Gypsy and Travellers health needs
Report for Healthwatch Cambridgeshire
Dr. Kate D'Arcy

The findings of this document have been summarised in the separate "Our Health Matters" report published by Healthwatch Cambridgeshire in March 2016.

Key findings:

- Most Travellers interviewed have complex medical needs and have experienced a range of different health issues.
- Outreach works well- specialist outreach workers are key in obtaining support and resources from support services. However, relying on specialist workers alone is not a sustainable solution and improved multi-agency working is necessary.
- Medical terminology and language is a barrier as terms and conditions are not explained fully.
- There is a poor flow of information to families about support services or take up of support independently (without outreach).
- Loneliness and isolation is an issue for older people.
- Most individuals interviewed only asked for help when they became desperate – this is frustrating when there is no response.

The project

The research to date has conducted interviews with 15 Gypsy and Travellers (included 1 male, 6 Irish Travellers and 9 Gypsy/Roma) across Cambridgeshire.

Interviews with Travellers were facilitated via gatekeepers working as Health outreach workers specifically within the Traveller community. Gatekeepers asked those they visited if they would be willing to talk about their health issues and needs, and consequently there was not a direct approach to involve those with particularly complex health needs. Nevertheless, all interviewed had a variety of health issues affecting themselves and their families.

Although the sample is small it substantiates the research which highlights poor health outcomes for these communities. The life expectancy of the Gypsy and Traveller populations has been estimated to be between 10 and 12 years less than the general population. Parry (2004) produced the only nation-wide health study conducted on Gypsies and Travellers health and found that they were significantly more likely to have an enduring condition, suffer poorer health and experience an earlier death than the general population and their infant mortality rate is three times higher than the national average. They are also significantly more likely to have a long-term illness or disability than members of the general population, over twice as likely to be depressed, and almost three times as likely to suffer from anxiety (Lane et al,2014).

Complex medical needs and issues were common in discussing about individual's own health care and their families. Loneliness and isolation was a real issue for older people living on sites and in housing, but more so in housing as they are less visible.

Overall it was very clear that there was a poor flow of information reaching Traveller people which also affected the support they received and the reporting they do. Those with diagnoses and in need of support had often suffered for a long time without relevant support services; this tended only to be alleviated through the help of the outreach worker.

Support, Information and Medical Language

Information individuals did receive from mainstream services (doctors and hospitals) often used medical terms which people found unclear. In one case, a research participant had to research her condition on the Internet, only to find out it was a form of cancer and then had to deal with processing this information herself. No-one interviewed was able to name or suggest services that could help with depression or violence, other than reporting to the police or telling the outreach worker.

In discussions about health and health needs there was a sense that Travellers want to be seen as strong and able to manage and only ask for help when they are really desperate. Research about health-related beliefs among Traveller communities (Cleemput et al, 2007) confirms this:

> Stoicism and self-reliance were specific beliefs that were described as intrinsic for Gypsies and Travellers, arising from their experience of adversity and portrayed as necessary for survival. They were associated with the understatement of chronic ill health, commonly expressed as being tough and not admitting or succumbing to minor health complaints.

People do only ask for help when they are desperate – this can lead to frustration if there is no response at this point, which is reflected in the quote below:

> I don't feel well at all. When I go to doctors, I have to keep waiting. I missed 2 appointments because I have been so sick. I then went to make a new appointment and they tell me they have none. They don't understand how much pain I am in. I cannot get up to doctors I said. She said you have a review for your lungs but you might not be able to get a general appointment until July if you don't phone by 2.30. This is what I am saying – you could be dead here! Some days I do not even wash- I do not go out of the caravan here. Not to the shop. I went to Primark and my legs just gave way. I could not stand. Collapsed.

This research participant had a range of serious medical conditions and also spoke of her isolation and depressive episodes. Multiple health needs are referred to as 'complex multimorbidity' in the health field. Multimorbidity is defined by having 2 or more disorders and is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. The 15 research participants were not selected for these reasons, but they did all have a range of health issues, thus findings support the research that indicates Travellers' health issues are severe.

> *"My life is a health issue..I have that many things wrong with me I would not know where to start! Every time I go to the doctor I have more."*

Issues were related to the particular condition of their health and basic challenges like collecting medication. One lady explained that she needed to take regular medication and has a nebuliser at home. Obtaining her medication from the local chemists could be an issue as it was too far to walk (five5 miles) and she did not drive.

> "Sometimes my medication is up there (chemist) for two - three days before I can get it. If not raining someone like my daughter will walk up with her little girls. Not too bad in summer – but winter not easy. Winter is bad."

Within families there were health consequences for those who were caring for example becoming anaemic due to the heavy caring workload:

> When he is restless…for example - 3 nights ago I heard a noise and he had gone from his bed – [she found him outside on the ground, he had grazed his back open].

There was no toilet in the home so everyone had to go outside. The family eventually received funding to get a toilet put in but needed to organise someone to fit it, which was taking a long time.

Low literacy levels among the adult Traveller population (Equality and Human Rights commission, 2010) are an issue for awareness raising, engagement in health consultations and taking medication and understanding conditions and medical diagnosis. Where there was no access to 'readers' in the family or close-by, people relied on chemists or doctors to explain medication; they would use colour or package size coding to organise what needed to be taken when and felt a huge sense of responsibility about medication when caring for others.

Getting doctors' appointments was a regular complaint, although many were happy with general health services some people felt they were discriminated against because they were a Traveller or because they could not access new technologies. For example, on-line booking of appointments or using text messages when they could not use these technologies.

One woman had been waiting for 6 months for an operation on her shoulder:

> *"I don't think we get a fair crack of the whip…Travelling people…we get a worse service, there seems to be one rule for them and one for us."*

When asked if she wanted to complain, or knew how to, she reported that she was learning to read and write to do just that. Critical questions were being asked on one site where it had been noted by several families that when they called for doctors' appointments they were often refused, however if the outreach worker called on their behalf they were successful.

Thus basic practicalities and additional needs often added to the stress and workload of caring for others. Outreach workers played a vital role in accessing support for minor and serious medical conditions and needs – arranging operations, helping secure referrals to other services to check on peg-feeds or catheter and driving people to appointments at the dentist, doctor or hospital.

Outreach

Outreach has traditionally been the way to engage hard to reach groups, as services recognise that an 'open door' policy will not draw them in. Save the Children (2007) confirm that there is evidence of Gypsy, Roma and Traveller families remaining excluded from many mainstream services and opportunities, particularly health and education services. They explain:

> an 'open door' policy in itself is not enough: an institution or system and the service it provides is in effect closed to anyone who does not know it and has no relationship with it (p.3).

Carr (2011) undertook research into the effectiveness and cost effectiveness of outreach programmes in improving the health of Traveller communities. Outreach was incorporated in this research to engage with different research participants. Carr found that outreach is a trust-building exercise which can ultimately improve participation in services. Developing the relationships is time consuming and not necessarily cost-effective, nevertheless the process demonstrates services' commitment and reliability and can in the longer term ensure that interventions are implemented effectively and can build capacity with and in communities. Interventions can also change attitudes and awareness of specific issues within the community. Carr's study reported on one project which addressed domestic violence, long-established relationships within the Traveller community facilitated engagement on a sensitive topic and contributed to building capacity in the community, and to developing social capital.

Unfortunately, this is not common practice across all services. Moreover, specialist outreach takes up a large amount of time per patient meaning that workers cannot cover everyone who needs help. Mainstream services are required to work alongside specialists in order to ensure a regular flow of communication and service provision for the whole community.

Observing general health access and service provision highlighted the poor communication flow between Travellers and mainstream services. Information from services is not being received by Travellers and their voices are not being heard by services. It can be proposed therefore that if individuals have difficulty accessing support for general conditions that their confidence in reporting more complex issues and seeking support for themselves for depression or domestic violence is limited.

Sensitive subjects

Interviews with Travellers were loosely structured on access and experiences of mainstream and specific services, their own health needs and their families' needs. Scenarios about depression, pregnancy and domestic violence were described to gain an idea about Travellers' understanding of available support for sensitive issues. Findings suggest that most Traveller women were open to such discussions but once again it was very clear that they had limited information about wider support services and who they should go to with mental health issues and domestic violence other than the police and their doctor.

A mother was seriously worried about her youngest daughter's mental health and she described a range of obsessive compulsive behaviours. Mum finally got a family worker to support after asking for 5 years. However, she is worried that this is not enough as she feels she needs specific medical attention for her disorders. As three out of four of her older siblings have had similar issues she wanted support early to avoid the problems this had led for her older children – exclusions from school and involvement in crime. The daughter is in school but they do not seem to have offered support.

Conclusion

This report has documented just a few of the health needs and issues found among a small sample of Traveller families across different areas of Cambridgeshire. Findings reveal that health issues for Travellers are significant and that there is a lack of support and information for their needs. As marginalized communities they should be a priority, yet it seems that many are highly reliant on specific outreach workers, rather than mainstream services.

This research process opened up discussions with service users to collect important information on prevalence and need, will be of interest to a range specific and general health providers and support services. Today services are delivered on evidence-based need. Without accurate information about Traveller families and the issues they experience service provision will simply not be made available. Further research is needed to gain a better understanding of Travellers needs across Cambridgeshire.

Our existing approach had started with data collection and this will be used to formulate appropriate interventions and develop and evaluate these with Traveller and Roma communities themselves. Responding to the issues raised in this report requires no miracle; but it does require us to take the needs of Travellers seriously. Travellers represent communities who already have the poorest outcomes and this should no longer be allowed to continue.

References

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