

**R**elationships  
**E**ducation  
**S**exuality  
**P**eople with disabilities  
**E**thics  
**C**onsent  
**T**raining

SUBMISSION TO THE IRISH CERVICAL  
SCREENING PROGRAMME 2007

## **ABOUT RESPECT**

In response to the lack of policy and services associated with sexuality and disability, organisations advocating for the rights of people with disabilities and sexual health organisations joined forces to form RESPECT. The goal of RESPECT is to make mainstream sexual and reproductive services more accessible for people with disabilities (PWD) as articulated in our vision statement:

*“An Irish society where PWD have access and opportunity to enjoy a fulfilling sex life and to make informed choices in their sexual and reproductive lives; where there is full access to high quality information, education and health services”.*

Members of RESPECT include: The Irish Family Planning Association (IFPA), Forum for People with Disabilities, Inclusion Ireland, Irish Sex Education Network, National Institute for Intellectual Disability (NIID) Trinity College Dublin and Enable Ireland.

With support from the Equality Authority as the implementing body of European Year of Equal Opportunities for All 2007, RESPECT established an advisory group that has undertaken a variety of projects including: the production of an information leaflet for sexual and reproductive health service providers, an analysis of the legal context of PWD and sexuality, proofing of current IFPA services, report on the current issues related to sexuality and disability and the development of training materials for mainstreaming disability within sexual and reproductive health services.

## **INTRODUCTION**

RESPECT welcomes the opportunity to make a submission to the Irish Cervical Screening Programme (ICSP) in order to highlight the needs and issues related to women with disabilities and cervical screening. The Women’s Health Council of Ireland, the World Health Organisation (WHO) and the International Agency on Cancer Research have emphatically supported the implementation of a national screening programme to “substantially reduce the incidence of, and mortality, from cervical cancer in the population.” (Women’s Health Council, 2006, p. 29) Women with disabilities, however, are less likely to enjoy the health benefits of such a screening programme because of discrimination, societal reluctance to engage in dialogue relating to sexuality and disability and a lack of disability mainstreaming into programme design and delivery.

Research from other countries that have already implemented a national cervical screening program consistently report that women with disabilities have a much lower uptake of cervical screening services than non-disabled women, despite the fact that women with disabilities share the same risk factors for developing cervical cancer (NSW Cervical Screening Program, 2004). The Women’s Health

Council of Ireland (2006) reports that the risk of developing or dying from cervical cancer has been found to increase with decreasing socio economic status. As women with disabilities constitute one of the most marginalized populations in Ireland, are more likely to live in poverty and face multiple forms of discrimination, one could argue that women with disabilities are a population the most in need of cervical screening.

Women with disabilities have the same right of access to health care as other women and therefore addressing the barriers and obstacles experienced by disabled women is essential to improving the level of service provided and consequently increasing uptake of the service.

The aim of this submission is to:

- Establish the right to health of women with disabilities
- Identify the barriers experienced by women with disabilities engaging in cervical screening;
- Set the policy context for accommodating the needs of women with disabilities
- Present the demographic of women with disabilities amongst the target population for cervical screening;
- Provide recommendations to the ICSP to maximise uptake of the programme amongst women with disabilities;

### **THE HUMAN RIGHT TO HEALTH**

The WHO (2004) recommends organised cervical screening as an integral part of a comprehensive sexual and reproductive health strategy. The right to access the highest attainable standard of health, including sexual and reproductive health, without discrimination has been identified and codified as an international human right of all women. Furthermore, the International Convention on the Rights of Persons with Disabilities places an obligation on the State to “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes”. Despite such international standards, women with disabilities continue to encounter institutional, attitudinal and environmental barriers to health services and information and are therefore one of the most underserved minority groups in every health care system (Johnson, Strong, Hillier, & Pitts, 2002)

### **BARRIERS TO ACCESSING SERVICES**

Research conducted by the Australian Research Centre in Sex Health and Society in 2002 identified three broad categories of barriers that impeded access to cervical screening services experienced by women with disabilities. The categories included: social barriers, life circumstances and subjectivity.

### *Social Barriers*

Cervical cancer is most often caused by a strain of the HPV virus that is transmitted through sexual contact. Doctors, nurses, carers and/or family members often falsely assume that women with disabilities cannot or should not have sex and therefore do not need to avail of cervical screening. Such paternalistic attitudes are harmful not only because it denies women's sexuality but also because it fails to take into account that women with disabilities are more likely to experience sexual violence in their lifetime and for a longer period than non disabled women. The dismissal and invisibility of disabled women's sexuality by doctors is of particular concern in light of the ICSP's findings that 76.5% of women participating in the first phase of the program were referred for screening at the discretion of their doctor.

The invisibility of women with disabilities is further expressed in the physical design of many primary care facilities, ignorance of health providers on the ways in which disability can affect the smear taking process and also the lack of information in appropriate formats. Ensuring all eligible women in the target population are facilitated in participating in the programme and addressing any of the social barriers preventing access to services are necessary to achieve maximum uptake.

### *Life Circumstances*

Women with disabilities constitute a diverse population with different impairments and different life experiences and therefore have different needs. For example, women with hearing impairments may require sign language interpreters, women with spinal cord injuries may need an adjustable exam table or may need to be in a different position to have the smear taken and women with intellectual impairments may need pictures or props to aid in their understanding. In addition to a variety of impairments, women with disabilities may also have different needs related to language, culture, race, socioeconomic status and sexual orientation. Whatever the life circumstances of the woman attending for screening, services must be individualized to meet the particular needs of each client with equal respect and dignity.

### *Subjectivity*

The ways in which a woman with disabilities views herself and her body has been identified as a complex, multi dimensional barrier to accessing cervical screening services. Many women without disabilities report fear, anxiety and embarrassment with regards to having smear tests. However, health providers encourage women without disabilities to participate in the screening because it is a vital component of preventative women's health care. For women with disabilities, the experience of having a smear can induce the same fears and anxieties but instead of receiving reassurance and support from their doctors, women with disabilities frequently encounter prejudice and ignorance which can exacerbate any anxieties or fears. Some women report that they feel as if society does not treat them as "real" women because they are perceived to be

unable to fulfil the gender roles assigned to women without impairments and hence do not require the same preventative health care. Negative stereotypes and assumptions about women with disabilities can serve to divorce women from their bodies and affect their decision about whether or not to have a screen.

### **IRISH POLICY CONTEXT**

In 2000, the Irish government adopted a policy of mainstreaming public services for people with disabilities. The policy was realized through legislation such as the Equal Status Act 2000 & 2004 and the Disability Act 2005 and also through several strategic plans such as the National Health Strategy, the National Women's Strategy 2007-2016 and the National Disability Strategy. The legislation placed an obligation on public services to facilitate access to buildings, information and services and also required key government departments to design Sectoral Plans that ensure access for people with disabilities will become an integral part of service planning and provision. The strategic plans recognise that people with disabilities are currently underserved in the health system and places special emphasis on addressing the barriers that prevent people with disabilities from getting the services they need. Furthermore, the Equality Authority, as a statutory agency, encourages all public services to define access as not only physical adjustments such as installing a ramp but also meaningful commitment to improving services to meet individual needs by adopting a planned and systematic approach to equality.

### **DEMOGRAPHICS**

The ICSP has announced it will be screening all women between the ages of 25 - 59. According to the 2002 census data, there are 61 925 disabled women between the ages of 25-59 living in Ireland. This figure accounts for approximately 7% of the total target population for cervical screening in Ireland. In order to achieve the recommended coverage rate of 80%, the ICSP must incorporate measures into planning and design of service delivery that will encourage the participation of women with disabilities.

## RECOMMENDATIONS

- ICSP should develop a national strategy for assisting women with disabilities to access regular cervical screening. This strategy should include the development of accessible information, education and training for health service professionals.
- Information about cervical screening for women with disabilities should be developed through consultation with women with disabilities, organisations which provide services to them or advocate with them and with smear test providers. Such information should be provided in a range of formats including plain English, clear graphics, video and audiotapes.
- Cervical screening should be promoted holistically as a part of a well women's health check with a particular focus on sexual health.
- Information about cervical screening should be disseminated widely through disability organisations, community health centres and smear test providers.
- Resources should be sought from Government to reduce the social barriers encountered by women in accessing cervical screening. This should include: the provision of hoists and moveable beds in services.
- The ICSP should establish clear guidelines for smear takers on issues of consent and confidentiality.
- Research with disabled women would reveal their needs in relation to existing services and shape further developments.

## References

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