

## PERSONAL PRACTICE

## Health care needs of Travellers

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Who are Travellers? The 1968 Caravan Sites Act ignored ethnicity and cultural distinctiveness by defining Travellers as: "persons of nomadic habit, whatever their race or origin".<sup>1</sup> However, in 1989, when the Commission for Racial Equality determined that Gypsies formed a distinct ethnic group, differences between "real Gypsies" and other more recent groups of Travellers were emphasised.<sup>2</sup> There are two main groups: new Travellers and traditional Travellers. The inclusive term "Traveller" is acceptable to most and is used here.

New Travellers are people from the settled community, who for various reasons have decided to adopt a nomadic lifestyle similar to that of traditional Travellers. Traditional Travellers are not a homogenous group. In the British Isles they mainly comprise English and Welsh Romanichal or Romany Gypsies, Irish Travellers, and Scottish Travellers, in addition to a growing number of European Romanichals (Roma). They each have their own language, beliefs, and cultural heritage. Linguistic and genetic evidence suggests that Gypsies originated in north India and began to migrate about 1000 years ago, first into Eastern Europe and eventually across the world. The first written description of Gypsies in England was in 1514.<sup>3</sup> The first anti-Gypsy law was passed in 1530 under Henry VIII and persecution and hostility have continued to the present day. Pahl and Vaile noted that: "distinctions between Travellers are less important than acceptance of the long tradition of Travellers living a marginal existence beside the settled population, with continuing antipathy between them".<sup>4</sup>

**Health care issues**

Gypsies and Travellers either "choose" to be mobile, or else they have settled and live like everyone else, so why should they receive any special services? Do they have any particular health problems? Would special provision improve the health of this disadvantaged group, or just increase their isolation and discourage the use of mainstream health care services?

Research on Travellers' health is mainly localised to particular geographical areas in the UK. Estimating the numbers of Travellers is difficult because of their nomadic lifestyle and the lack of any ethnic coding. There are no national morbidity statistics and only fragmen-

tary information on health status, making it easy for agencies to ignore their needs. In Ireland, after the "Travelling People Review" in 1983, the Health Research Board undertook a Travellers' health status study. Life expectancy for male Travellers was found to be 9.9 years less than for settled men and for female Travellers it was 11.9 years less (table 1).<sup>5</sup> The Irish Government set up a task force in response to these findings.<sup>6</sup> UK studies have also shown high perinatal and infant mortality (table 2),<sup>4,7</sup> poor health (such as a high rate of childhood accidents),<sup>4</sup> higher death rates from cardiovascular disease,<sup>8</sup> and a higher incidence of asthma.<sup>9</sup> Those who work with Travellers confirm this high morbidity from their experience.

The travelling lifestyle itself is not necessarily a cause for the disparity in health status; on the contrary, many Travellers and those working with them see the reduced opportunity to live their traditional lifestyle as a major cause of increased physical and mental ill health. My interviews with Travellers indicated that their ill health is partly attributed to changes in lifestyle. Two quotes from Travellers on a site and in a house respectively illustrate this perception: "the council took me life from me when I went and got caught in this place . . . when I was travelling my asthma was a lot better" and "wish I could travel, you're more healthier when you're travelling about. It's these houses

Table 1 Life expectancy at various ages for Travellers and the Irish population, 1987<sup>5</sup>

Age	Life expectancy (years)		Traveller deficit (years)
	Travellers	Irish population	
<i>Men</i>			
0	61.7	71.6	9.9
15	48.9	57.4	8.5
45	21.3	28.8	7.5
65	10.1	13.1	3.0
<i>Women</i>			
0	65.3	77.2	11.9
15	52.1	62.9	10.8
45	25.1	33.6	8.5
65	10.4	16.4	6.0

Table 2 Childhood mortality rates<sup>4</sup>

	Kent Travellers (1984)	England and Wales (1980)
Perinatal mortality rate	16.0	13.3
Stillbirth mortality rate	12.0	7.2
Infant mortality rate	17.5	11.9

Perinatal mortality and stillbirth mortality rates are quoted for each 1000 total births; the infant mortality rate is for each 1000 live births.

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which kill you, you know” (P Van Cleemput, 1999, unpublished). In the past, Travellers moved around in family groups, but many now experience enforced permanence either on isolated sites, with little privacy, or in houses, separated from their extended family. Because the obligation and funding for local authorities to provide sites has been removed and there is a chronic shortage of sites, more Travellers seek housing as an unwelcome and alien alternative. This might be why there are as many stress related physical and mental health problems among housed Travellers as those on sites, and it is suggested that specialist health visitors for Traveller families who move into houses should maintain contact with them for at least two years.<sup>10</sup>

Those who do still travel experience frequent fear and the reality of constant evictions and alienation of local people. In decades gone by Travellers were often welcomed for the trades and services that they provided to the local community, such as fruit picking, scrap metal dealing, etc. They had their traditional stopping places; most of which have now disappeared, along with some of the opportunities for casual work.

Many Travellers who have reluctantly resorted to a more settled way of life still choose to travel in the summer, despite the hardships. An Irish Traveller explains this need: “for Travellers the physical fact of moving is just one aspect of a nomadic mind set that permeates every aspect of our lives. Nomadism entails a different way of looking at the world, a different way of perceiving things.”<sup>11</sup>

### Causes of poor health

Poverty has sometimes been cited as the main cause of poor health in this group. Economic hardship, as with any other affected group certainly adversely affects their health, but I think that it is deprivation in the wider sense that is the determinant factor. Many of the 350 public Gypsy sites are situated in hostile environments that are deemed unsuitable for any other development, such as on old waste tips, or beside or underneath motorways. They invariably lack adequate basic facilities and are situated well away from other habitation and local amenities. Children in particular fare badly because, in addition to being distanced from amenities, they usually lack any play facilities on site. One of the main findings of research by the Children’s Society when looking at site provision was that children wanted safe play areas.<sup>12</sup> Travellers on sites are charged exorbitant rents and face the demand of a high deposit. They do not have tenants’ rights (they are licencees only) and so fear eviction if they complain. Ironically, it is only the poorest Travellers reliant on income support who can often “afford” to live on these sites because the rent is paid by their housing benefit. However, they still have to provide their own caravan and all the maintenance costs involved.

Alienation from society affects poor and rich Travellers alike and causes major disaffection. One example of this alienation is the situation of Travellers who are wealthy enough to buy

their own piece of land and therefore choose to live in a healthier environment. In most cases, they cannot obtain planning permission for their caravan to be on the land.<sup>13</sup>

There are other factors that affect the health status of Travellers. A national population based study of health of Irish Travellers showed a greater prevalence of congenital anomalies in Travellers compared with Irish Eastern Health Board region births (5.5% *v* 2.9%) and a significant difference in the prevalence of metabolic conditions with autosomal recessive inheritance (12.4/1000 *v* 1.3/1000). The incidence of first cousin marriages in the Traveller population was 19% compared with 0.16% in a settled population.<sup>14</sup> Families at risk require culturally sensitive genetic counselling to enable them to make informed decisions. The Traveller community perceives substantial economic and social advantages in these consanguineous unions (A Bittles, 1996, personal communication).<sup>15</sup>

### Education

Lack of education is another factor that can adversely influence health. Low literacy attainment is still a major problem for most adult Travellers, mainly because so few attended school on a regular basis, if at all. Despite the acknowledged good work of Traveller education support services throughout the country, school attendance, although much improved over the past decade, is still an issue. The 1996 Ofsted report stated that of an estimated 50 000 Traveller children aged 0–16 years as many as 10 000 secondary school aged children were not registered at all, and attendance by the remainder was considerably below the acceptable standard for settled children.<sup>16</sup> There are many reasons, apart from the obvious one of mobility, for the reluctance of Travellers to send their children to school, especially after they have passed primary school age. Some of the reasons are cultural, such as the tradition that from the age of about 12 the children need a family education to understand and take on roles and responsibilities within the family. Formal education still has little relevance to a culture that has always relied on practical skills and self employment. Often there is a fear about assimilation; that the children will not only be educated out of their culture but also that they may pick up different and unacceptable moral values. Parents are also often anxious about bullying and prejudice. Attendance is also affected by the need to participate in all the many cultural and religious events.

In addition, the 1996 Ofsted report points to mounting evidence that Gypsy and Traveller children are excluded from school in disproportionate numbers.<sup>16</sup> Mobility alone is clearly not the major factor, because Hawes reports that school attendance does not always improve when a family becomes housed.<sup>2</sup> In these situations, the family will often become more isolated and in many cases lose the support of specialist services.

Low immunisation uptake is often perceived as an issue arising from negative parental views.

However, most Travellers want their children to be immunised. There was a fear and consequent refusal of pertussis vaccination that persisted long after the publicity in the 1970s. Information in the community is largely passed on orally and received mainly from television. Therefore, professionals have an important role in dispelling myths and spending extra time in explaining medical matters clearly to a population with limited access to written information. The usual reason for low uptake is difficulty in access to services. The problems are compounded if the Traveller does not possess a record of immunisations received because they are not always able to recall their whereabouts when their different children were previously immunised. Many specialist health visitors carry out domiciliary immunisations to aid uptake.

No community is immune from child abuse and it must be acknowledged that abuse could more easily go undetected in the Traveller community. Traveller culture deems that they sort out problems without help or perceived interference from outside. There is historical distrust of social workers because many Gypsies and Travellers throughout Europe have lost children into care, usually because of lack of support for their lifestyle, rather than as a result of evidence of child abuse. However, Travellers view child abuse as totally abhorrent and most would claim that it does not exist within their culture. Most professionals working with Travellers would agree with Cemlyn<sup>17</sup> that there appears to be less evidence of child abuse in the very child-centred Traveller community than in the non-Traveller community. Travellers do tend to be strict disciplinarians but there is also a high level of physical affection within families.

Enlightened social services departments, such as Bromley, recognise the Traveller lifestyle and state that they take Traveller culture into consideration in their assessments and are careful to offer support. It is recognised that there is a strong cultural expectation that Travellers stay at home and learn their roles full time from early teens and girls in particular carry out domestic tasks and help rear their younger siblings from an early age.<sup>18</sup>

The issue of emotional security is paradoxical. On one level, babies and young children will rarely suffer from isolation or loneliness because of the company and affection from older siblings and cousins, as well as many adult relatives. Specialist health visitors for Travellers would rarely be consulted about the problem of crying, sleepless babies. Griffiths illustrates this with a quote from a mother about the best way to keep her baby amused: "just love it, kiss it, talk to it and cuddle it".<sup>19</sup> However, Griffiths and Arnold also point to children who do appear to suffer from emotional neglect, either because there have been too many siblings too quickly, or because mothers suffering from their own problems, such as domestic violence, deprivation and depression, are too absorbed in their problems to meet the emotional needs of their children.<sup>19</sup>

If there is a case of child abuse in a family it can be extraordinarily difficult for the child to alert a professional. They could justly perceive more disadvantages from bringing their plight to attention, in case they were ultimately separated from not only their parents but also their whole extended close family and culture. They would be unlikely to expect that the parents would accept outside support to enable positive change. Suspected child abuse, as in any situation, should be sensitively investigated and appropriate referral not avoided because of paradoxical anti-discriminatory values. However, if an appropriate referral has been made, it is important that involved professionals communicate and work together closely and maintain continuity if the family crosses departmental geographical boundaries.

The increasing pressures on the lifestyle of Travellers have already appeared to result in increased mental ill health and substance misuse, and consequently the issue of child protection is important. However, one important service that professionals can offer to children is to work to improve rights and conditions for their families; as Cemlyn points out: "welfare services have a role in counteracting neglect, including societal neglect".<sup>17</sup>

#### Access to health care

Poor access to health care is the almost universal experience of Travellers; inequality in the availability and use of health services in relation to need is in itself socially unjust and requires alleviation.<sup>20</sup> The alienation and discrimination experienced by Travellers is one of the most important factors influencing their health: "the central problem for the Traveller population in this country is the hostility of the settled population".<sup>13</sup> This hostility is expressed by all levels of society and is seemingly reinforced by successive government policies. The Criminal Justice and Public Order Act 1994 recently removed rights and introduced new penalties for travelling, thus effectively criminalising their nomadic way of life.<sup>22</sup>

The experience of trying to obtain health care can be extremely humiliating and rejecting. It increases stress and can cause a potentially serious delay in receiving appropriate treatment. Travellers often lack information about services, partly because of literacy problems. Many general practitioners will not have Travellers on their lists. A survey in East London showed that 10% of practices would not accept them at all.<sup>23</sup> Blatant prejudice about Travellers is evidently politically acceptable, although a similar policy about black patients would be treated as racial discrimination. Missed appointments are a frequent source of irritation to health care providers, but appointments might not be received when the family has no postal address or has been forced to move to another area. The situation has worsened since the introduction of the Criminal Justice and Public Order Act 1994. Travellers are now moved on much more quickly (often just by threat of enforcement), which adds to their problems in keeping medical appointments. Professionals are often reluctant to offer

further appointments even when the family want to attend. Travellers fear being detected too quickly by authorities because of the risk of eviction, so the first contact with health workers may be when a child has to be taken to the local hospital.

In some areas, where there are major difficulties, a salaried general practitioner approach is now being piloted for Travellers and homeless people. The obvious advantages are that the general practitioner is freed from financial concerns in meeting targets and can build up a trusting relationship with the Traveller community. Usually, the salaried general practitioner will have chosen to work with this group, as will the rest of the primary care team, and therefore be culturally sensitive and more readily understand their circumstances and concerns. Continuity of care will be more likely because of the trust engendered. It is also more likely that preventative services will be accepted because the surgery will be less likely to be seen as a “crisis only” venue. Although it can be reasonably argued that a Traveller specific service further reinforces the social exclusion of Travellers, until primary care services in general can more readily adapt to Travellers on their lists there will be a continued benefit in provision of salaried general practitioner services.

Other obstacles to provision of health care include different cultural attitudes to precise dates (including dates of birth) and time, and different perceptions of illness and treatment. In a study of Travellers’ perceptions and experiences of health, the concept of time figured frequently and was seen as an important issue.<sup>24</sup> Travellers generally appear to be under considerable pressure of time. The other pressures they experience, combined with lack of control in their lives, exacerbate this sense of urgency, which is hard to equate with an inflexible health care system. This is another factor that affects appointment keeping. Time spent with Travellers during consultation is viewed with as much importance as medicines.

Lack of access to medical records affects continuity of care, and the National Association of Health Workers with Travellers (NAHWT) is currently seeking government backing to launch and promote the use of a national client held record for Travellers.

### Health care provision for Travellers

What is needed to improve health for Traveller families? Health authorities should include Traveller health needs in their business plans, because special provision must be made to identify and meet the needs of this alienated and mobile population who regularly cross geographical boundaries. As with other minorities, the first essential is knowledge, understanding, and acceptance of their culture. This helps staff to overcome the various obstacles to health care and to deal with their own exasperation about the perceived lack of conformity in the Traveller community. The report on Traveller mothers and babies recommended that “because prejudice is fuelled by stereotyped images and misinformation” au-

thorities should provide specialist induction and in service training for all personnel working with Travellers and that “policies should be reviewed . . . to identify and eliminate discriminatory practices”.<sup>25</sup>

Community paediatricians can be helpful to families where there is a child with a chronic illness or disability. They can ensure that the parent is given copies of relevant letters and information about their condition to facilitate continuity of care when they travel. It is also helpful if fast tracking of appointments or some form of ready access can be arranged when a Traveller child moves into an area with an existing condition that requires follow up. Many such children experience long delays in obtaining replacement appointments. Some children will need multiple appointments with different disciplines; therefore, the paediatrician can help to coordinate the care by arranging for all appointments to take place on the one day. It is helpful to liaise with the health visitor who can remind parents of appointments. (Travellers who have never used calendars, diaries, etc can have difficulties with dates.) It is also helpful if the parent can be given the opportunity to contact the paediatrician directly by telephone if they are experiencing particular difficulties when away from the area.

In previous generations, traditional Travellers used to draw on herbal home remedies that had been handed down through the family. Many older Travellers can give examples of these remedies if asked, but my experience is that few actually use them today and that very few younger Travellers who have had greater contact with mainstream health care actually know the old recipes for herbal remedies. Ginety, however, found that Travellers in her research study still tried home remedies as a first resort.<sup>24</sup> However, more Irish Travellers, in particular, still tend to have great faith in “cures” from known “healers”. Many Travellers believe that there are certain people in the “settled community” who possess cures for specific conditions. “If there is anything seriously wrong we attend . . . there is a woman with the cure for epilepsy and a woman . . . who can take away the pains of burns leaving no scar.”<sup>24</sup> Despite their belief, many Travellers tend to use healers in conjunction with mainstream medicine today. I know of a Traveller who went to Ireland to seek a cure for a detached retina but still returned to keep his appointment with the ophthalmologist. Spiritual cures mediated by clergy and belief in healing as a result of going on pilgrimages to holy shrines such as Lourdes or Knock have also played an important role in the lives of Irish Travellers. Many attribute any health improvement to the power of prayer and healing.

Travellers need an advocate who can mediate between health professionals and other agencies on a local and national basis to ensure continuity of care. The traditional health visitor approach, driven by the professional agenda of preventative health care of young children and mothers, is often unsuccessful<sup>23</sup> and the Travellers’ concerns and problems

must be the starting point. Peck recognised this when she wrote: "I sometimes feel that I have lost my way as a health visitor, as the last thing a young Gypsy mother wants to hear about is preventive medicine or health education".<sup>26</sup>

The Traveller communities mistrust authority; an understandable attitude given their history of centuries of persecution and continued discrimination. They sometimes question the motives of those working with them—a sad reflection of the way that they expect to be viewed.

### Specialist health visitor

A good case can be made for a specialist health visitor and some districts have provided such posts since the early 1980s.<sup>4 17</sup> During the nineties, more posts have been created, although in many, the worker is expected to fulfil a poorly defined role in far too few hours. Although there is little documented evidence of the effectiveness of the role, Cemlyn comments that "the profile of health issues and health care rose very significantly" after a specialist health visitor was appointed in Avon.<sup>27</sup> A specialist health visitor can assess and respond to the needs of the large extended family. Knowledge of the family networks not only facilitates understanding but, because the worker will be visiting all the various households, she/he will find it easier to locate the family when they spend so much time in each others' homes. When trust is gained, more intimate health concerns will be discussed: "these women's confidences resulted from the specialist worker establishing 'street cred' as a person who was reliable and treated information confidentially".<sup>8</sup> More sensitive issues such as domestic violence, stress related and addictive behaviours, and many other health issues can be dealt with. The specialist health visitor, unlike the generic worker with a mixed caseload, is in a better position to undertake much needed community development work around such issues, and it is implicit in the role of the specialist that they work with the community and other agencies to deal with the wider factors affecting health, rather than purely working on an individual basis. Cemlyn emphasises the value of the "contribution of community development work in getting to know Gypsies and Travellers at an appropriate pace and in non-crisis situations, and supporting their communities on their own terms".<sup>28</sup>

A specialist health visitor can challenge policies that adversely affect the health of Travellers—for example, they can try to influence general practitioners who remove Travellers from their lists or refuse to take them on. Policy can be altered at national level—for example, by putting recommendations to the government on law reform concerning Travellers.<sup>13</sup> Inter agency forums should be established to coordinate policies affecting Travellers. Indeed, it is a specific recommendation in the recent Home Office "good practice guide on managing unauthorised camping" that health authorities and trusts, as well as local authorities, the police, and Gypsy

and Traveller organisations, should be involved in needs assessment, information gathering, and planning.<sup>29</sup> It would be beneficial for the local community paediatrician to be included in such forums.

An established network of health visitors would greatly improve continuity of care.<sup>30</sup> Each health authority should name a particular health visitor to have responsibility for the health care of Travellers within a district. A precedent has been established in the education system, whereby authorities are required to submit detailed bids describing the needs of Travellers in their area. The Department for Education centrally funds 65% of each authority Traveller education service budget.<sup>16</sup>

Specialist health visitors working with Travellers come under pressure to assume not only "health" tasks, such as mental health issues, but also those of other agencies such as housing or social services. This can lead to a dependency culture and dilute the health care input. "Ultimately a worker may become de-skilled and the Traveller receives only a second rate service."<sup>31</sup> However, as Cemlyn, who was employed as a specialist education welfare officer for Travellers, points out: "many other workers with Travellers also find themselves extending well beyond their professional boundaries".<sup>27</sup> Professional isolation is also a hazard "when the rest of the organisation offers little in the way of support, for example, as in not having policies which support their employees work".<sup>32</sup>

The health professionals working with Travellers need a clear remit and appropriate training and supervision. Opportunities for consultation with health colleagues, other agencies, and Travellers themselves are essential, to identify and to meet the health needs of this socially excluded community.

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### SCIDA

Geographical and ethnic variations in disease have an intrinsic fascination. Severe combined immune deficiency (SCID) with T and B cell lymphopenia is fairly common in groups of American Indians whose main common feature is a single language, Athabascan. They are, in the main, members of three tribes, Navajo and Apache in southwest USA and the Dogrib in northwest Canada. Their ancestors were hunter gatherers in the northwest some of whom began to migrate south in about the eighth century AD, the Navajo and Apache tribes forming in the 17th century. In these people the incidence of SCID is about 1 in 2000 births whereas in the US population as a whole it is around 1-2 per million live births. The SCID in Athabascan speakers (SCIDA) is autosomal recessive, the gene being on chromosome 10p. A peculiarity of this form seems to be presentation with oral and genital ulcers.

Over a period of 8½ years 12 children with SCIDA presented to a bone marrow transplant unit in San Francisco (Pearl C Kwong and colleagues. *Archives of Dermatology* 1999;135:927-31). Ten developed oral or genital ulcers or both before the age of 3 months. All had severe T and B cell lymphopenia. None of 21 children from non-Athabascan speaking families who presented with SCID during the same period had orogenital ulcers. The ulcers healed after successful marrow transplantation, T cell function apparently being more important than B cell.

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