existing policies, improve treatments, increase accessibility, and change attitudes towards and services for women with disabilities in hospitals and community clinics.

The research conducted was carried out using the Participatory Action Research approach, which is a full collaboration between professional researchers and research "subjects". The research methodology was qualitative.

Thirty women with disabilities participated in the in-depth interviews. The interviews were conducted among women aged 27-70 with a variety of disabilities (physical, sensory, cognitive, communicative and intellectual), from Jewish and Arab communities across Israel.

All of the women interviewed in the study had negative experiences when encountering the health system, whether during routine visits to clinics, elective tests (colonoscopy, ultrasound, mammography, etc.), fertility treatments, childbirth and/or surgeries. The negative experiences include encounters with professional staff (medical and nursing), as well as service providers (support and administrative) in community clinics and in hospitals.

The variety of difficulties and negative experiences can be categorized into three main areas:

### 1. Accessibility parameters

These parameters refer to the lack of physical and sensory accessibility. Difficulties are already encountered at the early stages of scheduling an appointment and accessing the building (parking lots, elevators, lavatories, etc.), line management while waiting, and treatment rooms (furniture, medical equipment, maneuvering space, etc.). Another aspect is the lack of accessibility of the service itself, which is reflected in difficulties in coordinating appointments and inaccessible reception desks.

## 2. Professional medical parameters

While some women want to be addressed directly, others need a companion to assist them. The women spoke of the lack of sensitivity and respect when given information relating to them - being spoken to "over their heads", their presence was ignored, or they were prevented from entering with an escort to assist them. The study also revealed the reluctance of medical teams to be flexible and creative in performing examinations. The disability often makes it difficult to conduct an examination or treatment in a conventional way, which forces it to be performed differently from the routine, and in a manner modified to the woman's body/condition. The women also reported doctors' lack of proficiency and knowledge about various disabilities and the medical consequences deriving from the disabilities. This often leads to misdiagnosis and wrong medical recommendations.

### 3. Interpersonal parameters

Most of the women in the study shared experiences that reflect a dismissive, blunt and humiliating attitude. Impatience towards them, treating them as time-consuming and hysterical, blaming them for the

doctor's difficulties in performing the test, disrespecting their privacy and treating them as an object. Their feelings are that the hospital staff (medical, nursing and other service provides) are not prepared, not attentive, not aware, and maybe even sometimes confused by the encounter with them.

The experiences encountered by women with disabilities can be seen in all fields of medicine, but they are much more prominent and prevalent in women's health medicine - in follow-up examinations in women's healthcare clinics, designated medical examinations (Pap, breast, mammography, etc.), fertility treatments and childbirth experiences. It should be noted that unlike other fields of medicine (psychiatry, orthopedics, etc.), all women require women's health medical services and examinations. This field is by its very nature intrusive and invasive, and requires exposure of intimate areas of the body. This can be complex for any woman, but more so for women with disabilities, for various reasons such as disability in movement, hypersensitivity to pain, body image etc.

It is assumed that some of the difficulties revealed in the study are not unique only to women with disabilities but can also be relevant to women without disabilities, as well as to men with and without disabilities (for example - difficulties in scheduling appointments, impatience on the part of service providers, etc.). However, a considerable part of the mentioned difficulties is intensified among women with disabilities. These impact not only the emotional state of the woman, but also her health. Indeed, over half of the women in the study, with all types of disabilities, reported postponing or avoiding visits, treatments, and/or examinations, a fact that has serious consequences for the early detection and treatment of diseases, as well as for women's quality of life.

In recent years, we see a welcome increase in awareness and social activism. Yet, alongside that, the difficult experiences, as reflected by the women with disabilities who participated in this study, point to the continued existence of stigmas and lack of knowledge in the medical system. A medical system that continues to believe that a woman with a disability does not have the skills and ability to understand what is being said; that a woman with a disability does not have the ability to decide about her body, and therefore there is no need to consult her; that a woman with a disability should be "approved" to be a parent; and that women are "hysterical" - therefore their requests, feelings, and experiences of pain are dismissed.

It is important to note that despite the predominance of negative experiences, almost all women were able to also share positive experiences, but this often required them to do some research and have several experiences until they found the right professional for their needs.



Alongside the criticism that women with disabilities have towards the health system, one cannot ignore the recognition of the women themselves regarding their responsibility to improve and change the situation. It is their responsibility and obligation to make all needed inquiries before arriving at the clinic, and to clarify exactly what they need so that the medical system will be able to provide an adequate and tailored response to their needs.

In conclusion, this study indicated that women with disabilities face a humiliating, disrespectful, belittling and insulting attitude when meeting the medical system, particularly with regard to women's healthcare medicine. This study also indicates that there is much

room for improving physical and service accessibilities, improving the level and quality of medical care, as well as providing training and tools to the professional teams, so that they can provide a humane and respectful service to women in general, and women with disabilities in particular.

Based on the findings of this study, a largescale quantitative national study is planned to be conducted among women with and without disabilities, and further actions will be taken to promote policy change with regard to women's health.

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