Implications for public health research of models and theories of disability: a scoping study and evidence synthesis

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Plain English summary

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Public health interventions can improve population health and reduce inequalities. However, we do not know how far these interventions – or the research that informs them – include the experiences of those with disabilities.

Our research asked whether or not current research on public health could do better to include the experiences of those with disabilities. We began by looking at what has been written about the experiences of disability. What we learned was then used to explore how well current research on public health interventions captured the experiences of people who have disabilities.

We found that disability can affect anyone, at any age. It can also affect those who are already ill. There is no typical experience. Public health research has been slow to understand this. Disabled people face many different forms of disadvantage and discrimination. This often means that they cannot get the help that they need. It appears that research has not always recognised this and has ignored how people can ‘flourish’ and ‘thrive’ with a disability. Policy, therefore, has not always known how best to support disabled people and has often had no information on which to base decisions.

Following discussions with politically active disabled people and public health professionals, we aimed to provide advice to those involved in research. This included developing a decision aid, called IDEAS (Inclusion, Dignity, Equality, Accessibility and Intersectionality), which aims to help researchers, commissioners and policymakers to make decisions that are more sensitive to the experiences of disabled people. Encouraging researchers and commissioners to take disability more seriously should hopefully improve what we know about the experiences of disability. It should also help society to develop interventions that improve disabled people’s health. This includes asking disabled people about the research that they think is important and involving them in the research process, as well as making resources available to support their participation in research.

Our conclusions point out the importance of recognising a person’s right to respect and dignity, while also understanding the influence of the social conditions in which a person lives on his or her experience of disability.
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