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Commentary

Public health and ethics: the case of prenatal screening and Down's syndrome

At the beginning of the 21st century, medical and social advances mean that for people with Down's syndrome (DS), it has never been a better time to be alive. Advocates such as Karen Gaffney, Sarah Gordy and Frank Stephens undo the persisting myth that their lives are not worth living. A generation ago, institutionalization was advised. Now the current life expectancy is around 60 and is likely to increase, and access to mainstream schooling and activities is becoming the norm.[1] Surveys show that quality of life for those with Down's syndrome, their siblings and families, is good in the majority of cases.[2,3]

Societal attitudes to disability in the UK however remain problematic, with increased reports of hate crime, and the United Nations (UN) identifies a wide range of improvements needed to improve people's lives.[4] The medical profession has in a number of cases lagged in recognizing the value of those with disability, conflating impairment, suffering, medical futility and disease with respect to Down's syndrome. Recent commentary strongly highlights tension in relation to new technology (non-invasive prenatal testing or NIPT) and ethics in prenatal screening, and the effect on the community, with a plea for stronger ethical consideration.[5]

The 2017 Nuffield report on NIPT examined these issues and draws attention to the need to improve information given at the offer of testing, but also the wider social context, and potential for harm through increased stigma and decreased acceptance or support for those with conditions.[6] This discourse could be advanced with a structured approach to public health ethics, full assessment of equality impact and the adoption of a human rights model of disability to create a more favourable context. Interestingly, the UN views that reproductive autonomy can be achieved without selective termination for impairment, and this has not featured in debate.[4]

For public health ethics, offering screening for DS to promote choices which may lead to selective abortion raises questions about justice, social cohesion and what it means to be healthy.[7] DS along with other conditions can now be considered not as a disease but as a variation which is a part of human diversity. Health gain resulting from screening is difficult to quantify, with older studies counting costs of future care avoided without assigning QALYs to the life of a person affected. This systematic bias could now be viewed as discriminatory, and medical teaching on these studies may need to be revisited.

Going forward, in the best-case scenario, present screening dilemmas could be the required catalyst for social change to recognize and urgently address pressing issues of inadequate care and rights and change negative attitudes.[8] In the worst case, billion-dollar commercial interests and unduly pessimistic language and information could heighten social anxiety about less than perfect children and lead to near disappearance of certain groups. In eloquently warning against a 'quarantine mentality' in relation to labelling people with genetic difference as 'undesirable', Merkel puts it thus: 'As physicians, one of our roles in society is to educate the public on the importance of tolerance towards those with disease or disabilities'.[9]

Public health professionals must be part of the solution in standing up to tackle stigma and barriers to health and care in disadvantaged members of the community. This is central to the realization of the right to health which should drive professional public health endeavours, and care is needed not to return to the eugenic thinking of the last century. With the past in mind, there is a need for a revitalized emphasis on public health ethics, rights and the application of equality principles in all we do.[10]

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