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Inequity in HPV vaccination, primary HPV screening, and sexual health education for people with learning disabilities, autism, and severe mental illness: A discussion.

The sexual lives of people with learning disabilities, autism or both, have long been subject to restriction and stigma [1, 2] and are often mediated by family members and support workers, as well as outdated policies that while initially designed to be protective, ultimately limit opportunity for sexual freedom and self-expression [3]. Moreover, a growing body of research indicates that far from being risk-aversive, current attitudes and practices increase the likelihood of risky sexual behaviours [4] by driving sexuality 'underground' and removing opportunities for sexual health education and discussion [5]. Further, these attitudes contribute to the general misunderstanding among families and health care providers (HCP's) that people with learning disabilities and/or autism are asexual [6] and do not require access to the same public health interventions as the general population [7], such as HPV vaccination [8] and sexual and reproductive health screening [9, 10]. However, research suggests that sexuality and relationships are an important part of how people with learning disabilities experience their lives [11], and yet, despite being fertile and sexually active, are unsupported in accessing appropriate sexual, reproductive, and gynaecologic healthcare [12]. Indeed, recent findings from a study investigating sexual health, orientation, and activity among autistic individuals, found that compared to the general population, they may express a wider range of sexual orientations, are more likely to be homosexual [13], have a lower mean age of first sexual activity and show no difference in rates of acquisition of sexually transmitted infections [2]. They are also found to be at an increased risk for poorer mental and physical health, have a lack of accessible sexual health information and screening, and may experience greater stress and discrimination arising from this intersectionality [2].

Rates of mental health problems are higher among people with learning disabilities and autism [14] and it is estimated that up to 40% of people with a developmental disability also experience mental illness, with 8.3% receiving a diagnosis of severe mental illness (SMI) [15]. Moreover, common risk factors exist for people with learning disabilities, autism, SMI, and a reduced likelihood of screening [16], including poverty and low educational attainment [17]. Women from these groups have been reported to be less knowledgeable about cervical cancer, screening, and sexual health [18]. A systematic review and meta-analysis, which included international data on more than 4.7 million individuals, concluded that people (women in particular) with mental illness, including SMI, are significantly less likely to undergo screening of any kind than the general population. [17] However, it is known that people who live with SMI are sexually active, likely to engage in risky sexual behaviour [19] and have been found to be at an increased risk for sexually transmitted infections and unwanted pregnancies [20]. In the UK, it is recognised that people with SMI have unaddressed sexual health needs [21] but that there is limited empirical evidence available to inform effective interventions. However, a small feasibility trial found that it is possible to promote sexual health in this group, and that fully powered trials are needed to establish the effectiveness of such health promotion interventions [22].

Clearly, common barriers to sexual and reproductive health exist for people with learning disabilities, autism, and SMI [20]. Addressing the significant structural and social barriers to sexual health services and screening promotion and encouraging conversations about reproductive health is a priority for all vulnerable groups to ensure equitable health outcomes. For example, it has been widely reported that the introduction of the Human Papilloma Virus (HPV) vaccination in England has 'successfully almost eliminated' cervical cancer in women born after 1995 [23]. However, while England's largely successful HPV vaccination [24] and cervical screening programmes [25] have achieved widespread coverage, there remains significant variation in uptake [26]. While there is little nationally representative data available regarding uptake among people with learning disabilities, autism and SMI, several small regional studies suggest they are less likely to receive both first and second doses of HPV vaccine [8, 27] and significantly less likely to undergo cervical/primary HPV screening [28] [29]. Recent changes in the legal framework around self-consent for HPV vaccination in England has potential to further exacerbate inequalities in uptake, due to the perceived (and actual) inability of people with learning disabilities, autism, and SMI to make an informed choice [30].

There is now widespread recognition that sexual and reproductive health rights (SRHR) are central to overall health and well-being [31], with the World Health Organisation (WHO) defining SRHR as a state of complete physical, mental and social well-being in all matters relating to the reproductive system, a safe and satisfying sex life, the capability to reproduce, and the freedom to decide if-and-when to do so [32]. In the UK, the Equality Act (2010) [33] states that reasonable adjustments must be made to remove barriers faced by people with learning disabilities, autism, and SMI, to receiving equitable access to healthcare services. However, addressing current ableist policies in service delivery will be key to upholding these rights. It is clear that both more research and greater intervention is needed if we are to achieve the visions laid out by these charters. Yet largely absent from the discussion on SRHR are the voices of people with people with learning disabilities, autism, and SMI, themselves. Their experiences require in-depth exploration if we are to advance knowledge in this area, and must inform the design and development of the research itself, through a diverse and participatory research environment [34]. Then may we begin to improve our understanding of the barriers and facilitators to HPV vaccination and primary HPV screening among vulnerable groups, to discover how people with learning disabilities, autism and SMI would like to be empowered in their decision-making, and use these insights to underpin the development of interventions that will improve uptake, and inform and encourage sexual health preventative behaviours.

It may be possible to further advance health equity by establishing the intersectionality [35] faced by belonging to more than one of these groups [36], and whether those who have a combination of learning disability, autism, and SMI have even lower uptake of HPV vaccination and screening, than those with just one. Moreover, incorporating an intersectional framework in future research will allow for a clear understanding of the multiple conditions of inequality often surrounding the lives of people with learning disabilities, autism and SMI, including ethnicity, socioeconomic position, gender identity and expression, and how this may intensify their experiences of marginalisation [1]. In recognising the synergistic and multiplying effects of this intersectionality, we may then move further towards advancing health equity, not only in improving access to HPV vaccination, screening, and sexual health education, but by addressing the structural and social stigma that has encouraged existing disparities. By challenging existing narratives, which limit opportunities for sexual and reproductive freedom and self-expression, we can empower people with learning disabilities, autism, and SMI in supported decision making and personal choice throughout their lives, thus fully exercising their most fundamental human rights.

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