



## **Have your say about the Government's new Child Health Strategy**

**A report on the findings from NCB's on-line survey with children and young people on health and well-being**

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June 2008

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## Background to the survey

The Government is creating a new strategy that aims to help children, young people and their families live healthier lives. It will help children and young people to keep well and also help those who are sick or have conditions requiring life long treatment and support.

The Department of Health (DH) asked National Children's Bureau (NCB) to run an on-line survey with children and young people to ensure their views inform the development of the child health strategy.

A questionnaire was designed so that children and young people can tell the Government their views on what 'being healthy' means to them and the changes they would like to see implemented to help them achieve healthier lifestyles. The questionnaire was confidential and most questions needed a tick in the appropriate box. Some of the questions in the survey were open ended and provided space for the young person to write about their experiences or views or to add another answer that they feel did not fit into the categories supplied in a question. This report shares the findings from the quantitative and qualitative analysis of these questions, in particular, emerging themes that arose and issues that young people identified as being important.

The survey was live for a month on the NCB website and sent out randomly to children, young people and services across the country. 1673 children and young people partially filled the survey and 1038 answered all the questions.

The first part of this report provides a summary analysis of each open question in the survey. This is divided up into five key sections: 1) who responded - examining demographics of respondents 2) what children and young people said about their health and well-being (health problems and disabilities they have), 3) what young people said about the help they receive for their illness/health problem, 4) what carers said about the help they receive and 5) what young people would like the government to do to improve their health and services. The final part of the report provides a summary which highlights recurring themes across the questions. Reference is made to the relevance of the five outcomes of Every Child Matters throughout the report.

## 1) Who responded?

### Key points

- Gender distribution was fairly equal with a similar number of males (48%) and females (52%).
- The majority of respondents were aged between 6 and 20 years of age and most ages were represented well. The mean age was 13.
- 5.7% of responses (63) were classified as 'other' for ethnicity. The largest group represented mixed race individuals, with a mix of Asian and White/British ethnicity (10/63).
- Respondents were distributed across the UK including England, Wales, Scotland and Northern Ireland. A great concentration of respondents from the North, Midlands and Southwest responded from certain towns/cities. Other responses from the South East and elsewhere tended to be more widely dispersed. There was a particularly high number of responses from certain areas, for instance from Telford, which could be due to a particular service using the survey as a project to engage with the young people. As the survey was sent out randomly there is no explanation for the high number of responses in certain areas.

**Gender:** Fifty-two percent (52%) of respondents were female, and forty-eight (48%) were male.

**Age:** Table 1 (below) illustrates the age distribution of respondents. The majority of respondents were aged between 6 and 20 years of age. The mean age was 13 and both the mode and median was age 12 with as many as 234 respondents in this category. Some respondents were outside of this main age range with one response from a 2 year old (probably carer filling out), and some responses from individuals in their 20's and 30's. Older ages (such as over 100) were specified, but these were excluded from the analysis.

**Table 1: Age distribution of respondents**

| Age           | Number | Age           | Number |
|---------------|--------|---------------|--------|
| Under 6       | 1      | 14 – 15 years | 191    |
| 6 – 7 years   | 10     | 16 – 17 years | 168    |
| 8 – 9 years   | 94     | 18 – 19 years | 49     |
| 10 – 11 years | 228    | 20+           | 26     |
| 12 – 13 years | 327    |               |        |

\* A full breakdown of age can be found in appendix 1

**Ethnic background:** From the standard categories provided for ethnic background the majority reported being White British (78.5%), with others reporting being Pakistani (2.4%), Indian (2.2%), any other mixed background (1.7%), White Irish (1.6%), other White background (1.6%), mixed – White and

black Caribbean (1.5%), African (1.4%) and Caribbean (1%). Smaller percentages arose for the remaining standard categories.

As well as closed options for ethnic background, the survey also provided the opportunity for young people to specify ‘other’ and to provide details. This represented 5.7% of responses (63 respondents).

There were a number of similarities in these open responses. The largest group represented mixed race individuals, with a mix of Asian and White/British ethnicity (10/63).

Full breakdown of ethnicity and further details can be viewed in appendix 2.

**Area of the country/postcode:** respondents were asked what the first part of the postcode of their main home address was. For analysis this was coded into town and then county data. One thousand one hundred and seven responses were received with 1018 identifiable postcodes.

Table 2 represents the highest distribution of responses by county. A large number of respondents were located in Shropshire (311/1018), Devon (103), West Yorkshire (94), Lancashire (67), South Yorkshire (43), West Midlands (38) and Greater Manchester (30). These counties represented 67% of the respondents. Respondents from the South East and other parts of the UK tended to be widely dispersed across a number of counties.

**Table 2 – County distribution of respondents**

| County             | Respondents |
|--------------------|-------------|
| Shropshire         | 311         |
| Devon              | 103         |
| West Yorkshire     | 94          |
| Lancashire         | 67          |
| South Yorkshire    | 43          |
| West Midlands      | 38          |
| Greater Manchester | 30          |

\* A full breakdown of county can be found in appendix 3

Table 3 represents the distribution of responses by town. A large number of respondents were from Telford (307/1018), Wakefield (79), Exeter (79), Manchester (30), Norwich (27), Stockport (27), Sheffield (25), Torquay (24), Lancaster (22), Warrington (22) and Birmingham (20). These towns represented 65% of the respondents. Respondents from the South East and other parts of the UK tended to be widely dispersed across a number of towns.

**Table 3 – Town distribution of respondents**

| Town      | Respondents | Town      | Respondents |
|-----------|-------------|-----------|-------------|
| Telford   | 307         | Sheffield | 25          |
| Wakefield | 79          | Torquay   | 24          |
| Exeter    | 79          | Lancaster | 22          |

|            |    |            |    |
|------------|----|------------|----|
| Manchester | 30 | Warrington | 22 |
| Norwich    | 27 | Birmingham | 20 |
| Stockport  | 27 |            |    |

\* A full breakdown of county can be found in appendix 4

## 2) What children and young people said about their health and well-being

### Key points

- Three hundred and twenty one (321) children and young people named their illness or health problem. The most common health condition was asthma or respiratory problems (125/321). Attention and psychological problems were also quite prevalent (51/321) representing both learning/attention difficulties and mental health issues. Allergies also affected as many as 28/321 involving mainly hay fever.
- Seventy eight (7%) respondents reported that yes, they *possibly* have a disability or impairment and 82 (7.5%) respondents reported that yes, they *definitely* have a disability or impairment.
- The prevalence of disability was not found to correlate with the prevalence of health problems. As attention/psychological issues were the most frequent category to be perceived to be a disability (61/180), this finding points to the importance of considering the need for psychological support for physical illness and the impact this may have on a young person's well-being. It also points to the need to cater for the needs of children and young people with learning/attention difficulties.
- Problems with senses (18/180) were the next most prevalent category to be considered a disability with many young people referring to loss of eyesight or hearing. Although asthma was such a common health problem in the sample only 11/180 people referred to it as a disability and those that did made reference to mobility issues. Similarly only one person considered their allergy to be a disability. Even when disability affected different health systems the young person often referred to the impact it had on mobility. Helping young people to be mobile, to continue with their lives and interact with others seems to be an important implication of these findings.

### Illness or health problem

One thousand six hundred and sixty four (1664) children and young people answered the question about whether they had an illness or health problem (99% of the total number of children and young people who took part in the survey). One thousand two hundred and one (1201) (72%) of respondents reported not having an illness/health problem and 463 (28%) reported having an illness or health problem. Of those that said they had an illness or health problem, 321 children and young people named their illness or health problem. Many young people named more than one health illness or condition, with some having as many as three or four. Illnesses/health problems were analysed and classified according to type of health problem and the system it affected biologically. The most frequent health categories/problems and examples of the types of illnesses involved are summarised in table 4.

From the table it is clear that the most common health condition was asthma/respiratory with 125/321 young people suffering from this illness. Attention and psychological problems were also quite prevalent (51/321) representing both learning/attention difficulties and mental health issues. Allergies also affected as many as 28/321 involving mainly hay fever. Muscular/skeletal problems (26/321), skin complaints (24/321) and heart/cardiovascular/blood problems (19/321) were also fairly common. Other health systems affected involved digestive, head/brain (non-psychiatric), endocrine, reproductive, nervous, urinary, senses, lymphatic/immune, glandular and sensory/motor/integrative. Patterns in co-existing illnesses mainly involved asthma and allergies or psychological problems associated with the impact of physical illness. A more detailed breakdown can be viewed in appendix 5.

**Table 4 – Types of health problems in the sample**

| Type of Health Problem  | Count | Examples   |
|-------------------------|-------|--|
| Asthma/respiratory      | 125   | Mainly asthma, few cases of breathing problems and cystic fibrosis   |
| Attention/psychological | 51    | Autism, ADHD, Asperger's, Dyspraxia, Fragile X, mental health issues (including depression, anxiety, OCD, eating disorders and psychosis). |
| Allergies               | 28    | Mainly hay fever, few cases of nut allergy and penicillin  |
| Muscular/skeletal       | 26    | Arthritis, Osgood-Schlatters, Spondylolisthesis, Marfan Syndrome, Phosphoglycerate Kinas Deficiency, Multiple Exostosis                    |
| Skin complaints         | 24    | Mainly eczema, few cases of burns, skin cancer, rash, psoriasis.   |

\* A full breakdown of types of health problem can be found in appendix 5

### Disability or impairment

Out of 1107 children and young people who answered the question about whether they had a disability or impairment, 947 (85.5%) reported that they did not have a disability or impairment. 78 (7%) respondents reported that yes, they *possibly* have a disability or impairment and 82 (7.5%) respondents reported that yes, they *definitely* have a disability or impairment. Therefore in total 14.5% of the sample reported they 'possibly' or 'definitely' have a disability or impairment. This figure is in line with other national research where 14% of young people reported having a long standing illness or disability<sup>1</sup>.

Respondents were also given the opportunity in the survey to describe what they considered their disability to be with an open ended question. One hundred and eighty young people supplied an answer. The illness or health issue that the

<sup>1</sup> Findings from the 2005 Families and Children Study (FACS) (2007). Department for Work and Pensions. Research Report 424.

young person recorded was analysed according to the same system categories identified above for illness/health problem. The most frequent health categories/systems that were identified as a disability are summarised in table 5. Many young people named more than one health illness or condition at a time.

Interestingly, the prevalence of disability was not found to correlate with the prevalence of health problems (as in previous section). The most common category to be perceived to be a disability was attention/psychological with 61/180 referring to this category. Problems with senses (18/180) were the next most prevalent category with many young people referring to loss of eyesight or hearing followed closely by the category of muscular and skeletal problems (15/180). Although asthma was such a common health problem in the sample only 11/180 people referred to it as a disability and those that did made reference to mobility issues. Similarly only one person considered their allergy to be a disability. Even when disability affected different health systems the young person often referred to the impact it had on mobility.

**Table 5 – Perceived disability in the sample**

| Type of Health Problem  | Count | Examples   |
|-------------------------|-------|--|
| Attention/psychological | 61    | <i>"I find learning difficult", Autism, ADHD, Asberger's, Dyspraxia, Fragile X, downs syndrome, global developmental delay, mental health issues (including depression, anxiety, OCD, eating disorders and psychosis).</i> |
| Senses                  | 18    | <i>"very little sight in my left eye", "partially deaf", "slightly blind in one eye", "visually impaired."</i>   |
| Muscular/skeletal       | 15    | <i>"I have marfan syndrome and it causes some long term problems", "hip and knee problems", "slipped vertebrae in my back", perthes' disease, multiple exostosis.</i>  |
| Asthma/respiratory      | 11    | <i>"asthma impairs my life quite a bit", "cannot walk due to brittle asthma".</i>  |

A more detailed breakdown can be viewed in appendix 6.

### 3) What children and young people said about the help they receive for their illness/health problems

#### Key points

- Young people receive help for their health problem or illness mainly from close others including parents/foster/adoptive carers, other family members and friends. If a family member was qualified in a medical profession this was referred to. They also received help to a lesser degree from health professionals including doctors/nurses, hospital/medical specialists and psychologist/counsellor/psychiatrists. A number of young people also used the other category as they felt they did not get any help at all or relied on themselves. Identifying ways in which young people feel they can turn to health professionals will be of vital importance to increase the numbers of options for confiding/support to young people. Of even greater importance is the need to identify which young people in society feel that they do not receive any help, why this is, and how they could be encouraged to seek support when needed.
- Where young people would like to receive help may provide some insight into how to encourage help seeking behaviours. It was frequently mentioned that they would like the involvement of close others or to be in familiar locations (such as a friend/family home). Others felt that confidentiality/privacy was of vital importance and had a preference for natural/outdoor environments. A smaller proportion would choose health venues, but when they did so they seemed to be a place that the young person was familiar with. Other suggestions involved familiar locations such as school and during activities/at shops/cafes/place of worship. A key commonality seems to be a location that the young person feels comfortable with or makes them feel relaxed and safe to talk.
- In terms of the type of help young people would like to receive for their illness/health problem elements of social and practical support were stressed. A recurrent theme was the desire to have someone to talk to and listen about their health problems/illness, for health professionals to truly listen and to gain support from family and friends. Interestingly the recurrent theme of the important role close others can play is stressed once again. This may have implications for involving the whole family in plans for health care.
- Young people also felt that extra understanding and awareness is needed by teachers and schools, health professionals and the general public about their health problem. This may help to reduce the psychological impact of physical illness, a need often identified.
- A desire for direct help with their illness and life was also expressed with requests for better medication/surgery/treatment, cures, help to ease symptoms, increase mobility and more psychological help/interventions.
- Young people recognised that their geographical location, age and financial situation impacted on access to services. To prevent social

exclusion, they would like equal access to services for all, improved efficiency/range of services (more frequent appointment times/less waiting/better diagnostics/assessments), continuity in care and improved information supply to young people from health professionals. They would also like support with increasing their healthy behaviours such as healthy eating and exercise.

### Who young people receive help from

Three hundred and fifty six respondents answered the question about who they receive help from for their illness/health problem. The majority (44%) receive help from their *family doctor* and over a quarter (28%) from the *hospital*. Another 28% responded using the 'other' category (100 responses).

There were a number of similarities in these open responses. The most prevalent can be viewed below in Table 6 with examples from the young people.

The most prevalent response (32/100) involved parents/foster/adoptive carers. Reference was also made to other family members (7/100), and friends (3/100). If a family member was qualified in a medical profession this was also referred to (5/10). Health professionals such as doctors/nurses (15/100), hospital/medical specialists (13/100) and psychologist/counsellor/psychiatrists (6/100) was also fairly common. A number of young people also used the 'other' category as they felt they did not get any help at all or relied on themselves (17/100).

In a similar vein to the quantitative question responses these open replies reflected the fact that young people felt they received a great deal of help from close others, and to a lesser degree health care professionals.

**Table 6 – Who do you receive help from for your illness/health problem?  
Other category**

| Help from  | Count | Examples  |
|--|-------|---|
| parents/foster/adoptive carers                         | 32    | <i>Parents, mom and dad,</i>  |
| doctor/nurse   | 15    | <i>Community nurse, asthma nurse, GP and Drs, hospital Dr, medical advice from GP</i>         |
| hospital specialist/physiotherapist/physical therapist | 13    | <i>Hospital heart specialist, OT and physio, cardiovascular specialist, asthma consultant</i> |
| don't get help/none/myself                             | 11    | <i>I don't get help for it, nobody, noone, myself</i>   |
| other  | 17    | <i>Drug dealers, witch doctor, school, chemist, mechanic</i>                                  |

A more detailed breakdown can be viewed in appendix 7.

### **What other help young people would like**

Two hundred and seven respondents answered the open question about what other help they would like for their illness/health problem. Eighty three young people said they would not like any help or couldn't think of anything that would help. The remaining 124 made a number of suggestions for the type of help they would like.

There were a number of similarities in these responses and a number of themes emerged from the data. Themes below are ordered in terms of similarity and prevalence. Some responses contained more than one theme.

- **Social and practical support**

Many young people referred to elements of social and practical support regarding the help they would like for their health problem/illness. A recurrent theme was the desire to have someone to talk to and listen about their health problems/illness. This referred both to the cathartic nature of talking and the recognition that health professionals should take note and listen:

*"someone to talk to about issues, and illnesses in life"*

*"I get really scared about my heart and I'd like a doctor to listen to me properly."*

Some young people would like more support from their family or friends (7/124) and a few mentioned that it would be helpful to gain support from mentors or someone in a similar situation (3/124).

- **Understanding/awareness**

Some young people pointed out that extra understanding and awareness is needed by teachers and schools, health professionals and the general public about their health problem. Fifteen young people would like teachers and schools to provide extra help and understanding in relation to their illness/health problem:

*"help with college work that is missed and a greater understanding amongst health care professionals and teachers etc about what my illness entails."*

*"understanding and awareness of autism, help at school. I don't get help at school as I am seen as too able my stats are in May but I don't get any extra help with this."*

Some would also like health professionals to have more of an understanding of the impact the illness might have on their lives (e.g. school work, social life) and their daily needs (4/124) and 2/124 would like more understanding from the general public.

- **Help with their illness and life**

Young people also suggested many ways that their illness/health problem could be helped directly or the impact on their lives reduced. Young people also wanted to have better medication/surgery or treatment (15/124). Other suggestions included a cure or for something to make their illness go away (6/124), help to ease symptoms (3/124) and with mobility/access due to disability (1/124). Young people also referred to the need for psychological help/interventions (6/124):

*“more help psychologically as my illness requires many admissions to hospital, I am ventilated and get very scared”*

*“to get help with my self esteem instead of just getting given anti depressants”*

- **Improved health services for all**

Many young people referred to issues of accessibility of services, improved efficiency/range of services, continuity in care and improved information supply to young people. Twelve mentioned they would like more available services that are accessible to all regardless of location (rural/urban) or age of the young person. For example:

*“Better access to support- my asthma remains uncontrolled because despite all my doctor's support the consultant at the local hospital was dismissive and this has made seeking further help/ ways to control it difficult. There's should be equal services regardless of age or location (e.g. rural or city)”.*

Twelve would like more frequent appointments and at more suitable times (i.e. not just in school time) and shorter waiting times. They would like more help with their health aids, better diagnostics and more assessments (5/124).

A key theme that emerged was that young people would like doctors and health professionals to provide more information/explanation or advice about their health problem or illness (12/124):

*“need to be informed more with what was going on with my treatment instead of me asking all the time.”*

*“Someone to explain to me more about my problem in a way I can relate to”.*

Other suggestions included home visits/help at home (3/124), more consistent care (4/124) involving the same health professional or venue, financial support/allowances (5/124) to continue use of health services/professionals.

- **Support with healthy behaviours**

Requests were also made for support and guidance on healthy behaviours (7/124) including eating and exercise and more events/sporting activities/activities to keep them occupied generally.

### **Where young people want to talk about their health problem**

One thousand one hundred and ten respondents answered the question about where they would choose to talk to somebody face to face about a health problem. Over half (60%) reported wanting to talk to somebody face-to-face about a health/support problem *at home*, nearly a third (31%) at a *doctor's surgery*, 20% *at school* and another 20% at a *hospital*. 13.5% (150) reported '*somewhere else*'.

There were a number of similarities in these open '*somewhere else*' responses and a number of themes emerged from the data after an index was applied. Themes below are ordered in terms of similarity and prevalence. Some responses contained more than one theme.

- **Involvement of close others in familiar locations**

Many of the young people mentioned that it was important to talk in a familiar safe environment with family or friends. Some would like to talk in a family member's home/vehicle, their own home (29/150) or a friends home (18/150). For example:

*"in my dads lorry"*      *"at my nans"*      *"At my caravan"*      *"mates house"*

Others would like to talk to family/pets (11/150) or friends (11/150).

- **Confidentiality/privacy and natural/outdoor environments.**

The nature of the environment in which young people confide also seemed to be of importance. Many felt it should be somewhere private/confidential in quiet/their own space (27/150) and others would like to talk outside in a nice/natural environment (13/150):

*"somewhere private where no one can here what we r talking bout"*

*"at the park on the bench"*      *" in a park or open space"*      *"somewhere quiet -garden/field"*

- **At a health/services venues**

Nineteen young people mentioned that they would like to talk at a health/services venue including Connexions office, at counselling sessions, at homeopaths surgery, youth advisory service, sickle cell centre, young carers centre, prison, CAMHS, health centre and a nursing home.

Other places young people would like to talk included shops/café's, school/college, place of worship, during other activities/groups (e.g. football,

dancing, boys brigade, on holiday), online or using text. Eighteen young people replied don't know or responded in a joke manner (e.g. *in a garbage can*) or their response was unidentifiable.

## 4) What young carers said about the help they receive

### Key points

- Young carers receive help mainly from close others including parents/foster/adoptive carers, and friends/girl/boyfriends. Reference was also made to other family members, the family/friends of the person they were caring for and other children/young carers. They also received help to a lesser degree from health care professionals, such as support workers/home carers, doctors/nurses, social workers and school/teachers. A number of young people referred to the fact that they rely on themselves for help and some felt they had no-one or didn't know who to get help from. Once again identifying ways in which young people feel they can turn to health professionals will be of vital importance to increase the number of options for confiding/support to carers or ensuring that enough support is provided to the whole family system where caring is often a shared responsibility. Of even greater importance is the need to identify which young carers in society feel that they do not receive any help, why this is, and how they could be encouraged to seek support when needed.
- Interestingly, when asked what sort of help they would like and why, nearly a third (10/33) responded that they wouldn't like any help or didn't have anyone to help. Many requested that they would like help to increase their understanding of the illness or to increase their confidence in how to care. Some also were concerned that the person being cared for needed more activities to prevent them from being bored and they wanted the ill person to feel better and to experience a better healthcare system where health professionals would be friendly and talk more to the individual. The importance of being sensitive to the young person's desires and needs is therefore a necessity and many young people may want encouragement in their role to become more skilled. Such requests fit in with the Every Child Matters outcome to enable children to make a *positive contribution* and play an important role. Clearly there is need to balance when encouragement in the caring role is important and how this fits with the young person's own needs. Indeed a great deal of young people also mentioned they would like support and for someone to take over so they could see friends, have a break or get on with school work. The importance of helping young people to *enjoy and achieve* in the face of caring responsibilities is of great importance.
- Some young carers suggested they would like someone to talk to and to gain support and help psychologically. Suggestions for help involved friends or relatives helping and a better healthcare system.
- From the answers to this set of questions the impact that caring can have on a young person's emotional well-being and everyday life is clear.

### Who young people get help from as a carer

Out of 1262 children and young people that answered the question about whether they care for someone with a health problem, 489 (39%) reported being

a carer. This figure reveals a very high rate of young carers considering recent publications from the Department of Health have broadly estimated ‘between 2% and 4% of children have been carers to some extent during their childhood<sup>2</sup>’. Of those 489 who reported being carers, 315 (64%) said that they receive help with their caring duties. Help is received primarily from *other family members* (63%) (e.g. parents and grandmothers) and 12% from their *doctor* and 8% from *the hospital*. Eighteen per cent (71) replied that they get help from ‘*someone else*’ (open question). There were a number of similarities in these open responses. The following table 7 reveals the most frequent responses. Some responses contained more than one theme.

The most prevalent response (19/71) involved parents/foster/adoptive carers, followed by friends/girl/boyfriend (15/71). Reference was also made to other family members (10/71), the family/friends of the person they were caring for (4/71) and other children/young carers (3/71).

Others that young people got help from included health care professionals, such as support workers/home carers, doctors/nurses, social worker and school/teachers (6/71).

In a similar vein to the quantitative question responses these open replies reflected the fact that young people felt they received a great deal of help from close others, and to a lesser degree health care professionals.

A number of young people referred to the fact that they rely on themselves for help (4/71) and some felt they had no-one or didn’t know who to get help from (6/71).

**Table 7 – If you do get help, who do you get it from – someone else –please state who**

| Help from                           | Count | Examples  |
|-------------------------------------|-------|---|
| parents/foster/adoptive carers      | 19    | <i>Mummy, my mum + dad because they listen to me, My aunty or mum</i> |
| other family                        | 10    | <i>my nan, my family anyone one of them</i>                           |
| friends/girl/boyfriend              | 15    | <i>my friends, boyfriend, my mate Maria</i>                           |
| family/friends of person caring for | 4     | <i>that persons family, their family an mine</i>                      |

A more detailed breakdown can be viewed in appendix 8.

### **What sort of help young carers would like**

When asked what sort of help they would like, 40% of young carers who answered the question said they would like *someone to provide some care for them as well*, with 27% wanting *someone to talk to* and 15% wanting *more information about the illness/health problem*. 8% (33) responded as ‘*other*’. There were a number of similarities in these open responses. The following index

<sup>2</sup> Carers at the heart of 21<sup>st</sup> century families and communities: a caring system on your side, a life of your own. Department of Health Impact Assessment (10 June 2008). Department of Health.

(table 8) was constructed to describe these with examples from the young people. Some responses contained more than one theme.

The most prevalent response was that the young person didn't have anyone to help or wouldn't like any help (10/33). Suggestions for help involved friends (4/33) or relatives (1/33) helping. Others felt like they needed a break at times with respite (3/33) or they needed psychological help or help with goals (2/33). It was also pointed out that the person being cared for needed health professionals to be nice/friendly and to talk more (2/33) and activities to prevent boredom/keep them occupied (2/33). Other suggestions (6/33) ranged from unidentifiable answers to a suggestion of classes.

**Table 8 – what sort of help would you like? Other (please specify)**

| Help would like                                  | Count | Examples  |
|--|-------|---|
| no-one/none                                      | 10    | <i>no help</i>  |
| friends helping                                  | 4     | <i>that my friends came and help more often</i><br><i>My Best Friend</i>  |
| respite/a rest                                   | 3     | <i>someone helping or talking to the children out while I have a rest</i><br><i>more time out</i>   |
| health professional being nice/friendly/talking  | 2     | <i>A nurse being more polite and not being rude and horrible to the person I care for (my nan)</i><br><i>someone to talk to the person about that person's problem.</i> |
| better treatment/care                            | 2     | <i>health system improved, person cared for has poor health care</i>  |
| activities/things to keep person occupied/active | 2     | <i>something they could do to stop them getting bored in the house</i>  |
| someone to help psychologically/with goals       | 2     | <i>someone to help me achieve my goals</i>  |

A more detailed breakdown can be viewed in appendix 9.

### **The main reason young carers would like more help**

Thirty seven percent (37%) of carers who said they would like additional help said the main reason was so that *I can talk to someone about my worries*. A quarter would like *someone to take over so I can see my friends* and 26% *someone to take over so I can do my school work*.

Twelve per cent (49) replied 'other' (open question). There were a number of similarities in these responses and a number of themes emerged from the data. Themes below are ordered in terms of prevalence. Some responses contained more than one theme.

- **Young carers would like help so they can have a break and for their caring not to impact on their own life too much (8/49)**

This theme was in line with the findings from the quantitative responses (see above) that many young people would like someone to take over so they could see friends or do school work:

*“to stop me getting so tired and run down as well to see my friends more”*

*“some one who can help while i've got important things to do like school etc”*

- **Young carers would like help to increase their understanding of the illness or to increase their confidence in how to care (6/49)**

*“so I can understand about the illness fully”.*

*“so I do not get anything wrong”*

- **Young carers would like help so they have someone to talk to and can gain support (5/49) and someone to help psychologically (4/49)**

*“someone I can just express my feelings to”*

*“so that all the strain doesn't fall on me and someone can share the strain”*

*“so I can be calm and get on in life”*

- **Young carers would like to make the ill person better and to experience a better healthcare system (3/49) and to feel less bored (2/49).**

*“to make them better so they can live”.*

*“improved health care at present time there is little interest from health system”*

*“because they get bored on there own with nothing to do”*

#### 4) What children and young people would like the government to do to improve their health and services

##### Key points

- **Food/tackling obesity/exercise/smoking/drugs** - Young people suggested there was a need to promote healthier foods, to make it more affordable (in comparison to junk food) or to provide free samples/food. Many suggested shops should stop selling junk food or it should be banned. Exercise should be encouraged with opportunities and places for sport and exercise for all regardless of geographical location, age or money. Smoking and drugs should be tackled and school was thought to be the ideal place to encourage healthy behaviour.
- **Creating space for activities** - Young people would like more spaces to play and open green spaces. The importance of fun, play and social activities in promoting health was stressed. They would like more things to do and places to go within their community and for the development of more clubs.
- **Improving the community/environment for young people** - A desire for a safe environment with reduced crime, discrimination and bullying was often suggested and a clean, pollution free environment with more hygienic services.
- **Approaches the government needs to consider when developing its strategy** - A suggestion was made to promote the benefits and reasons for being healthy and to provide leaflets and advice. Alternatively letting people know the consequences of bad health behaviours was recommended. Young people were very aware of the power of advertising and felt this should be used for health promotion. Participation by young people in the government's health strategy was stressed to be of vital importance with young people recommending the government should listen to what they have to say and talk to them and provide young people with more choices/say and power in decision making and the health process.
- **Child friendly services and staff** – Requests were made for more specialist services and staff to provide services for the health needs of young people. Young people would like approaches that are more child friendly in the health care system and staff that help/look after/are nice and respect young people.
- **Accessible services to all regardless of location and financial issues** - Many of the young people in the survey were aware that their geographical location or financial situation impacted on their ability to access healthcare. They suggested more health services should be available that are accessible to all and services/food should be more affordable or free for young people.

- **Psychological help, support and awareness** – Suggestions were made for the development of strategies to focus on improving mental health confidence and self-esteem. They would like more support from school/teachers and more awareness/understanding from the public.

### **The most important thing that government could do in its strategy to improve children and young people’s health and well-being**

Seventy two percent (72%) of respondents think it is a good idea that the government is making plans to help children, young people, their families and communities to become healthier, but 21% were unsure whether this was a good idea. Eight hundred and twelve young people responded in the survey to an open question asking what they felt the most important thing the government could do in the forthcoming strategy to improve children and young people’s health and well-being. A great deal of thought was put into responses and the data provided a very rich source of information.

There were a number of similarities in these responses and a number of themes emerged from the data. Themes below are ordered in terms of similarity. Some responses contained more than one theme.

#### **A - Food/tackling obesity/exercise/smoking/drugs**

Two hundred and forty seven responses made suggestions regarding healthy eating and how to tackle obesity. Many suggested the need to **promote healthier foods** to young people. Ideas included providing advice to young people, setting up clubs where they could try out foods, cooking classes in schools, educating the parents, increased advertising of healthy foods and more availability in shops:

*‘there should be clubs where young people can try out new healthy foods.’*

*‘Providing more fresh healthy foods in shops than processed microwavable junk. I think cooking lessons should be part of the curriculum for both girls and boys of all ages so that when they are older they won’t resort to eating take-aways and ready meals’*

*‘Educate the parents as to what to do to keep their children healthy. Overweight parents tend to make overweight children.’*

A key way ahead that young people identified to be of great importance was **making healthier food more affordable or to provide free food**. Many pointed out that ‘junk food’ is often cheaper and this trend needs to be reversed as money is an issue for many of their families. Suggestions included cheaper prices in supermarkets, and providing free fruit or school meals for young people:

*‘make them a cheaper price and give them a piece of fruit everyday at school 4 free’*

*'It is sad that the cost of food has to come into the decision of whether a family eats healthily or not. But unfortunately, when it is cheaper to eat unhealthy ready-made meals, this is sometimes the case. I think there has to be a financial incentive to buy healthy food, perhaps some sort of government subsidy for supermarkets so that they can sell healthy food cheaper than unhealthy food'*

Young people also felt that a stricter policy on junk food needed to be in place with 53/812 suggesting that the government should **stop shops from selling junk food or ban junk food**. Suggestions included reducing the amount of adverts for junk food and preventing supermarkets from selling processed food:

*'encourage the major supermarkets to stop selling processed junk and convenience food'*

Both **promoting and encouraging exercise (66/812)** and **providing opportunities for sport and exercise (91/812)** were identified as key priorities. Many felt that school was an important place to encourage exercise and that more time should be put aside for sporting activities or physical activity daily. Some people mentioned it was important not to push young people too much and to provide activities that they would enjoy.

A key theme that emerged was that young people overwhelmingly felt that more opportunities for sport and exercise needed to be provided in the community. Suggestions included specialist classes for young people in leisure centres, summer camps, activities to be carried out with family/friends and trips. Again a key message was that current leisure activities need to be made more affordable and more accessible:

*'Put sport into the state school curriculum and make everyone take exercise. My sister has no sport at her school and has to take her sport out of school.'*

*'Make leisure centre across the UK, caring for young children and teens. There should be sports and activities for young children in the centres.'*

*'When they talk about doing more exercise they then need to follow up with providing the young people with means to do more exercise at an affordable local location.'*

Young people also felt it was important to **tackle smoking and drugs (16/812)**. Suggestions included providing more facilities in the community to prevent boredom and providing money to school so that specialists could visit to talk about the issues involved.

**School was thought to be an ideal place to encourage health behaviours(68/812)** including healthy eating and exercise. Many thought there should be more exercise on the school timetable and educational lessons about healthy eating should be available.

## **B – Creating space for activities**

A key theme that emerged was the need to create space for activities for children and young people. Many referred to the need for **more spaces to play and open green spaces (30/812)** as these were often lacking in the community. Often houses or office buildings were noted to be replacing green space and many would like the opportunity to run and exercise in the open air.

The importance of **fun, play and social activities in promoting health** was stressed (49/812). Rather than a series of rules, health promotion should be incorporated in fun activities/days in a way that children can relate to and understand:

*'The Government should try and organise fun activities and communicate with children and young people so that the child/young person feels comfortable in that way.'*

*'make healthy eating and exercise seem less as set rules and something that is fun and that friends can do together, also that eating healthy means eating salads or nothing at all, there are a lot more options.'*

Young people also stressed they would like **more things to do and places to go (47/812)**. Often they felt that their community did not provide much for young people and that age appropriate activities needed to be in place as there were often gaps in provision:

*'They should be a lot more places closer to home where young people can go and do different activities that don't cost a lot, we live in a small town in Cumbria and we don't have a lot of money so we don't really ever get the chance to go places because everywhere where we could go are either to far away so the travel costs a lot or it costs to much for us to actually get in the place.'*

*'more things to do for young people so they are getting out & about'*

**Providing more clubs (14/812)** to meet people, exercise or for somewhere safe to go was also suggested.

## **C – Improving the community/environment for young people**

Young people in the survey seemed to be very conscious of issues regarding safety and the community/environment. Some would like **a safe environment with reduced crime, discrimination and bullying (36/812)**. Suggestions included increased safety from drugs and bullying with the creation of safe places that all people and religions could go to including spaces for play. Empowering young people with skills to deal with bullies and racism was another idea:

*'Make more places for young people to go within a safe neighbourhood'*

*'Teach them something to stand up to cruel bullying such as horrible names, immature imitations and so on.'*

Young people would also like to **create a clean, pollution free environment and more hygienic services (8/812)**. Reference was made to reducing littering, toxic fumes from factories and cars and increasing cleanliness in hospitals and health services.

#### **D – Approaches the government needs to consider when developing its strategy**

Many suggestions were made about the nature in which the government needs to tackle the forthcoming health strategy and approaches that are more likely to be successful with children and young people.

A frequent suggestion was to **promote the benefits and reasons for being healthy and to provide leaflets and advice (67/812)**. If young people knew why behaviours made a difference, how important they were, in context, with useful advice and information they stated they would be more likely to try them:

*'Use reasons why to be healthy and use things that children like, aren't expensive and are available to everyone.'*

*'I think they should advertise healthy eating more often and get doctors to talk to young people and tell them how important it is to be healthy.'*

Another approach would be to **let people know the consequences of bad health behaviours (16/812)**. Comments were made that if young people knew about the consequences and how to change things, they would be more likely to be healthy:

*'Encourage them and scaring them. By showing them pictures of what you would look like in 20 years or something like that.'*

*'Make people more aware of the health problems around us, how they are caused and what happens to us.'*

Frequent reference was also made to **using the power of advertising (43/812)** in health promotion for young people, banning fast food advertisements and promoting exercise and healthy behaviours.

Finally, a key essential theme that emerged in this section was the importance of participation of young people in the development of a health strategy. It was suggested that government should carry out further actions to **listen to what young people have to say and talk to them (40/812)** and to **provide young people with more choices/say and power in decision making and the health process (71/812)**. Suggestions included after viewing the current survey the government should talk more to young people about their ideas and views and actively listen. If this did not happen it was felt that the approach would not be appropriate and young people may not respond:

*'Listen to the youth more as it is for them, and if they do it without asking, we could be unhappy with how it is done, so instead of it making us healthier, it could discourage people, because they don't like to do it that specific way.'*

Providing young people with choices in decisions on how to be healthy was also considered to be important. Even presenting young people with a variety of options from the government to provide them with a role in decision making would be useful. Reducing the amount of negative press coverage on young people's behaviour was also suggested with an increase in positivity and trust for young people along with a focus on what they can do instead of what is not possible.

## **E – Child Friendly Services and Staff**

Requests for child friendly services and staff were frequently made by young people in the survey. There were suggestions for **more specialist child services and staff (27/812)** to provide services to cater for their needs. It was stressed that often their illness or disability did not allow them access to the specialist care and advice that they felt was necessary:

*'Understand that people with autism have difficulty explaining their [problems and that going to smelly surgeries hurts my nose and that all the people hurt my ears and other senses. That I hate people touching me even to examine me. Autism awareness and a special package that fits me.'*

*'I think the government should start a health centre for children'*

**Young people would like approaches that are more child friendly (13/812) in the health care system and staff that help/look after/are nice and respect young people (24/812).** Suggestions included staff developing the ability to communicate with children in a way in which they can understand and relate to, being friendly and kind and to create change gradually whilst communicating with the young person openly:

*'Employ staff that can communicate well with children and can understand children.'*

*'make the services cheap and young people friendly'*

## **F – Accessible services for all regardless of location and financial issues**

Many of the young people in the survey were aware that their geographical location or financial situation impacted on their ability to access healthcare. They suggested **more health services should be available that are accessible to all (28/812)** not just people living in big cities or with excellent public transport:

*'They should be a lot more places closer to home where young people can go and do different activities that don't cost a lot, we live in a small town in Cumbria and we don't have a lot of money so we don't really ever get the chance to go places because everywhere where we could go are either to far away so the travel costs a lot or it costs to much for us to actually get in the place.'*

Young people felt that **services/food should be more affordable or free for young people (82/812)**. Once again the need for affordable healthy food, exercise options and activities was stressed.

## **G – Psychological help, support and awareness**

The need for psychological help, support and awareness from others was felt to be of great importance. Suggestions included the development of **strategies that focus on improving mental health, confidence and self esteem (23/812)**. Reference was made to the impact that physical health can have on emotional well-being and the many strains and stresses that young people are under. It was felt that **young people would like more support from school/teachers (6/812) and more awareness/understanding from the public (3/812)** regarding these issues:

*'Statistics show that our generation are the most examined generation in history. I am currently in the final year of my GCSE's and feel so stressed out to the point where I am miserable and so overworked that me and my friends get health problems. The government has to do something about the pressure that they are putting on young people because it is affecting our wellbeing and is leading to the largest killer amongst young people being that of mental illness leading to suicide.'*

*'to provide more support for young carers, give us time away and not feel like we always have to fight for some support from school and social work etc'*

## **H – Other/don't know**

Other suggestions (56/812) included:

- Help lines
- Educating parents
- Integrating with the community to see the real world
- Increased breastfeeding

Forty nine responses said they did not know/couldn't think of anything.

Interestingly, many of the young people's ideas for the promotion of healthy foods and exercise, such as providing advice and information and free fruit/food do fit with current policies such as the School Fruit and Vegetable Scheme, the Food In School Programme (FiS) and the Healthy Schools Programme. However, it is clear that many young people in the current sample are not in areas where all of the schemes are available, so considerations about accessibility to all regardless of geographical location and income are important.

A key message across the themes seems to be that even though health messages are often understood by young people the opportunities to carry these out with places to exercise/go or carry out activities needs to be provided. Health messages also need to be child friendly and fun. The need to *enjoy and achieve*

was clearly expressed by the young people and seemed to be vital to the success of health promotion and a health strategy. Safety also seemed to be an issue that young people would constantly refer to in being able to access services, so considerations into how this can be provided needs to take place.

Young people in the survey were very keen to be consulted and involved in decision making. The suggestions made were both insightful and numerous. Young people felt they wanted more power/to have a say in the health process generally with the right to make their own choices and decisions regarding healthcare. Some young people expressed concern that their views were not always taken on board and didn't think any action would be taken, so the necessity of consulting and feeding back change/ideas and progress seems to be an important way ahead.

## 6. Suggestions for how health services could be improved

### Key points – suggestions for how health services could be improved

- **Accessible and efficient services to all regardless of location and financial issues** – young people would like more health services (increasing number and size) that are accessible to all. They would like more staff, especially specialists for children and increased funding and help for people that need it. A request was made for more efficient services with shorter waiting times/more frequent check-ups, appointments at suitable times, better medication/surgery/treatment and cleaner more hygienic health venues.
- **Child Friendly Services and Staff** – young people would like health venues to be more child friendly with toys, activities and facilities when waiting. They would like access to information and for doctors and health professionals to provide more information/explanation and advice. Suggestions were made for more leaflets/handouts and when presenting information to young people, health professionals need to ensure it is child friendly. Requests were made for health professionals to be friendly and nice, to treat young people with respect, not to patronise them and for them to have more choices/power and say about their own healthcare. The need to talk to someone about their concerns and for someone to listen was often expressed, with a request for privacy and for the information to be confidential. Some young people suggested that mentors or the opportunity to talk to other young people in a similar situation would be useful.
- **The wider community and extra support** - Young people often referred to how they felt in their environments and they would like to feel safe in their community. Requests were made for more awareness and understanding about their health problem or illness in society, from school/teachers and also support from family and friends. Some suggestions for improved support included special classes/services at school, drop-ins generally and home visits or help at home.
- **Healthy Lifestyle Support** – young people suggested that health services could be improved by providing healthy lifestyle support regarding eating and exercise, for more events/activities/sporting opportunities to be available, increased advertising of healthy behaviours, the provision of free talks/presentations in accessible locations and a specialized phone line/internet site for health issues.

Seven hundred young people answered the open question asking them to make one suggestion about how health services for children and young people could be improved.

There were a number of similarities in these responses and a number of themes emerged from the data. These were often in line with themes from young people's suggestions for the government's health strategy. Themes below are ordered in terms of similarity. Some responses contained more than one theme.

### **A – Accessible and efficient services to all regardless of location and financial issues**

As with the last question, young people felt there should be **more health services (increasing number and size) that are accessible to all (80/700)**. Often due to geographical location and lack of public transport many felt they were missing out. also It was felt there **should be more staff, especially specialists for children (23/700) and increased funding and help for people that need it (17/700)**:

*'I feel that children's health would be greatly improved if the expertise in children's health and illness was distributed across the country giving equal opportunities for every single child no matter where they live.'*

*'Making them more easily accessible as children may not feel safe using public transport but may not want a parents help in getting there'*

Young people felt there should be more efficient services **with less waiting time/more frequent check-ups and appointments at suitable times (i.e. out of school) (51/700)**:

*'no long waiting times and children should receive a checkup when parents or carer thinks so, not when they can fit you in next.'*

*'try and make us meet the doctor at the weekend, some people like school'*

**They would like better medication/surgery/treatment (11/700) to help with their illness and cleaner/more hygienic health venues (14/700)**

### **B - Child friendly services and staff**

Young people in the survey seemed to be very aware that health services were designed by adults often in an adult environment. Many mentioned they would generally like services to be more child friendly. A frequent suggestion included making **venues more child friendly with toys/activities or facilities especially when waiting for appointments (77/700)**:

*'by having more stuff to do while you are waiting.'*

*'to have more colour and stickers and pictures on the wall and friendly nurses and doctors to help out'*

*'got like a room so you can play games and tell people your problems.'*

Access to information was also considered to be important with requests made for **doctors and health professionals to provide more information/explanation and advice (39/700)** generally. **Suggestions included more leaflets/handouts (12/700) and when presenting information to young people, health professionals need to ensure it is child friendly (28/700):**

*'I think that nurses in hospitals should introduce themselves and tell you what they are going to do or what is going to happen. They should also tell you what medicine/tablet they are giving you.'*

*'More information should be provided for young people so that they know which health services are available to them and where to go to get confidential advice and support.'*

*'They could talk more directly to the child with the problem and not the parents or carers and explain things in a way we can understand.'*

Young people would like **health professionals to be friendly and nice, to treat them with respect, not to patronise them (60/700)** and to have **more choices/power and say about their own healthcare (46/700):**

*'My health service is not very friendly and I am scared of going there, it is hot and not very clean, I would like it if it was more welcoming and the people who run the health service spent more time making people feel relaxed and not embarrassed to talk about any problems they have.'*

*'Not being told to go away if we're hanging around because we are not sure if we want to go in Explain things in simple terms without being patronising and taking notice of things like morals and beliefs.'*

*'The doctors could talk to me more and listen to me rather than talking to my mum'*

*'Talk to the child and involve them in their own health decisions'*

The need to **talk to someone about their concerns and for someone to listen** was often expressed (45/700), with a request for **privacy and for the information to be confidential (24/700):**

*'Being able to talk confidentially to a doctor without my parents.'*

*'more health professionals for people to talk to about problems available easier'*

Some young people suggested that **mentors or the opportunity to talk to other young people in a similar situation (5/700)** would be useful:

*'it should be with teenagers who have more knowledge about the thing we go through now-a-days, not some time 20 years ago'*

## **C – The wider community and extra support**

Another key theme that emerged was the need for extra support from the community, health care professionals and those close to the young person.

Young people often referred to how they felt in their environments and they **would like to feel safe in their community (17/700):**

*'I think that young people's lives can be improved by extending the amount of safety in neighbourhoods, towns and cities. I sometimes feel unsafe when out in town.'*

*'Safer communities so you don't get stabbed'*

*'maybe if there were more safe places to go where you can feel safe and have someone to talk to at school and more sport centres'*

Requests were also made for **more awareness and understanding about their health problem or illness in society (17/700)**. A few also would like **more help and understanding from school/teachers (3/700)** and others **would like the support of family and friends (6/700):**

*'disability awareness'*

*'If I talk to a teacher for instance, sometimes I don't feel like I'm being listened to. I just feel like they 'pretend to care'.'*

*'making them feel safe with their friends and family there beside them'*

Suggestions for improved support included **special classes/services at school (32/700)**, **drop ins generally (12/700)** and **home visits or help at home (5/700):**

*'at least once a week a doctor or nurse comes to a school and has a private conversation with you'*

*'have more health reps come to local schools to show us what to watch out for, and help us to prevent problems occurring.'*

*'More drop in centres and nurses in schools. providing advice and contraception'*

*'sometimes a doctor or a nurse comes in to see the people'*

## **D – Healthy Lifestyle Support**

Young people suggested a number of options for increasing healthy lifestyle support. These were consistent and provided similar content/themes to the previous question on the government's strategy:

- Health services could be improved by providing healthy lifestyle support regarding eating and exercise (68/700). School was a popular choice for this
- There should be more events/activities/sporting opportunities to keep young people occupied (26/700)
- There should be increased advertising of healthy behaviours (21/700)
- Provide free talks/presentations in accessible locations (4/700)

- Provide a specialised phone line for health issues or an internet site (6/700)

## **E – Other and don't know**

Sixty four respondents could not think of a suggestion or didn't know. 39/700 suggested other alternatives such as warmer swimming pools, having doctors/nurses complete a survey, removing the stigma of STD clinics, and for health professionals to have warmer hands.

In considering how to improve healthcare services and with all of the themes above consistently young people referred to the impact that physical illness can have upon their own lives and psychological well-being. The need to talk was referred to once again, as was the need for support and extra awareness/understanding from health professionals, teachers and family. In order for young people to *be healthy* and to *enjoy and achieve* it seems vital to consider these needs and to cater for them. Again catering for all young people seems to be another issue, with many feeling they miss out on services due to their geographical location, lack of public transport or due to money.

Young people expressed a desire to contribute to decision making and wanted a voice in their own health-care. Treating the young person as their own expert with their own decisions with equal power (or more) to their parents was pointed out as a vital way ahead as was more child friendly efficient services with shorter waiting times and more appointments/consultation generally. Wanting to have more information and to make a positive contribution was also a consistent message. It seems likely that allowing participation of young people in their own health care and decision making will help to provide more confident and resilient young people who are *emotionally and physically healthy*.

## 7. The links between the questions and recurring themes

The qualitative responses that young people supplied provided a rich data set with a vast array of suggestions and observations. From the analysis of themes it is clear that young people were consistent in their views/answers across the questions and a number of similar themes arose out of the range of questions.

The presentation of recurrent themes below has been grouped using the five outcomes of the Every Child Matters framework in order to highlight policy implications. Stories that young people have provided about good or bad experiences of health services are also used for illustration of points.

### **Be Healthy**

Young people were keen to suggest ideas for the promotion of health and provided a large number of ideas for how to increase health behaviours in young people and to help them live healthy lifestyles. Consistently across questions they felt that encouraging exercise and healthy eating was vital and this needed extra promotion and advertising with accessible services for all.

#### *Key messages for young people to be healthy*

In order for children and young people to be physically, mentally and emotionally healthy key messages included:

- Make the services more child friendly – supply things to do whilst waiting, create a warmer health environment, and make sure health professionals explain things in an understandable format. A success story from one young person illustrates the power of this approach:

*“When I had a sore hip joint the doctor explained to me exactly what was wrong and how they are going to help me in a way I could understand. This encouraged me and also taught me a bit of scientific information; it was nice knowing exactly what was wrong with me and was ensured that the treatment I was getting was going to help me.”*

- Supply information/advice for young people – young people wanted to know more about their health conditions and to have more information in a child friendly format. They want to be addressed as individuals with power, choices and a voice that can be heard.
- Services need to be accessible – young people wanted more specialist health services nearer to home, regardless of where they lived (rural/urban). They want them to be age appropriate and accessible by all forms of transport including walking. Some suggested home visits.
- Young people would like shorter waiting times for appointments, more check-ups, suitable appointment times (out of school) and believe an

- increased workforce in the healthcare system is needed to meet these demands.
- Young people with illnesses and young carers both received and wanted most help from their family/friends. They also received help to a lesser degree from health professionals including doctors/nurses, hospital/medical specialists and psychologist/counsellor/psychiatrists. A number of young people also felt they did not get any help at all or relied on themselves. Identifying ways in which young people feel they can turn to health professionals will be of vital importance to increase the numbers of options for confiding/support to young people. Of even greater importance is the need to identify who the young people are in society who feel that they do not receive any help, why this is, and how they could be encouraged to seek support when needed.
  - Where young people would like to receive help may provide some insight into how to encourage help seeking behaviours. Many mentioned they would like the involvement of close others or to be in familiar locations (such as a friend/family home). Others felt that confidentiality/privacy was of vital importance and had a preference for natural/outdoor environments. A smaller proportion would choose health venues, but when so they seemed to be a place that the young person was familiar with. Other suggestions involved familiar locations such as school and during activities/at shops/cafes/place of worship. A key commonality seems to be a location that the young person feels comfortable with or makes them feel relaxed and safe to talk. The involvement of close others and the whole family for health care plans maybe one possibility.

#### *Types of illness/disability and implications*

One of the most common illnesses in the sample involved attention and psychological problems representing both learning/attention difficulties and mental health issues. Interestingly, those with mental illness/attention/learning difficulties were also most likely to rate themselves as having a disability. This finding points to the importance of considering the need for psychological support for physical illness and the impact this may have on a young person's well-being. It also points to the need to cater for the needs of children and young people with learning/attention difficulties and mental health problems.

Problems with senses were the next most prevalent category to be considered a disability with many young people referring to loss of eyesight or hearing. Although asthma was such a common health problem in the sample only 11/180 people referred to it as a disability and those that did made reference to mobility issues. Similarly only one person considered their allergy to be a disability even though it was a common illness. Even when disability affected different health systems the young person often referred to the impact it had on mobility. Helping young people to be mobile, to continue with their lives and interact with others seems to be an important implication for helping young people with disabilities to be healthy.

### *Psychological impact of illness or caring*

The psychological impact of illness and caring for others was a repeated theme. The story below illustrates the impact that physical illness can have:

*"My mum had a brain tumour and a stroke 5 years ago, when I was 12, she is now paralysed down the left side of her body. I have been so stressed with caring for my mum that I have had to have counselling and have an eating disorder. I have felt very alone as no one seems to want to help me care for my mum.*

Young people frequently mentioned that they would like psychological help to help with the impact of caring/their illness, and some did have help from psychologists or psychiatrists. They especially wanted someone to talk to about their problems in a safe environment and where they could talk privately and confidentially. The importance of emotional well-being was also stressed with requests for help with self esteem and self confidence and a suggestion was made that these often need to be dealt with first before tackling other issues.

Young people also felt that extra understanding and awareness is needed by teachers and schools, health professionals and the general public about their health problem. This may help to reduce the psychological impact of physical illness.

### **Make a positive contribution**

Where relevant to the question, most young people suggested that social support for their illness or health problem or as a carer was vital and they wanted to be supported socially, emotionally and practically. Most young people wanted to receive help from family or friends generally for their health/problem or illness and when asked where they'd like to talk about a health problem face to face they often mentioned in the comfort of their own home or at a friends/family members home. Young carers also stressed that they would like social support from family and friends, so this category consistently appeared as one of the most important across questions. In a similar vein, young people also said they would be happy to support others and carers felt this was important for the mental wellbeing of the ill person:

*"well when I was six I had an asthma attack at school and my best friend come out of school just to see me which made me happy"*

*"my close dear friend has a health problem and it makes her and me feel better to spend time with her to keep her mind of things. she is a very close friend and I care much for her, there so the hospitals are doing a great job and she always has a smile on her face she is very confident and a privilege to be around. she is an amazing girl to have her mind set to do one thing".*

*"my grandad had a heart attack right in front of me I rang an ambulance straight away and then I did c.p.r that I learned at ernal wood school I was so scared but luckily I kept his heart beating longer enough for the ambulance to come".*

Interestingly, when asked what sort of help carers would like and why nearly a third responded that they wouldn't like any help or didn't have anyone to help. Many requested that they would like help to increase their understanding of the illness or to increase their confidence in how to care. Some also were concerned that the person being cared for needed more activities to prevent them from being bored and they wanted the ill person to feel better and to experience a better healthcare system where health professionals would be friendly and talk more to the individual. The importance of being sensitive to the young person's desires and needs is therefore a necessity and many young people may want encouragement in their role to become more skilled. Such requests fit in with the Every Child Matters outcome to enable children to make a *positive contribution* and play an important role. Clearly there is a need to balance when encouragement in the caring role is important and how this fits with the young person's own needs. Indeed a great deal of young people also mentioned they would like support and for someone to take over so they could see friends, have a break or get on with school work. The importance of helping young people to *enjoy and achieve* in the face of caring responsibilities is of great importance

When asked about ideas to develop a health strategy young people were keen to state that they should be consulted and involved in decision making. The suggestions made were both insightful and numerous. Young people felt they wanted more power/to have say in the health process generally with the right to make their own choices and decisions regarding healthcare. They want healthcare professionals to listen to them and respect their views and to engage with them as individuals and not just their parents. Some young people expressed concern that their views were not always taken on board and didn't think any action would be taken, so the necessity of consulting and feeding back change/ideas and progress seems to be an important way ahead.

Treating the young person as their own expert with their own decisions with equal power (or more) to their parents was pointed out as a vital way ahead as was more child friendly efficient services with shorter waiting times and more appointments/consultation generally. Wanting to have more information and to make a positive contribution was a consistent message. It seems likely that allowing participation of young people in their own health care and decision making will help to provide more confident and resilient young people who are *emotionally and physically healthy*.

### **Enjoy and achieve**

School was frequently suggested as a suitable venue both for promotion of healthy behaviour and for the location of health services. Suggestions were made for specialists to attend schools to talk about healthy eating and exercise, to provide someone to talk to confidentially and to provide health services/support for those with an illness or disability.

Interestingly, many of the young people's ideas for the promotion of healthy foods and exercise, such as providing advice and information and free fruit/food do fit with current policies such as the School Fruit and Vegetable Scheme, the Food In School Programme (FiS) and the Healthy Schools Programme. However, it is clear that many young people in the current sample are not in areas where all of the schemes are available, so considerations about accessibility to all regardless of geographical location and income are important.

A number of references across questions were made about school teachers and it was suggested that they needed more understanding and awareness about illnesses/problems.

Providing access in schools for young people with health concerns or disabilities was also a theme:

*"I received no support in school for my dyspraxia or dyslexia, I was fobbed off repeatedly, they said I didn't try hard enough. At 8 years old I still couldn't write my name, the teacher said I was lazy. An educational psychologist showed my dyslexia to be extremely severe, but there was no money to help me, I didn't quite fit the criteria and that's because I had a high IQ. I received physio and occupational therapy under the NHS for 6 months and then told to get on with it. My mum gave up her job, de-registered me from school and within 6 months she had taught me to read. I now love reading, I have, together with my mums support, educated myself to a very high standard, it wasn't hard, I just follow the things I am truly interested in. I love maths and physics. I have chosen not to do gcse's as it is too costly as a private candidate. I will go to university because that's what I want to do. My mum has supported me all the way through, just the two of us. She is exceptional, she wanted to prepare me to make my own way in the adult world and she has done that. I feel very bitter with the educational system and feel sorry for other children that will have experienced the same as I did. But without that experience I wouldn't be who I am now. I have been lucky; I have a future with no limits".*

*"I have to attend a Mainstream school, which is eighteen miles away from my home. This was the only school with experience in dealing with Asperger's Syndrome, because my local council will not allow children to attend specialist units".*

Consistently across questions young people commented they would like more places for sport and recreational activities and many felt these did not exist in their area. Young people would like more open/outside spaces and interestingly often they would like to talk to someone about a health problem or issue in relaxing environments outside such as parks. Combining fun activities with health promotion was considered to be a healthy recipe and a request for more clubs and places to go/things to do was made. The need to *enjoy and achieve* was clearly expressed by the young people and seemed to be vital to the success of health promotion and a health strategy. Safety also seemed to be an issue that young people would constantly refer to in being able to access services, so considerations into how this can be provided needs to take place.

## **Stay safe**

Young people frequently mentioned the impact that drugs, bullying and crime had on their psychological well-being making it difficult to enjoy and achieve and live their life as they would like. As a recurrent theme they would like safer environments where they could feel safe to access/travel to health services or take part in recreational activities. There was a concern that public transport was not always safe and more 'safe' environments to play or carry out sport was needed:

*"there was no where young people could go to exercise so me, my little brother and his friend just ran around the hole HLC building but we ran into a big gang of bullies, they beat up my brother and that is all because we didn't have any were to go to run about and exercise..."*

Feeling safe when talking to professionals was another key concern with a desire for confidentiality and privacy.

## **Achieve economic wellbeing**

The cost of being healthy was pointed out repeatedly across questions. Young people felt healthy food should be supplied at a cheaper rate or free food such as fruit should be provided in schools. Many also felt that cheaper services for the use of leisure/sport facilities needed to be provided.

The reduced accessibility of health services in many locations emerged as a recurrent theme. Many felt the journey to a hospital or other health venue was too far especially if they lived in a rural area or did not have much money:

*"I live in a small town in Cumbria where there isn't much at all for a young person too do so the youths in my town are starting to become problems to our community, causing as much trouble as possible, to simply keep themselves occupied. We definitely need more opportunities, cheap opportunities or opportunities that are closer to home. Just because we don't live in a city doesn't mean we don't want to get involved in activities. The countryside always seems to get left out!"*

Increasing accessibility to all, especially of specialist services was stressed to be important in achieving equality and improving health and opportunities for all children and young people.

## Appendix 1 - the age distribution of respondents

|      |             |                    |
|------|-------------|--------------------|
| data | count       |                    |
| 0    | 13          |                    |
| 2    | 1           |                    |
| 6    | 3           |                    |
| 7    | 7           |                    |
| 8    | 38          |                    |
| 9    | 56          |                    |
| 10   | 95          |                    |
| 11   | 133         |                    |
| 12   | 234         |                    |
| 13   | 93          |                    |
| 14   | 100         |                    |
| 15   | 91          |                    |
| 16   | 102         |                    |
| 17   | 66          |                    |
| 18   | 36          |                    |
| 19   | 13          |                    |
| 20   | 6           |                    |
| 21   | 3           |                    |
| 22   | 3           |                    |
| 23   | 2           |                    |
| 24   | 1           |                    |
| 27   | 1           |                    |
| 33   | 1           |                    |
| 34   | 1           |                    |
| 36   | 2           |                    |
| 38   | 1           |                    |
| 39   | 2           |                    |
| 40   | 1           |                    |
| 46   | 1           |                    |
| 72   | 1           |                    |
|      |             |                    |
|      | <b>1107</b> | <b>total</b>       |
|      | 13.0804     | mean               |
|      | 4.295151    | standard deviation |
|      | 12          | median             |
|      | 12          | mode               |
|      | 0           | min                |
|      | 72          | max                |

## Appendix 2 - Index of Ethnic Background from 'other' category

| Ethnic Background                                | Count |
|--|-------|
| Welsh/White welsh                                | 4     |
| English/White English                            | 2     |
| Scottish/White Scottish                          | 1     |
| Irish  | 1     |
| British  | 1     |
| Eastern European                                 | 2     |
| other White European                             | 4     |
| mixed White/British/Irish                        | 6     |
| other mixed White                                | 4     |
| Indian/Pakistani/Chinese/Asian and White/British | 10    |
| Black  | 1     |
| Black British                                    | 1     |
| Black African                                    | 1     |
| Black African and mixed                          | 1     |
| Black British and white                          | 1     |
| town   | 3     |
| religion   | 2     |
| other  | 16    |

### Appendix 3 – County distribution of respondents

| County             |     |                   |             |
|--------------------|-----|-------------------|-------------|
| Shropshire         | 311 | Gloucestershire   | 2           |
| Devon              | 103 | Dundee City       | 1           |
| West Yorkshire     | 94  | Somerset          | 1           |
| Lancashire         | 67  | Worcestershire    | 1           |
| South Yorkshire    | 43  | Cardiff           | 1           |
| West Midlands      | 38  | City of Edinburgh | 1           |
| Greater Manchester | 30  | Cornwall          | 1           |
| Essex              | 27  | Inverness-shire   | 1           |
| Norfolk            | 27  | Orkney Islands    | 1           |
| London             | 27  | Scottish Borders  | 1           |
| Cheshire           | 25  | Monmouthshire     | 1           |
| East Yorkshire     | 19  |                   | <b>1018</b> |
| Wiltshire          | 19  |                   |             |
| Staffordshire      | 16  |                   |             |
| Leicestershire     | 16  |                   |             |
| Hampshire          | 12  |                   |             |
| Surrey             | 11  |                   |             |
| Kent               | 11  |                   |             |
| Cumbria            | 10  |                   |             |
| North Yorkshire    | 9   |                   |             |
| Middlesex          | 9   |                   |             |
| Northamptonshire   | 8   |                   |             |
| Merseyside         | 7   |                   |             |
| Nottinghamshire    | 6   |                   |             |
| Hertfordshire      | 5   |                   |             |
| Yorkshire          | 5   |                   |             |
| Cambridgeshire     | 5   |                   |             |
| East Sussex        | 5   |                   |             |
| Renfrewshire       | 4   |                   |             |
| Dorset             | 4   |                   |             |
| Northern Ireland   | 4   |                   |             |
| Derbyshire         | 4   |                   |             |
| Bristol            | 3   |                   |             |
| Tyne & Wear        | 3   |                   |             |
| Buckinghamshire    | 3   |                   |             |
| Herefordshire      | 3   |                   |             |
| Conwy              | 3   |                   |             |
| Cleveland          | 2   |                   |             |
| Oxfordshire        | 2   |                   |             |
| Bedfordshire       | 2   |                   |             |
| Aryshire           | 2   |                   |             |
| County Durham      | 2   |                   |             |

## Appendix 4 – Town distribution of respondents

| Town                                  | count |                     |   |
|---------------------------------------|-------|---------------------|---|
|                                       |       | Wolverhampton       | 4 |
| Telford                               | 307   | Derby               | 4 |
| Wakefield                             | 79    | Preston             | 4 |
| Exeter                                | 79    | Bristol             | 3 |
| Manchester                            | 30    | Halifax             | 3 |
| Norwich                               | 27    | Dartford            | 3 |
| Stockport                             | 27    | Bromley             | 3 |
| Sheffield                             | 25    | Ilford              | 3 |
| Torquay                               | 24    | Harrow              | 3 |
| Lancaster                             | 22    | Twickenham          | 3 |
| Warrington                            | 22    | Guildford           | 3 |
| Birmingham                            | 20    | Croydon             | 3 |
| Reading                               | 19    | Sutton              | 3 |
| Doncaster                             | 18    | Milton Keynes       | 3 |
| Stoke-On-Trent                        | 16    | Hereford            | 3 |
| Leicester                             | 16    | Llandudno           | 3 |
| Huddersfield                          | 11    | Crewe               | 2 |
| Carlisle                              | 10    | Northwest London    | 2 |
| Darlington                            | 9     | Redhill             | 2 |
| East London                           | 9     | Teeside             | 2 |
| Hull (officially: Kingston-upon-Hull) | 8     | Oxford              | 2 |
| Northampton                           | 8     | Luton               | 2 |
| Coventry                              | 8     | Kilmarnock          | 2 |
| Bolton                                | 7     | Canterbury          | 2 |
| Bradford                              | 7     | Maidstone           | 2 |
| Portsmouth                            | 7     | Southeast London    | 2 |
| Liverpool                             | 7     | Durham              | 2 |
| Colchester                            | 7     | Newcastle Upon Tyne | 2 |
| Nottingham                            | 6     | Gloucester          | 2 |
| Walsall                               | 6     | Uxbridge            | 2 |
| Southend-On-Sea                       | 5     | Dundee              | 1 |
| Leeds                                 | 5     | Stevenage           | 1 |
| Southwest London                      | 5     | Taunton             | 1 |
| York                                  | 5     | Worcester           | 1 |
| Cambridge                             | 5     | Cardiff             | 1 |
| Brighton                              | 5     | Edinburgh           | 1 |
| Southampton                           | 5     | Enfield             | 1 |
| West London                           | 5     | Truro               | 1 |
| Romford                               | 4     | Inverness           | 1 |
| Shrewsbury                            | 4     | Tonbridge           | 1 |
| Paisley                               | 4     | Kirkwall            | 1 |
| Chelmsford                            | 4     | Blackburn           | 1 |
| North London                          | 4     | Tweeddale           | 1 |
| Hemel Hempstead                       | 4     | Newport             | 1 |
| Bournemouth                           | 4     | Wigan               | 1 |
| Ipswich                               | 4     | Fylde Coast         | 1 |
| Belfast                               | 4     | Chester             | 1 |

|        |      |            |   |
|--------|------|------------|---|
| Oldham | 4    | Sunderland | 1 |
|        | 1018 |            |   |

## Appendix 5 – Types of health problems in the sample

| Type of Health Problem               | Count | Examples   |
|--------------------------------------|-------|--|
| Asthma/respiratory                   | 125   | Mainly asthma, few cases of breathing problems and cystic fibrosis   |
| Attention/psychological              | 51    | Autism, ADHD, Asperger's, Dyspraxia, Fragile X, mental health issues (including depression, anxiety, OCD, eating disorders and psychosis). |
| Allergies                            | 28    | Mainly hay fever, few cases nut allergy and penicillin   |
| Muscular/skeletal                    | 26    | Arthritis, Osgood-Schlatters, Spondylolisthesis, Marfan Syndrome, Phosphoglycerate Kinase Deficiency, Multiple Exostosis                   |
| Skin complaints                      | 24    | Mainly eczema, few cases, burns, skin cancer, rash, psoriasis.   |
| Heart/cardiovascular/blood           | 19    | Heart problems (defects, murmur, and mitral valve prolapse) high blood pressure, sickle cell disease, leukaemia, anaemia.                  |
| Digestive                            | 12    | Celiac, IBS, crohns, bowel malfunction, colitis  |
| Head/brain (non psychological)       | 11    | Migraines, cerebral contusion, hydrocephalus, aqueduct stenosis, agenesis corpus callosum  |
| Endocrine                            | 10    | Diabetes and thyroid   |
| Reproductive or sexually transmitted | 8     | AIDS (4), approaching menopause, endometriosis, scrotal oedema and ovaries.  |
| Nervous System                       | 6     | Multiple sclerosis and epilepsy  |
| Urinary System                       | 6     | Water infections, renal failure, one kidney  |
| Senses                               | 5     | Hearing loss, auditory processing disorder, needing glasses.   |
| Lymphatic and immune                 | 4     | Chronic fatigue, systemic lupus  |
| Glandular                            | 2     | Mesenteric adenitis and t-cell Hodgkin's lymphoma of the glands  |
| Sensory/motor/integrative systems    | 2     | Cerebral palsy   |
| Unknown/minor/temporary              | 31    | Mystery, private, illness, small spots, gene problem, cold, the world, glue ear, death.  |

## Appendix 6 – Perceived disability in the sample

| Type of Health Problem               | Count | Examples  |
|--------------------------------------|-------|---|
| Attention/psychological              | 61    | <i>"I find learning difficult"</i> , Autism, ADHD, Asberger's, Dyspraxia, Fragile X, downs syndrome, global developmental delay, mental health issues (including depression, anxiety, OCD, eating disorders and psychosis). |
| Senses                               | 18    | <i>"very little sight in my left eye"</i> , <i>"partially deaf"</i> , <i>"slightly blind in one eye"</i> , <i>"visually impaired."</i>  |
| Muscular/skeletal                    | 15    | <i>"I have marfan syndrome and it causes some long tern problems"</i> , <i>"hip and knee problems"</i> , <i>"slipped vertebrae in my back"</i> , perthes' disease, multiple exostosis.                                      |
| Asthma/respiratory                   | 11    | <i>"asthma impairs my life quite a bit"</i> , <i>"cannot walk due to brittle asthma"</i> .  |
| Sensory/motor/integrative systems    | 8     | Cerebral palsy, <i>"I can't walk properly"</i> , <i>"limited mobility."</i>   |
| Heart/cardiovascular/blood           | 6     | Heart defect, heart murmur, sickle cell, PKU, remission of leukaemia.   |
| Head/brain (non psychological)       | 4     | Cerebral contusion, hydrocephalus, head illness, paroxysmal tonic upgaze and cerebellar ataxia.   |
| Skin complaints                      | 3     | Eczema, albinism  |
| Digestive                            | 2     | <i>"Stomach bag"</i> , <i>"poo"</i>   |
| Nervous System                       | 2     | epilepsy  |
| Urinary System                       | 2     | 1 kidney  |
| Endocrine                            | 2     | diabetes  |
| Allergies                            | 1     | hay fever   |
| Glandular                            | 1     | t cell non Hodgkinson's lymphoma of the glands  |
| Lymphatic and immune                 | 1     | Chronic fatigue and chronic pain syndrome   |
| Reproductive or sexually transmitted | 1     | <i>"my willy"</i>   |
| None                                 | 33    |   |
| Don't know                           | 5     |   |
| Other                                | 18    | <i>"nothing to discuss"</i> , <i>"go away"</i> , <i>"I get sick most of the time"</i> , <i>"nystagma"</i> , CPD.  |

**Appendix 7 – Who do you receive help from for your illness/health problem? Other category**

| Help from  | Count | Examples  |
|--|-------|---|
| parents/foster/adoptive carers                         | 32    | <i>Parents, mom and dad,</i>  |
| doctor/nurse   | 15    | <i>Community nurse, asthma nurse, GP and Drs, hospital Dr, medical advice from GP</i>         |
| hospital specialist/physiotherapist/physical therapist | 13    | <i>Hospital heart specialist, OT and physio, cardiovascular specialist, asthma consultant</i> |
| don't get help/none/myself                             | 11    | <i>I don't get help for it, nobody, noone, myself</i>   |
| medication/surgery                                     | 8     | <i>I take tablets daily, inhaler, surgery, take thyroxine</i>                                 |
| other family   | 7     | <i>family</i>   |
| psychologist/counsellor/psychiatrist                   | 6     | <i>Psychologist, counsellor, consultant psychiatrist</i>                                      |
| someone close who is trained                           | 5     | <i>Mum – she's a nurse, nan and granddad they are trained paramedics but retired</i>          |
| friends  | 3     | <i>Friends</i>  |
| children's centre/community services                   | 3     | <i>Autism outreach, children's centre, community services</i>                                 |
| internet/phone help voluntary                          | 2     | <i>Childline, on-line diet group</i>  |
| complementary therapist                                | 1     | <i>homeopath</i>  |

**Appendix 8 – If you do get help, who do you get it from – someone else – please state who**

| Help from                           | Count | Examples  |
|-------------------------------------|-------|---|
| parents/foster/adoptive carers      | 19    | <i>Mummy, my mum + dad because they listen to me, My aunty or mum</i> |
| other family                        | 10    | <i>my nan, my family anyone one of them</i>                           |
| friends/girl/boyfriend              | 15    | <i>my friends, boyfriend, my mate Maria</i>                           |
| family/friends of person caring for | 4     | <i>that persons family, their family an mine</i>                      |
| other children/young carers         | 3     | <i>Young Carers, other children</i>                                   |
| doctors/nurses                      | 1     | <i>Family and nurses/doctors</i>                                      |
| psychologist/psychiatrist           | 1     | <i>Psychiatrist</i>   |
| support worker/home carers          | 3     | <i>a local support worker, HOME CARERS</i>                            |
| social worker                       | 1     | <i>Social worker</i>  |
| school/teachers                     | 1     | <i>the teachers at there school</i>                                   |
| myself                              | 4     | <i>me and myself, no 1</i>  |
| no one/don't know                   | 6     | <i>I told you I don't get help, NOT SURE</i>                          |
| other                               | 13    | <i>any body, A dentist. your nabor</i>                                |

## Appendix 9 – what sort of help would you like? Other (please specify)

| Help would like                                  | Count | Examples  |
|--|-------|---|
| no-one/none                                      | 10    | <i>no help</i>  |
| friends helping                                  | 4     | <i>that my friends came and help more often<br/>My Best Friend</i>  |
| respite/a rest                                   | 3     | <i>someone helping or talking the children out while I have a rest<br/>more time out</i>  |
| health professional being nice/friendly/talking  | 2     | <i>A nurse being more polite and not being rude and horrible to the person I care for (my nan)<br/>someone to talk to the person about that person's problem.</i> |
| better treatment/care                            | 2     | <i>health system improved, person cared for has poor health care</i>  |
| activities/things to keep person occupied/active | 2     | <i>something they could do to stop them getting bored in the house</i>  |
| someone to help psychologically/with goals       | 2     | <i>someone to help me achieve my goals</i>  |
| relatives helping                                | 1     | <i>I help my grandad to look after my nan when I am down there with other family members</i>  |
| doctor/other health prof to help                 | 1     | <i>the doctor to help because they need the help.</i>   |
| more people helping                              | 1     | <i>everyone she knows caring</i>  |
| something to ease pain/symptoms                  | 1     | <i>I would like something to make her back hurt less</i>  |
| other  | 6     | <i>classes</i>  |