



## A response to Sexual Health and Wellbeing for Wales, 2009-2014: Draft Working Paper

4<sup>th</sup> September 2009

### About us

Consumer Focus Wales is the new statutory organisation campaigning for a fair deal for consumers.

Consumer Focus Wales is the voice of the consumer and works to secure a fair deal on their behalf. It was created through the merger of three consumer organisations – energywatch, Postwatch and the Welsh Consumer Council. This new approach allows for more joined-up consumer advocacy, with a single organisation speaking with a powerful voice and able to more readily bring cross-sector expertise to issues of concern.

In advocating for consumers we aim to influence change and shape policy to better reflect the needs of consumers. We do this in an informed way owing to the evidence we gather through research and our unique knowledge of consumer issues. We have a particular focus on vulnerable consumers, particularly those on low incomes, people with disabilities, people living in rural areas and older people. In addition, we also seek to identify where other consumers may be disproportionately disadvantaged by a particular consumer issue or policy.

Consumer Focus Wales welcomes the opportunity to respond to this consultation on the draft working paper looking at Sexual Health and Wellbeing for Wales 2009-2014. In this instance, we believe that the working paper has implications for all consumers. The draft working paper is slanted strongly towards the needs of those aged 24 and under, since this age group made up more than two-thirds of cases of those diagnosed with a Sexually Transmitted Infection (STI) in Wales in 2005<sup>1</sup>. People in Wales aged 24 and under are much more likely than older age groups to be diagnosed with syphilis, gonorrhoea, chlamydia, herpes simplex and genital warts.

However, this must not lead to neglect of other groups, particularly older age groups who are experiencing rising levels of STIs<sup>2</sup> due to changing trends in lifestyles. Research by our predecessor organisation, the Welsh Consumer Council<sup>3</sup>, demonstrated that people aged

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<sup>1</sup> National Public Health Service Communicable Disease Surveillance Centre. HIV and STI Trends in Wales: Surveillance Report, November 2007. Cardiff: National Public Health Service

<sup>2</sup> A T Bodley-Tickell, B Olowokure, S Bhaduri, D J White, D Ward, J D C Ross, G Smith, H V Duggal, P Goold. Trends in sexually transmitted infections (other than HIV) in older people: analysis of data from an enhanced surveillance system. *Sexually Transmitted Infections* 2008; **84**: 312-317

<sup>3</sup> Welsh Consumer Council (2006) Sexual Health and Young People: reducing the barriers to services

65 and over often felt uninformed about sexual health issues and were much less likely than younger people to know the location of their nearest sexual health clinic. Service provision must take account of these generational attitudinal differences and not allow the needs of statistically less prominent groups to go unnoticed. The draft working paper has an insufficient focus on the needs of older people and we would like to see actions specified to recognise and address their requirements from sexual health services.

## **Overview**

Broadly we welcome the Welsh Assembly Government's draft working paper and agree with its overall aims. The paper has acknowledged the complexity of the causal factors behind sexual ill health and teenage pregnancy, recognising that alcohol and drug consumption, poverty and social exclusion, low educational attainment and low life aspirations all increase the likelihood of contracting an STI or becoming pregnant early in life. We also welcome the working paper's rights-based approach to sexual health and wellbeing, this being something that resonates strongly with our views on universal access. That said, we have a number of specific comments on issues we believe need greater attention. Our views are summarised below.

### **Action Area 1: Cultural change**

#### *Rights-based approach to sexual health and wellbeing*

A rights-based approach necessitates a greater focus on people's differing needs, and the draft working paper includes an extensive list of particular groups who may be vulnerable and therefore have specific access requirements. However, the paper is not explicit about the mechanisms through which the theory of the rights-based approach is translated into practical outcomes. Exactly how will the planning of services take account of the needs of these groups? What methods will be used to analyse the nature of their requirements and respond accordingly? A rights-based approach is a laudable goal but what does it look like in practice?

If the list in the draft working paper is intended to form a checklist of vulnerable groups, it needs some further thought. For example, it does not include a reference to people who are vulnerably housed or homeless, even though this group is widely understood to have specific problems accessing healthcare – one study<sup>4</sup> found that homeless people were 40 times less likely than the general population to be registered with a GP.

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<sup>4</sup> Crisis Policy Brief (December 2002) *Critical Condition: Vulnerable single homeless people and access to GPs*

## *Participation*

We welcome the fact that participation is included here as a driver for cultural change, although we feel the topline statement, 'Sexual health information and services need to be developed in partnership with those using them to ensure that their needs are being met', is inadequately reflected in the actions themselves, which concentrate on encouraging participation from young people and people living with HIV. People may require sexual health services at any stage of their lives and are also likely to dip in and out of services. This must therefore be reflected in ongoing monitoring and evaluation of sexual health services. Participation must also incorporate service non-users in order to find out their reasons for non-use.

With this in mind, it would be helpful if the draft working paper were to include a clearer outline of the intended make-up of the National Sexual Health Advisory Board, incorporating representation from a broad range of people, not just young people and people living with HIV. It may be more appropriate to incorporate a sub-group into the Board structure in order to make room for sufficiently diverse representation, including those who are from harder-to-reach groups, e.g. older people and BME people, to ensure their specific needs are considered, with a nominee from the sub-group appointed to sit on the main Board.

We also feel the draft working paper needs to acknowledge the difficulties in this area which are specific to sexual health, that is, the likelihood that many will be extremely reluctant to come forward and talk even in a general way about services, let alone about their own experiences. There is a great danger that participatory exercises end up doing no more than rounding up the usual suspects, leaving vast sections of the population unrepresented. The Welsh Assembly Government should work with stakeholders such as the Family Planning Association to identify ways of engaging with these different groups in local communities.

## **Action Area 2: Better prevention**

### *Sex and Relationships Education*

In terms of the delivery of Sex and Relationships Education (SRE) we would draw your attention to a recommendation arising from the Welsh Consumer Council's report on sexual health and young people, which argued that schools-based SRE should be delivered wherever possible by peripatetic specialists rather than by teachers. Similarly, Estyn's 2007

report 'Sex and Relationships Guidance'<sup>5</sup> recommends that SRE should be delivered by specialists.

We note the commitment to develop and publish updated guidance for the delivery of SRE in schools, and we hope that this will include a firm statement on the use of peripatetic specialists, since this is what young people themselves clearly prefer.

### *SRE in the wider community*

The commitment to develop guidance for SRE in the wider community is very welcome. As the draft working paper correctly states, some of the young people most vulnerable to teenage pregnancy or sexual ill health may not attend school, or may respond better to SRE in a community environment. SRE in settings such as Pupil Referral Units, Young Offenders Institutions, residential homes, Further and Higher Education settings, and the youth sector, should reflect best practice and not be in any way inferior to that provided in schools. For example, the draft working paper states that schools 'need to take account of pupil's (sic) views on what content they need at different stages'. In the same way, young people should have a say in how community-based SRE is delivered and participation should be encouraged here as well as in schools.

### *Access to information, advice and contraception*

Allocation of resources within the Welsh NHS needs to reflect the draft working paper's assertion about the cost-effectiveness of prevention measures, specifically that 'for every £1 spent on contraception, £10 is saved for the public purse'. Family planning advice agencies report that funding for some condom and morning-after pill schemes is still too low and we would like to see a joined-up approach to assure the future of such schemes together with funds allocated for publicising their services.

The Welsh Consumer Council's report argued that the price of contraceptives could still be a prohibitive factor for young people, despite the reduction of VAT to 5 per cent. We would call for the resulting working paper to include a commitment from the Welsh Assembly Government to lobby at UK and European level for VAT to be removed from contraceptives altogether.

We note the commitment to review provision of existing sexual health information. This is very much needed. People may need information on sexual health at any time in their lives

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<sup>5</sup> Estyn (2007) Sex and Relationships Guidance

and yet the prevailing approach focuses on the young, neglecting the needs of older age groups. It is not realistic to expect people to educate themselves about sexual health if they do not perceive the relevance of such information to their own circumstances, for example if they are in a monogamous long-term relationship. However, such relationships may come to an end at any life stage, and at that point an individual may suddenly enter into new sexual relationships with a low level of awareness about how to have safer sex. This is why information needs to be delivered in many different ways, and the Welsh Assembly Government can help by producing high-quality multilingual resources for use by community groups such as Women's Institutes, Merched y Wawr, ethnic minority networks and others. These resources should be developed in collaboration with different client groups to better understand how people wish to receive information and in what format.

As an outcome of this review the Welsh Assembly Government should commit to fund the availability of bilingual leaflets at sexual health clinics. Currently clinics have to buy leaflets from organisations such as the family planning association and, since these tend to be available only in English, the expense of translating and printing Welsh leaflets must be met by the clinics themselves. Clinics are often the first port of call for organisations which wish to distribute such leaflets and this can add up to a considerable expense. There should be no limits on provision of leaflets like these – they should be available to whoever wants them, at any time.

We note that websites will be included as part of this review. Given that websites are often a popular source of sexual health information for young people, due to the anonymity and convenience of the internet, we would urge the Welsh Assembly Government to make an assessment of the quality of information currently available online, ensuring that there exists a reliable, bilingual website that includes a wide range of sexual health and relationships advice, and that consumers are signposted there through the NHS and other pathways.

### *Sex, drugs and alcohol*

The integrated approach towards service delivery described in the draft working paper is highly appropriate. It is common for sex, drugs and alcohol to be closely linked in people's daily lives and it makes sense to echo this in services, providing access to information and contraceptives at a time when they are most needed. However, the point that the draft working paper fails to grasp is that access to information and contraception needs to be slanted not towards addicts, who tend to engage in low levels of sexual activity (sex workers excepted – see below), but primarily towards recreational drug users and drinkers who are not receiving substance misuse services. Conversations with sexual health clinicians reveal that people who have an active social life, involving recreational drink and / or drug use, tend to have a good level of awareness about sexual health issues and yet are not always

careful, because their judgement is impaired in the moment when they make the decision to have sex.

This problem needs innovative thinking and we would urge the Welsh Assembly Government to carry out a scoping exercise to identify best practice, which may include SRE that incorporates drug and alcohol education; working with student unions to ensure all students in Wales have ready access to free contraceptives, STI testing, information and advice; and working with contraceptive manufacturers to build comprehensive provision of condom vending machines not just in men's and women's public toilets in town centres but also in other environments and places where experience and research tells us there may well be incidences of sexual activity. Provision should be based on an understanding of people's behaviour and not just on convenience or tradition.

We would also like to see the working paper include support for outreach work such as that carried out by the Terrence Higgins Trust which targets places where people are known to congregate for casual sex, providing information, condoms, STI testing and support to help people protect themselves.

We are concerned that sex workers are not mentioned in this section, or indeed anywhere else in the draft working paper aside from two very brief references. The sexual health needs of this group should be the focus of considered service provision, taking into account the reality of the lifestyles of sex workers, in which alcohol and drugs often play a large part. People working in the sex industry are highly likely to be living with multiple layers of disadvantage and as such will need targeted resources, such as outreach, in order to get access to the services they are entitled to under the rights-based approach. The Welsh Assembly Government should include in the working paper a strategic set of actions to enable sex workers in Wales to protect their sexual health and wellbeing.

### **Action Area 3: Modern sexual health services**

#### *Integrated sexual health services*

We recognise that the recent integration of family planning and GUM services has led to important gains on waiting times. The picture has changed somewhat since the publication of the Welsh Consumer Council's report, which found that when people had to wait weeks for an appointment they experienced high levels of stress and anxiety, and often did not cease sexual activity during this time. We welcome the Welsh Assembly Government's two-day target for access to core sexual health services, although we note that performance against this target varies widely between NHS trusts, from 34.9 per cent in Hywel Dda NHS Trust to 100 per cent in Gwent NHS Trust in July 2009, with an all-Wales average of 85.2

per cent<sup>6</sup>. The draft working paper is not explicit about how greater compliance with the two-day target is to be achieved. We call on this issue to be given greater consideration within the working paper and tackled by the Assembly Government as a priority.

The working paper rightly points out that service provision needs to include geographical outreach and user-friendly opening in order to widen access in a way that is consistent with a right-based approach, and that users need to be involved in the design of the service. To this we would add that it is also important to involve non-users, in order to ascertain the reasons for non-use, and therefore we would prefer the wording here to be changed from 'involving users' to 'involving users and local communities'.

A further consideration is that some consumers may not necessarily want to use services in their local community because of confidentiality fears, particularly in the context of small towns and villages. Service planning needs to take account of the fact that people accessing the service may not be drawn solely from the local area.

The Welsh Consumer Council's report recommended that the Welsh Assembly Government should consider running a programme in Wales similar to England's National Chlamydia Screening Programme. We note that the screening approach has not yet been replicated in Wales and we would urge the Welsh Assembly Government to consider in depth the successes and failures of the English programme and how these can be built on for the benefit of consumers in Wales.

We would also emphasise that, while access to essential healthcare is the primary consumer issue, a truly consumer-friendly sexual health service needs to commit to standards of customer care. This is particularly important given the fact that people accessing sexual health services are likely to be nervous and emotionally vulnerable. The Welsh Consumer Council report detailed a number of incidents where people had not been treated well by staff at family planning and GUM clinics. A number of research respondents spoke of dismissive and uncommunicative staff.

The draft working paper should include a commitment to high standards of customer care in the newly integrated sexual health service, recognising that poor performance here will deter some people from accessing services altogether.

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<sup>6</sup> Welsh Assembly Government Health Statistics

*'They were quite blunt really, they weren't very welcoming and we were in our school uniform so we felt a little bit like intimidated.'*

*'When we got in to see someone the one lady was incredibly rude. Because I wasn't actually there to be tested, I just went in with my friend, but I was going there to get information as well, because I was told you could get some information. And when I went in there the lady started asking me questions about the procedure and I told her I wasn't there to get tested, and she was just really rude, she made me feel like I was wasting her time. She just got a couple of leaflets and chucked them at me basically.'*

*'They could have been a bit more helpful, given me more information, she could have given me opening times. She didn't mention anything about the student health centre either. I suppose [she could have been] a bit more professional about it – do you know what I mean. More caring, reassuring. The nurse I spoke to over the phone didn't seem that reassuring.'*

A further aspect of customer care relates to confidentiality, a key area of concern for consumers who are often unsure of their rights when it comes to sharing personal information. The Welsh Consumer Council heard from young people who had visited a family planning or GUM clinic and been asked for personal information despite feeling reluctant to share their details. Many felt that they had no choice, and were unaware that they did not have to give that information. Some were also unsure as to whether the information was going to be kept confidential, and there seemed to be confusion as to whether information would be passed on to parents if the individual was under 16 years of age. In one case, a schoolgirl awaiting STI results was told that the clinic would telephone the results to her home number, and she was very anxious in case her parents picked up the phone.

Health professionals need to ensure systems are in place for protecting confidentiality. They need to let service users know their rights in this area, taking time to inform young people that their information will be kept confidential even if they are under 16, and that they are under no obligation to provide personal details.

### *Primary care*

The Welsh Consumer Council's study found that confidentiality and customer care could also be a problem in general practice surgeries, with individuals feeling pressurised to give personal information about the nature of their problem to receptionists.

*'There were constantly, I'd say there was maybe about twelve people around me. Which doesn't really bother me because I'm not from around here anyway, but I did think if I was from [mid Wales town] – it's not very private in terms of people from here, it's a small town and they would know each other and might feel a bit uncomfortable about that. Especially as it's only once a week and you can't just make an appointment and just walk in.'*

With this in mind, we welcome the working paper's commitment to include sexual health in Continuing Professional Development programmes for GPs, Practice Nurses and practice administration staff, and we would like to see customer care and confidentiality covered by this training.

Community pharmacies are often the first port of call for people seeking sexual health services and information, and as such we welcome the commitment to develop a service specification for providing an enhanced service within community pharmacy settings. In people's busy day-to-day lives it is often more convenient to seek advice or pick up contraceptives from a local pharmacy than to go to a sexual health clinic. Here again we stress the importance of good customer care and an appreciation for the sensitive nature of consumers' requirements. We would like to see the service specification include criteria on confidentiality, in particular that a private space should be available in which consumers can discuss issues with pharmacy staff out of sight and earshot of other customers. The availability of such services should also be clearly signposted. Criteria on staff training also need to be included so that consumers are dealt with sympathetically and, if necessary, signposted appropriately. Staff should inform consumers who are purchasing contraceptives or pregnancy tests that it may be possible to get these free in other places such as GP surgeries.

### *Abortion services*

The commitment to a rights-based approach to sexual health services is seriously compromised by the inequalities in access to abortion that currently exist in Wales. The fact that no abortion services exist in north Wales means that women have to travel to Liverpool

and Chester to access this service, a considerable journey for those who happen to live in the most westerly local authorities such as Gwynedd and Anglesey. The draft working paper refers to a need for 'appropriate access to NHS funded abortions' – it is surely inappropriate that a woman must travel 100 miles or more to access these services. Availability of abortion services must be included in local sexual health service development plans and this must lead to improved access for women in north Wales.

Access to abortion services is a difficult area to research, partly because of the emotive and consequently very secretive nature of the problem. However, some research<sup>7</sup> has indicated that women can experience difficulties at the point at which they ask a GP to refer them for a termination, when some GPs refuse to do so, due to moral objections to the principle of abortion. This need not necessarily be a problem – provided the GP signposts the patient appropriately to a GP who will refer her – but this study found that some women experienced considerable service-related delays which meant they often had to wait for more than three weeks for the procedure to take place. The Welsh Assembly Government should make a commitment to develop firm guidance to GP surgeries to ensure that, if a GP objects conscientiously to abortion, he or she will signpost the patient to a GP who will be willing to refer the patient for a termination.

#### *Psychosexual and sexual dysfunction services*

Although the draft working paper includes a section on psychosexual services there are no specific actions mentioned. How is WAG intending to address inequalities and barriers in access to psychosexual and sexual dysfunction counselling? The draft working paper does not address this question. NHS waiting times to see a psychosexual therapist are very long, particularly in north Wales where people have to wait up to 52 weeks for an appointment. This is unacceptable. We would like the draft working paper to include a commitment to widen access to this service in line with a rights-based approach, ensuring equality of provision across Wales (along with resulting actions which seek to achieve this).

#### **Action Area 4: Strengthening research and surveillance**

We welcome the commitments to improve the collection and collation of health intelligence and research data, particularly the move to identify inequalities by profiling the sexual health of the population of Wales. However, it concerns us that the draft working paper does not contain any reference to data on customer satisfaction. This is something that needs

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<sup>7</sup> S Finnie, R Foy, J Mather. The pathway to induced abortion: women's experiences and general practitioner attitudes. *J Fam Plann Reprod Health Care*. 2006 Jan;32(1): 15-8

systematically to be measured in order to compare performance and encourage a stronger focus on improving the service user experience. We call on the Welsh Assembly Government to include customer satisfaction as a measurement in the ongoing monitoring of the strategy.

## **Summary and conclusions**

In summary, whilst we broadly welcome the proposals outlined in this paper, we would like a number of issues to receive further attention. In particular we would like to see action to ensure:

- Meaningful, representative participation in the design and evaluation of services
- A clear plan for the creation of rights-based access for all
- Innovative thinking in the provision of information, advice and contraception for people from all walks of life
- Commitment to high standards of customer care across the sexual healthcare sector.

By adopting a rights-based approach to service provision, and seeing that approach through to its logical ends, everyone in Wales can have equal access to the sexual health information and services they need. We strongly support this approach and would welcome the opportunity to work with the Welsh Assembly Government to realise the objectives of the draft working paper, by representing the consumer interest, by carrying out research and by advising on building customer focus into service delivery.

### **For more information contact:**

**Jennie Bibbings**

**Senior Policy Advocate**

**Consumer Focus Wales**

**3<sup>rd</sup> Floor, Capital Tower**

**Greyfriars Road**

**Cardiff**

**CF10 3AG**

**Tel: 02920 787153**

[jennie.bibbings@consumerfocus-wales.org.uk](mailto:jennie.bibbings@consumerfocus-wales.org.uk)