Editorial

What should public health be doing for disabled people, and why aren’t we?

The Family Resources Survey 2007/08 estimated that as many as 18% of adults have a physical disability or sensory impairment—one in seven adults of working age, and one in two adults over the age of 65. Increasing life expectancy inevitably means that these proportions will increase with time. People with disabilities are more likely than non-disabled people to live in poverty, are less likely to be in employment and have lower educational attainment. Those who are employed earn, on average, 16% less than non-disabled people. Disabled people also have more health problems, are more likely to be overweight, less likely to take recommended levels of exercise and more likely to have mental health problems. By any standards, this is a vulnerable group.

And yet, when embarking on a needs assessment for disabled people in our local population, an informal search for existing needs assessments (excluding brief entries in JSNAs), via online search engines and an extensive public health network, produced just one piece of work on physical disabilities that had been done in the last 5 years, one that had been done in 1992, and none for sensory impairment. In contrast, a simple Google search for sexual health needs assessments produced several pages of recent regional and PCT needs assessments, guides for doing sexual health needs assessments and dedicated data sets and toolkits.

It could be argued that the recent public sector equality duty (PSED), the evolution of JSNAs and increased partnership working could render a full needs assessment of disability unnecessary, and in some areas that may be the case. In our local population, the needs assessment was informed by epidemiological information from the JSNA, and went on to provide a rich additional source of information for both the PSED (including the Health Impact Assessment) and the JSNA, focusing primarily on the needs and priorities that were voiced by local disabled people. The requirements of the PSED, together with enhanced opportunities for joint working with local authorities, mean that there has never been a better time to do a needs assessment for disabled people, as willingness to look at this area is not only high, but mandatory.

So why is it that public health professionals apparently shy away from disabled people?

There are a number of likely contributing factors.

Firstly, the nature of disability is that it is often invisible. People with severe visual impairment may have an assistance dog or a white stick, but it is unusual for partially sighted or hearing-impaired people to have similar external evidence of their disability. Also, many visual and hearing impaired people do not register. Because disabled people are less likely to be employed they are underrepresented in the workplace, and they often withdraw from social contact more generally.

Another reason is that disability is an extremely broad and complex area. Initial appraisal yielded around a dozen potential needs assessments that could quite happily stand alone. Where to start?

Yet another reason may be more personal. Many people feel uncomfortable around disabled people. Should we assist them, if so how? If we get it wrong, will they be offended or annoyed? What if we speak to them and they are unable to hear us, or unable to respond? What if they also have a learning disability—will they understand us? If we try and help or communicate, will it be difficult or embarrassing, and will we wish we hadn’t?

Fitzgerald and Parkes reviewed these difficulties, and say of clinicians trying to communicate with disabled patients:

‘The fact that, unlike the patient, we can escape from the frustration—by escaping from the patient—encourages us to do just that’.

They go on to say:

‘We give up trying to communicate, avoid interaction, and inadvertently indicate that we wish they would stop troubling us. Consequently, it is common for patients with communication defects to feel that they have become a burden to all who meet them. They may be tempted to give up trying to cope with a world that feels unappealing and rejecting’.

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Whatever the reasons, disabled people suffer quietly from this neglect. They attend GP surgeries or hospitals and find that receptionists and health professionals do not know how to communicate with them, assuming that they will bring a companion. Interpretation for signers is often not offered, alternative formats for visually impaired not available, hearing loops not present or not functioning, counters too high for wheelchair users to see over. Few staff understand the importance of telling visually impaired people where things are located, or who is in the room. They do not realize that many profoundly deaf people are unable to use mainstream written materials, and that lip-readers are unable to do so if someone has turned away from them. Deaf people miss appointments because they do not hear their name being called, and blind people because they cannot read the appointment letter.4

Yet under the Equality Act 2010 organizations are breaking the law if they are not actively addressing these issues, and many can be addressed with little difficulty and little funding. If we, as a specialty, are going to include disabled people among those whose well-being we strive for, we need to

• become disability aware through appropriate training (NB diversity and equality training is not sufficient).
• consider the needs of disabled people in every needs assessment we conduct, and every service we commission or provide
• consult closely with disabled people, as only they know about the small but important things that make the difference between a service they are able to use, and one that they cannot.
• ensure that specific access, communication and training requirements appear in all contracts.
• assess accessibility by insisting on audits of local services, using, for example, the Disability Access Self Assessment Audit Toolkit.7
• make disabled people the next group whose needs, or health impact, we assess.

In our locality, the production of a needs assessment has had considerable impact. The local authority has adopted ‘access’ as their priority area for meeting the requirements of the PSED, awareness training is being planned and rolled out in the local authority and local acute and community NHS trusts, an initiative to increase access to services by engaging the business community is underway and local disabled people report a sense of their needs being heard and addressed.

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References