

# TOWARDS PEOPLE-DRIVEN CARE

Engaging and Empowering Individuals, Carers and Families through  
Integrated Community Care



*2° transnational Conference  
on Integrated Community Care  
Turin, 26-27 febbraio 2019*



People with severe physical, mental or sensory limitations are in Italy about 3 millions

Most are women (54%)

Most are old people (61%)

Only 35% women with disabilities are employed (vs 52% disable men )

Disable women are more limited in social relationships and leisure time than healthy women



VERBA Association committed in 2009 a research about «disable women responding to the female cancer screening program»

It turned out that disable women get cancer more than healthy women



*The pivotal factors are:*

A sedentary lifestyle

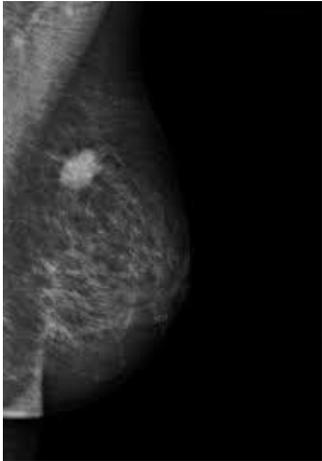
An inability to do self palpation

Medicines taken and Radiation exposure

Poor reproductive history

The other important results of the research point to that physical and motor disability makes it difficult to disable women to undergo normal screening tests because of the structural inadequacy of the places in charge

# Response to screening programs and incidence of female tumors in women with motor disabilities, in Turin 2009:

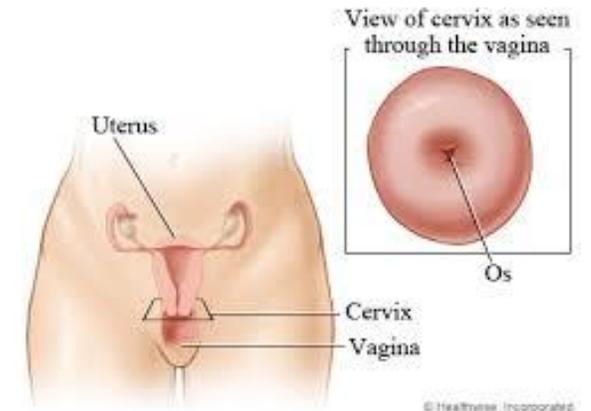


## Mammographic screening data:

- Responding healthy women  $> 50\%$
- Responding disable women  $\sim 50\%$

## Cervix cancer screening data:

- Responding healthy women  $> 50\%$
- Responding disable women  $\sim 28\%$



## Discriminations exhibited by health operators, including professionals:

- They commiserate and see disability before the person
- They consider the disable person as not belonging to any gender
- They assume the impossibility of enjoying life

## Discriminations exhibited by the services:

- environmental barriers
- specific services' lack



In 2013, an agreement was signed between the Family Consultants of Public Health Service and Verba Association: the first «cervix cancer screening service» accessible to disable women was opened in Turin

The service was placed in the frame of the services provided to healthy women



Subsequently, the service was implemented with other gynecological services, paying special attention to the unknown phenomena of violence on women with disabilities

In 2014 the Fior di Loto Ambulatory opened in Via Silvio Pellico in Turin



# FIOR DI LOTO organization

**Mediation of the Verba Association (telephone filter for specific needs analysis)**

**Ability to perform multiple services in a single access (gynecological examination, senologic examination, pap test, hpv test, gynecological ultrasound, contraceptive interview)**

**Dedicated room without architectural barriers**

**Dedicated health care workers with continuity of care**

**Time spent on each visit: 1 hour, to allow an improvement of communication**



## HEALTH STAFF

(a real example of partnership between no profit association and health public service)

**gynecologist** and **midwife**  
*(from public health service)*

**psychologist** trained in the field of violence  
possibility of **mediation of sign language**  
*(from the verba association)*



# DISABLED WOMEN, double discrimination: gender and health

36% disable women are subject to physical or/and sexual violence

Disable women are 2-3 times more exposed to sexual abuse in the childhood

The author of violence is often the care giver!

*(Istat data 2015)*



In conditions of disability, it can happen:

- to blame oneself, thus justifying the violence received
- to perceive violence as an act of male interest
- to communicate with difficulty

The disable girl, especially if with intellectual disability, often is not educated to sexuality. Therefore she has more difficulty to recognize violence

Dependency on the care of others can tie the victim to a mistreative caregiver, both for an inadequate sense of gratitude and for the necessity of receiving care

# Tipology of women accessing Fior di Loto

Average age	Women who gave birth	Contraception	Physical disability	Psychic disability
39	30%	40%	50%	50% (20% associated )

## Year 2017

<b>Visits</b>	<b>117</b>
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<b>Cases treated</b>	<b>82</b>
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## Year 2018

<b>Visits</b>	<b>187</b>
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<b>Cases treated</b>	<b>106</b>
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## The numbers of the violence!

year	cases number	cases of suffered violence		
		Total	Domestic	Sexual
2015	28	2 (7%)	2	0
2016	67	7 (10%)	4	3
2017	82	15 (18%)	7	8

She is a fine thirty woman with physical disability (spastic paresis from birth). We know that she was the victim of domestic violence: the ex-partner began to mistreat and humiliate her during pregnancy and continued after birth of the baby for some years. The lady finally came out of the situation of abuse and made a denounce, even if she is not yet able to live with her daughter in autonomy.

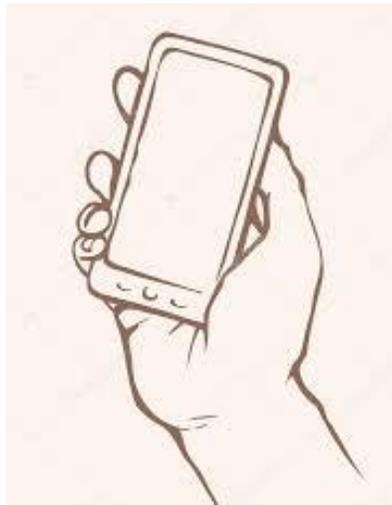
While we help the woman position herself on the bed for the gynecological examination, a sock slips off because of a woman's movement. Casually we see the foot has all the nails damaged. I think it was a severe onychomycosis and I would prescribe medical treatment, but the woman tells me that she has already cared for her nails but unsuccessfully.

It is strange that it does not heal, so I ask her more about. So she tells us that her nails were torn some years ago. When she lived with a violent partner, who took care of her and also helped her to wash and get dressed. In that case she was helpless against the abuse. He tore her toenails one after another, instead of cutting them! The lady has never told anyone such torture she suffered, not even to her lawyer. If she had not slipped the sock and if I had not asked, she would never have told us what happened. It was also painful for us to listen to such a story, a punch in the stomach!

Violence must be checked, so that it can be told. Telling is the first step to healing. Telling requires someone ready, in terms of time and availability, to listen. We health operators must not be contented with non-convincing answers, even if reality surpasses imagination, as in the reported case. Domestic violence has a higher incidence among women with disabilities and often the abuser is the caregiver



The young woman is accompanied by an educator. The visit is required for genital check. The anamnesis is of suspected sexually transmitted diseases. The lady contacted men on a chat until she was deprived of her mobile phone. During the interview the lady told the following story: "I messed up with the chat - while I was looking for a boyfriend, I met some men who gave me appointment near the mall - they asked me to show my breast - it bothered me that they had oral sex with me - it happened in the bathrooms of the shopping center and also in the parking - they held me firmly with their arms at the end they told me to leave".



Thirty-years-old woman with psychic disabilities. Disability is clinically obvious but not certified. The lady has been a victim of violence for 7 years. The author of the violence was her former partner. Because of a severe violence the woman was hospitalized. Subsequently she was hosted in a community for mistreated women.

The lady is accompanied to our clinic for contraceptive treatment. During the visit the lady tells for the first time that she had an abortion because of the beatings. She says she lost so much blood and the embryo but no one could witness... as "He gave that to the dog to eat"!

Time to listen and ask,  
time to say and do,  
time to spend with continuity  
all this in the frame of an interdisciplinary  
approach

... it allows one to face delicate situations without prejudice

... it allows one to open that inner window to see with different eyes  
the many aspects of life

