An insight into the Health of Gypsies and Travellers

A booklet for Health Professionals in Cambridgeshire
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Introduction

This booklet is aimed at primary care, secondary care, hospital and community staff, but may also be useful for other allied health professionals.

It sets out information about individuals from Gypsy and Travelling communities in relation to their health and health care. It has been developed as a guide for health professionals to help them understand how and why members of Gypsy and Travelling communities may behave in certain ways regarding their health.

It also sets out issues for health professionals to consider when working with individuals from Gypsy and Travelling communities. Key areas to note are important areas around literacy, hygiene and cultural issues around gender, which are mentioned throughout this booklet.

The information included in this booklet is intended as guidance and may not apply to all the individuals from Gypsy and Travelling communities that health professionals work with.
Who are Cambridgeshire’s Gypsies and Travellers?

Romany people have lived in England for over 500 years, and Irish Travellers have lived here since the 19th Century. In Cambridgeshire, records dating back to 1515 make reference to Gypsies(1).

Whilst there are no reliable figures for the numbers of Gypsies and Travellers in Britain today - they are not counted by the Census, figures estimate a total Gypsy and Traveller population of 300,000 (CRE, 2004).

The Eastern Region has 11% of the general population of Gypsies and Travellers in England - making them one of the largest minority ethnic groups. An estimated 6,500 - 7,000 Gypsies and Travellers live in Cambridgeshire. Over 50% of the Gypsies and Travellers living in Cambridgeshire live in houses(2).

Many Gypsies and Travellers living in Cambridgeshire today have historic links with the county.

The Gypsies and Travellers living in the UK are made up of many different groups:

- Romany Gypsies
- Irish Travellers
- Scottish Travellers
- Welsh Travellers
- New Travellers
- Circus and Fairground people
- Bargees

each with their own lifestyle, culture and traditions. They may be settled in housing, living on private or local authority sites, or homeless with no place to stop. They may travel all year round, seasonally or not at all.

Many experience prejudice and discrimination and misconceptions about Gypsies and Travellers can prevent them from being able to receive services such as healthcare, access to education, and suitable accommodation.


(2) Cambridge Sub-Region Traveller Needs Assessment. (Robert Home and Margaret Greenfields, 2006)
English Romany Gypsies and Irish Travellers are recognised as ethnic minorities under the Race Relations Act 1989. The ethnic status of Gypsy, Roma and Irish Travellers is unaffected by where they live - whether it is mobile accommodation or permanent housing.

The health problems of Gypsies and Travellers can be complex and are often caused by, or made worse by, where they live and/or their living conditions.

Traditionally, Gypsy and Traveller attitudes to health care include a belief in self-reliance or reliance on family, a suspicion of health services and a belief that they can’t do any good anyway.\(^{(3)}\)

It is important for health care professionals working with individuals from Gypsy and Travelling communities to have an understanding of Gypsy and Traveller Culture and appropriate ways to act and communicate.

\(^{(3)}\) The Health Status of Gypsies and Travellers in England: A Report to the Department of Health (University of Sheffield, 2004)
Gypsies and Travellers and Health Care

Many perceive Gypsies and Travellers as living a romantic and care-free life of their choice. The reality is they are more prone to ill-health than other groups, are five times more likely to have health problems, and have a life expectancy 10-12 years less than the settled population.

One in five Gypsy and Traveller mothers will experience the loss of a child, compared to one in a hundred in the settled community, and levels of pre-natal mortality and still birth are also higher[4].

Life expectancy is 10-12 years less than that of the settled population.

The Health Status of Gypsies and Travellers in England, University of Sheffield, 2004

Bob and Marie’s Story

In their early 50’s and with grown up children, Bob and Marie* have travelled all their lives. Their grandchildren attend their local school, and as they are experiencing failing health and finding it harder to find places to stay they have indicated a wish to live a more settled life.

The Ormiston Travellers Initiative Advocacy Service helped them to apply for planning permission on a piece of land they had bought, and supported them to register with a GP. Bob had not seen a doctor since losing an eye in an accident at two years of age.

His advocate encouraged him to go for a health check, whereupon Bob discovered he had dangerously high blood pressure and diabetes. Marie was diagnosed with arthritis. Both are now receiving health care. Bob’s life-threatening conditions have been stabilised as a result.

* Names have been changed to protect identity

Lack of understanding of Gypsy and Traveller culture and needs, coupled with unstable accommodation can make it difficult for Gypsies and Travellers to receive healthcare\(^{(5)}\).

When a health professional or service is identified as being good, Gypsies and Travellers may revisit and use this service and may travel great distances to do so. It is felt that this person can be trusted and valued, and this person often comes to be seen as a good friend.

Appointments

When attending health care appointments Gypsies and Travellers may be accompanied by other family members. This is for support and in case they encounter prejudice.

Gypsies and Travellers may miss appointments. This is not intended to be disrespectful, and there are many reasons why appointments are missed. The main reason is eviction, but missed appointments could also be down to poor literacy and/or cultural differences. For example, many Gypsies and Travellers may not use calendars or diaries, and lifestyles may not be based around the usual 9.00am - 5.00pm timings.

Gypsies and Travellers may also have different priorities. For example the whole community is expected to attend a Traveller funeral without exception, and if a man is offered work he will take it and all the family will travel with him.

Consider alternatives to written communication. It is better to remind Gypsies and Travellers about any appointments they have by phone or face-to-face.

For Gypsies and Travellers living in a house is associated with long-term illness, poorer health state and anxiety. Those who rarely travel have the poorest health.

The Health Status of Gypsies and Travellers in England, University of Sheffield, 2004

Language differences

It is important to note that differences in language and understanding may impact on your work with individuals from Gypsy and Travelling communities. It is important that health professionals do not use jargon.

Gypsies and Travellers will often take a lead from other people’s behaviour, particularly if they can’t read. For example if they see others smoking in a particular area they may assume it is OK to smoke there.

Family Health Care

Men and women from Gypsy and Travelling communities may gather separately to focus on specific needs. Men and women’s issues are often discussed separately and dealt with in different ways. For example, if a woman has a new baby breastfeeding may not be discussed in front of men.

Gypsy and Traveller Hygiene

Most Gypsies and Travellers have high standards of hygiene, and elaborate rituals of cleanliness. For example they will use separate bowls for washing dishes, clothes, and food preparation, as well as different parts of the body. This is important to note if treating a Gypsy or Traveller in their home or particularly if treating them at a hospital session.

It may be useful to have a sensitive discussion with patients to explain about treatment and to understand their hygiene routines.

It can be useful to check people’s understanding following a discussion or consultation.

Information leaflets are not always appropriate due to difficulties with literacy. Consider other forms of providing information such as audio tape, video or dvd.
Home Visits

For ambulance and health service staff it is perfectly appropriate for standard risk assessment procedures to be used but it is not necessary to be accompanied by the police when making a home visit. The suggestion that this would be necessary may be seen as highly insulting and disrespectful.

Gypsies and Travellers may feel proud and protective of their home. Please respect this.

Be aware that bathroom and toilet facilities are considered a personal space and some Gypsies and Travellers may feel uncomfortable about a visitor using, or asking to use, them.

Appointments can be unusual for members of Gypsy and Travelling communities, so even if you plan to visit at a set time that patient may wait in all day.

It is good practice to ask about taking your shoes off when entering a Gypsy or Traveller’s caravan or house.

It might help to be thoughtful of this when planning appointments, and arranging to visit early in the day.
Primary Care

Many individuals from Gypsy and Travelling communities may not feel comfortable going to a doctor’s surgery, hospital, office or other place of authority and may be accompanied by at least one family member. This can be due to a number of reasons:

- bad experiences in the past
- the expectation that they will be treated badly
- insecurity or lack of confidence
- lack of literacy.

Gypsy and Traveller women may prefer to have a female doctor, particularly as there are cultural issues which are relevant if issues such as sexual health - for example smear tests, breast health, pregnancy, and symptoms of the menopause - are to be discussed. (See Family Health Care, pg. 10.)

In primary care a detailed oral explanation of how to take any prescribed medication would be useful, as there may well be literacy issues in reading instructions.

Markie’s Story

Markie* is a young man who suffers from depression and anxiety. He was prescribed night time medication to help him sleep and to reduce his anxiety. He was told to take three 10mg tablets every night. His Mum looked after the tablets and made sure he took them. Markie’s literacy is not good and neither is his Mum’s, and they made sure the people at the surgery were aware of this. Markie was improving gradually but then started to feel worse for no real reason. He felt tired, lethargic and believed his medication wasn’t helping him. He told the people treating him and they suggested he take an extra dose of his mood stabilising medication during the day to see if that helped.

The Ormiston Travellers Initiative Advocacy Service supported Markie to tell the consultant he wasn’t happy and to ask for his medication to be reviewed. The consultant contacted the surgery and went through the details of what was being dispensed. It was found that the night time medication had been changed and the dose of each of the tablets was now 30mg. Markie and his Mum had not been told, couldn’t read the packaging and Markie had been taking three times his prescribed dose at night. In addition he had taken an extra one in the daytime as he had confused the night time tablets with the mood stabilising tablets, due to them being supplied in blister packs without their branded packets.

*A names have been changed to protect identity.
Individuals from Gypsy and Travelling communities often go to Accident and Emergency in order to access health care. There are a number of reasons for this:

- they may be unable to register with a doctor’s surgery
- lack of information about services available or they are unaware of services
- a lack of literacy to read information and a reluctance to admit this
- unable to read medication packets
- unable to read first aid books or access or read the Internet
- a lack of clear understanding of what is said when attending a clinic, due to jargon and medication terms being used that are not understood.

Gypsies and Travellers may not like being left alone in hospital. They can feel vulnerable on their own as a Gypsy or Traveller, as they may come up against prejudice and may not understand things. They may get frightened and worry that someone will give them the wrong medication on purpose.

Gypsies and Travellers are used to being outside so may find it difficult being confined in a room in a hospital.

It may be helpful to try and place patients from Gypsy and Travelling communities near an entrance or in a single room if one is available. This may help meet the needs of the large number of visitors that may visit the patient whilst they are in hospital.
Privacy

Most women from Gypsy and Travelling communities would prefer to see a female health professional for any appointments.

Intimate issues are usually discussed in the presence of peers and members of the same sex only.

Privacy is extremely important. It would not be appropriate for bed covers to be removed from a patient if there are other Gypsies and Travellers or other people in the room.

Gypsies and Travellers may feel very uncomfortable in clothes and sheets provided by the hospital due to cultural views around cleanliness.

You should consider allowing patients from Gypsy and Travelling communities to use their own clothes and own bed sheets if at all possible.

Visitors

It is expected that family and friends will visit anyone in hospital in large numbers. It is suggested that wherever possible you should:

- make use of a close relative to act as a mediator to reduce the numbers visiting and to make visiting arrangements
- place the patient in a single room, if possible near to the entrance to avoid as much disturbance to others as possible
- in the case of a terminally ill patient, or where death seems very likely it might be important to note that there may well be large numbers of visitors and vehicles arriving from across the country to visit this person.

Even if visitors are unable to see the patient, they may be found around the hospital or in the hospital grounds as being close by is important.

Meals

Gypsies and Travellers may be unwilling to eat hospital food and may eat food brought in by friends and relatives. This is because they know this food has been prepared correctly according to their cultural views.

To avoid the wrong food being eaten, it will be helpful to make it clear if the patient must eat a special diet, or if the patient should not eat at all due to impending surgery.

Putting medical instruments on the table where meals are served should be avoided.

Discharging Patients

Gypsies and Travellers may need more support at discharge as they may not be able to read instructions on health care leaflets or prescriptions.
Childbirth, Ante-natal and Pre-natal Care

It has been a tradition within Gypsy and Travelling communities that fathers do not attend childbirth, and in many cases of childbirth this may still be the case. Pregnancy aftercare and breastfeeding is traditionally not discussed in front of men or strangers. Men may disappear when the midwife or health visitor visit the new mother and baby.

After childbirth many mothers may wish to leave hospital as soon as possible despite being offered longer term in-patient care. This is because they want to get away from the hospital environment, which they may feel is dirty, and to get back to their families.

It is common for mothers from Gypsy and Travelling communities to dispense with breastfeeding in favour of bottle feeding, due to privacy issues with men and women. If the baby is breastfed, this is unlikely to be done in front of strangers.

Children are often cared for by extended family members. This is for practical reasons as communities may not always be in one place.

One in five Gypsy and Traveller mothers will experience the loss of a child. This compares to one in a hundred in the settled community. Levels of pre-natal mortality and stillbirth are also higher.

Gypsies and Travellers have significant problems accessing health and maternity care and suffer a disproportionate number of health problems as a result.

Children from Gypsy and Travelling communities are between 1 1/2 and 2 times more likely to die in the first year of life than children in the settled community.

International Minority Rights Group

Lack of access to ante-natal care, possibly due to missed appointments (see pg. 9), coupled with the impact and stress of evictions has a detrimental effect on the health of mothers, babies and children. Mothers from Gypsy and Travelling communities experience the highest incidence of maternal death in childbirth. Women living on the roadside have significant problems getting post-natal care (Maternity Alliance).

A recent study by Patrice van Cleemput on access to and experiences of primary care for Gypsies and Travellers includes some useful information about requirements for culturally safe services.

A copy of the report is available to download from the Ormiston website at www.ormiston.org or the Cambridgeshire Primary Care Trust website at www.cambridgeshirepct.nhs.uk

Mobile or home phone reminders would be seen as helpful in order to improve attendance at ante-natal care sessions.
Young Gypsies and Travellers

“It’s dangerous for our baby brother. If we were on the side of the road he couldn’t play outside the trailer in case a car hit him.”

Jemma, 11 - Children’s voices: changing futures The views and experiences of young Gypsies and Travellers

Young Gypsies and Travellers may be kept away from drugs and sex-awareness sessions at school. Education in these areas is considered inappropriate by parents as they feel that awareness of them may lead to risk-taking behaviour.

The younger generation would not normally be expected to discuss gender or sex issues with the older generation, and young Gypsies and Travellers would not normally get sex education from their parents. Young Gypsies and Travellers may feel very uncomfortable in any situation where they would be expected to change or undress in front of strangers or others.

Child accident rates are thought to be higher than average for Gypsy and Traveller children, and many have speculated that this high accident rate is due to the poor condition and location of local authority sites and unauthorised stopping places.

Most Gypsy and Traveller parents want a better future for their children and many will seek a more settled lifestyle while their children attend school. However evictions, racism and bullying can prevent children’s attendance and inhibit their achievements. In 1999 Ofsted reported that ‘Gypsies and Travellers have the lowest results of any ethnic minority group and are the group most at risk in the education system’.

(9) Raising the Achievement of Minority Ethnic Pupils (Ofsted, 1999)
Emotional Wellbeing and Mental Health

Many Gypsies and Travellers live with huge anxiety caused by the constant fear of eviction, the need to find somewhere to stop, racism, discrimination and poor access to health services and medical care. Many stress related illnesses are linked to the problems caused by homelessness, and exacerbated by the lack of sites or the location of sites.

Those who are homeless may have to stop in unsuitable places and face frequent evictions which can be a frightening and stressful experience, especially for children.

“Getting moved from place to place ... you have to stay in laybys and you get really frightened.”

Thomas, 8 - Children’s voices: changing futures The views and experiences of young Gypsies and Travellers

Inadequate facilities and poor accommodation affect the health and wellbeing of Gypsies and Travellers.

Gypsy and Traveller families have a reduced life expectancy, a range of chronic health conditions and a high rate of disability. There are high levels of stress on carers and poor psychological health. Depression stems from a complex mixture of ill health, bereavements and everyday fears and experiences of prejudice, racism and institutional racism.

Research shows there is insufficient accommodation for Cambridgeshire’s Gypsies and Travellers, meaning some have to camp on unauthorised sites or to purchase and develop land before the planning process is completed, simply because there is no where else to go. Children living on a transient site are more vulnerable to poor environments and air pollution and suffer related illnesses ... children need more opportunity for therapeutic play.

(11) Cambridge Sub-Region Traveller Needs Assessment (Robert Home and Margaret Greenfields, 2006)
Alfie’s Story

In his late teens Alfie* had been badly beaten up whilst enjoying a night out in his local town. Although his physical injuries healed he was left very emotionally unwell and had nightmares, flashbacks and panic attacks. He was too afraid to leave the caravan site where he lived and stopped working or socialising. He was so unwell his GP referred him to the local Community Mental Health Team where his consultant psychiatrist suggested he write down his experiences and read them over every day - to help him come to terms with what had happened. Alfie’s literacy was not good as he had not received a full education. He found the need to read and write was a barrier to his getting better.

The Ormiston Travellers Initiative Advocacy Service attended appointments with Alfie and suggested to the therapist that Alfie record his experience on audio tape and listen to it every day instead. This worked well and subsequently a plan was developed to encourage Alfie to start venturing out into the community on his own.

The Ormiston Travellers Initiative Advocacy Service also supported Alfie to get a referral to a psychologist who is now providing regular talking therapy sessions.

Alfie now has a girlfriend, is more independent and confident and is hoping to set up his own home and return to work soon.

* Names have been changed to protect identity

“The women linked psychological distress to poor living conditions, economic factors, loss of family support, bereavement, marital/parenting issues and social pressures ... there was a strong tradition of problem-solving within family groups and a reluctance to seek help outside the community.”

Improving Mental Health Services for Travellers in Cambridgeshire, Cate Treise and Geoff Shepherd, Cambridge and Peterborough Mental Health Partnership NHS Trust, 2005
Bereavement and Funerals

Gypsies and Travellers may gather in large numbers when a member of the family or community is seriously ill, and relatives may stay close by the patient the whole time. If a patient does die many family and friends may expect to visit the hospital and go to the home to support the bereaved family with the loss. Many family members may also come to the hospital when the body is due to be placed in the coffin.

A death is experienced deeply by extended family and the whole community, as well as the immediate family.

It is traditional for relatives as well as friends to stay awake throughout the night at the bedside or home of the deceased. It is also very important if at all possible for family and close friends to be present at the moment of death.

It is expected that children would be absent from school for some time to be able to attend a funeral and to support the family. This may entail travelling a long distance and staying with the family.

Men may gather separately to the women at this time.

Taking care of the grave is important and it is customary for the grave to be visited regularly - often daily - to pay respects, remembrance, place flowers and ensure tidiness. This may go on for many years and people may congregate in cemeteries as part of their daily routine.

It has been traditional for close family to wear black for 12 months from the day of the funeral, sometimes longer.
A death is experienced deeply by extended family and the whole community, as well as the immediate family.

Families may refer to the departed family member in the present tense for many years after their death and to identify property as still belonging to that person.

It may seem that disproportionate amounts of money are spent on the funeral and headstone. It is highly disrespectful to walk on the grave.

Sally’s Story

In her early 20’s, Sally* lived on a local authority Gypsy Caravan Site. Her emotional wellbeing was affected when her dearly beloved brother took his own life. Many of the immediate and extended family felt guilty and ashamed of what had happened and Sally, who was suffering very badly, went to her GP for support. He referred her to the local Community Mental Health Team where she received a medication review and was offered talking therapy.

The person supporting Sally had some experience of working with Gypsies and Travellers but was very worried about Sally - who was attending her brother’s grave daily for a long time after his death. It was felt within the team that this was excessive behaviour and they were thinking Sally should be sectioned for her own protection.

The Ormiston Travellers Initiative Advocacy Service gave information and support to the Community Mental Health Team and explained that daily visits to graves for recently bereaved people from Gypsy and Travelling communities was quite common. The team were able to treat Sally without sectioning her and she made a full recovery.

* Names have been changed to protect identity
What can you do as a health professional?

- Have an awareness of the cultural issues of Travelling communities. Attend cultural awareness training sessions, but remember to treat all Gypsies and Travellers as individuals.
- Involve Gypsies and Travellers in training health service staff and in awareness-raising sessions.
- Consider how cultural issues may impact on the health and health behaviour of individuals from Gypsy and Travelling communities.
- Keep Gypsies and Travellers informed about decisions that affect their lives. Explain clearly what you are doing and why, and how long treatment will take and services will last.
- Consider how you may reduce some of the barriers to accessing health care, such as:
  - ensuring all services are accessible and user-friendly
  - considering outreach services as having to travel and a lack of transport can be a barrier to accessing services
  - being friendly positive and open yourself when working with Gypsies and Travellers
  - talking to families to find out why they may not be accessing mainstream services
- Work in partnership with other organisations who are already working with individuals from Gypsy and Travelling communities. For example Traveller Education Services and the Ormiston Travellers Initiative.
- Give clear and thorough explanations of how prescribed drugs should be taken, including information such as:
  - how many to take
  - when to take them
  - how long to take them for.
- Read the documents listed on page 23 to find out more.

The University of Sheffield’s 2004 report, *The Health Status of Gypsies and Travellers in England: A report to the Department of Health*, also recommends:

- partnerships between Gypsies and Travellers and health workers
- employing specialist Gypsy and Traveller health workers
- identifying Gypsies and Travellers in ethnic monitoring
- increasing GP registration.

A recent study by Patrice van Cleemput on access to and experiences of primary care for Gypsies and Travellers includes some useful information about requirements for culturally safe services.

A copy of the report is available to download from the Ormiston website at www.ormiston.org or the Cambridgeshire Primary Care Trust website at www.cambridgeshirepct.nhs.uk
References, further reading and useful contacts

References
(9) Raising the Achievement of Minority Ethnic Pupils (Ofsted, 1999)
(11) Cambridge Sub-Region Traveller Needs Assessment (Robert Home and Margaret Greenfields, 2006)

Further Reading
- Making a Difference (Traveller Health Partnership)
- A Better Road - An information booklet for health care and other professionals (Available from www.grtleeds.co.uk)
- Improving mental health services for Travellers in Cambridgeshire (C Treise and G Shepherd, 2005)
- Gypsies and Travellers: Fact or Fiction? - Cambridgeshire’s Gypsies and Travellers challenge the myths surrounding their way of life (Ormiston Children & Families Trust. Available from www.ormiston.org)
- Disability, Social Care, Health and Travelling People (R Morris and L Clements, Traveller Law Research Unit, Cardiff Law School, 2001)
- Improving Mental Health Services for Travellers in Cambridgeshire (C Treise and G Shepherd, Cambridge and Peterborough Mental Health Partnership NHS Trust, 2005)
- East Cambridgeshire and Fenland Travellers Health Needs Assessment (S Wood, Cambridgeshire PCT, 2006. Available from Ormiston Travellers Initiative and Cambridgeshire Traveller Health Sub-Group.)
Useful contacts

Ormiston Travellers Initiative (Cambridgeshire)
01480 496577
www.ormiston.org

Ormiston Travellers Initiative (Norfolk)
01362 854264
www.ormiston.org

Ormiston’s Travellers Initiatives provides a range of activities aimed at supporting Gypsy and Traveller children, young people and their families, and ensures that communities are involved in relevant consultation with service providers, giving opportunities to influence service development and delivery.

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Cambridgeshire Primary Care Trust
01223 884008
www.cambridgeshirepct.nhs.uk/

Cambridgeshire Traveller Health Sub-Group (Cambridgeshire PCT)
01223 884105
jean.fosbeary@cambridgeshirepct.nhs.uk

The Cambridgeshire Traveller Health Sub-Group provides a forum through which providers and commissioners of services that impact on Travellers health in Cambridgeshire can work in partnership to influence strategy and policy in order to improve health outcomes and reduce health inequalities.

Training providers

Myriad Consultants
01462 643212
www.myriadconsultancy.co.uk

The Gypsy Media Company
07966 786242
info@englishunlimited.co.uk

Friends, Families, Travellers
www.gypsy-traveller.org
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Ormiston Children & Families Trust works to promote the well being of children and young people, especially those disadvantaged by their life experiences or circumstances. This is achieved through direct service provision and by raising awareness of related issues through research, publications, conferences and events. Many of the children and young people we work with are:

- experiencing stigma and isolation caused by prejudice and discrimination
- in danger of becoming isolated and excluded both from school and the wider world
- affected by the imprisonment of their parent
- at risk of, or experiencing, emotional or physical harm
- caring for parents or siblings within their family.

We are one of the largest voluntary providers of support services to children and families in the Eastern Region. Ormiston opened its first project in 1981 and we currently have 29 community and prison-based projects across five counties.

Cambridgeshire Community Services

Cambridgeshire Community Services is responsible for providing a range of NHS and social care services in the Cambridgeshire area, commissioned by and accountable to Cambridgeshire Primary Care Trust. Our integrated health and social care community services are for children, older people and adults across Cambridgeshire and include:

- fully integrated health and social care services for adults and older people (district nursing, care management, physiotherapy, occupational therapy and personal care)
- specialist nursing and therapies
- four community hospitals
- children’s acute services at Hinchingbrooke Hospital, Huntingdon
- children’s community services
- diagnostic and outpatient clinics
- minor injury and Huntingdonshire out-of-hours GP services
- public health programmes.

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