Providing respite care in a rural environment

Specialist multidisciplinary teams are an appropriate response to caring for people with HIV/AIDS in urban areas. In rural settings the problems are rather different and alternative approaches must be considered.

North Wales is one of the most beautiful spots to visit for a short break, particularly in the early spring. In fact, the local population swells by 50 per cent in the peak holiday season.

While providing high quality services is what we all strive for, regardless of location, in North Wales there are several disadvantages which clients experience, particularly in accessing support. Clients who live near the coastline can access services via the local genito-urinary medicine (GUM) departments, transport permitting. For clients living further away from these centres, particularly in the mountains, accessing basic support is difficult in adverse weather conditions. Fear of being identified by family members or someone from the local village is an additional problem. A large number of Welsh people leave their roots to seek treatment in England.

Living in a rural community is an ideal for many. For the HIV positive person it raises many issues which often necessitate that person having to leave family and close friends for fear of being identified, stigmatised and often rejected. On the other hand, a person who is popular within the local community, because of doing 'good works' for example, can find lots of support and care. This is, however, a rare experience. People affected by HIV disease are even afraid to seek help from their GPs for fear of their HIV status being revealed.

Although North Wales is quite a large area and for some geographically isolating, there is a close family network that is alive and active. Within a rural community there are many remote villages with only a small number of residents. Although the local grapevine is something accepted in the village way of life, when HIV is mentioned in relation to an individual the results can be disastrous. Many people hide their gay lifestyle from families and friends for fear of being ostracised and thus deny themselves hospital care and support. Smith et al (1990) reported that 'it is common for loved ones to tell friends and relatives that their son or daughter is dying of cancer and not AIDS.' Yet when I had the occasion to provide support for a client in the terminal stage of the disease his request was to have anything but AIDS on his death certificate.

Drug misuse is also prevalent in North Wales. The chaotic lifestyles of drug misusers and the illegal nature of their activities separates them from the rest of the community. Again, because of the low numbers in semi-rural areas, specific services for HIV positive drug misusers are looked upon as an inappropriate use of resources and their needs are very different from other groups. For a drug misuser, being HIV positive is often not the biggest concern, being overshadowed by more immediate worries such as money, legal problems and homelessness.

While many cities have specialist HIV teams in operation, this is not an appropriate model for a rural community like North Wales where the prevalence is perceived to be low. It has been well documented that despite the advantages of having centres of excellence in larger cities, they, like respite/care services within a rural community, can cause further stigmatisation and rejection for HIV positive people and their carers and family. In most areas of low incidence therefore generic services provide the care, or attempt to see that there is at least a basic level of service. Many nurses and doctors will never have had contact with someone with HIV and as a result might have fears about the disease, resulting in negative attitudes towards affected clients.

In and around North Wales considerable efforts have been made by the voluntary sector to raise HIV awareness, particularly regarding the provision of a suitable respite facility for those infected and affected by HIV/AIDS. In spite of the removal of ring-fencing for money for HIV/AIDS services, health promotion units across Wales remain totally committed to raising the issues which surround HIV/AIDS. Indeed, if it was not for a small group of dedicated individuals striving to involve local schools and bring new technology into the local discos then no-one would be counteracting the fear, ignorance and prejudice that still abounds in a rural community like North Wales.

My involvement with the Ingleby Trust started in June 1988 when the need to address local issues around HIV/AIDS became apparent. At that time the local community's response was, to say the least, very confused. The media hype together with adverts out-
lining the dangers of the HIV/AIDS not only frightened local people but resulted in several close-knit communities constructing a wall around themselves in the belief that AIDS was something imported by outsiders. Today's response is one of apathy and anecdotal evidence suggests that teenagers see HIV/AIDS as a problem for their parents, not them.

The founding fathers of a local charity negotiated with service users and various representatives of local health and allied professional groups to establish a respite centre. A suitable property was identified and a sensitive approach was used to win support from within the local community. Sadly, despite excellent media coverage, once the local community got wind of what was happening considerable pressure was exerted on the charity; the local response was 'not in my back yard.' This was despite every effort to allay fear. The arguments against the centre ranged from fear of children being contaminated by blood-stained syringes to fear of HIV positive clients contaminating the local sewerage system. The media tried desperately to educate people to develop a compassionate and humanitarian response, but to no avail.

Trying to raise issues around the needs of any marginalised group relies heavily upon the skills of the media. Regrettably, it has to be said that this same media coverage might well have deterred those infected or affected by HIV from accessing respite care and support for fear of being identified and sustaining further antagonism. Given the negative responses from a local community in a rural area like North Wales, the question which must be asked is how do we move forward in allaying the unfounded fears that divide a local community? The reduction in funding is now beginning to affect AIDS awareness initiatives and the support which voluntary groups need to maintain basic services for HIV positive people. Without the dedication of our HIV voluntary groups who continue to provide a 24 hour service, clients would not have a quality, needs-led service. In North Wales, however, we are fortunate to have excellent working relationships with skilled colleagues based at the GUM departments and local social services. Representatives from the voluntary and statutory sectors work exceptionally well together, with the client very much on the agenda.

In May 1996, an organisation consisting of a team of professional volunteers decided that in light of the local uproar towards another voluntary organisation's commitment to provide a respite centre at a local tourist spot a new dimension in respite care was needed. The most recent media coverage highlighting local prejudice and ignorance towards a proposed respite centre has resulted in a new concept in developing respite care services from satellite centres which will remain totally anonymous to the general public.

The Ingleby Trust, now a registered charity, has embarked upon the development of an ideal solution to respite care for HIV positive people, their carers and families seeking a choice of respite services. The Trust has contracted respite from two centres which have met their criteria and protocols regarding respite provision. We now offer to our clients a choice of two units, one for adults and the other for families with children. One respite centre is in the countryside, the other on the coast. The Trust has developed a self-empowerment model which is ideal for clients not wishing direct care at present. However, in the future we hope to develop a complete care package including terminal care at a designated centre or in the client's own home.
When developing a suitable strategy for the provision of HIV/AIDS respite care, it is all too easy to duplicate services and consequently affect the viability of the services. Several years ago a renowned GUM service operating in Glamorgan, South Wales, developed a marvellous model outlining their commitment to such provision. The Ingleby Trust is indebted to this document and has developed its own respite care protocol working in partnership with the local GUM departments and allied service providers. We believe that to reinvent the wheel takes time, considerable funding and in the process loses the majority of volunteers because of disillusionment with the organisation.

A multidisciplinary core HIV/AIDS team comprising the senior nurse manager, co-ordinator and consultants from genito-urinary medicine clinics, the consultant clinical psychologist for HIV and the social services principal assistant in HIV/AIDS. The functions of this core group are to:

- Establish close liaison between all services
- Identify needs of users and providers
- Access general services
- Access respite services
- Inform the appropriate key worker of the need for services
- Plan and monitor care
- Co-ordinate services
- Evaluate services
- Plan future services
- Act as a resource for the north west (UK and Wales)
- Liaise with HIV preventative initiatives.

Other professionals involved in the care of an individual/family/carer can be co-opted on to the team as and when necessary in order to contribute to the planning of future care. Such professionals might include those from other agencies such as education, environmental health, and voluntary groups, as well as other health professionals. The team accepts all referrals of clients who are affected or infected with HIV, including those newly diagnosed, cross-boundary referrals, re-referrals and those attending departments and organisations other than genito-urinary medicine.

The Ingleby Trust has developed a specialist model of respite care (Table 1) within a generic model via its two satellite units and with the back-up of a trained care team of volunteers who have accessed high quality training from a centre of excellence in an urban environment. The Trust places considerable emphasis on the type of training necessary for a mobile, fully operational care team. The Trust also sees the relevance of seconding members of that care team to attend the ENB 934 and 280 courses at Manchester College of Nursing and Midwifery. We believe that by developing the skills within the care team clients and carers will be assured of receiving high quality respite services from one of our approved centres.

Our volunteers are aware of the negative and positive attitudes that surround HIV/AIDS in a rural community. Although the Ingleby Trust is a small operation aiming to provide high quality respite care, it sees the way forward in addressing local prejudices is by a combined effort and working in close collaboration with all members of the multidisciplinary team. Client advocacy is a combined responsibility for the representatives operating in the team. Because of decreased funding of HIV services across the board, I believe that both the statutory and voluntary agencies can only achieve high quality services by working as equal partners to serve a client group whose illness has separated them from mainstream nursing and medical support.

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Reference

Care: Choice or challenge?
The RCN HIV Nursing Society holds its annual conference on November 29 in central London.
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