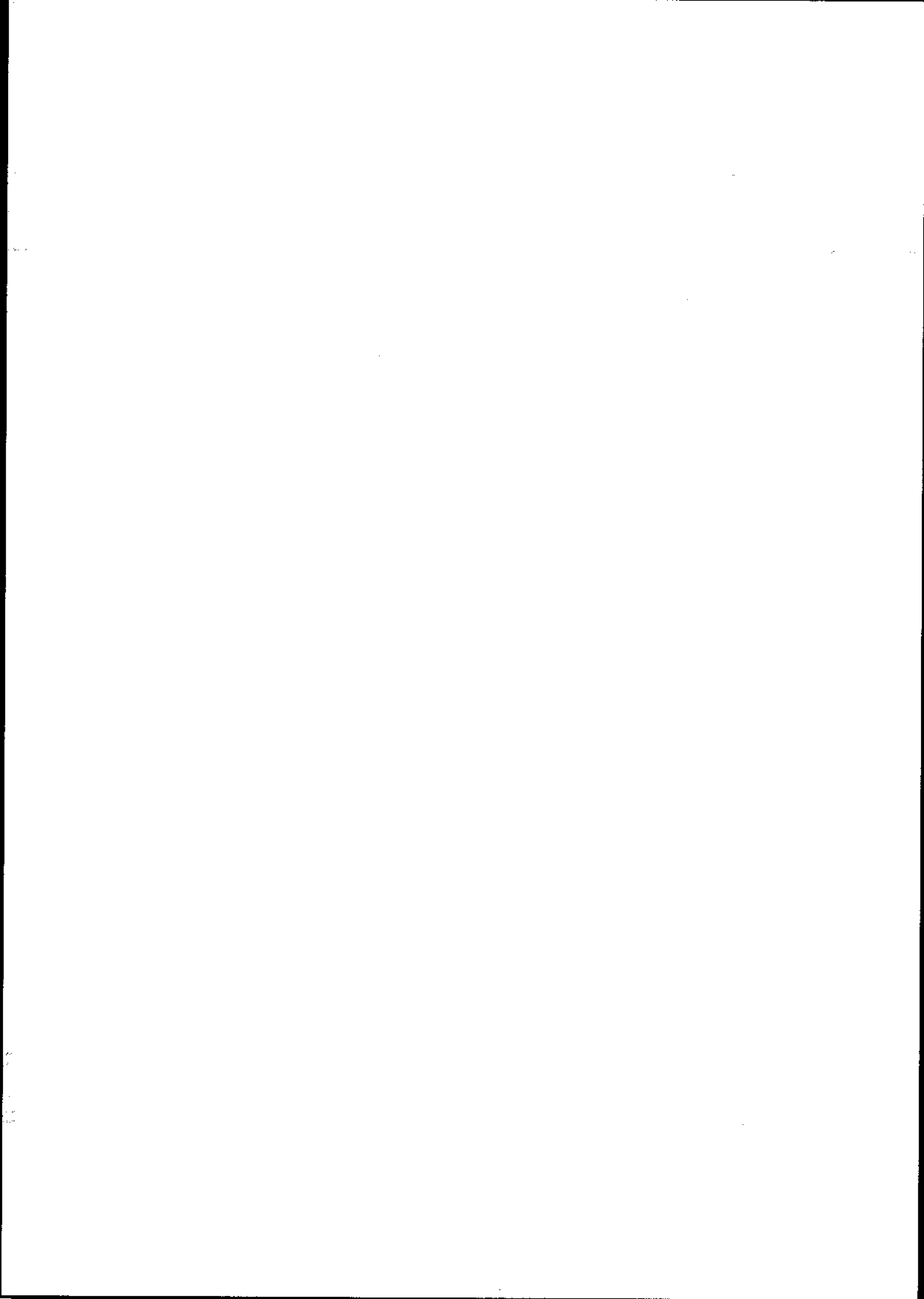


APPENDIX ONE
QUESTIONNAIRES FOR SCHOOLS



**QUESTIONNAIRE ON CHILDREN WITH CHRONIC
ILLNESS OR PHYSICAL DISABILITY**

PRIMARY SCHOOL

Name and Address of School:

Telephone Number:

Name of Liaison Teacher:

Please return this questionnaire in the envelope provided

**QUESTIONNAIRE ON CHILDREN WITH CHRONIC ILLNESS
OR PHYSICAL DISABILITY**

PRIMARY SCHOOL

Purpose of this questionnaire

The purpose of this questionnaire is to identify all children in primary school who could participate in the project on 'Service support for children with a chronic illness or physical disability in mainstream schools'.

Confidentiality

This information is confidential to the school. Please do not use the child's name on the form. We suggest that you use a code as a way of identifying the children referred to on the form.

Which children are we interested in?

Please fill in this form for all children in primary school known to have a chronic illness or physical disability.

Who should fill in the form?

By now your school has probably decided which teacher will be liaising with us over the next few months. It is probably simplest if this person is responsible for returning the form to us. The liaison teacher may know enough about children in primary school to complete the form, but please do what ever is easiest for your school.

What happens once the form is completed?

Please return the form to:

Jane Lightfoot, Social Policy Research Unit, University of York,
Heslington, York, YO1 5DD.

A stamped addressed envelope has been provided.

We will not be able to invite the families of all children with a chronic illness or physical disability in primary school to take part in the project. We will use the information we from this questionnaire to invite the families children with different types of service support needs to participate in the study. We intend to invite parents to take part in the study by letter. In order not to break confidentiality we would ask you to pass letters from us on to the family.

Who do I contact for further information or advice?

Please feel free to telephone Jane Lightfoot or Suzanne Wright on 01904 433608, Monday-Friday, 9.00 am - 5.30 pm.

WHAT WE MEAN BY 'CHRONICALLY ILL OR PHYSICALLY DISABLED CHILDREN'

This study is about health service support and, as you know, children with chronic illnesses and physical disabilities need a wide range of different types of support. We want to make sure we include the following groups of children in the study:

- 1 *Children with serious, recurrent illnesses*
- 2 *Children who require continuous health support during the school day*
- 3 *Children who are technology dependant*
- 4 *Children with mobility difficulties*
- 5 *Children with life threatening conditions*
- 6 *Children regularly absent from school, due to a chronic illness/physical disability*
- 7 *Children who regularly have a treatment requiring a stay in hospital*

Examples of children who might fall into one or more of these groups include those with: cystic fibrosis, cerebral palsy, muscular dystrophy, diabetes, epilepsy, severe asthma, cancer, tracheostomies, ME, severe allergies, renal failure, rheumatoid disorders, haemophilia, sickle cell anaemia.

There are a couple of points to make about this list:

- This is a list of the children we think should be included in the study. However, this study is about school life and you are probably in better position than us to say which children are having most difficulty managing in mainstream education and for whom teaching staff need extra help. If you think there any groups of children we have missed out, or if there are any children who you think particularly warrant attention, please let us know in the space provided in the questionnaire (Pt 7).
- Some chronically ill/physically disabled children in your schools may have a Statement of Special Educational Needs due to their health needs. We are interested in including children both with and without Statements in the study.

**CHILDREN WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY
PRIMARY SCHOOL**

PLEASE DO NOT USE THE CHILD'S NAME ON THIS FORM

Child's Code		
Year		
Gender (M/F)		
Chronic Illness/Physical Disability		
Statement of SEN? (Yes/No)		
If no statement, are they at any stage on the Code of Practice? (Yes/No)		
Reason for Statement (Health/ Education)		
1. Recurrent but not Continuous Illness? (YES/NO)		
2. Health Support Needed in School? (YES/NO)		
3. Technology Dependent? (YES/NO)		
4. Mobility Difficulties? (YES/NO)		
5. Life Threatening Illness? (YES/NO)		
6. Regularly Absent from School? (YES/NO)		
7. Regularly Require Inpatient treatment? (YES/NO)		
8. Please comment on any other aspect of the illness which causes difficulty in school.		

**QUESTIONNAIRE ON CHILDREN WITH CHRONIC
ILLNESS OR PHYSICAL DISABILITY**

SECONDARY SCHOOL

Name and Address of School:

Telephone Number:

Name of Liaison Teacher:

QUESTIONNAIRE ON CHILDREN WITH CHRONIC ILLNESS OR PHYSICAL DISABILITY

Purpose of this questionnaire

The purpose of this questionnaire is to identify all children in school who could participate in the project on 'Service support for children with a chronic illness or physical disability in mainstream schools'.

Confidentiality

This information is confidential to the school. Please do not use the child's name on the form. We suggest that you use a code as a way of identifying the children referred to on the form.

Which children are we interested in?

Please fill in this form for all children in school known to have a chronic illness or physical disability.

Who should fill in the form?

By now your school has probably decided which teacher will be liaising with us over the next few months. It is probably simplest if this person is responsible for returning the form to us. The liaison teacher may know enough about children in school to complete the form, but please do what ever is easiest for your school.

What happens once the form is completed?

Please return the form to:

Jane Lightfoot, Social Policy Research Unit, University of York, Heslington,
York, YO1 5DD.

A stamped addressed envelope has been provided.

We will not be able to invite all children with a chronic illness or physical disability in school to take part in the project. We will use the information from this questionnaire to invite children with different types of service support needs to participate in the study. We intend to invite parents and children to take part in the study by letter. In order not to break confidentiality we would ask you to pass letters from us on to the family.

Who do I contact for further information or advice?

Please feel free to telephone Jane Lightfoot or Suzanne Wright on 01904 433608, Monday-Friday, 9.00 am - 5.30 pm.

WHAT WE MEAN BY 'CHRONICALLY ILL OR PHYSICALLY DISABLED CHILDREN'

This study is about health service support and, as you know, children with chronic illnesses and physical disabilities need a wide range of different types of support. We want to make sure we include the following groups of children in the study:

- 1 *Children with serious, recurrent illnesses*
- 2 *Children who require continuous health support during the school day*
- 3 *Children who are technology dependant*
- 4 *Children with mobility difficulties*
- 5 *Children with life threatening conditions*
- 6 *Children regularly absent from school, due to a chronic illness/physical disability*
- 7 *Children who regularly have treatment requiring a stay in hospital*

Examples of children who might fall into one or more of these groups include those with: cystic fibrosis, cerebral palsy, muscular dystrophy, diabetes, epilepsy, severe asthma, cancer, tracheostomies, ME, severe allergies, renal failure, rheumatoid disorders, haemophilia, sickle cell anaemia.

There are a couple of points to make about this list:

- This is a list of the children we think should be included in the study. However, this study is about school life and you are probably in better position than us to say which children are having most difficulty managing in mainstream education and for whom teaching staff need extra help. If you think there any groups of children we have missed out, or if there are any children who you think particularly warrant attention, please let us know in the space provided in the questionnaire (Pt 8).
- Some chronically ill/physically disabled children in your schools may have a Statement of Special Educational Needs due to their health needs. We are interested in including children both with and without Statements in the study.
- We will not be able to include children with severe learning difficulties in the project since, to take part, children need to be able to comprehend the research questions as concerned with service support.

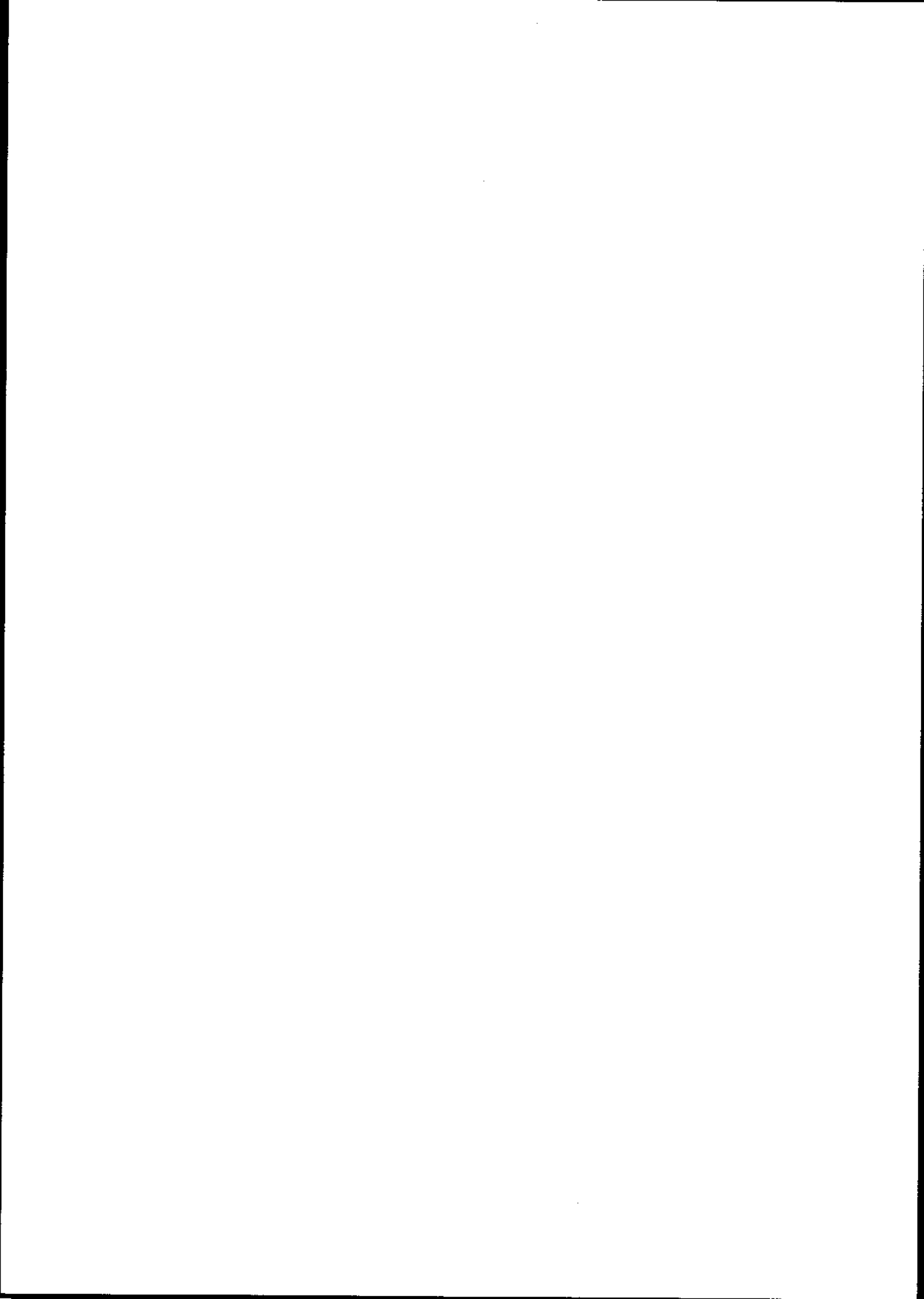
**CHILDREN WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY
SECONDARY SCHOOL**

PLEASE DO NOT USE THE CHILD'S NAME ON THIS FORM

Child's Code		
School year and age		
Gender (M/F)		
Chronic Illness/Physical Disability		
Statement of SEN? (Yes/No)		
If no statement, are they at any stage on the Code of Practice? (Yes/No)		
Reason for Statement (Health/ Education)		
1. Recurrent but not Continuous Illness? (YES/NO)		
2. Health Support Needed in School? (YES/NO)		
3. Technology Dependent? (YES/NO)		
4. Mobility Difficulties? (YES/NO)		
5. Life Threatening Illness? (YES/NO)		
6. Regularly Absent from School? (YES/NO)		
7. Regularly Require Inpatient Treatment? (YES/NO)		
8. Please comment on any other aspect of the illness which causes difficulty in school.		

APPENDIX TWO
LETTER, INFORMATION LEAFLET, RESPONSE AND
CONSENT FORMS FOR PARENTS

Primary school
Secondary school



PRIMARY



Dear Parent

Health Support in School Project

We are carrying out a research project funded by the NHS to look at health service support for children with special health needs attending mainstream school. The local health and education authorities have agreed to participate in this project, as has your child's school.

As part of the project we will be holding a discussion group for parents of young children with an illness or disability. To respect your privacy we have asked the school to pass this letter on to parents who might be interested in taking part in the project. Enclosed with this letter is a leaflet which explains the project and answers some questions you may have before deciding whether to take part.

We can help with any reasonable costs to enable you to come to the parents' meeting such as transport or child care costs.

If you are interested in taking part in the project, please could you fill in the response form and return it in the stamped addressed envelope provided.

Please do telephone us on 01904 433608 if you have any questions about the research project.

Thank you

Yours sincerely

Suzanne Wright

Jane Lightfoot

Enc: Project leaflet
Response form

PROJECT LEAFLET FOR PARENTS

Health Support in School Project

The purpose of this leaflet is to tell you about the project and explain what will happen if you decide to take part.

Who is writing to you?

We are researchers based at the Social Policy Research Unit at the University of York. We have experience of working with children and young people of all ages in schools, hospitals and home settings. This work has made us aware of the importance of health-related support in school.

The aim of the project

The aim of the project is to help improve support from the NHS for children and young people in mainstream schools who have special health needs. This will be done by:

- Interviewing young people with special health needs, their parents, and their teachers to find out what support they need from the NHS in schools.
- Presenting these views to professionals who work with young people and to local health and education authority managers.
- Holding meetings so that the local health and education authority managers can plan for improved NHS service support in schools.

Why should I take part in the project?

Until recently it was rare for health and education authorities to consider the views of children, parents and teachers when planning support services for children. This project is a way of letting health and education authorities know about the kind of support you and your child need.

Who is taking part in the research?

A total of sixty children and young people, along with their parents and teachers, will be included in the study. *Children aged under 8 years will not be interviewed.* Their views will be represented by their parents and teachers taking part in a group discussions.

Professionals from local health and education services, and NHS and LEA managers will be asked to take part in workshop meetings.

Why am I being asked to take part?

We are looking for families who can tell us about health service support for children and young people. Your school has agreed to help us by passing this letter on to any families who might be interested in the project.

What will I be asked to do?

We are asking you to attend a local parents' meeting. Approximately ten parents will attend each meeting. The purpose of the meeting is for us to find out about parents' experiences of health service support and the kind of support they would like.

What will happen to the information?

Everything we discuss is confidential. We will not identify you in discussions we have with teachers or any other health or education professionals.

The information we collect will be summarized and presented at workshops for health and education professionals and managers. The information will also be written up as a report and sent to the NHS Executive who funded the research. You will be sent a summary of the report. We hope that the report will be used by health and education services nationally in planning future services for children and young people with a chronic illness or disability.

What happens next?

If you decide you would like to consider taking part in the project, fill in the form saying 'yes' and return it in the envelope provided. Once we have received this form one of us will contact you to discuss the project further. Whether you take part in the project or not will not affect any of the health or education services that you currently receive.

We expect the parents' meeting to take place in July 1997.

How can I find out more about the Project?

We would be pleased to answer any questions you have about the research. You can write to Suzanne Wright or Jane Lightfoot at the Social Policy Research Unit, University of York, Heslington, York, YO1 5DD or telephone us on (01904) 433608.

PARENTS RESPONSE FORM

Health Support in School Project

Name

Child's Name

School

Class

I am willing to consider taking part in the project

(please tick)

Please give your address and telephone number. This will enable us to contact you to tell you more about the project. If you then decide you are interested in taking part we will be in touch nearer the time of the parents' meeting.

Address:

Telephone Number:

Please return this form in the envelope provided

Please do telephone Suzanne Wright or Jane Lightfoot between 9.00am and 5.30 pm, Monday to Friday, on 01904 433608 if you want to ask any questions about the project.

CONSENT FORM FOR PARENTS

Health Support in School Project

I have read the project leaflet and understand the purpose of the project and what it involves. I understand that the project is strictly confidential and neither myself or my child will be named in any project reports. I understand that I can withdraw from the project at any time without giving a reason.

I am willing to take part in the group meeting for parents.

(Please circle your answer)

Yes No

Name

Signature

Date

SECONDARY

Dear Parent



Health Support in School Project

We are carrying out a research project funded by the NHS to look at health service support for young people with special health needs who attend mainstream school. The local health and education authorities have agreed to participate in this project, as has [school]

As part of the project we will be interviewing young people with a chronic illness or physical disability to get their views about their needs in school. We will also be talking to parents. To respect your privacy we have asked the school to pass this letter on to parents who might be interested in taking part in the project. Enclosed with this letter is a leaflet which explains the project and answers some questions you may have before deciding whether to take part.

If you are willing to consider taking part, please pass on the separate information pack to your child. The pack includes a letter, information leaflet and a response form and will help your child decide whether he or she would consider taking part in the project.

If you are interested in the project, please could you fill in the response forms from yourself and your child and return them in the stamped addressed envelope.

Please do telephone us on 01904 433608 if you have any questions about the research project.

Thank you

Yours sincerely

Suzanne Wright
Jane Lightfoot

Enc: Project leaflet
Response form
Letter, leaflet and response form for your child

PROJECT LEAFLET FOR PARENTS

Health Support in School Project

The purpose of this leaflet is to tell you about the project and explain what will happen if you decide to take part.

Who is writing to you?

We are researchers based at the Social Policy Research Unit at the University of York. We have experience of working with children and young people of all ages in schools, hospitals and home settings. This work has made us aware of the importance of health-related support in school.

The aim of the project

The aim of the project is to help improve support from the NHS for children and young people in mainstream schools who have special health needs. This will be done by:

- Interviewing young people with special health needs, their parents, and their teachers to find out what support they need from the NHS in schools.
- Presenting these views to professionals who work with young people and to local health and education authority managers.
- Holding meetings so that the local health and education authority managers can plan for improved NHS service support in schools.

Why should I take part in the project?

Until recently it was rare for health and education authorities to consider the views of children, parents and teachers when planning support services for children. This project is a way of letting health and education authorities know about the kind of support you and your child need.

Who is taking part in the research?

Young people with an illness or disability are being contacted through a number of schools in [research sites]. A total of forty young people, along with their parents and teachers, will take part in the study.

Professionals from local health and education services, and NHS and Education Authority managers will be asked to take part in workshop meetings.

Why am I being asked to take part?

We are looking for families who can tell us about health service support for young people. Your child's school has agreed to help us by passing this letter on to any families who might be interested in the project.

What will I be asked to do?

First, we need your permission to talk to your child and your child's own consent to talk to us. We plan to meet all young people individually to get their views on the support they currently receive and the support they would like in school. Interviews will be at a time and place that is convenient to your son/daughter.

Secondly, we are asking if we can come and talk to you. The purpose is for us to find out about parents' experiences of health service support and the kind of support they would like.

What will happen to the information?

Everything we discuss is confidential. We will not identify you in our discussions with teachers or any other health or education professionals.

The information we collect will be summarized and presented at workshops for health and education professionals and managers. The information will also be written up as a report and sent to the NHS Executive who funded the research. You and your child will be sent a summary of the report. We hope that the report will be used by health and education services nationally in planning future services for young people with a chronic illness or disability.

What happens next?

If you decide you would like to consider taking part in the project, fill in the form saying 'yes' and return it in the stamped addressed envelope provided. Once we have received this form one of us will contact you to discuss the project further. If you then decide you do want to take part in the project we can make the necessary arrangements. Whether you take part in the project or not will not affect any of the health or education services that you may currently receive.

We plan to talk to parents and to children between June and the end of September.

How can I find out more about the Project?

We would be pleased to answer any questions you have about the research. You can write to Suzanne Wright or Jane Lightfoot at the Social Policy Research Unit, University of York, Heslington, York, YO1 5DD or telephone us on (01904) 433608.

PARENTS RESPONSE FORM

Health Support in School Project

Name

Child's Name

School

Class

I am willing to consider taking part in the project

(Please tick)

Please give your address and telephone number. This will enable us to contact you to tell you more about the project.

Address:

Telephone Number:

Please return this form in the envelope provided

Please do call Suzanne Wright or Jane Lightfoot between 9.00am and 5.30 pm, Monday to Friday, on 01904 433608 if you want to ask questions about the project.

CONSENT FORM FOR PARENTS

Health Support in School Project

I have read the project leaflet and understand the purpose of the project and what it involves. I understand that the project is strictly confidential and neither myself or my child will be named in any project reports. I understand that I or my child can withdraw from the project at any time without giving a reason.

I am willing to allow my son/daughter to take part in the project.

(Please circle your answer)

Yes No

I am willing to take part in the group meeting for parents.

(Please circle your answer)

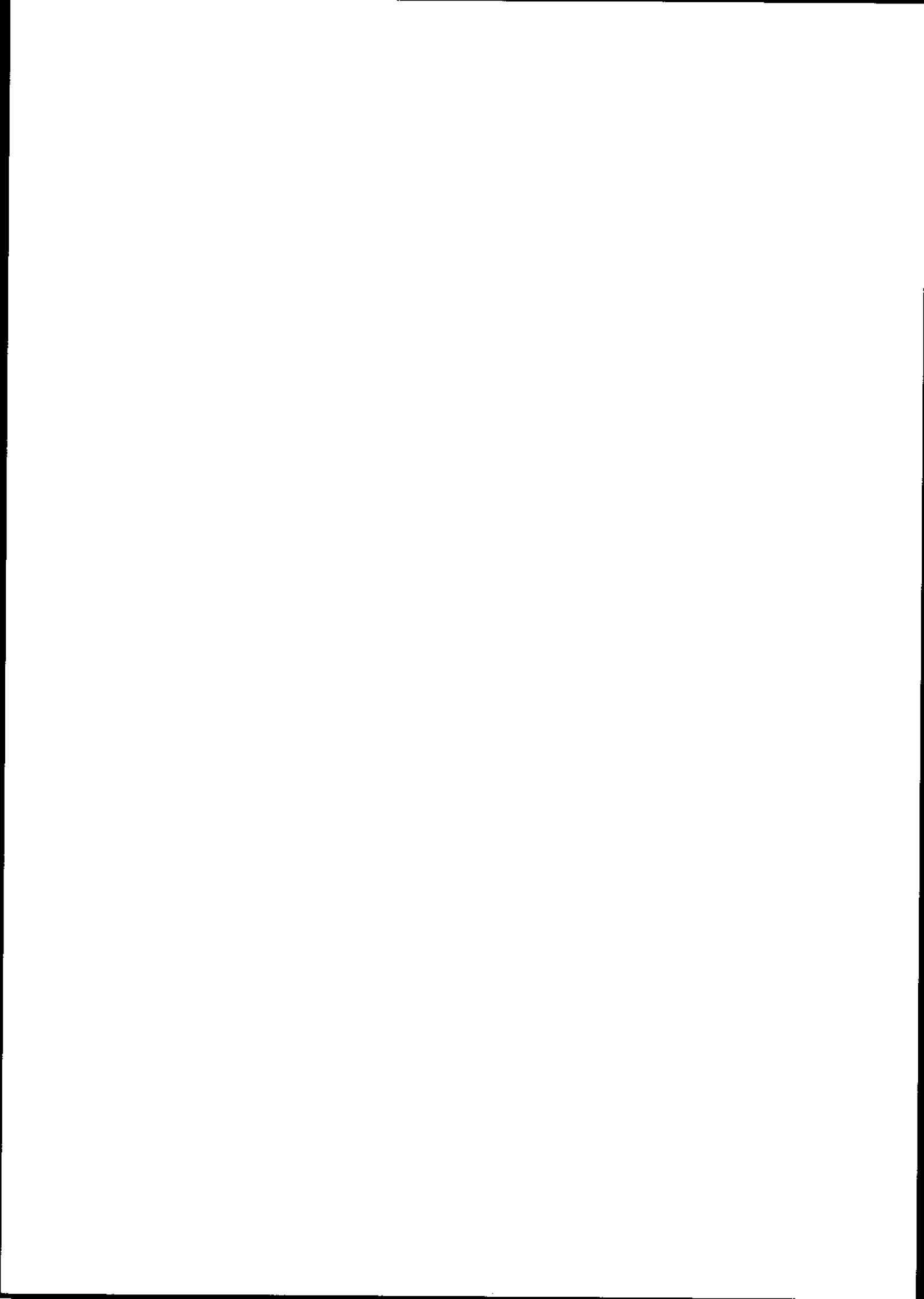
Yes No

Name

Signature

Date

APPENDIX THREE
LETTER, INFORMATION LEAFLET, RESPONSE AND
CONSENT FORMS FOR YOUNG PEOPLE





Dear Student

Health Support in School Project

We are doing a research project which we hope will help improve the support that young people with special health needs receive from teachers and health professionals while they are in school.

As part of the project we would like to talk to some young people who have had a long term illness or disability while at school.

To respect your privacy we have asked your school to pass this letter on to students who might be interested in taking part in the project. The leaflet enclosed explains the project and what it would mean if you agreed to take part.

We have written to your parents about the project for two reasons. First, we need to have their agreement that you can take part in the project. Secondly, we are hoping that they will take part by talking to us too. The purpose of us talking to your parents is to get their views on the support your family has received from health staff.

If you are interested in being involved, please could you fill in the attached form and return it with your parent's form in the envelope provided.

We hope that you are interested in the project and think it is worth taking part.

Thank you

Suzanne Wright

Jane Lightfoot

Enc

PROJECT LEAFLET FOR YOUNG PEOPLE

Health Support in School Project

The purpose of this leaflet is to tell you about the project and to explain what will happen if you decide to take part.

Who is writing to me?

We are two researchers, Suzanne Wright and Jane Lightfoot. We work at the University of York. The health service has asked us to do this project. They would like to improve the help that they give to young people in school. The best way to find out about what needs to be done is to ask young people.

Who is taking part in the research?

Young people with special health needs, along with their parents and teachers, are being contacted in schools in [research sites]. A total of forty young people will be asked to take part in the study.

Local health and education staff working with children and young people will be asked to take part in workshop meetings.

Why am I being asked to take part?

We are looking for young people who can tell us what it is like to have an illness or a disability in school. Your school has agreed to help us by passing this letter on to anyone in their school who might be interested in talking to us. We are interested in meeting with young people, *even if they feel they have had no problems managing in school.*

What are you trying to find out from me?

We would like to know : *about your life in school; your good and bad experiences with health and education staff; and what would make your life in school easier.*

What will I have to do?

First, one of us would like to talk to you so that we can tell you about the project and you can tell us a little bit about yourself. You can then decide whether you would like to take part. We can then meet to talk about your school and what could be done to

make school life easier for you. Whenever we meet it will be at a time and place that suits you.

Will my parents or teachers be told about what I say?

No, everything we discuss is confidential. That means that we will not discuss what you say with your parents, teachers or anyone else without your permission. Your name will not be used when we write up reports of the project

What will happen with the information?

We will write a summary of what young people have told us. We will then hold meetings and present this information to health and education staff. The staff will be asked to use this information to think about how they should change their services for young people.

After the meetings we will write up a report. We will send you a summary of the report. The report will be sent to the health service who asked for the research to be done. We hope that the report will be used by them in planning help for young people in the future.

Do I have to take part in the project?

No, you do not have to take part. If you do decide to take part you can still change your mind at any time. We will accept your decision. We will not ask you to give a reason for refusing to take part.

What happens next?

If you decide you might like to take part in the project fill in the form saying 'yes' and return it with your parent's form in the envelope provided. One of us will then phone or write to you to arrange for us to meet.

**If you would like to talk to Suzanne or Jane about the project,
telephone 01904 432627 between 9.00am and 5.30pm Monday to Friday.**

YOUNG PERSON'S RESPONSE FORM

Health Support in School Project

Name

Age

School

Class Teacher

I am willing to consider taking part in the project

(Please tick)

Please give your address and telephone number so that we can contact you to tell you more about the project.

Address:

Telephone Number:

Please return this form in the envelope provided.

You can call Suzanne Wright or Jane Lightfoot between 9.00am - 5.30pm, Monday to Friday on 01904 432627 to ask questions about the project.

YOUNG PERSON'S CONSENT FORM

Health Support in School Project

I have read the project information sheet.

Yes No

I understand that everything I say is confidential and my name will not be used in the project report.

Yes No

I understand that I can change my mind about taking part in the project at any time. I do not have to give a reason for changing my mind.

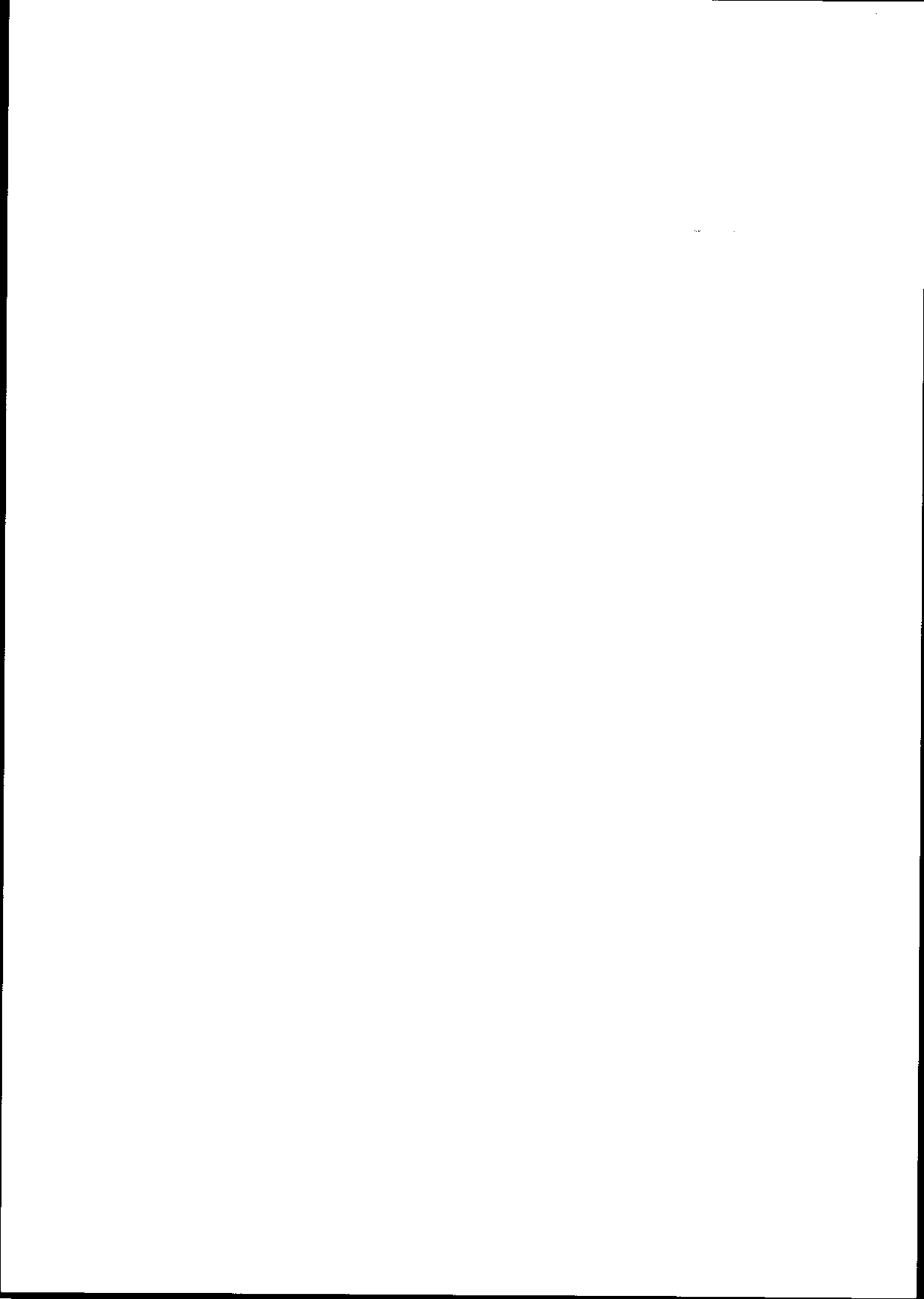
Yes No

I agree to being interviewed as part of the project on 'Health Support in School'.

Name

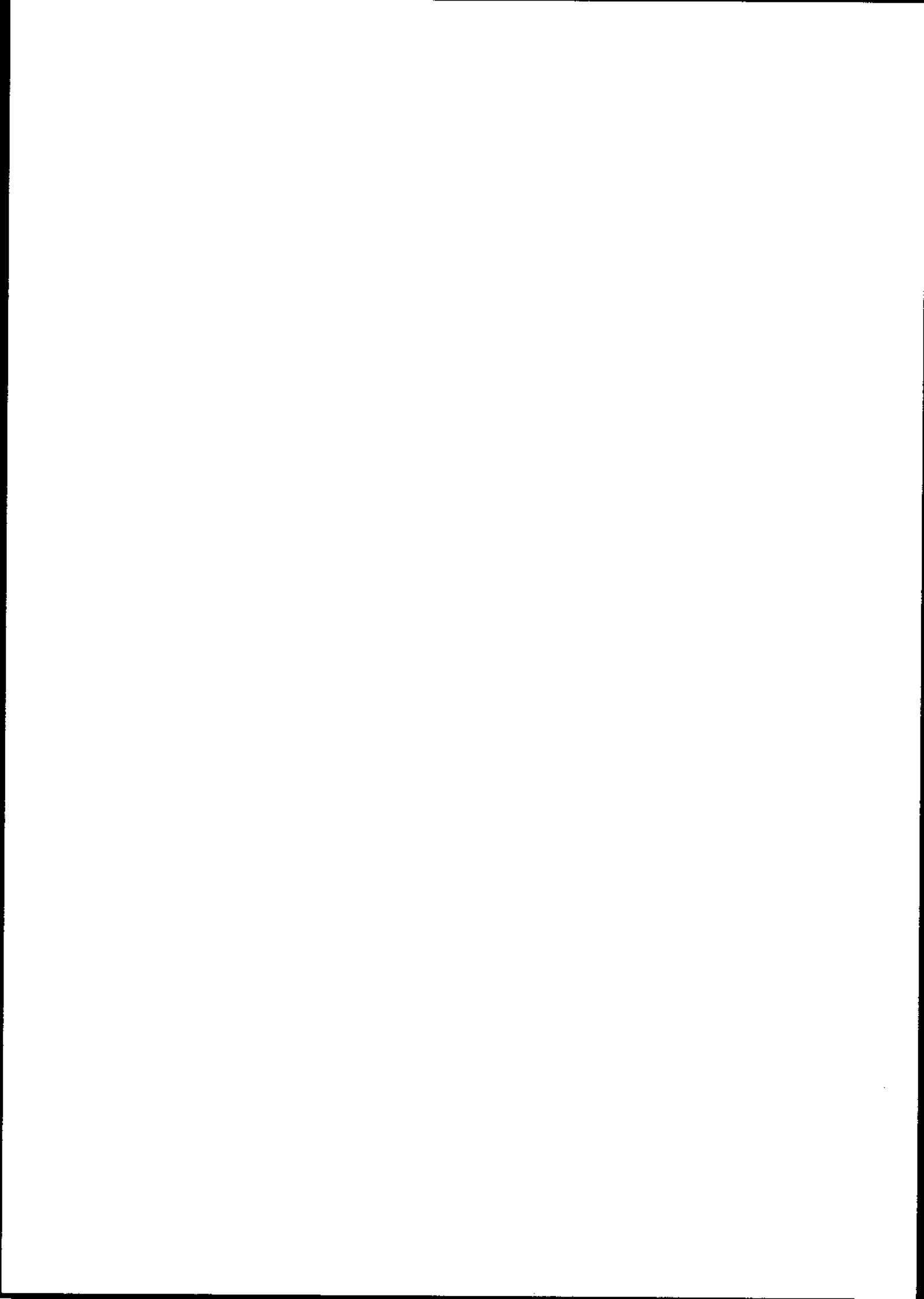
Date

APPENDIX FOUR
HEALTH CONDITIONS OF YOUNG PEOPLE OF
SECONDARY SCHOOL AGE

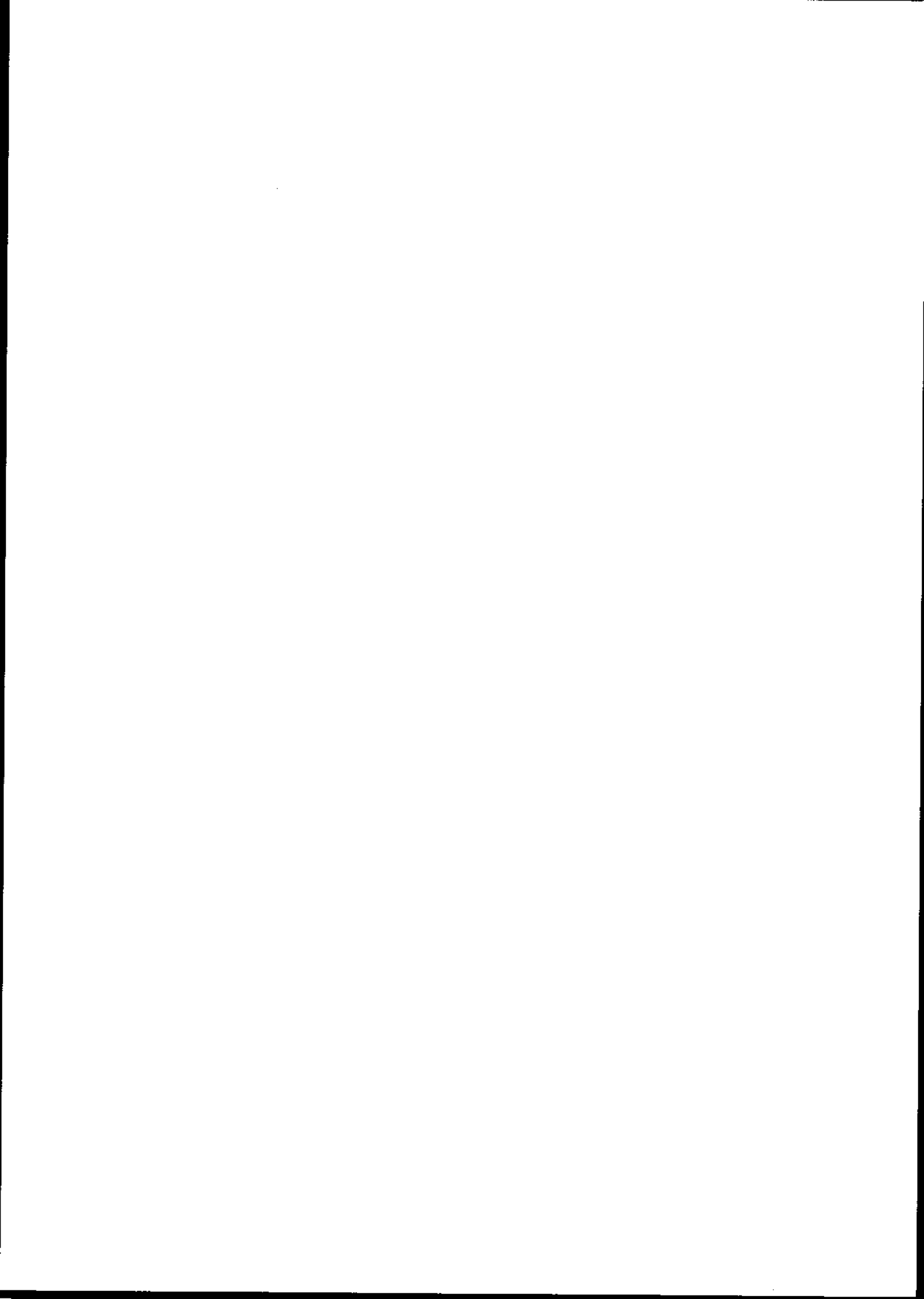


**Health conditions of young people
of secondary school age**

Health condition	Number
asthma (severe)	1
cerebral palsy	4
cerebral palsy and epilepsy	1
charcot marie tooth disease	1
cleft palate	1
cranial tumour	1
cystic fibrosis	1
diabetes	2
diabetes and food allergies	1
eczema (severe) and asthma	1
haemophilia	1
hearing and sight difficulties	1
heart condition	1
heart and lung condition	1
juvenile arthritis	2
ME	5
neutropenia	1
perthes disease	1
renal failure	2
russell silver syndrome	1
spina bifida	2
tracheostomy	1
Total	33

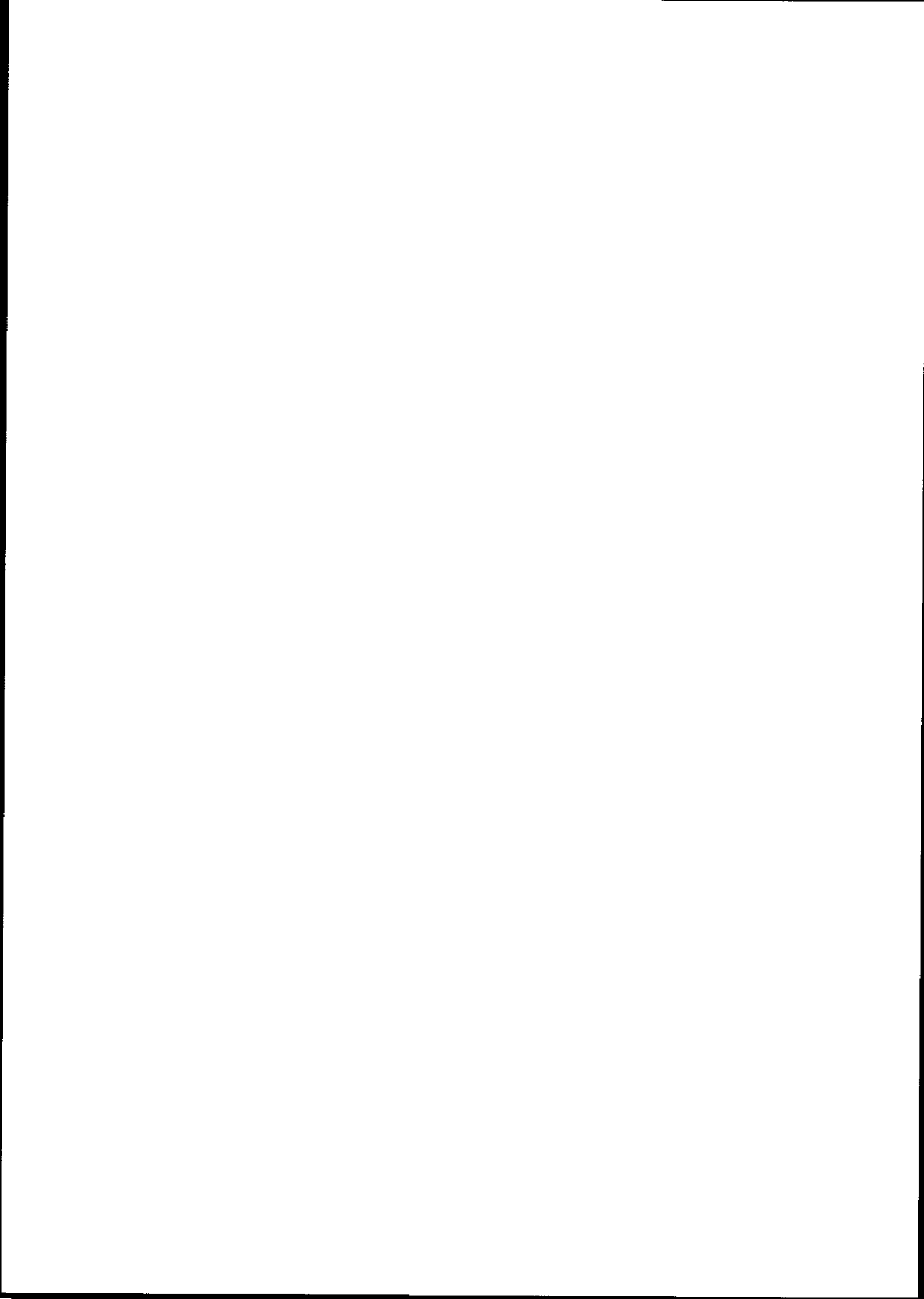


APPENDIX FIVE
HEALTH CONDITIONS OF CHILDREN OF
PRIMARY SCHOOL AGE

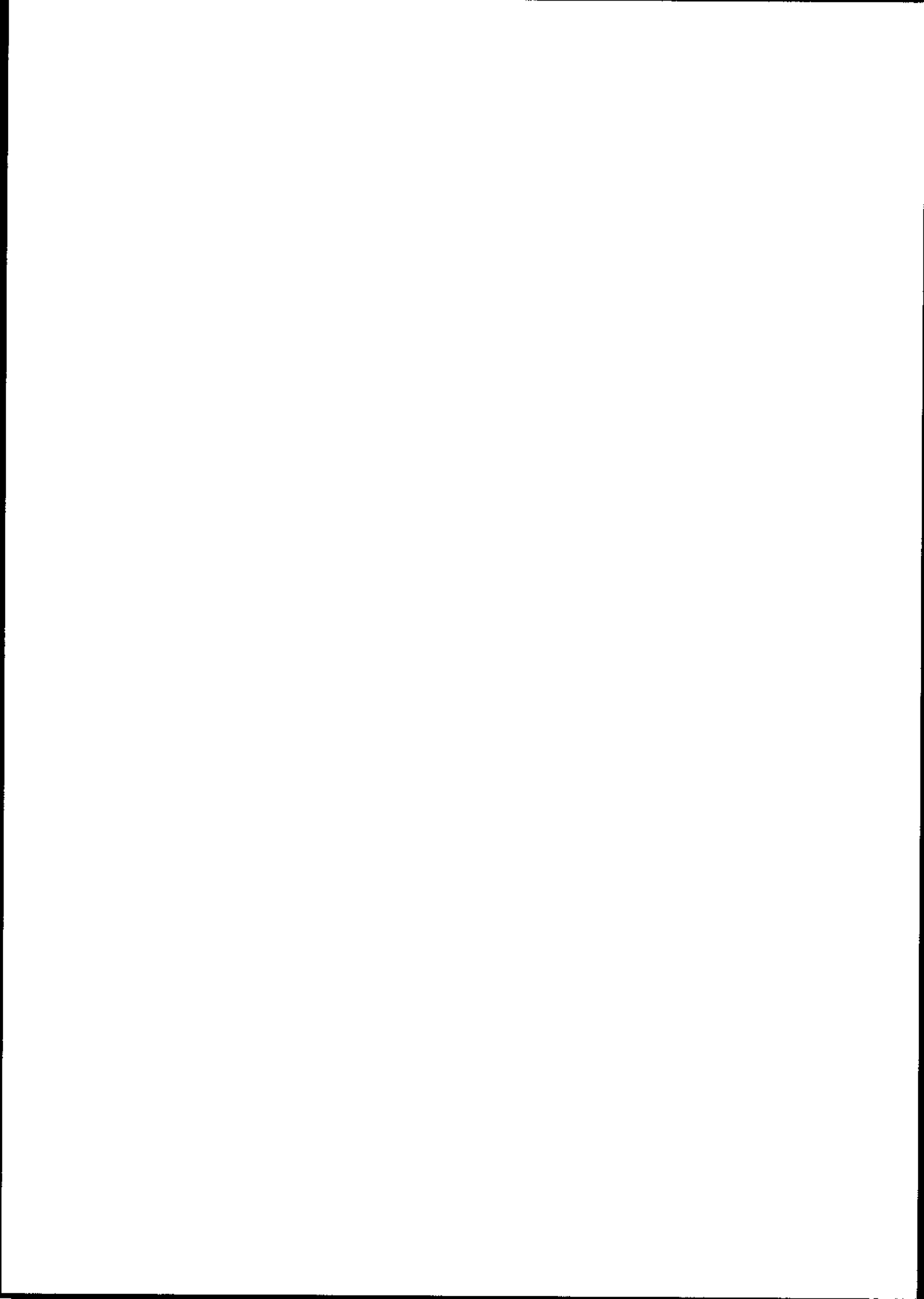


**Health conditions of children
of primary school age**

Health condition	Number
asthma (severe)	3
asthma and eczema	1
bowel problems	1
cerebral palsy	1
cystic fibrosis	1 (2 children)
diabetes	3
di-george syndrome	1
down's syndrome	2
friedrich's ataxia	1
hearing loss	2
hirsprung's disease	1
holoram syndrome	1
leigh's syndrome	1
muscular dystrophy	2
nut allergy	1 (2 children)
nut allergy, asthma and eczema	1
tracheostomy	1
visual impairment	1
Total	33



APPENDIX SIX
TOPIC GUIDE FOR INTERVIEW WITH YOUNG PEOPLE



SERVICE SUPPORT PROJECT

INTERVIEW WITH YOUNG PERSON: TOPIC GUIDE

INTRODUCTION WITH FAMILY

Thank you

Introduce Self

Explain Project

We are doing a project about the help that young people in schools get when they have a health problem. We want to find out about :

1. The help that young people get in schools
2. How this help could be improved.

We want to talk to young people because they know a lot about this. They are the experts. I am here to find out what you think about the help you have had. There aren't any right or wrong answers.

Later on in the project we will be meeting with managers in health and education. Do you know what I mean by Managers? They are the bosses of people like teachers, nurses and doctors. They decide how money is spent and the type of help that children and teenagers get when they have a health problem.

Today we are going to talk about:

- Your school
- Your health
- How your health affects things in school
- Who helps you and what they do
- What you think of the help you get

Explain about Stopping and Passing

When we are talking, you can change your mind about wanting to talk whenever you want. Also, if you don't want to answer a particular question that's ok. We can just go on to the next question. You don't have to give me a reason for stopping or skipping a question.

Maybe we should agree before we start what you will say if you want to stop or to skip a question. What words would you like to use?

Confidentiality

Everything we talk about will be private. That means that I won't tell your parents, your teachers or anyone else what you say.

At the end of the project I will write up a report of what all the young people I meet tell me. I won't put your name in the report.

I will tape record what we say. That's just to save me writing everything down. I won't write your name on the tape. I will use a code. The only people that will listen to the tape are me and the other person I work with, (name).

Is that OK?

Any questions ?

Check that can speak to young person alone

Check with the young person and the parent that it's OK to talk to the young person on their own.

Consent Form**PRELIMINARIES WITH YOUNG PERSON ALONE****Tape Recorder**

Recap about confidentiality

Show the code number on the tape

Ask if they want to take charge of the tape recorder during the interview

Stopping and Passing

Remember, if want to stop at any time or want to skip a particular question you just have to tell me. (Confirm the words child will use to stop or pass).

No Right or Wrong Answer

This isn't a test. There aren't any right or wrong answers. I am here because I am interested to find out about the help that you have and you are the expert on this.

GENERAL QUESTIONS

Young Person's Age

Family

Do you have any brothers or sisters?

What age are they?

School

I think you are atschool. Is that right?

What year are you in?

How long have you been at that school?

If been to other secondary schools get details of how long at each. Ask about experience at other schools as a way of getting opinion of current school.

How many different teachers do you have?

How many are in your class?

FEELINGS ABOUT SCHOOL

School Work

What is your favourite *subject*? Why?

What subjects do you not like? Why?

Sports

What *sports* do they do at your school?

Which do you do?

Which do you like? Which do you not like? Why?

Relationships

What are the *teachers* like?

Which ones do you like? Why is that?

How about the ones that aren't so nice? Who are they? Why do you not like them so much?

What are you *classmates* like?

Which ones do you like. Why is that?

How about the ones that aren't so nice? Who are they? Why do you not like them so much?

Extra Curricular Activities

Are there any *clubs or groups* you can join at your school?

Do you go to any of them?

If Yes: What are they like?

If No : Why not?

General

So what is your school like *in general*. Is it a good school to go to or not? Why?

Secondary School Leavers

What are you going to do now that you have left school?

How do you feel about that? Why?

How do you feel about leaving school? Why?

HEALTH

Introduction:

I don't know a lot about your health except that you have [condition] and I don't know a lot about that? Could you explain it to me?

Duration of Illness

When did you first find out you had [condition]?

Treatment

Do you have to have any treatment for it or see health people about it? Who?

Do you see any of those people at school?

IMPACT OF HEALTH ON SCHOOL

General:

Does having [condition] make any difference to things in school?

Refer back to previous probes about aspects of school:

Does it make any difference to your school work?

Does it make any difference to the sports you take part in?

Does it make any difference to how your teachers treat you?

How about to the way that the other people in your school treat you?

Does it make any difference to the clubs and societies you can join or to what you do at those clubs?

Typical School Day

It might help me to understand what it's like to have [condition] in school if you describe school day and things that you do differently to the others in your class. Do you think you describe a school day for me? Maybe you could start with getting up in the morning and getting ready to go?

Missing School

Do you have to have much time off school?

Do you miss out on any particular classes?

Positive Aspects

Are there any 'good' things that happen in school because of your [condition]?

Plans For Future

Have you thought about what you want to do after you leave school? What would you like to do?

Does your health make any difference to your plans for what you do after school?

THE HELP I GET (MAP)

Introduction

I would like to find out about all the help you get to manage in school

It would help me to understand it if you could draw a diagram of all the people who help you.

Clarify that it can be practical or emotional help

Some people might help you in practical ways - helping you get about, sorting out your medicine etc.

Others might help by being there for you talk to, sticking up for you.

Clarify that anyone that they think helps can go on the map

You can put anyone on the map - your friends, parents etc. Anyone who you think helps.

Using the diagram

For each person on the map ask:

What do they do?

How do you feel about that?

Clarify that it can include people seen outside the school building

Once interviewee has added everyone to map ask:

Is there anyone else who you see outside of school who does things which makes life easier for you in school?

How about your doctors, nurses etc?

Check out health and education professionals previously mentioned by the child but not put on the map. Do they help with school?

SENTENCE COMPLETION

Introduction

I have got four sentences written on a piece of card, but they aren't finished. They are all something to do with the help you get . Can you finish the sentence off for me?

1. The person who helps me most with school is.....
2. I like it when people.....
3. I don't like it when people.....
4. I would like more help with.....

HOW HELP MIGHT BE IMPROVED (LIST)

Thinking about all the different types of help you get with school, can you make a list of:

Things I would like to change

Things I would like to stay the same

OTHER HELP

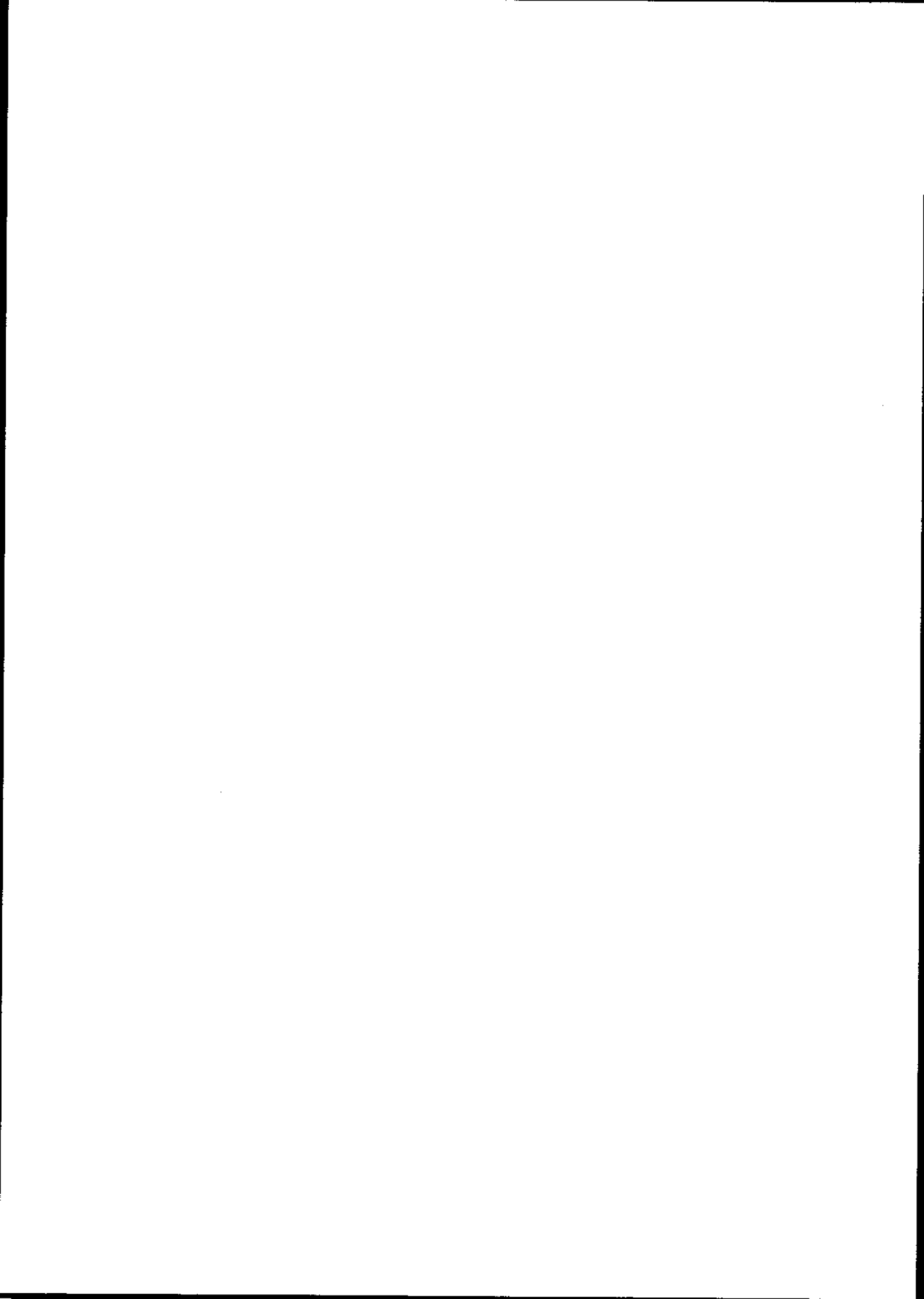
We have talked a lot about the help you get. Is there any other help you would like which you don't get at the moment?

Do you need any extra help to prepare you for leaving school ?

IS THERE ANYTHING ELSE YOU TO SAY ABOUT THE HELP YOU GET?

EXPLAIN WHAT HAPPENS NEXT IN THE RESEARCH STUDY

APPENDIX SEVEN
TOPIC GUIDE FOR INTERVIEW WITH PARENTS



SERVICE SUPPORT PROJECT
PARENT INTERVIEW: TOPIC GUIDE

PRELIMINARIES

Thank you

Introduce self/SPRU

Explain project

The NHS has asked us to do this project because they want to find out how they can improve the help that some children need in relation to school. So the purpose of the project is to:

1. *find out about the help* that children with an illness or a disability get in relation to school and
2. how it might be *improved*.

To find out about this, we are talking to parents, to teachers and to students in secondary schools because you know most about it: you are the *experts*.

When we have collected all this information we will be holding a *meeting with local education and health managers* to pass on what people have said. The information will be *anonymous*: we will not use people's names. The idea of this meeting is for managers to know both what they are getting right and where they might do things differently to make sure that children, parents and teachers get the help they need.

As researchers, we do not have the power to make managers act on what we say. But managers inhave given us permission to do the project here because they are *interested to find out* what people need and what they think about services.

Today I'd like to talk to you about

-(your child's) health
- your experiences and views in terms of any helpgets in relation to managing in school
- any ideas you have on how things might be improved.

We can then pass on this advice to managers to help them improve things for children in the future.

Confidentiality

Everything we talk about will be private.

I will tape record what we say, just to save me taking notes. We use codes instead of names on the tapes. The only other person who could listen to the tape is Suzanne, who is working with me on this project.

At the end of the project we will write a report, but we will not use people's names. We'll send you a summary of the report so you can see what was said.

Any questions?

Consent form

form + copy of information sheet

GENERAL QUESTIONS

How many children are there in the family?

What ages are they?

.....goes toschool. Is the right?

How long hasbeen attending this school?

HEALTH

Introduction

I don't know much about(child's condition). Could you explain it to me?

Duration of illness

When did you first find out?

Treatment

Is any treatment necessary? What is it?

Who does your child see? How often?

Where (e.g. hospital/clinic/home/school)?

IMPACT OF HEALTH ON SCHOOL

General

Does having.....make any difference to your child in school? How?

Probes:

- school work?
- taking part in sports?
- taking part in after school clubs, etc?
- any difference in the way the child is treated: by teachers? by other children?

Does your child have to **miss much school**? How impact does that have? How do you deal with it?

Do you think there are **any positive aspects** for your child in school through having...?

How does havingaffect your child's **plans for the future** (i.e. after school)?

THE HELP MY CHILD GETS IN SCHOOL (*THE MAP*)

Introduction

I'd like to find out about the different types of help your child gets to help him/her manage in school. It would help me to understand this if you could draw me a diagram. What I was thinking was to draw a circle or something in the middle of the page to represent your child and then to mark around that anyone who helps your child.

- *you can put anyone on the map - e.g. teachers, doctors, your child's friends...*
- *some people might do practical things; others might be there as someone your child can talk to*

Using the diagram

For each person ask:

What do they *do*?

How do you *feel* about that?

The School Health Service

Is there a school doctor? A school nurse? What do they do?

Then probe people seen outside school

Is there anyone your child sees *outside* school who does anything which makes their life easier at school?

e.g. doctors, nurses?

Check out anyone mentioned in the 'Health' section who isn't on the map: do they help in relation to school?

Parent's role

As a parent, what do you have to do to help your child manage in school?

How do you feel about this?

Liaison Between Professionals

Looking at the various people on the diagram, do any of them work together in any way? Do they help each other? Do they give each other advice?

What do you think of the way they work together?

Liaison Between Professionals and Parent

What help or advice do you get from professionals?

ANY OTHER HELP

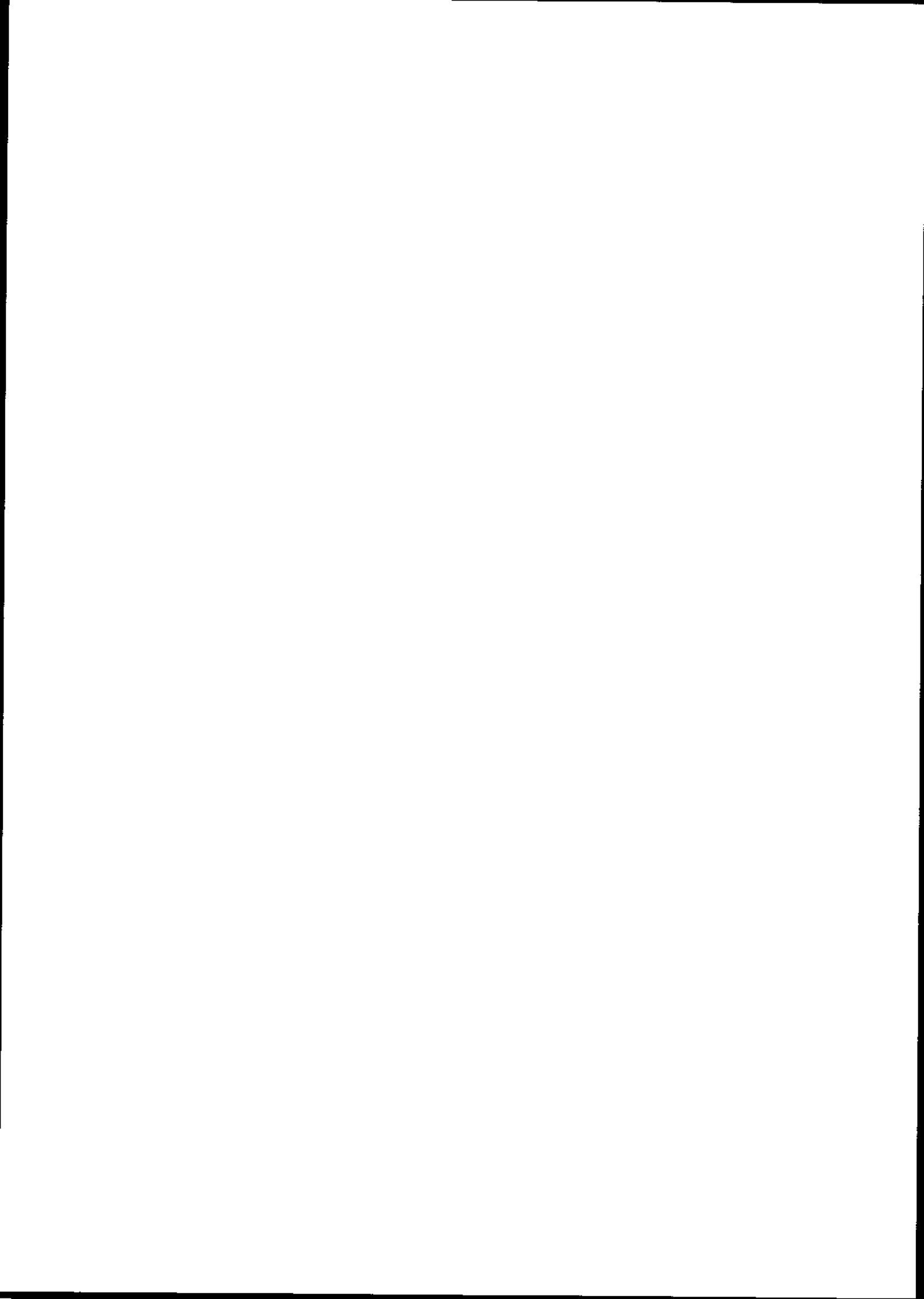
We have been talking mainly about the help your child *does* get. Is there any other help which you think is needed *which you do not get at the moment?*

IS THERE ANYTHING ELSE YOU WOULD LIKE TO SAY?

CLOSURE

- go through '*What happens next*' sheet for parents
- leave *paper* and *SAE* in case they want to write to us with any more comments.

APPENDIX EIGHT
JOB TITLES OF WORKSHOP DELEGATES



WORKSHOPS: INVITED DELEGATES

SITE A WORKSHOP

Education

LEA staff

Assistant Director (Special Services)*
Advisory Teacher
Head of Pupil Referral Service*
Integrated Support Service Teacher
Parent Partnership Co-ordinator
Senior Responsible Officer for Statementing

School staff

SENCO, Secondary School
SENCO, Secondary School
SENCO, Primary School

Health

Health Authority Staff

Consultant in Public Health**

NHS Trust staff

Lead Consultant Community Paediatrician
Consultant Community Paediatrician*
Consultant Community Paediatrician
Community Paediatrician
Child Health Support Manager
Diabetes Liaison Nurse
Occupational Therapy Manager
Paediatric Physiotherapist
School Nursing Co-ordinator

* did not attend

** attended for presentation of research findings only

SITE B WORKSHOP

Education

LEA staff: B1

Assistant Education Officer (responsible for writing Statements)

Learning Support Teacher (Physical Disabilities)

LEA staff : B2

Parent Partnership Officer

Physical Disability Support Teacher

Principal Educational Psychologist

Planning and Commissioning Manager*

School staff : B2

SENCO, Secondary school

SENCO, Primary school

Health

Health Authority

Consultant in Public Health*

NHS Trust: B1

Senior Clinical Medical Officer

Senior Paediatric Occupational Therapist

General manager, Community and Mental Health Services

Consultant Paediatrician*

A medical social worker also attended (who works from the local Child Development Centre based at the hospital)

NHS Trust: B2

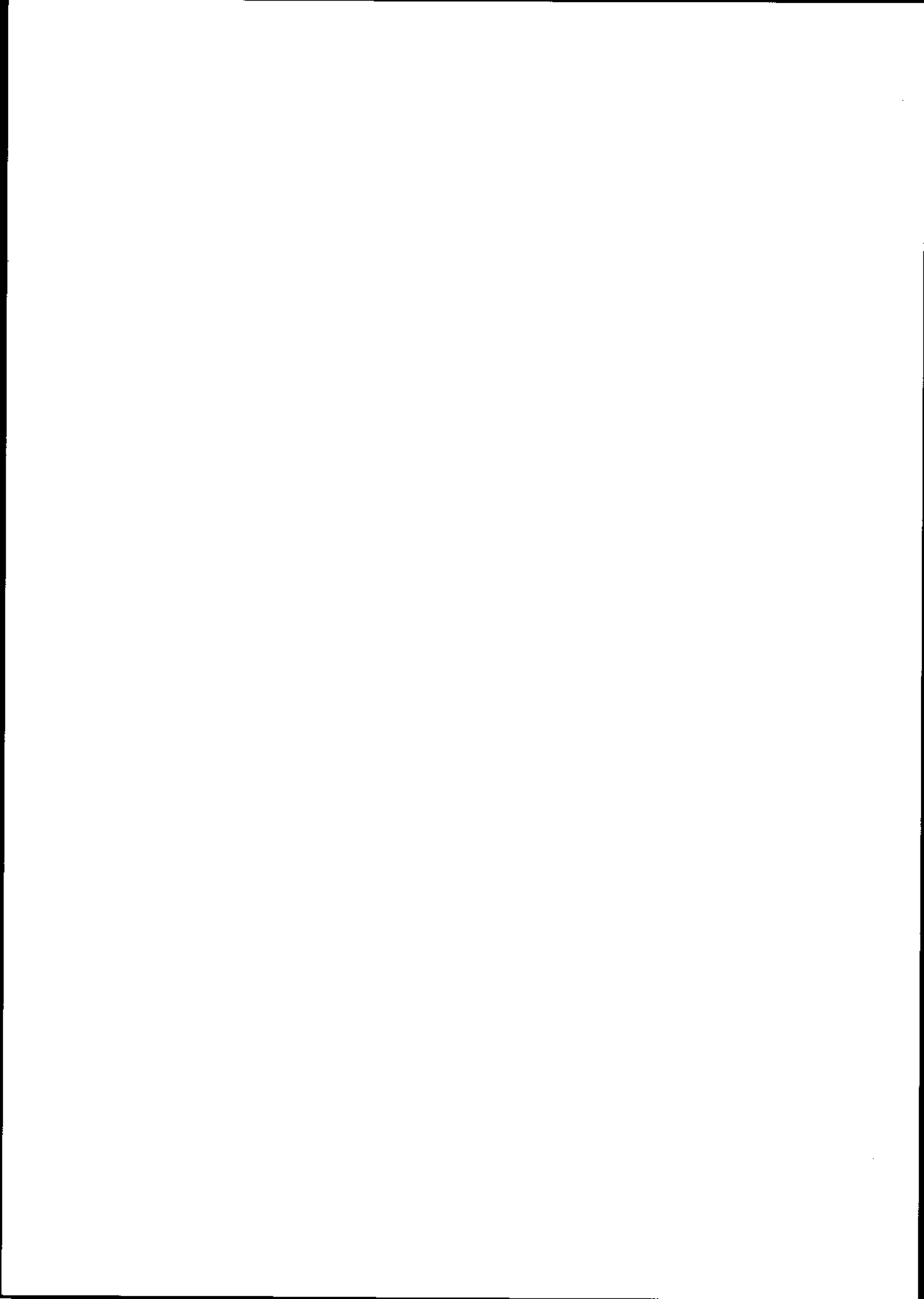
School Nurse Co-ordinator

Community Paediatrician

District Speech Therapy Manager

* did not attend

APPENDIX NINE
WORKSHOP EVALUATION FORM



***SERVICE SUPPORT FOR CHILDREN WITH CHRONIC
ILLNESS OR PHYSICAL DISABILITY ATTENDING
MAINSTREAM SCHOOL***

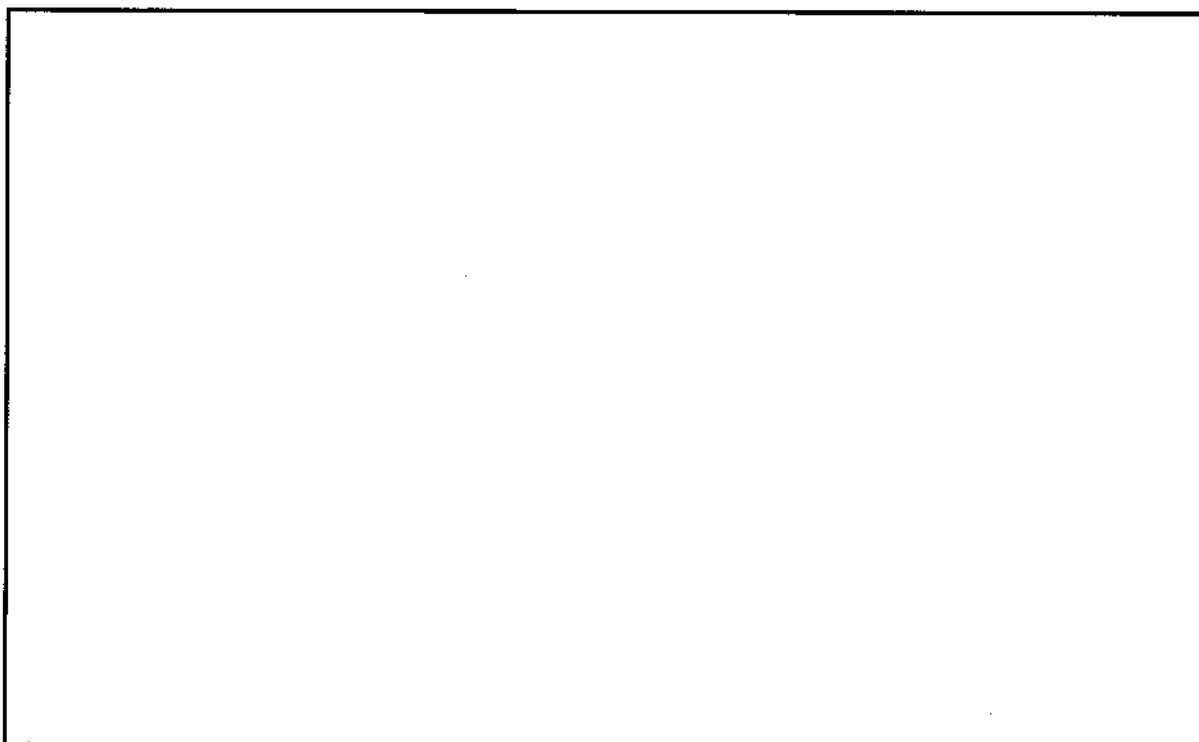
**WORKSHOP EVALUATION FORM
Wednesday 1 July, 1998**

In order to help us prepare for other similar events, it would be helpful to have some feedback on the workshop. We would be grateful if you could complete this questionnaire before leaving the hotel.

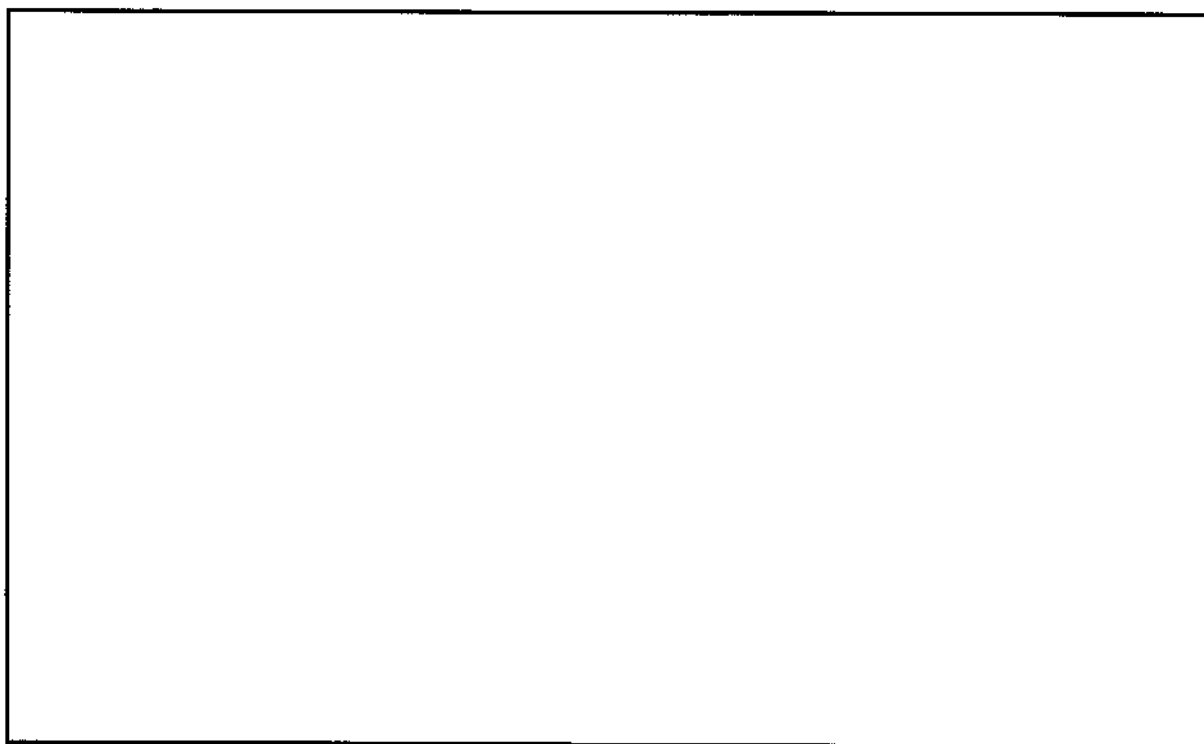
Please give your comments on the workshop below. We are particularly interested in any aspects of the day you found helpful and/or unhelpful.

Sessions on research findings:

Group work sessions:

A large, empty rectangular box with a black border, intended for notes or discussion during group work sessions.

Is there anything the research team could have done differently which would have improved the day?

A large, empty rectangular box with a black border, intended for providing feedback on the research team's performance.

Thank you

REFERENCES

- Armstrong, R., Rosenbaum, P., and King, S. (1987) 'A randomised controlled trial of a buddy programme to improve children's attitudes toward the disabled', *Developmental Medicine and Child Neurology*, 29: 327-336.
- Bagnall, P. and Dilloway, M. (1996) *In Search of a Blueprint: a survey of school health services*, London: Department of Health/The Queen's Nursing Institute.
- Beresford, B. (1997) *Personal Accounts: involving disabled children in research*, Norwich: The Stationery Office.
- Bolton, A. (1997) *Losing The Thread: pupils' and parents voices about education for sick children*, London: National Association for the Education of Sick Children.
- Bone, M. and Meltzer, H. (1989) *The Prevalence of Disability among Children*, OPCS Surveys of Disability in Britain, Report 3, London: HMSO.
- Botting, B. and Crawley, R. (1995) 'Trends and patterns in childhood mortality and morbidity', pp 61-81 in Botting, B. (ed.) *The Health of Our Children: decennial supplement*, Office of Population Censuses and Surveys Series DS no. 11, London: HMSO.
- Bradbury, A.J., and Smith, C.S. (1983) 'An assessment of the diabetic knowledge of school teachers', *Archives of Disease in Childhood*, 58: 692-696.
- British Paediatric Association (1991) *Towards a Combined Child Health Service*, London: British Paediatric Association.
- British Paediatric Association (1995) *Health Needs of School Age Children*, London: British Paediatric Association.
- Bronfenbrenner, U. (1997) 'Ecological models of child development', pp 37-43 in Gauvain, M. and Cole, M. (eds.) *Readings on the Development of Children*, New York: Freeman and Company.
- Carey, P. (1993) 'Dealing with pupils' life crisis: a model for action', *Pastoral Care in Education*, September 1993, 12-18.
- Carey, P. (1997) 'Pupil's Life Crisis', in David, K., and Charlton, T. (eds) *Pastoral Care Matters in Primary and Middle School*, Chapter 7, London: Routledge.
- Charlton, A., Pearson, D. and Morris-Jones, P.H. (1986) 'Children's return to school after treatment for solid tumours', *Social Science and Medicine*, 22: 1337-1346.
- Chekryn, J., Deegan, M., and Reid, J. (1987) 'Impact on teachers when a child with cancer returns to school', *Children's Health Care*, 15, 3: 161-165.

Cleave, H., Carey, P., Norris, P., Sloper, P., While, D., and Charlton, A. (1997) 'Pastoral care in initial teacher education: a survey of secondary teacher education institutions', *Pastoral Care*, 15, 2: 16-21.

Closs, A., and Burnett, A. (1995) 'Education for children with a poor prognosis: reflections on parental wishes and on an appropriate curriculum', *Child: care, health and development*, 21: 387-394.

Coulter, A., Entwistle, V. and Gilbert, D. (1998) *Informing Patients: an assessment of the quality of patient information materials*, London: King's Fund.

Court, S. (1994) *The Health-Education Boundary: a study of primary school teachers' understanding of childhood illness and its potential to disrupt the educational process*, unpublished MSc thesis, University of Newcastle-upon-Tyne.

Department for Education (1994a) *The Education of Sick Children*, Circular 12/94, London: Department for Education.

Department for Education (1994b) *Code of Practice on the Identification and Assessment of Special Educational Needs*, London: Department for Education.

Department for Education and Employment (1997) *Excellence for all Children: meeting special educational needs*, London: The Stationery Office.

Department for Education and Employment/Department of Health (1996) *Supporting Pupils with Medical Needs in School*, Circular 14/96, London: Department for Education and Employment.

Department of Health (1994) *Negotiating School Health Services*, London: Department of Health.

Department of Health (1996) *Child Health in the Community: a Guide to Good Practice*, London: NHS Executive.

Dyson, A., Lin, M., and Millward, A. (1998) *Effective Communication Between Schools, LEAs and Health and Social Services in the Field of Special Educational Needs*, Newcastle upon Tyne: Special Needs Research Centre, Department of Education, University of Newcastle.

Edwards, M. and Davis, H. (1997) *Counselling Children with Chronic Medical Conditions*, Leicester: BPS Books.

Eiser, C. (1980) 'How leukemia affects a child's life', *British Journal of Social and Clinical Psychology*, 19: 365-368.

Eiser, C. (1990a) 'Psychological effects of chronic illness', *Journal of Child Psychology and Psychiatry*, 31: 85-98.

Eiser, C. (1990b) *Chronic Childhood Disease: an introduction to psychological theory and research*, Cambridge: University Press.

Eiser, C. (1998) 'Practitioner review: long term consequences of childhood cancer', *Journal of Child Psychology and Psychiatry*, 39, 5: 621-633.

Eiser, C., and Town, C. (1987) 'Teachers' concerns about chronically sick children: implications for paediatricians', *Developmental Medicine and Child Neurology*, 29: 56-63.

Ennett, S., De Vellis, B., Earp, J., Kredich, D., Warren, R., Wilhelm, C. (1991) 'Disease experience and psychosocial adjustment in children with juvenile rheumatoid arthritis: children's versus mothers' reports', *Journal of Pediatric Psychology*, 5: 557-568.

Fowler, M.G., Johnson, M.P., Atkinson, S.S. (1985) 'School achievement and absence in children with chronic health conditions', *The Journal of Pediatrics*, 106: 683-687.

Freudenberg, N., Feldman, C.H., Clark, N.M., Milman, E.J., Valle, I., Wasilewski, Y. (1980) 'The importance of bronchial asthma on school attendance and performance', *Journal of School Health*, November: 522-527.

Henning, J.R.N. and Fritz, G.K. (1983) 'School re-entry in childhood cancer', *Psychosomatics*, 24, 3: 261-269.

Hirst, M. and Baldwin, S. (1994) *Unequal Opportunities: growing up disabled*, London: HMSO.

House of Commons Health Committee (1997) *Health Services for Children and Young People in the Community: home and school*, third report, London: The Stationery Office.

Howe, G.W., Feinstein, C., Reiss, D., Molock, S. and Berger, K. (1993) 'Adolescent adjustment to chronic physical disorders - 1: comparing neurological and non-neurological conditions', *Journal of Child Psychology and Psychiatry*, 34, 7: 1153-1171.

Johnson, M.P., Lubker, B.B., and Fowler, M.G. (1988) 'Teachers' needs assessment for the educational management of children with chronic illness', *Journal of School Health*, 58, 6: 232-235.

La Greca, A. (1990) 'Social consequences of pediatric conditions: fertile area for future investigation and intervention', *Journal of Pediatric Psychology*, 15, 3: 285-307.

La Greca, A. (1992) 'Peer influences in pediatric chronic illness: an update', *Journal of pediatric psychology*, 17: 775-784.

Lamb, B. and Layzell, S. (1994) *Disabled in Britain: a world apart*, London: SCOPE.

Lansky, S. (1980) 'The child with cancer', *The American Journal of Pediatric Haematology/Oncology*, 2, 1: 89-94.

- Larcombe, I. (1995) *Reintegration into School after Hospital Treatment*, Aldershot: Avebury.
- Larcombe, I.J., Walker, J., Charlton, A., Meller, S., Morris Jones, P. and Mott, M.G. (1990) 'Impact of childhood cancer on return to normal schooling', *British Medical Journal*, 301: 169-171.
- Lavigne, J.V., and Faier-Routman, J. (1992) 'Psychological adjustment to pediatric physical disorders: a meta-analytic review', *Journal of pediatric psychology*, 17, 2: 133-157.
- Le Febvre, A. and Munro, I. (1978) 'The role of psychiatry in a craniofacial team', *Plastic and Reconstructive Surgery*, 61: 564-569.
- Lehr, D. (1990) 'Providing education to students with complex health care needs', *Focus on Exceptional Children*, 22, 7: 1-12.
- Lightfoot, J. and Bines, W. (1997) *Keeping Children Healthy: the role of school nursing*, York: Social Policy Research Unit, University of York.
- Lynch, E.W., Lewis, R. and Murphy, D. (1992) 'Educational services for children with chronic illnesses: perspectives of educators and families', *Exceptional Children*, 59, 3: 210-220.
- Menke, E.M. (1987) 'The impact of a child's chronic illness on school-aged siblings', *Children's Health Care*, 15: 132-140.
- Midence, K. and Elander, J. (1994) *Sickle Cell Disease: a psychological approach*, Oxford: Radcliffe Medical Press.
- Morrow, V. and Richards, M. (1996) 'The ethics of social research with children: an overview', *Children and Society*, 10: 90-105.
- Mulderij, K.J. (1996) 'Research into the lifeworld of physically disabled children', *Child: care, health and development*, 22: 311-322.
- Mulhern, R.K., Crisco, J.J. and Camitta, B.M. (1981) 'Patterns of communication among paediatric patients with leukemia, parents, and physicians: prognostic disagreements and misunderstandings', *The Journal of Pediatrics*, 99, 3: 480-483.
- National Association for Colitis and Crohn's Disease (1998) *When a Child has Ulcerative Colitis or Crohn's Disease: how teachers can help*, St Albans: National Association for Colitis and Crohn's Disease.
- Nettles, A.L. (1994) 'Scholastic performance of children with sickle cell disease', pp 123-140 in Nash, K.B. (ed) *Psychological Aspects of Sickle Cell Disease: past, present and future directions of research*, New York: The Howarth Press.

Norwich, B. (1997) *A Trend towards Inclusion: Statistics on Special School Placements and Pupils with Statements in Ordinary Schools, England 1992-96*, Bristol: Centre for Studies on Inclusive Education.

Office for Standards in Education (1997) *The SEN Code of Practice: two years on*, London: Office for Standards in Education.

Pless, I.B., Power, C. and Peckham, C.S. (1993) 'Long-term psychosocial sequelae of chronic physical disorders in childhood', *Pediatrics*, 91: 1131-1136.

Ritchie, J. and Spencer, L. (1994) 'Qualitative data analysis for applied policy research', pp 173-194 in Bryman, A. and Burgess, R.G. (eds.) *Analyzing Qualitative Data*, London: Routledge.

Russell, P. (1996) 'Issues arising from the implementation of the Code of Practice on the identification and assessment of special educational needs', *Child Psychology and Psychiatry Review*, 1, 3: 110-111.

Sameroff, J. (1991) 'The social context of development', pp 167-189 in Woodhead, M., Carr, R. and Light, P. (eds) *Child Development in a Social Context 1; Becoming a Person*, Routledge: London.

Sebba, J. (1997) *What works in Inclusive Education?*, Ilford: Barnados.

Shaw, L. (1998) 'Children's experiences in school', pp 73-84 in Robinson, C. and Stalker, K. (eds) *Growing up With a Disability*, London: Jessica Kingsley.

Sloper, P., Larcombe, I.J. and Charlton (1994) 'Psychosocial adjustment of five-year survivors of childhood cancer', *Journal of Cancer Education*, 9: 163-169.

Spencer, C.H., Renee, Z.F. and Rabinovich, C.E. (1995) 'The school experience of children with arthritis', *Pediatric Rheumatology*, 42: 1285-1298.

Spirito, A., DeLawyer, D.D., Stark, L.J. (1991) 'Peer relations and social adjustment of chronically ill children and adolescents', *Clinical Psychology Review*, 11: 539-564.

Tackett, P., Kerr, N. and Helmstader, G. (1990) 'Stresses as perceived by children with physical disabilities and their mothers', *Journal of Rehabilitation*, 56, 3: 30-34.

United Nations (1989) *Convention on the Rights of the Child*, London: HMSO.

Varni, J., Katz, E., Colegrove, R., and Dolgin, M. (1993) 'The impact of social skills training on the adjustment of children with newly diagnosed cancer', *Journal of Paediatric Psychology*, 18: 751-767.

Varni, J.W., Rubenfeld, L.A., Talbot, D., and Setoguchi, Y. (1989) 'Stress and social support, and depressive symptomatology in children with congenital acquired limb deficiencies', *Journal of Pediatric Psychology*, 14, 4: 515-530.

Vaughn, S., Schumm, J.S. and Sinagub, J. (1996) *Focus Group Interviews in Education and Psychology*, Thousand Oaks, California: Sage.

Vaz, J. (1995) 'Personal health records for school children with multiple health needs', *Child: care, health and development*, 21: 191-198.

Wallander, J.L. and Varni, J.W. (1998) 'Effects of pediatric chronic physical disorders on child and family adjustment', *Journal of Child Psychology and Psychiatry*, 39: 29-46.

White, P.H., and Shear, E.S. (1992) 'Transition/job readiness for adolescents with juvenile arthritis and other chronic illness', *The Journal of Rheumatology*, 19, 33: 23-27.

Wikler, L. (1981) 'Chronic stresses of families of mentally retarded children', *Family Relations*, 30: 281-288.

Woodroffe, C., Glickman, M., Barker, M. and Power, C. (1993) *Children, Teenagers and Health: the key data*, Buckingham: Open University Press.