



FFT report commissioned
by Healthwatch Brighton

Hidden Incontinence

Urinary Tract Infections and Bowel Problems
in the Traveller Communities
in Brighton and Hove

Report compiled by Michelle Gavin Friends Families and Travellers





INTRODUCTION

Friends, Families and Travellers (FFT) is a lead organisation seeking to address the problems facing the Gypsy and Traveller communities, providing advice and information along with a wide range of other services to Gypsies and Travellers nationwide.

.....

FFT is the only national charity (registered charity no.1112326) which works on behalf of all Gypsies and Travellers regardless of ethnicity, culture or background. FFT is also a non-profit making company limited by guarantee (no. 3597515).

.....

FFT works nationally and for this project worked solely with Travellers within Brighton & Hove City - whether they are resorting to or residing in Brighton & Hove.

.....



BACKGROUND TO REPORT

This report was commissioned following the findings of a previous report which was conducted during the period July - September 2013, where 44 individuals from the Gypsy and Traveller community were interviewed and responded to an FFT questionnaire on Urgent Care services in Brighton and Hove for the CCG.

The engagement methods used were assertive outreach (site visit), FFT office drop in, telephone (housed clients who are known to FFT) and a visit to the Transit Site visit using the Health Bus.

Notably, the survey flagged up three key areas of health which could be greatly improved and targeted for additional work. One of these, bladder and bowel issues, was highlighted as a particular problem for community members. Upon speaking to those interviewed it was found that 24 interviewees out of the 44 surveyed were suffering with bowel and kidney problems, resulting in incontinence for a significant number of interviewees. 17 of the 24 people within this group were living on sites.

Ethnic Origin	Numbers suffering from bladder and kidney problems
Romany Gypsy	6
Irish Traveller	6
New Traveller	12

The issues identified were as follows:

Health Problem	Numbers who flagged this as an issue and age range			
	18-22	23-39	40+	Total
Bladder Problems	8	10	6	24
Bowel Problems	3	8	7	18
Total	11	18	13	42

The results of the original survey showed that there were 42 separate health incidents among 25 individuals. FFT wanted to see if there was any correlation between the initial high levels of health related issues of bowel/bladder problems/incontinence and lack of accessible sanitation and toilet facilities on unauthorised sites.

BACKGROUND TO DEMOGRAPHICS.

The reduced differences in life expectancy and healthy life expectancy for people within the Travelling Community are well documented in national research. Even after controlling for socio-economic status and comparing to other marginalised groups, Gypsies and Travellers have worse health than others: 38 % of a sample of 260 Gypsies and Travellers had a long-term illness, compared with 26% of age and sex matched comparators. (Sheffield report Parry et al., 2004)

Within the City of Brighton & Hove a snapshot report from Jobcentre plus (28 May 2013) states that Gypsy or Irish Travellers had unemployment rates of at least twice the City average at 15.3%. Furthermore, these figures worsen when looking specifically at male unemployment where 8% of White/UK/British men are unemployed compared with 23% of Gypsy or Irish Traveller men.

<http://bmecp.org.uk/wp-content/uploads/BME-Communities-Snapshot-report-final.pdf>

Additionally, economically inactive people - who are not seeking, or available for, work within Brighton & Hove City, mirror the national average - with a large proportion of this group citing student status as a reason for this. However for Gypsies and Travellers in Brighton & Hove, being long term sick or disabled (31 % female and 41 % male) is a significant contributory factor.

<http://bmecp.org.uk/wp-content/uploads/BME-Communities-Snapshot-report-final.pdf>

Brighton and Hove City has no permanent Travellers Site at present. A permanent site is currently in course of development which will house 12 families, and this is scheduled to be operational by June 1016.

The transit site at Horsdean is temporarily closed for Traveller families because access is required to carry out the building works for the new site. The transit site has a capacity for 21 pitches and can be used by Travellers for a maximum of three months before they are required to leave as per the terms of their license. These Travellers may not re-enter before another three month period has passed.



METHODOLOGY FOR SECOND IN-DEPTH REPORT ON BLADDER AND BOWEL PROBLEMS WITHIN THE GYPSY AND TRAVELLER COMMUNITY.

The evidence collected has been gathered during the period of October - November 2015 and used various methods of data collection:

- Bespoke questionnaire
- Telephone interviews
- 1:1 interviews
- Assertive outreach/site visits
- Focus Group discussion

The majority of those interviewed were contacted during assertive outreach on unauthorised encampments, knocking trailer doors. This method allowed FFT to collect data from those resorting to Brighton & Hove in addition to those residing. FFT also contacted local Gypsies and Travellers to conduct telephone interviews - these were established clients from FFT’s database, enabling the survey to include clients living in bricks and mortar accommodation. General notes were made during the focus group discussion, which was facilitated by FFT. Gypsies and Travellers would be highly unlikely to respond to online surveys or paper surveys without the assistance of a peer interviewer or known outreach worker due to literacy problems, lack of internet access and trust issues.

Demographic profile

The following table shows the profile of the 34 respondents broken down by ethnicity and gender.

Ethnic Origin	Numbers Surveyed and Gender	
	Male	Female
Romany Gypsy	2	5
Irish Traveller	1	12
New Traveller	4	8
Welsh Traveller	1	1
Total	8	26

In terms of tenure, 12 people were living in bricks and mortar, 3 were on a private site and 19 were on unauthorised encampments.

27 out of the 34 were resident around the Brighton area, with the remaining 7 resorting to Brighton and Hove for various reasons.

The 34 respondents reported an extensive range of bladder, bowel and kidney problems as well as a high incidence of urine infections. In fact all seven interviewees in the 18 - 22 age range reported that they had experienced urine infections.

Health Problems reported	Age range			Total
	18-22	23-39	40+	
Total respondents	7	13	14	34
Reporting bladder problems	2	6	10	18
Reporting bowel problems	0	4	10	14
Reporting kidney problems	3	5	10	18
Reporting urine infections	7	10	9	26

Although the figures in the above table undoubtedly include an element of double counting due to the interconnectedness of the data, the overall picture is clearly one which demonstrates a startlingly high prevalence of bladder, bowel and kidney problems within the travelling communities.

By way of additional background information, 31 of the 34 respondents were registered with a GP, 18 had accessed medical assistance via Accident and Emergency services, 15 had been referred to specialist services and 16 were using medical aids or medication directly related to bladder, bowel and kidney problems at the time of the survey.



Impact on mood and self esteem

16 of the 34 respondents reported a low general mood and eight reported poor self-esteem. 15 reported that their medical condition impacted adversely on their personal life with 12 reporting mental health issues or 'bad nerves'. 17 reported that it affected their night time and sleep pattern.

Impact on lifestyle

Nine of the 12 respondents living in bricks and mortar reported that they had moved into fixed housing because of health related issues. 30 of the 34 respondents had lived in caravan accommodation with no access to sanitation or toilet facilities.

19 of the respondents had reduced their fluid intake because of their medical condition, 16 had made dietary changes and 14 stated that they suffer from constipation.

22 respondents (all of those not living in bricks and mortar) reported having to make use of toilets in petrol stations and supermarkets and 19 referred to the need to 'hold on and wait' for excessive periods of time. 16 talked of the need for careful planning of their day and night.

Nine respondents reported that their medical condition had affected their ability to work and eight of these were in receipt of Employment Support Allowance.

'This is the first time I have spoken about this to anyone. I am too embarrassed. You don't feel like anyone else would understand.'

'Yes I have lived on unauthorised sites with no toilet and I would dig latrines. However my health became so bad an FFT support worker registered me with a GP and advocated for me with the doctor. I have bowel bladder and kidney problems and now I live in a flat. I miss my community but my health was so bad I would not have lasted another winter.'

'I have been put on a drip with anti-biotics loads of times and I am only 22 years old. More toilets please!'

Comments from the questionnaires

Some of the richest and most insightful information in this survey comes not from the quantitative data but from the comments made by respondents in completing the questionnaires. Many of these comments are reproduced in full below.

'It is very difficult living on the roadside when you have IBS.' 54 year old man.

'I moved back to bricks and mortar after several years on the road and all my bladder and constipation problems went away. I really appreciate that I have a toilet - although I miss the community living.'

'My 14 year old daughter suffered terribly with urine infections. One time we used the walk in clinic and she was sent to hospital. She had a kidney infection. It becomes normal.'

'Sometimes places are funny about you using the toilets. It is very hard and difficult for kids.'

'Ten urine infections in the last year - regular anti-biotics every couple of months and I am always constipated. I live on the roadside and I am 28 years old.'

'I just thought I had a small bladder and didn't realise it was to do with my living environment. I needed to go frequently and couldn't 'hold on' this would affect me. I didn't seek medical advice because I didn't see it as a medical problem. I have had accidents and this is extremely embarrassing.' New Traveller woman.

'It is ten times worse for pregnant women. I have been on antibiotics all my life - they don't work anymore.' 20 year old Irish Traveller

'I hadn't realised how my health had been affected by these issues till I answered the questions here. I had just got used to the gradual changes'

'My daughter is now with the kidney specialist at Great Ormond Street'

'Since moving into bricks and mortar I have appreciated the facilities- however I now feel trapped and depressed. I miss living on site.' Male 50 years old



'I have been admitted to hospital many times to A and E because of severe kidney infections. This has been ongoing since I was 8 years old. I was first referred at 8 years to renal specialist at children's hospital.'

'We were stopped from using the public toilets at one site. I was too frightened to drink too much if I was on site with nowhere to go to the loo. I didn't drink enough at school which made my urine very strong. I have spent my whole life 'holding on' and now I have problems with my bowel. I have so many notes and files in my medical records about my kidneys. I worry just how bad I will be when I am older. I think the damage is done. Even though I live in a house now I still get infections very easily.' 22 year old woman

'I am very careful about drinking too much fluid. I drink cider vinegar for my kidneys.'

'I have been blocked from using public toilets all over the country. Petrol stations are the worse - one even put a no Travellers sign on its toilets.'

'Let us pay for portaloos!'

Addressing the problems

The survey asked respondents how they thought the local authority and CCG could help improve these health conditions within the Gypsy and Traveller communities.

Overwhelmingly, everybody who responded agreed that portaloos facilities should be offered on unauthorised encampments. A large proportion of respondents agreed that local authorities should ensure that nearby public toilets should be unlocked.

There were many comments which stated that provision should be made to build more permanent and transit sites - also to allow more private sites planning permission or encourage self-build schemes.

More authorised sites are required where toilet facilities can be provided - or 'tolerated' sites where portaloos could be provided. Where long term toleration is offered, compost toilets could be built.

Conclusions

The statistics from the questionnaire show that 88% of respondents had lived in caravan accommodation with no facilities at some point in their lives.

Of these 64% said it had affected the amount of fluids that they took.

70% said they suffered with anxiety/depression.

60% said they had been admitted to A and E services due to related bladder/urinary tract/kidney problems

84% said they had suffered with urinary tract issues

50% had been referred to a specialist

56% said it affected their night time sleep pattern.

This small snapshot indicates a clear correlation between issues surrounding hidden Traveller incontinence and lack of accessible sanitary facilities.

We believe that local authorities should work with Public Health and CCGs to fund basic toilet provision to unauthorised encampments. They should use the arguments of cost benefit analyses and savings to NHS/LA budgets working towards integrated care models (see Appendix 5).

Local authorities should look at more appropriate ways to minimise health related issues with Travellers who are encamped on public land through longer toleration and provision of portaloos.

Further work should be done on the promotion of good healthy bowel and bladder health to the Gypsy and Traveller communities through commissioning a targeted piece of work on this subject.

Underpinning the success of such initiatives is the overriding imperative of more site provision to meet the acknowledged national shortfall, both in the private and in the socially rented sectors.



APPENDICES

.....
Appendix 1 - Details of focus group meeting
.....

Appendix 2 - Human Right to water and sanitation
.....

Appendix 3 - The impact of lack of sanitation on young children
.....

Appendix 4 - Long term problems resulting from urinary tract infections
.....

Appendix 5 - At What Cost? A cost-benefit analysis pathway
.....

Appendix 1
FOCUS GROUP MEETING HELD IN NOVEMBER 2015

FFT facilitated a focus group on ‘Hidden Incontinence in the Traveller Community; Bladder and Bowel care’ in November 2015. The group was also an opportunity for FFT to introduce Healthwatch to community members. The group was attended by 10 Travellers, comprising six New Travellers, one Welsh Traveller, two Irish Travellers and one Romany Gypsy. Five of the participants were in the age range 18-24, one was 24-39 and four were 40+.

.....
Magda from Healthwatch addressed the group and gave a presentation about the work which Healthwatch does both locally and nationally. None of the attendees had heard of Healthwatch and were very interested in the role that Healthwatch plays within the health sector. Magda answered many questions in a question and answer session. She was asked how people could be supported when making a complaint and how much support people could expect. She was asked about recent findings from the Quality Care Commission, about Healthwatch on the Health and Wellbeing board, about GP surgeries and the use of 111 services, and about A and E statistics. All the group were very interested in Healthwatch and several said that they would be in touch to feed intelligence to Magda - particularly around poor service through 111. All the attendees were given the latest hard copy of the Healthwatch magazine and other handouts.
.....



Focus group discussion

Note that the participants are referred to by their initials to preserve anonymity.

The group began by discussing how many people had lived or were living in caravan accommodation on unauthorised sites. From here we had a raise of hands as to whether any of us had experienced problems with urinary tract infections, kidney infection or bowel problems. Straight away everybody who was present agreed that they had all had issues with bladder problems and the entire group had experienced urine infections.

SA explained that she had been hospitalised on 4 occasions within 2 years - using A and E emergency care services. She had on each occasion been given intravenous drips and antibiotic medication intravenously. All stays had resulted in overnight care before she was deemed well enough to return home. On no occasion did any health operatives ask or enquire what she thought have caused the emergency admissions. She said that she had never been asked about why she was suffering from kidney infections and the constant urine infections that she suffered.

KP an English Gypsy with 7 children and 16 grandchildren explained that she was currently encamped on a car park with her daughter (who was sitting next to her) Her 17 year old daughter **ED** - was 4 months pregnant. They were also being evicted. She explained that her daughter's first baby is due in April and that it is extremely unsettling for her to be moved so often from pillar to post by the Local authority. **KP** explained that **ED** had been taken into hospital twice already with issues around the pregnancy. The second time she was taken in (a few days before) she was found to be dehydrated, placed on a ward and given rehydration drips until she was deemed fit. She was released at 2am in the morning from the ward.

MG explained that this was not unusual and that many Travellers suffered with similar issues if they were 'roadsiders' living on unauthorised encampments with no access to running water or toilet facilities.

MG went on to explain that this will often result in many women not drinking enough fluids when pregnant because they were not close to any public facilities and when pregnant it is very much harder to 'hold on' when the baby is pressing on the bladder etc. **MG** explained that some Local authorities will provide a portaloos on unauthorised encampments at the last trimester of pregnancy.

ED agreed that it was difficult keeping hydrated because she was not in an area close to a public toilet - and the toilet nearby at the petrol station had been out of order.

SA explained that she had been given a toilet on an unauthorised site but when the camp had been evicted and moved on to another site the local authority did not deliver another toilet because they could not get access down the track and would not place the portaloos at the end of the track for use. She went on to add that for the last few weeks of her pregnancy she had no toilet on site at all.

Everyone agreed that at some point when they had been on the roadside they had all experienced or knew other Travellers who had experienced issues around need to use toilet facilities and how it had impacted throughout the pregnancy.

Everybody agreed that there were not enough public facilities in accessible places. **KP** said that most sites were miles away from a public loo and that it was completely normal to 'hold on' to your urine for an unnaturally long time. If the weather was bad and you were stuck on site without being able to get off the track because of the mud or ice, then you were unable to do anything.

Everybody had experienced prejudice when using facilities other than local authority loos. Four people stated that petrol stations were the worst. They said that when they were encamped close to petrol stations with facilities it was not unusual for the toilets to be 'closed' or locked. One Traveller was a regular customer of one petrol station and said that she used the toilets regularly - however when her family and others moved to a nearby piece of public land the toilets were immediately shut - until they had moved off and then they were reopened.

SA said that she had suffered with lots of water infections during her life. She had been born on site and they became part of your life - you got used to them. **EB** said that using public toilets put you at higher risk of getting an infection as so many people used them and it was hard not to get 'splash back' which is known to be a cause of urinary tract infections in women (e-coli).



Another woman said that she had known someone who had become incontinent and was so ashamed because she no longer felt like anybody in the community. She had been referred to the incontinence service in Lewes and had been given pads. The woman was so ashamed that it impacted on her mental health and she became so anxious and depressed that she 'went into herself and her nerves went against her'.

GC said that people still didn't like to talk about it - but it was on everybody's minds all the time. If you were living on site your whole day would be taken up with opportunities to use the bathroom or you would plan to go and dig a hole when it was pitch black and nobody was around.

MG asked the group if they felt this was a safety issue for women as well. She went on to add that in other countries like India, in rural locations, young women were prey to sexual assault when they left the immediate home to look for a place to go to the toilet in the fields.

Some of the women from the New Traveller community recounted stories where they felt they had been watched and felt vulnerable. A fairly recent account from a woman known to the community was spoken about - she had caught somebody watching her. It had consequences for both the woman and the alleged perpetrator. The woman felt very unsafe and violated and the other was from the community and had to leave immediately for fear of reprisals.

We concluded the discussion by thinking about how everyone felt about the problems related to lack of toilet provision. EB summed up feelings by saying that it just becomes normal and you work your whole day out around going to the loo something that a majority of people who live in bricks and mortar don't even give a second thought to. Incontinence and bowel and bladder related issues are not freely spoken about. People cite embarrassment and feel uncomfortable about openly talking publically about such issues and many will not speak with close relative and friends let alone health professionals.

Toolkit resources for the focus group:

<https://www.bladderandbowelfoundation.org/wp-content/uploads/2015/07/Healthy-Drinking-25-03-15-No-guides.pdf>

Appendix 2

A HUMAN RIGHT TO ACCESS WATER AND SAFE SANITATION

Gypsy and Travellers from a traditional and cultural background will rarely use toilet facilities inside their homes - there are strict rules of cleanliness which require Travellers to adhere to codes of sanitary standards and practices within the home. The customs are known as 'mochadi' (ritually unclean) as opposed to 'chikli' (merely dusty or acceptably dirty). For instance it is 'mochadi' to have a toilet in a caravan where food is prepared or to wash one's body in a bowl for washing. Within the New Traveller community similar rules apply and a majority of trailers or trucks are 'dry' (no water facilities, plumbing or toilets). New Travellers will also use public facilities - however New Traveller will seek sites near wooded areas or quiet private spots where they can dig latrines and bury faeces. This practice is normal for New Travellers who are encamped upon unauthorised pieces of land. Travellers who are on licensed private land or tolerated land will often build compost toilets which adhere to the eco principles of the community.

In 2010, the United Nations General Assembly and the Human Rights Council recognised clean drinking water and safe sanitation to be a human right essential to the full enjoyment of life and all other human rights.

Declaring that access to sanitation and water is a human right constitutes an important step towards making it a reality for everyone. It means that:

- Access to basic sanitation and safe water is an entitlement, rather than a commodity or a service provided on a charitable basis.
- Progress on access to basic sanitation must be accelerated.
- Efforts should focus on those least served, including the hardest to reach and most vulnerable.
- Communities and vulnerable groups need to be empowered and engaged in decision making processes.

Sanitation services need to be sustainable and affordable for all. People are expected to contribute financially or otherwise to the extent that they can.

Appendix 3

THE IMPACT OF LACK OF SANITATION ON YOUNG CHILDREN

FFT outreach workers have noted that young children will often wear nappies for a longer period than other children in their age cohort- this is anecdotal and something which FFT outreach workers have noted purely in families living on unauthorised encampments. It would seem that there is a natural correlation between this and the perceptions that when on unauthorised encampments it can be much harder to toilet train a child who has no immediate access to a toilet. Children should not have to 'hold on' until they are able to access a public toilet- particularly if it is many miles /minutes away. Some families will not have access to a car/van during the day, particularly if the vehicle is being used for work purposes and will not arrive back on site until the evening.

Net cost of urine testing

Urine testing	Unit cost £	number of patients current	Current costs (£000s)	Proposed number of patients	Proposed costs (£000s)	CHANGE Numbers of patients	CHANGE Costs (£000s)
Nitrate Test only	£0.13	41,221	5				
Microscopy only	£8.00	12,366	99				
Culture only	£8.00	12,366	99				
Culture and Microscopy	£16.00	267,937	4,287				
Nitrite and culture	£8.13	4,122	34				
Urgent Microscopy	£12.00			182,848	2,194		
Follow up culture	£8.00			182,848	1,463		
Leukocyte Esterase and nitrite test	£0.13			731,391	95		
TOTAL		338,012	4,524	1,097,087	3,752	759,075	-772

Unit Costs for imaging interventions

Description	Unit cost £	Source
Micturating Cystourethrogram (MCUG)	124.05	Whiting P et al (2006)
Di mercapto succinic acidtest	120.00	Deshpande and Verrier Jones (2001)
Ultrasound, scan>15 mins (RA US2)	62.00	2007-2008 Indicative Tariff to support Unbundling of diagnostics
Ultrasound, scan>15 mins (RA US3)	92.00	2007-2008 Indicative Tariff to support Unbundling of diagnostics
Conventional ultrasound	25.84	Whiting P et al (2006)
Contrast enhanced ultrasound	124.05	Whiting P et al (2006)
Average Ultrasound cost	75.97	Calculation

'Urinary tract infection in children: diagnosis, treatment and long-term management' (available online at www.nice.org.uk/CG054).



Appendix 4

Long term problems associated with recurring urinary tract infections:

- Kidney infections/ failure
- Bladder
- Stress incontinence
- Urge incontinence

The urgent and frequent need to pass urine can be caused by a problem with the detrusor muscles in the walls of the bladder. The detrusor muscles relax to allow the bladder to fill with urine, and then contract when you go to the toilet to let the urine out.

Sometimes the detrusor muscles contract too often, creating an urgent need to go to the toilet. This is known as having an 'overactive bladder'. The reason your detrusor muscles contract too often may not be clear, but possible causes include: drinking too much alcohol or caffeine

- poor fluid intake - this can cause strong, concentrated urine to collect in your bladder, which can irritate your bladder and cause symptoms of over activity
- constipation
- conditions affecting the lower urinary tract (urethra and bladder), such as urinary tract infections (UTIs) or tumours in the bladder
- neurological conditions
- certain medications

Causes of overflow incontinence

Overflow incontinence, also called chronic urinary retention, is often caused by a blockage or obstruction to your bladder. Your bladder may fill up as usual, but as it is obstructed you will not be able to empty it completely, even when you try. At the same time, pressure from the urine that is still in your bladder builds up behind the obstruction, causing frequent leaks.

Your bladder can become obstructed as a result of:

- an enlarged prostate gland (in men)
- bladder stones and constipation

Overflow incontinence may also be caused by your detrusor muscles not fully contracting, which means that your bladder does not completely empty when you go to the toilet. As a result, the bladder becomes stretched. Your detrusor muscles may not fully contract if:

- there is damage to your nerves, for example as a result of surgery to part of your bowel or a spinal cord injury
- you are taking certain medications



Holding onto faeces ‘Fighting the urge’

Other health problems may cause chronic constipation, including diabetes, hypothyroidism, Hirschsprung’s Disease, and inflammatory bowel disease

It is important to not ignore the call. When you get your body’s signal that the rectum is full, it’s normal to wait until you can conveniently reach a bathroom. But when you routinely put off having a bowel movement as long as possible, it can lead to constipation and ultimately to urinary or faecal incontinence.

Throughout the questionnaire and comments made it was said that the lack of available toilet facilities forced people to ‘hold on’ and wait until they were able to access a toilet.

The number of available public toilets within Brighton is 44 (excluding current closures) these toilets are provided by the local authority and cover the whole Brighton & Hove area. Of these toilets many close during the winter months and reopen in Spring/Summer. Also a majority will be locked and closed by 4pm. A majority of open toilets will open at 8am

Within the City, Brighton & Hove operates a ‘use our loo’ scheme - where customers and non-customers are able to use the toilets of supermarkets, some pubs, clubs and churches.

There are 19 loos open during business hours - libraries, leisure centres and municipal buildings.

http://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/downloads/toilets/Mar_13_opening_hours_and_facilities.pdf

Local authority cost cutting measures have meant that public toilets are being lost each year due to maintenance and running costs. Toilets are being sold and re-let for private business and council rents. In light of further proposed cuts to the Local Authority budget in the region of £70 million over three years - it is likely that further buildings will be closed down and sold off where possible.

Appendix 5

AT WHAT COST? A COST BENEFIT ANALYSIS PATHWAY

Scenario

Bridie is 15 years old and lives with her family in a caravan. She travels around the country with her family but she considers Brighton her home. She was born here, she is registered with a GP here, she goes to school here and all her best friends are from here. Bridie lives on unauthorised encampments throughout the City. Her family pull up on plots of local authority land. There is nowhere for Bridie and her family to encamp which is authorised. This means that Bridie and her family usually move from one camp to another every 14-21 days.

Bridie and her family are Irish Travellers. They do not have any access to running water or toilet provision. Bridie’s family fill up water butts every day from the local petrol station and use this water for washing, cooking and drinking. Bridie’s trailer is not fitted with a toilet. It is culturally inappropriate to have a toilet within the caravan. Bridie uses the public toilets and also the toilets at school or at the petrol station.

Recently one petrol station has been locking its toilets. When Bridie’s mother enquired at the petrol station why they were locked she was told ‘so the Travellers can’t use them’. This was the closest toilet to Bridie’s camp, the next public toilet being 3 miles up the road at the local Asda.

Bridie and her Mother were very upset – they knew this would make life very hard for them. Bridie’s mother did not have access to a vehicle during the day because her husband used it for work. He left the camp early in the morning and was not back until about 6.00 pm each evening.

Bridie and her mother would now have to organise their day around this problem. Bridie’s two younger brothers were 4 - 5 years old and her baby sister was just three. It was not such a problem for them as both the boys were able to discreetly pass urine in a secluded spot away from others near some bushes in the adjacent wooded area. Her little sister was still wearing nappies. Bridie’s Mum preferred to wean and potty train her children later than settled mothers did because of the lack of local toilet facilities.



Bridie and her mother could not use the woods and therefore often they would wait several hours before passing the first urine of the day. Bridie’s Mum would get all the children dressed, breakfasted and ready before heading off into town on public transport.

Finally Bridie and her Mum would be able to use the toilets for the first time in the day. Bridie was very fearful that she would need to go again when she returned to the camp after the shopping trip was finished so she refused to drink any fluids. Bridie’s Mum was also very mindful of not drinking too much in case she should need to relieve herself before 6.00 pm when her husband was at home.

That evening after dinner all the family drove up to the nearest public toilets and used the facilities. Bridie was feeling a little unwell and had noticed that she had a stinging sensation and that her urine was a very dark coffee colour. She also had a tummy ache. She had not been able to have a bowel movement – in fact it had been 5 days since she had passed a stool. She remembered that she had felt an urge two days ago but she fought against it because she was at the camp and it would be two hours before she was able to visit the local toilets.

Bridie felt very unwell - she had felt like this many times before. In fact she had visited her GP regularly about this throughout the whole year. Each time the GP had told Bridie that she had a urine infection. The GP had asked Bridie to supply her with a urine sample - the doctor suspected that she had an infection and prescribed anti-biotics.

Each time Bridie went to the GP the results were the same. The tests came back positive for e-coli.

The GP was concerned that Bridie had so many reoccurring bladder infections and decided to refer her to the children’s hospital to see an urologist.

Bridie never told her GP about her circumstances and never told her GP about her terrible bouts of constipation. Bridie had suffered a very bad bout of constipation only a month ago - but this time she had also soiled her underwear when suddenly she was unable to stop the flow of liquid faecal matter.

Bridie was extremely embarrassed and kept this information secret.

Bridie counted that she had seen her GP 6 times that year about urinary infection - each time the GP had made an appointment for her to visit the surgery and each time she had sent off urine samples for tests. Bridie had always been given the antibiotic medication.

Bridie became so poorly one evening that her father had to take her immediately to the Accident and Emergency department at the local hospital. The doctors at children’s A and E were very concerned that she was suffering from a kidney infection. Bridie was shivering and had a terrible headache; she felt cold and could not focus. The GP explained that she had pyelonephritis, it affects one in 830 people a year and is usually caused by bacteria getting into the urethra (the tube through which urine passes out of the body) and then travelling up through the bladder into one of the kidneys.

Bridie, was given antibiotics and a hydration drip to flush out the infection, and kept in hospital for five days. Bridie was taken for a scan.

Bridie was able to tell the hospital doctors at the children’s hospital about her problems with constipation and the times that she had held on and not drunk enough fluid. After five days Bridie was allowed to go home.



COSTING PATHWAY 1

One visit consultation to your GP costs £45 (11 minutes)

One prescription from your GP costs £41.35. This includes the cost of the drug too.

The 2013 Units Health and Social Care report from the Personal Social Services Research .

Each time her urine was tested it cost NHS £21

NICE clinical guideline 54- urinary tract infection 2007 Urinary tract infection in children: diagnosis, treatment and long-term management' (available online at www.nice.org.uk/CG054).

£270 GP visits £248.80 in medicine Testing £126 Total cost = £644.80

The 2013 Units Health and Social Care report from the Personal Social Services Research

According to the department of Health report 2014: a one night stay in a hospital bed costs £250 per night. The average cost of a non-elective inpatient short and long stay combined excluding excess bed days is £1,489. The average cost of an excess bed day is £273 (£264)

Scans at the hospital cost-£124.05

Urinary tract infection in children: diagnosis, treatment and long-term management' (available online at www.nice.org.uk/CG054).

So Bridie's stay in hospital had cost the NHS a total of **£2705**

For this year alone Bridie has cost NHS £3,349.80

COSTING PATHWAY 2

The local Gypsy liaison officer and the outreach health visitor are making a visit to an unauthorised encampment at one of the local parks. They knock on Bridie's parent's trailer door and are welcomed in by Bridie's Mum.

Bridie's Mum explains to the visitors that she is a bit worried about Bridie. She has been looking very pale and not drinking very much.

The Health visitor was a specialist Gypsy & Traveller health visitor and was very aware of the impact that lack of sanitation has on the community. She asked to see Bridie and after chatting to her ascertained that she probably had a urine infection. Bridie's Mum made an appointment to see the GP later on that day.

The Gypsy Liaison officer and the health visitor contacted the local authority and ordered a portaloo for the encampment. The cost of the facility was shared by the local authority and Bridie's family.

The family stayed on the site for another two months until the local authority directed them to an alternative tolerated spot. This site had a public toilet accessible to the camp - literally a few minutes' walk. Bridie and her family stayed well and nobody contracted a urine infection again during this period.

One visit consultation to your GP costs £45 (11 minutes)

One prescription from your GP costs £41.35. This includes the cost of the drug too.

The 2013 Units Health and Social Care report from the Personal Social Services Research.

Total NHS cost £86.35

Cost to pooled budget public health and CCG to hire a chemical portaloo from a local company would cost £24.00 per week

2 months costs = £96.00 (£96 paid by Bridies family)

Total cost to public bodies = £182.35



This snapshot has shown the costing pathways for a single year but what if Bridie continues to live on unauthorised encampments with no access to toilet facilities - let's take a look at Bridie's life 10 years down the line....

Bridie married another Traveller and now has four children of her own. Bridie married at 16 years old and joined her husband travelling around the country looking for work. She lives with her husband on unauthorised encampments because although she is on waiting lists in Sussex, Brighton and Surrey she has not been able to access any local authority site provision.

She had serious complications with one of her pregnancies and had a caesarean section. She struggled after this pregnancy and found that she was constantly getting urinary tract infections. She was provided with a portaloo from the local authority Traveller Team during the last trimester of her pregnancy. She found that she was unable to control her bladder and had developed a weakness. She started to use pads on account of this because everyday motions such as sneezing and coughing would make her leak urine and soil her clothes. Bridie was extremely embarrassed about this didn't tell her midwife or health visitor.

Bridie thought that this would improve after her 'body had settled down'. Several months went past and Bridie continued to suffer with incontinence - only it was getting worse. Bridie was no longer allowed to have the toilet on the unauthorised site because the Local authority said that she had recovered from her caesarean and they were no longer prepared to supply a toilet for her and her family. Bridie asked if it was possible to pay for the service but was refused. The local authority did not provide this type of service. Bridie became very anxious about this because she was at a stage where she could no longer control her bladder- when she needed to go she needed to go.

Bridie became so anxious that she began to have problems sleeping. When she did sleep she was waking up to a wet bed. This was extremely embarrassing for Bridie as she was so ashamed, and her relationship with her husband suffered because she could not talk to him about it. Bridie spent more time sleeping on the sofa in her trailer - always anxious that she may have an accident. Bridie started to feel very low and without any energy. She felt trapped at home and panicky because she thought that she was being talked about by other people and other Travellers. Bridie started to feel so low that she stopped going out to the shops and to appointments. She was worried that she would need to change her clothes and everybody would look at her and judge her. Bridie became so low that she started having thoughts about harming herself. All through this time she was looking after her children and also her home. Eventually one day it became too much for Bridie and she broke down to the Traveller health visitor who was making an outreach visit to see her children. She spoke with Bridie and made an immediate appointment with Bridie's GP.

Bridie was accompanied to the GP by an outreach worker who works with Gypsies and Travellers. She was not able to attend on her own because she had become so gripped with panic and fear that she could not leave the door of her trailer without support. Bridie was given anti-depressant medication and tablets for her 'nerves'.

The GP was concerned about Bridie and asked about her weight. It appeared that Bridie had lost a lot of weight since the birth of her last child. Bridie did not tell the GP that her diet was not good and that these days she rarely ate. Bridie had had an accident several months ago where she had soiled her clothes whilst just standing in her trailer washing up her pots and pans. She hadn't realised that she was soiling herself until after it had happened. She had been severely constipated since they had taken the toilet away and this had given her a very swollen and sore stomach.

Since then Bridie had been frightened to eat much food in case it happened again. Bridie had also cut down on any drinks she was having. This of course made her dehydrated and more constipated. It also made her urine very dark and smelly. Bridie felt like she was in a vicious circle with nowhere to turn. Bridie felt so tired all of the time so another Traveller woman told her that she should try drinking 'energy drinks'. Bridie stopped drinking any water and replaced this fluid intake with energy drinks. Bridie felt that these drinks helped her manage her daily routine.



During another consultation Bridie’s GP took some blood from Bridie and examined her. He prescribed some medication for constipation and also gave her another course of antibiotics for her water infection. The GP was very concerned that Bridie was having constant infections and she just couldn’t understand it.

Bridie came away from the GP who made another appointment for Bridie to attend in one months’ time. The situation did not change- Bridie became more anxious and cut down her food and fluid intake even further. Bridie was getting her fluid intake from energy drinks. Within two months Bride was admitted to the Accident and Emergency department in a great deal of abdominal pain; she presented with an extremely high temperature and was feverish - she was assessed and placed on the digestive diseases ward.

After tests and examinations a consultant approached Bridie and told her that she had diverticular disease. He told her that she would require surgery. In rare cases; a severe episode of diverticulitis can only be treated with emergency surgery. This is when a hole (perforation) has developed in the bowel. The specialist told Bridie that in her case she would need an open colectomy - where the surgeon makes a large incision (cut) in your abdomen (stomach) and removes a section of your large intestine.

When Bridie came out of surgery she was told by members of the nursing team that the surgeon had decided that the large intestine needed to heal before it could be reattached.

In Bridie’s case, stoma surgery provided a way of removing waste materials from her body without using all of her large intestine. Bridie was told it is known as “having a bag” as a bag is stuck to the skin on your belly and the faeces are collected in the bag.

Bridie was very shocked that this had happened and felt ashamed. She was in hospital recovering for 10 days and had regular appointments with her GP and the practice nurse. She also sought a lot of advice from the stoma nurse.

Bridie’s depression became very deep as she found it very hard to come to terms with emptying the colostomy bag and care around the bag. She needed lots of extra dietary advice and had appointments with an NHS dietician about managing her diet and increasing her fluid intake. During this period the local authority was informed by a health professional that she would require help with access to water and also toilet provision. The local authority arranged for Bridie and her family to be allowed to stay temporarily on a site where they provided a basic portaloo and water standpipe access.

This was a very bad time in Bridie’s life and her relationship with her husband deteriorated. She could not stand for him to see her body as she felt so much shame for the bag. She struggled to leave her home as she felt that everybody was judging her and she imagined that strangers were talking about her.

Bridie’s GP was very concerned and increased her medication for anxiety and depression. He also accessed her onto a course of talking therapies - which Bridie did not enjoy going to and also she found it very difficult to attend the appointments - missing several. Bridie felt that the therapist was ‘looking down at her’ because she didn’t understand her culture. Bridie felt inferior and judged.

When the intestine had healed sufficiently Bridie went back into hospital for more surgery. The bag was removed and Bridie felt better but her bladder infections continued regularly. Bridie’s GP referred her to the incontinence clinic. Bridie had several appointments at the clinic and was given exercises and pads to wear. Bridie is now on medication for incontinence.

Bridie is still suffering from all her issues and is still looking for a permanent site on which to encamp - especially as now her daughter is also having problems with urine infections and she has been referred to the children’s hospital to see the urologist and kidney specialist.



COSTING PATHWAY OVER THE 10 YEAR PERIOD

GP visits - 6 per year on average 6 x 10 = 60 - £2700

A and E visits - over the 10 year period = 30 - £9000

Medication - reoccurring issues = anti-biotics and anti-depressants - £2400

Specialist nurse - A 15 minute appointment with your nurse in a GP practice costs £13 x 20 = £260

Stoma bags - £45.00 x 30 (lasting 2 weeks for 8 months) = £720.00

Retention strips and seals x 5 boxes £18.00 x 5 = £90.00

Adhesive removers/wipes x 5 boxes £11.00 x 5 = £55.00

<http://www.neneccg.nhs.uk/resources/uploads/files/Stoma%20Care%20Guidelines.pdf>

Talking therapies - CBT Therapist qualified for 12 week session total cost to NHS + £1440.00

Emergency surgery- Hospital stay- Non--elective inpatient stays (long stays) £2,716

Unit Costs of Health and Social Care 2014 from the Personal Social Services Research

Follow up surgery and hospital stay - The average cost of a non-elective inpatient short and long stay combined excluding excess bed days is £1,489

The average cost of an excess bed day is £273 (3 due to infection) = £819

The 2013 Units Health and Social Care report from the Personal Social Services Research

Ambulance - see - treat and convey = £235.00 x 2 over 10 years = £470.00

Transforming NHS ambulance services paramedic service s unit costs.

Estimated cost to NHS = £22,153.00

We leave Bridie still requiring care and now with the added worry of her daughter’s bladder problems. Bridie will have many years left of her life and if her situation does not change Bridie’s conditions will continue to further impact on NHS in terms of bed availability, prescription charges, mental health, incontinence services, GP and nurse services.

It would seem appropriate to recommend that in this situation resources should be pooled between the Public Health team in the local authority and the CCG to help facilitate the provision of sanitation for Bridie and her family. It could be facilitated by the Traveller Team service and a cost could be charged to Bridie and her family to offset against - until such time that the service was no longer required (in the event that a permanent site were found or that the family had moved into bricks and mortar accommodation or temporary transit accommodation) This is demonstrated in scenario 1 costing pathway 2



SUMMARY OF POTENTIAL COSTS

In this era of austerity and with the financial pressures that our NHS is being put under it would seem that an early intervention of provision of basic toilet facilities would save large sums of money over the long term. Of course there would also be savings to central Government as long term health conditions are reduced and therefore health related benefits would also be minimised. This, in turn, would help with the issue of employment opportunities and caring within the community etc. The human aspect of Bridie’s story should also be taken into consideration - what price could anybody place on the cost of wellbeing to individuals and families?

.....
If any local authority were to perform a costing exercise to reduce cost of unauthorised encampments in their locality it would seem appropriate to include any long term costs that are picked up from the NHS budget locally according to each local commissioning group. It should also be considered that long term health conditions will impact on local authorities in Adult Social care settings. With a commitment for integrated care announced by NHS England, The Department of health and local authorities it would seem appropriate for local authorities/ public health and CCGs to act with an emphasis on developing proactive care models and not continue to focus on acute care.

.....
The overall aim is to shift the balance of care from urgent response and hospitalisation to prevention and self-care. Responsibility for local implementation is with the Clinical Commissioning Groups and local authorities. It is possible to support and deliver better outcomes for customers/patients from the Travelling Communities who do not have anywhere authorised to encamp. In the United Kingdom there are an estimated 5,000 or so families (say around 25,000 people) who live on the side of the road and who, as a direct result, may be suffering from the related health and wellbeing conditions.

.....
From the survey it is apparent that there is a correlation between bladder/bowel issues and lack of suitable toilet and sanitation provision.

.....
Many clients unable to access basic sanitation would be left with a long term chronic health condition which would continue to cost NHS large sums of money for individual care. Early intervention would certainly appear to offer a substantial cost saving measure. Looking at the figures relating to 2013 Jobcentre Plus snapshot for Brighton these indicate that many Gypsies and Travellers who are in working age group category are suffering with long term chronic health conditions. Therefore the cost saving in employment terms could also be

factored in. If Public Health and the CCG were to pool resources to produce a modest budget for the local authority to provide provisions for unauthorised encampments we may conclude that much more positive health outcomes for this patient group could be achieved.

.....
Such an approach could also foster better relations between the settled community and the Traveller community. One of the regular complaints from members of the settled community relates to the human faeces allegedly left in parks and other public places when Travellers are evicted. This suggests that younger children are using the cover of bushes and trees to toilet as they are unable often to ‘hang on’ as may an adult. It is not likely that many adult Travellers would openly defecate, as this study has demonstrated, because of the numbers who have health conditions related to bowel and bladder issues.

.....
The provision of toilet facilities by the Local authority or relevant public body would certainly foster better relations between the two communities and thus be acting upon the Equalities Act 2010 Duties of the public body: Foster good relations between people who share a protected characteristic and those who do not.

.....
The provision of sanitation does not necessarily mean that the local authority would have to bear the full cost of such provision. An appropriate charging scheme could be arranged for water and sanitation facilities without creating any implied licence to encamped Travellers. Notably this is already happening in certain counties and policies regarding such arrangements could be aligned with the similar policies successfully implemented by counties such as North Devon to obviate any fear of creation of a legal license.

.....
On the subject of toilet facilities it is often assumed that Gypsies and Irish Travellers would make use of a toilet fitted within the caravan itself. However, more often than not such toilets are removed from Gypsy and Traveller caravans for the strict hygiene reasons which exist within the cultures. It is therefore necessary to provide portable toilets for use on unauthorised encampments and ideally family units would not wish to share toilets for the same reason. However, the Gypsy and Traveller community generally accept that individual toilets cannot always be provided and compromises are usually made on both the side of the Council and the families. It is sometimes common practice for human waste to be disposed of through burying or in compost toilets.

.....
<http://www.teignbridge.gov.uk/CHttpHandler.ashx?id=4700&p=0> Devon Consortium Wide Gypsy and Traveller Protocol for Unauthorised encampments



FFT Community Base 113 Queens Road Brighton East Sussex BN1 3XG
Telephone **01273 234 777** Fax **01273 234 778**
fft@gypsy-traveller.org www.gypsy-traveller.org