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An tSeirbhís Náisiúnta Scagthástála
National Screening Service

Executive Summary

Breaking Down Barriers:

An Assessment of the Needs
of Disabled People in Accessing
Population-Based Screening
Services in Ireland

Executive Summary

Introduction

In the Irish 2016 Census, 643,131 people stated they had a disability, accounting for 13.5 percent of the population. Advocating for disability inclusion in the health sector, the World Health Organization (WHO) states that in order to attain the highest possible standard of health and well-being for all, disability inclusion must be made intrinsic to health sector priorities, including public health, of which health screening is a part.

The Irish National Screening Service (NSS), part of the Health Service Executive (HSE), encompasses four national population-based screening programmes: BreastCheck for breast cancer screening, CervicalCheck for cervical cancer screening, BowelScreen for bowel cancer screening and Diabetic RetinaScreen for diabetic retinopathy screening. The proportion of the eligible population for cancer screening in Ireland with a disability is 19%, 12% and 22% for BreastCheck, CervicalCheck and BowelScreen, respectively.

To inform efforts to increase access to screening among disabled people in Ireland, this study sought to explore the needs of disabled people in accessing national screening services. This was the first study of its type to be carried out in Ireland. The study direction, scope and methodology was informed by NSS staff members and an advisory committee consisting of disabled people.

Study aim and Design

This study aimed to examine the perspectives and experiences of disabled people in accessing screening services and to assess factors that influence their uptake of, and participation of population-based screening programmes. The research was qualitative in nature, consisting of focus groups and interviews. Twenty disabled people participated in the study, representing those with Intellectual Disabilities, Autism, physical impairment, visual impairment, and the Deaf community. In addition, five healthcare professionals and five family carers were involved in the study. The data collected from the interviews and focus group discussions were analysed using thematic analysis.

Key findings of the research study

The findings from this study align with the findings in international literature. The findings are discussed in the context of each stage of the screening process, namely pre-screening, screening, and post-screening.

Pre-Screening Stage

Four out of eight people with intellectual disabilities stated they had never received a screening invitation for a particular service despite being eligible. Given the small sample, it is difficult to say if this is widespread; however, it merits further investigation.

Some disabled people expressed concerns about their dependency on others to make an appointment and attend the screening services.

Inaccessible communications (e.g., letters containing too much text) make it more challenging to decide whether to attend screening services or not.

A requirement to travel longer distances to attend screening, as opposed to accessing screening closer to home, was discussed as a barrier to screening (due to higher travel cost and other logistical difficulties).

Disabled people suggested that it would be helpful if they were able to view a video of a screening test involving someone they can identify with in information resources.

Screening Stage

Disabled people reported numerous positive experiences, such as the willingness of professionals to provide double appointments (e.g., appointments of longer duration), a supportive and compassionate approach, and the provision of information in Braille by request.

Some disabled people are concerned about negative attitudes among professionals involved in screening, such as assumptions regarding suitability for screening people with intellectual disabilities and the use of non-person-centred language.

Some disabled people prefer to have the screening test at a familiar place and with familiar people around them to provide support.

The screening professionals spoke of issues in relation to obtaining informed consent for screening, especially from people with intellectual disabilities.

Disabled people also expressed concern about the lack of accommodation and accessibility in screening settings, such as confined spaces and inflexible equipment.

Some disabled people reported that comorbidities make it challenging to access screening services.

Some disabled people expressed the need for support to collect the sample for bowel screening.

Post-Screening Stage

Some disabled people faced difficulties in amending the register to record their disability status.

Some disabled people are willing to disclose their disability and needs, but they would prefer to disclose this information electronically (e.g., via online web forms) rather than directly to screening staff.

Some participants reported pain and discomfort after the screening, and others felt irritation and sight disturbance after attending Diabetic RetinaScreen.

Disabled people had a positive experience in that they received their screening results in a format that was accessible to them. However, they had to request this service.

Recommendations

Involve disabled people in all aspects of screening service design.

Provide in-service disability awareness training to all staff involved in screening.

All communications should be made accessible at scale.

Develop a clear protocol for the chaperone process.

Provide guidelines and training on reasonable accommodations, to include travel; costs; equipment; appointment times, durations, and locations; physical accessibility, accompaniment, and support personnel.

Develop information and educational materials targeted at disabled people, their caregivers and family members, to include preparation for screening and what to expect.

Include disability status and needs as part of the health screening record.

Develop a platform/system to allow for feedback post-screening.

Provide clear information about screening location accessibility.

Establish/explore a system for sharing information between the four screening services.

Promote awareness of how to register and check the screening register.

Investigate the lack of invitations reported by people with intellectual disabilities.

Conclusion

This report identified the positive experiences of disabled people in accessing the screening services and the strategies the NSS adopted to improve access. Despite these efforts, disabled people still experience several issues and challenges in accessing screening services. The significant role of the NSS in promoting and implementing screening among eligible participants is highly valued among the participants. However, disabled people suggested the importance of collaborative work between the NSS, Disabled People's Organisations (DPOs), and disability services to improve access to screening services. There is an urgent need for the collection of information about disabled people who are eligible for screenings and have accessed to those services to help service improvement.



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