



Hello Everyone. I'm Helen, I'm nearly 50 and I live in a small West Yorkshire town in an old bungalow with my daughter and two grandsons. My major health issue is a 'female problem' so I won't go into details in this mixed company.

If I had a magic wand? I would change the system that relies on me being able to attend at the GPs and explain my problems to a person I see less than twice a year. In the current system, I wait until things are really bad before I will go to my GP 'list-holder' and I always come away feeling embarrassed and that the problem has not really gone away. I feel that the GP is there to stop me seeing consultants or other experts for as long as possible (in order to keep practice costs down). This is a very common experience and I believe it is extremely counterproductive.

By the time I finally got to see a consultant my condition was much worse than it had been the first time I spoke to the GP, and beyond the point where physiotherapy could make much difference (which I am told it could have if I had been given specialist advice much sooner). Indeed the consultant was upset, if not surprised, by how long I had endured the condition rather than return to the GP.

So my magic wand is that rather than having access to only one generalist 'gateway to care', I wish I could have been directed to people, be that lay people or clinicians, who had specific experience of my particular problem and to who I could chat regularly and easily (by skype perhaps?). Perhaps then, I may not have kept quiet about my problem for so long, as it quietly got worse and worse. I understand that I needed encouragement as much as I needed a



‘gateway’ diagnosis, and indeed, as I will live with this condition for the rest of my life, I still do.

So here we are at the end of a three year project. I want to begin by thanking Friends Families and Travellers, our partners in this project, for sharing this journey with us, for sharing the break-throughs and the frustrations, and for the excellent work they have done along the way.

In 2012 we were at the beginning of a journey into the new health architecture created by the Health and Social Care Act. I’m not going to tire my audience by going through a list of our activities as part of the project, you can read about them in the report in your packs, or by visiting the Leeds GATE website. I want to get straight to what we have learned since then.

As Jessica points out - health inequity costs everyone, not just, as we have described it here, those at the margins, although in personal terms they may well pay the highest price. People who live ‘at the margins’, be that due to ethnic or gender identity, homelessness or other vulnerability, are excluded in many ways but they are rarely helpless. They wouldn’t survive if they were. Indeed people develop excellent strategies of their own to support health, which whilst perhaps not always recommended (sharing prescription tablets for example), absolutely are the best response available to the circumstances they find themselves in, and, whilst we may be in a position to offer help, their experience and judgement must be respected.

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February 2015



The 2011 ONS census, the first ever to include an ethnicity category for Gypsies and Travellers, found that 50% more Gypsy and Traveller people, proportionally compared to the rest of the population, provide 50+ hours of unpaid care to family members. Imagine the financial value of all that care? Our cost benefit analysis work, 'Gypsy and Traveller Health – Who Pays?', clearly indicated that small adjustments, especially in bringing support closer to home, for example via outreach, can lead to huge savings further downstream. I think everyone in this room probably knows that is likely to be the case even without reading our report, although of course I recommend that you do.

Indeed a really significant feature of this new health architecture is the duties it has placed on the secretary of state for health and other bodies, to ensure reducing health inequalities. Easier said than done of course but there is increasing consensus as to how best this might be achieved. Hence the significant encouragement towards 'people powered solutions' and towards co-producing services based on a dialogue of equals where the patient/carer voice is regarded as expert, for example in the Five Year Forward View which Olivia has been speaking about.

I first heard of people powered health via the wonders of twitter just about three years ago. I was almost evangelical with excitement about how these different approaches, condition groups, personal health budgets, and especially the role of 'care navigators' would be able to support and improve healthcare access and outcomes for our Gypsy and Traveller community members. I write funding bids, I rattle on to colleagues at NHS England, local public health specialists

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and to emerging contacts within the CCGs. As yet to no avail. However, during this time I have watched a plethora of navigator roles emerging, most notably the London Pathway projects for homeless people aimed, very successfully I believe, at reducing hospital readmissions. Sadly tho, apart from this example, most of these new roles appear to be generic, not specialist according to the known vulnerabilities of certain 'Inclusion Health' groups. In fact I would say that some of these new roles are not really 'people powered' at all. And now money for projects is just tighter and tighter. Existing services are reducing and our Health and Wellbeing Board and CCG colleagues throw their hands in the air at the idea of finding 'new money for brand new services' which would appear to be likely to benefit small, often comparatively tiny, populations. I fear we are in grave danger of missing the boat once again.

I believe this is a short sighted approach which dooms us to continuing health inequalities. And, as we have heard from Dr Connolly we aren't alone in this belief. Our experience is very much that innovative solutions for any given 'marginal' group, are likely to have benefit, for others such as via developing good practice. Indeed there is often benefit for those of us who may not actually regard ourselves as marginal. One example of this might be the information from RCGP which states that, if you include health 'numeracy', 61% of us are not functionally health literate. That's 61% of all of us. So, health information which is suitable for illiterate or semi-literate people, or where English is not the first language, is actually of considerable benefit to all of us, as are actions which challenge



clinicians sometimes indiscriminate use of exclusive, in-group, language.

During the lifetime of this project we have developed our understanding of how small changes of statutory approaches to vulnerable groups and, where they exist, to their trusted organisations, can have really significant impact on cost effectiveness. After all people don't chose to be 'on the margins' of our society. They are either born there, or they are pushed their by circumstances during their life course. If we really want to break down health inequality, it is time that those with power, those in the privileged 39% of people who are 'health literate', accept that those on the margins are not witless, in fact they often do incredibly well with what little they have.

I will go further, and say that until we start to view our marginal communities, and all the individuals within them, as having just the assets we need to improve health outcomes, we will get nowhere. Trust goes both ways. It's all very well suggesting that we patients should trust the professionals to know what is right for us (ie please don't share your painkillers), but it is high time that the professionals, the GPs, the Commissioners, Ministers and decision makers, trusted, and invested, in us. I call specifically on budget holders to be bold, to stop expending resources in the same old places, on the nearest and dearest. If health innovation can work on the margins, it can work nearer into the cosy middle of our 39% too. How will you know? By trusting marginalised people to know what they need. If good practice can work at the margins, it can work everywhere, but you won't know that unless you try.

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But. What does trusting us mean? Does it mean that you will trust us if we can mirror your assets? If we can fill a form in just as you imagined it should be done? If we can read and understand page after page of contract? Does it mean trusting us to hear about your commission or funding pot? I don't think it should mean that. I can fill a form in, but what I'm really good at is bringing people together and inspiring them. We have very effective and open financial procedures, but that isn't what we are best at. Trusting us doesn't mean that we can 'be like you', you need to trust us exactly because we are not like you. Don't rely on marginal people to be where you are, to know what you know. Commissioners need to learn to seek out difference, like attracts like, you won't find marginal people in your comfort zone.

If only we could really have the courage to do what Professor Sir Marmot has suggested, ie target our resources in greater proportion to those at the margins, and if we can deliver on the NHSE 5 year forward view by really trusting and investing in the expertise, and difference, of marginalised people, we could genuinely change the health landscape for everyone and I urge everyone here to do what they can in making this a reality, for all our sakes.