

CARING FOR A SICK CHILD TAYSIDE SURVEY



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CARING FOR A SICK CHILD

TAYSIDE SURVEY EXECUTIVE SUMMARY

Action for Sick Children (Scotland) (ASC(S)) is the only charity in Scotland which represents, promotes and safeguards the interests of all sick children. We have campaigned for more than thirty years for children and young people to secure the highest standard and quality of care when they are ill in hospital, at home or in the community. With funding from the Gannochy Trust, our Tayside Area Co-ordinator undertook a survey in 2007, the purpose of which was to investigate and assess how living in rural and urban areas affects the healthcare needs of children and their families. The survey included questions on issues such as travel to appointments, access to services, educational support for sick children and employment issues for parents who require time off to be with their sick child.

The survey findings are complemented by Action for Sick Children (Scotland)'s Family Facilities Survey (2007). (If you wish to receive a copy of the results of the Family Facilities Survey please contact ASC(S) office on 0131 553 6553.)

The statistical results of the Tayside Survey are summarised as follows:

Fifty-six families participated in the survey (42 urban / 14 rural). Families from within the Tayside area were eligible to participate. This included families from within the geographical boundaries of Perth and Kinross, Dundee City and Angus.

Age Ranges

The ages of the children, included in this survey, can be broken down as follows:
Below school age: 15 Nursery: 8 Primary school: 21 Secondary school: 11

Medical Details

Thirty five people stated that they felt their child had a long-term illness or condition, 16 felt it was not long term and five did not know (possibly because they were awaiting diagnosis).

A further break-down of the duration of the illness is as follows:

	Up to 3 mths	3-6 mths	6-12 mths	12 mths+
Urban	11	0	2	26
Rural	5	2	1	6

Mobility

Fourteen families reported that their child had mobility issues. This equates to, 10 being wheelchair users two needed splints, one had crutches and one had a frame.

Incontinence

Twelve families responded that their child does have incontinence issues. Eighteen have no incontinence issues and a further 26 replied that this question was not applicable.

Telemedicine Facilities

No respondents reported having been offered Telemedicine facilities.

Travel To and From Appointments

The breakdown for one round trip is as follows:

Distance Travelled to Appointments	Number of families
up to 10 miles	15
10-20 miles	8
21-30miles	9
31- 60 miles	20
61-100 miles	4

Nine families relied on public transport (two of these were from rural locations). Thirty-seven used their own transport (or relied on family or friends) and a further five used both. The remaining five did not specify. However, their responses revealed that they all reside in Dundee.

Education

Below school age: 15 Nursery: 8 Primary school: 21 Secondary school: 12

Time Absent from School Due to Ill Health

	1-3 weeks	3-6 weeks	6 weeks+
urban	12	3	11
rural	7	2	4

- note that these figures include children who attend nursery/playgroup. Two children were not reported as having taken any time off due to illness.

Only two children had provision for education during their absence. Four people responded that they were aware of the existence of local guidelines in relation to education of children during times of illness/absence.

The majority of families felt that schools were supportive and understanding (30 out of 41) and that their child was kept up to date with school work and was engaged with the school during times of illness and absence. Three felt the school could do more to help the child educationally and two felt that the child could do more educationally but was being “held back” by the lack of school support. More families of secondary school children had concerns about the provision.

Financial Impacts / Working and Caring

Forty-five (36 urban / 8 rural) families have taken time off work during the last year to be with their children during their illness. Nine people have given up work to become carers. Three people had given up work temporarily and a further six permanently to become carers for their children.

Disability Living Allowance

Fifteen families receive DLA at the present time in respect of their children.

Childcare and Impacts on Siblings

Most people rely on family and friends for childcare of siblings and so do not incur additional costs. However, there is considerable concern about the effects on siblings due to the attention given to sick children, i.e., jealousy by siblings and feelings of guilt by parents.

CONCLUSION

Whilst there seems to be little evidence of families being disadvantaged in services provision in the rural community, families do report concerns about accessing specialist services mainly due to travel constraints.

The principle concerns of families from both urban and rural communities centre upon education provision, securing time off (paid or otherwise) from work to be with their sick child, care of siblings, and managing financial aspects such as travel costs, home adaptations and other associated costs.

Some impacts could be reduced if families had improved access to information, for example, how to claim travel costs to and from hospital/clinics and how to access educational support for their unwell child. The survey appendix includes a list of organisations and contact details, signposting families to where they may receive specialist advice and support.

It is felt that the survey proves the need for improved communication particularly by local authorities and statutory agencies to inform families of where they may receive assistance regarding their entitlements and rights when their child is unwell.

INTRODUCTION

Action for Sick Children (Scotland) – Who We are and What We Do

Action for Sick Children (Scotland) (ASC(S)) is the only charity in Scotland which represents, promotes and safeguards the interests of all sick children. We have campaigned for more than thirty years for children and young people to secure the highest standard and quality of care when they are ill in hospital, at home or in the community.

Action for Sick Children (Scotland) works with the Scottish Government, NHS Scotland and other relevant bodies to ensure policy and legislation meet the needs of sick children and young people.

As well as supporting individual families across Scotland, we aim to work collaboratively with Health Authorities, local authorities and other health care professionals, other voluntary bodies and statutory agencies, in order to inform children and young people and their families and carers, of their health-related rights and responsibilities.

The Tayside Project

In July 2006 Action for Sick Children (Scotland) was awarded funding from the Gannochy Trust, to enable the organisation to continue its work in Tayside and Angus. This support from the Gannochy Trust funded a part time area co-ordinator post to investigate and assess how living in rural and urban areas affects the healthcare needs of children. Specifically the aims were to:

- identify how families are affected when sick children need hospital care
- measure the impact on siblings
- assess the childcare arrangements needed for siblings when parents visit a sick child in hospital
- assess whether appropriate preparation is available and provided for families undertaking stressful events for example elective admissions
- assess whether appointment times allocated at primary care sites take account of patients' home addresses
- assess the accessibility of services
- assess transport to health care facilities

Discussions with families prior to compiling the survey questionnaire revealed a number of issues that would have little (if any) bearing on their location but which nevertheless had an important impact and questions relating to these issues were therefore included.

The impacts specifically mentioned by families, included the attitudes of employers when a child is unwell and which required the parent or carer to take time off. They also mentioned problems specifically relating to Disability Living Allowance applications and the costs incurred in altering homes or purchasing specialist

equipment. Education featured highly as an important issue, and survey questions allowed respondents to talk about the issues for young people facing exams during periods of illness.

It was always going to be impossible to cover all possible circumstances since they can vary tremendously from family to family. However, questions were structured in such a way that all families could participate no matter what their child's illness or condition (acute and chronic, as well as mental health or psychological illnesses). One parent commented that she felt the draft survey did not allow specifically for children suffering with mental illness and psychological trauma. As a result we solicited feedback from other families whose children were suffering from psychological problems. Their feedback was that the questionnaire did not discriminate in any way and that the questions were structured to allow for appropriate responses.

It was essential to the integrity of the questionnaire that it was not used by respondents as a platform for complaints against any organisation, authority or individual. Only one family attempted to use the survey in this way and they were directed to consult the complaints procedures for the body concerned.

Prior to conducting the survey, ASC(S) looked into the need to submit the questionnaire to the Ethics & Research Committees of Tayside Health Board. We were advised that it was not necessary to make a formal submission via the committee because patients' details were not being divulged, families would be invited to take part and that there was no obligation to participate or reveal more than they wished.

The survey aimed to accommodate all ages from birth to school leaving. The criterion was that to participate in the survey, the child or young person must attend school or be below school age. Therefore, young persons in fifth and sixth year were able to be included, although in reality, the oldest participant was 16 years.

The term "family" or "parent/carer" is intended to include all persons, individuals, or organisations involved in the care or well-being of a child or young person, whether on a formal or informal basis. However, for the purposes of this survey it is generally accepted to be the person or persons who have full time responsibility for the child or young person and may include grandparents or other relative or partners of parents. The list or compilation of persons included is not exhaustive.

Timescale

The Tayside Survey was conducted between May 2007 and September 2007.

Rationale

NHS Scotland in partnership with the Scottish Government and in consultation with other statutory and voluntary agencies are currently reviewing Children's Healthcare Services. The reviews and studies will impact on healthcare provision and planning for Children's Services in the future, and are anticipated to become a positive driving

force for improvement of standards and provision for all involved, either as a recipient of the services or as a provider.

Our experience with children and their families at times of illness has revealed that their concerns are greater than those directly pertaining to the illness itself and that financial impacts, education and periphery items such as waste disposal are all impacts that are not directly or collectively considered by any agency involved in children's healthcare.

It is therefore appropriate that Action for Sick Children (Scotland) should undertake to explore the wider issues faced by families when they have child who is sick, particularly if the child requires hospital care. Consequently, the survey has aimed to take account of the issues raised by families that have not previously been measured and in order to satisfy this objective, we adopted an inclusive methodology and followed a consultative process. The survey is not an academic research study. It should be noted, that families were always intended to be at the heart of any resulting document and that it should be used as a tool to signpost families to available sources of support.

Methodology

The survey was conducted via postal submission of the questionnaire or via face-to-face interviews carried out by the Area Co-ordinator with the carer. The project generated coverage in the local press with an appeal for families to participate in the survey.

A total of 56 families took part in the survey; 15 questionnaires out of the 56 were returned in response to the press publicity and 41 were completed through visiting the Child and Maternal Health Department at Ninewells Hospital (hereafter referred to as "Ninewells") in Dundee.

Twenty-six families who responded to the publicity were sent a questionnaire, guidance notes a copy of ASC(S) Data Protection and Confidentiality policy documents and an SAE.

41 surveys were completed at Ninewells. Some families chose to complete the forms themselves, others asked for assistance and in those cases the surveys were completed on a one-to-one basis. A further 15 questionnaires with SAEs were distributed on Wards 29 and 30, but these were not returned.

Information from the surveys was recorded onto the database from which statistical data could be collated. This excluded any identifiable details.

Definition of "Child"

The Children (Scotland) Act 1995¹ defines a child as a person under the age of eighteen years for the purposes of support for children and their families, including services from the NHS.

¹ Children (Scotland) Act 1995, section 93(2)

However the following paragraph explains in greater detail the variations which exist in adolescent healthcare within the NHS and which affect the collection of data for this survey.

“The NHS uses a range of operational definitions of 'child' and 'adolescent' and these often affect the nature of, and location in which, health care is provided for children and young people. Acute care in dedicated paediatric facilities is most often limited to children up to the age of thirteen or fourteen years although some facilities care for young people up to fifteen or sixteen years of age. Adolescents from fifteen years are usually cared for on adult wards and the extent to which they have access to dedicated facilities or staff trained to meet their needs varies widely across the country. Community-based services and primary care tend to adopt a more flexible approach, although again this varies.”²

From this it is possible to see that although practice varies across the country, in the main young people over the age of 15 were not included in the survey as they are still mainly accommodated in adult wards and therefore not accessible to the researcher. The exception to this is the one young person aged 16 whose family responded to the press publicity. It should also be noted that provision around age appropriate care is changing in line with the recommendations in the Action Framework and more young people will be accommodated up to and sometimes beyond the age of sixteen in the future.

Geographical Boundaries

The geographical boundaries pertaining to the unitary authorities of Perth and Kinross, Dundee City Council and Angus were observed. The postal code areas are shown in the following table:

Dundee City		Angus	
DD1 1	Dundee - Centre, The Howff	DD10 8	Montrose
DD1 2	Dundee - E of Centre, Victoria Rd	DD10 9	Muirton of Ballochry; Hillside; Ferryden
DD1 3, DD1 4	Docks; University Complex	DD11 1	Arbroath
DD1 5	Dundee - W of Centre	DD11 2	Arbroath W; Carmyllie
DD2 1	Ninewells; Airport; Botanic Gdns	DD11 3	Arbroath NW; Colliston
DD2 2	Menziesshill; Balgay Hill	DD11 4	Arbroath N; Chapelton
DD2 3	Lochee	DD11 5	Inverkeilor
DD2 4	Menziesshill	DD5 4	Monifieth
DD3 0	Bridgefoot; Auchterhouse	DD7 6	East Carnoustie
DD3 6	Dundee Law	DD7 7	Carnoustie W; Barry
DD3 7	Hilltown; Football Grounds	DD8 1	Forfar W; Douglstown

² Source: Making It Work For Scotland's Children: Child Health Support Group Overview Report 2003 Scottish Government: <http://www.scotland.gov.uk/Publications/2003/09/18214/26652>

DD3 8	Kings Cross Hosp; Cleington Rd	DD8 2	Forfar E; Letham
DD3 9	Downfield	DD8 3	Forfar N; Tannadice
DD4 0	Whitfield; Tealing	DD8 4	Kirriemuir
DD4 6	Dundee - E of Centre, Princes St; Arbroath Rd	DD8 5	Balintore; Kirkton of Arlie
DD4 7	Craigie	DD9 6	Brechin W
DD4 8	Douglas and Angus	DD9 7	Brechin E; Glen Esk
DD4 9	Fintry; Claverhouse	PH12 8	New Tyle; Meigle
DD5 1	West Ferry		
DD5 2	Broughty Ferry		
DD5 3	Baldovie; Monikie		
Perth & Kinross			
DD2 5	Longforgan; Invergowrie; Muirhead	PH2 0	Perth S; Dunning
KY13 0	Crook of Devon; Balado	PH2 6	Scone
KY13 8	Kinross	PH2 7	Perth E; Errol; St Madoes
KY13 9	Milnathort	PH2 8	Perth S; Rhynd
PH1 1	Perth SW	PH2 9	Abernethy; Bridge of Earn; Glen Farg
PH1 2	Letham; Hillyland	PH3 1, PH4 1, PH5 1	Auchterarder; Muthill; Blackford
PH1 3	Muirton; Almondbank; Luncarty; Methven	PH6 2	Comrie; St Fillans
PH1 4	Stanley; Bankfoot; Caputh	PH7 3	Crieff E
PH1 5	Perth Centre	PH7 4	Crieff W
PH10 6	Blairgowrie	PH8 0, PH9 0	Dunkeld; Ballinluig
PH10 7	Ratray		
PH11 8	Alyth; Glen Isla		
PH13 9	Coupar Angus		
PH14 0	Inchtute		
PH15 2	Aberfeldy; Kenmore		
PH16 5	Pitlochry; Kinloch Rannoch		
PH17 2, PH18 5	Blair Atholl; Loch Rannoch		

ANALYSIS OF STATISTICAL INFORMATION

Part One – Personal Details (questions 1 – 9)³

A total of 56 responses were collated.

Fifteen people responded to publicity and requested surveys. The other 41 respondents were either interviewed individually at the Child and Maternal Health Department at Ninewells Hospital or were issued with the form to complete themselves.

The age ranges of the children and young people who participated in the survey ranged from birth to 16 years.

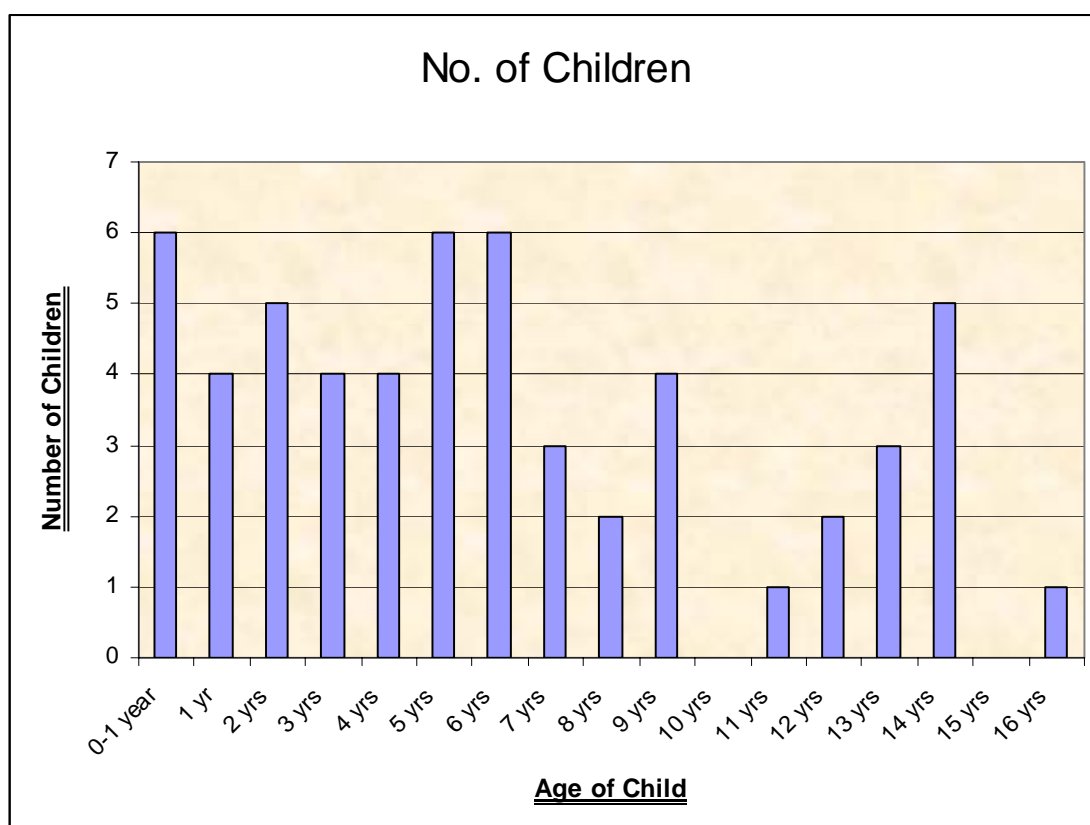


Figure 1 – Number and age of children

The ages of the children, included in this survey, can be broken down as follows:

Below school age: 15
Nursery: 8
Primary school: 21
Secondary school: 11

³ Please refer to Appendix 1 - Questionnaire

The following table shows the number of children from each geographical area as follows:

Arbroath: 8 *
 Dundee 14
 Carnoustie: 5
 Perth: 11
 Auchterarder: 1*
 Montrose: 3*
 Kirriemuir: 1*
 Brechin: 2*
 Broughty Ferry: 2
 Forfar: 3*
 Dunkeld: 1
 Bridge of Earn: 1
 Monifieth: 1
 Coupar Angus: 3*

* Rural

Please refer to pages 7 and 8 of this report for full details of the postcode areas.

The Scottish Government Statistics Division defines an area as either urban or rural according to the size of its population. There are nine different categories within the Scottish Government classification depending on the population size.

- Three families from the Arbroath area, one from Forfar and the remaining ten participants from Coupar Angus, Dunkeld, Brechin, Montrose and Auchterarder were defined as Rural. This resulted in a total of 14 responses being categorised as “rural,” representing 25.45% of the total responses. Thus the statistical break-down equates as 42 Urban / 14 rural.
- The rural areas defined by the Scottish Government Statistics Division set their criteria according to the size of the population of the area. For the purposes of this survey, this was taken into account and an additional weighting was given to the distances travelled and access to public transport. Therefore, although Arbroath is not considered to be rural, three families of the eight families from the Arbroath area were counted as rural as they did not reside within Arbroath, but outside of the town.

Part Two – Medical Details (Questions 10 – 27)⁴

Thirty-five stated that they felt their child had a long-term illness or condition, 16 felt it was not long term and five did not know (possibly because they were awaiting diagnosis). A further break-down of the duration of the illness is as follows:

	Up to 3 mths	3-6 mths	6-12 mths	12 mths+
Urban	11	0	2	26
Rural	5	2	1	6

⁴ Please refer to Appendix 1 – Questionnaire P.2

Three people did not specify the estimated time-scale of their child’s illness so these figures represent 53 out of 56 responses.

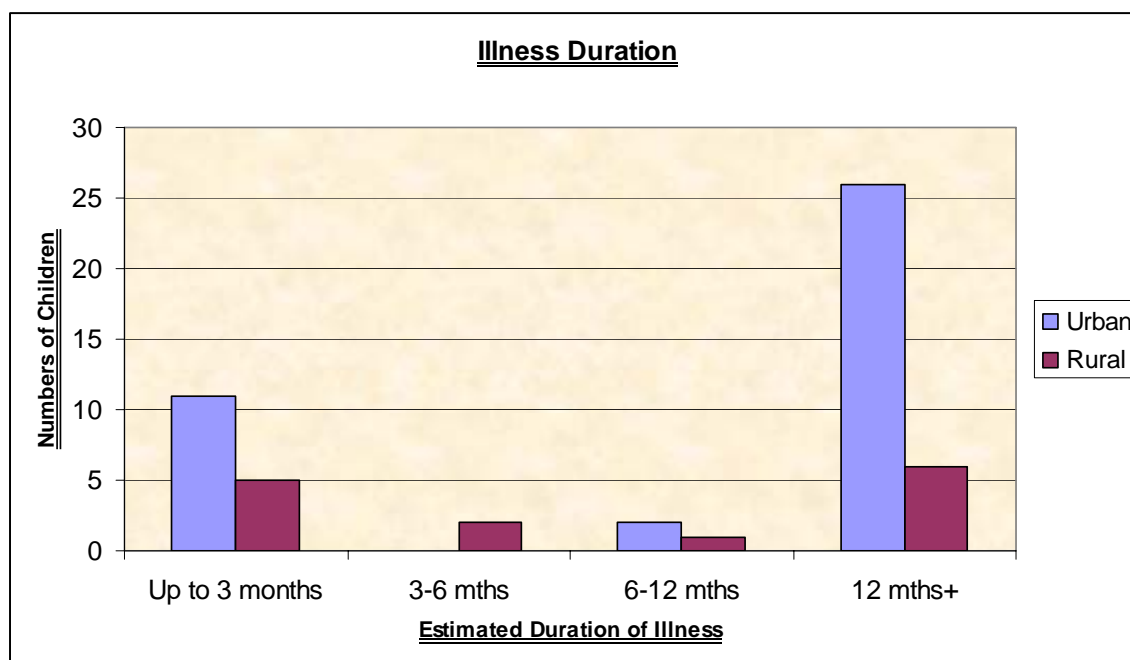


Figure 2 – Duration of Illness

Part Three – Specific Practical Medical Issues / Information⁵

Mobility

Fourteen families reported that their child had mobility issues. This equates to, ten being wheelchair users, two needed splints, one had crutches and one had a frame.

One family reported that a wheelchair had been purchased privately because they did not feel that the Tayside Orthopaedic Rehabilitation Technology Centre (TORT Centre) was best able to accommodate the specific needs of their child, however, they also stated that the choices/styles of wheelchairs available also influenced this decision. They preferred to pay for a lighter frame as opposed to the more utilitarian styles provided by the NHS and in order to meet their choices they had to make a private purchase.

It should be noted that families expected that some of their babies and toddlers are likely to be affected by future mobility problems but this is not a current issue for those still in prams or buggies. Therefore, for the purposes of the survey they are not regarded as having mobility issues at the present time and so do not feature in these statistics.

Incontinence Issues (Questions 23 – 25)

Families were asked if their child had any incontinence issues. Twelve families responded that their child does have incontinence issues. Eighteen have no incontinence issues and a further 26 replied that this question was not applicable.

⁵ Please refer to Appendix I – Questionnaire P.3.

Discussions with families about incontinence revealed a number of families with young children expected their child to experience incontinence problems in the future, due to the nature of their problems, but for whom it was not currently a problem as the child was still in nappies. Two families whose children currently experience incontinence problems voiced concerns about fortnightly bin collections. One parent specifically commented *“Nappies – local authority removal –as bins emptied every two weeks, can be overflowing/smelly at times.”*

Telemedicine Facilities

No respondents reported having been offered Telemedicine facilities – indeed many specifically asked what this was. It is possible that if more families had responded from the rural areas, they would have used the Telemedicine, but this facility is not so relevant for families residing relatively close to Ninewells.

Travel To and From Appointments

Examining the questions relating to the distances travelled to hospital/clinics, the breakdown for one round trip is as follows and shown in Fig. 3:

Distance Travelled to Appointments	Number of families
up to 10 miles	15
10-20 miles	8
21-30miles	9
31- 60 miles	20
61-100 miles	4

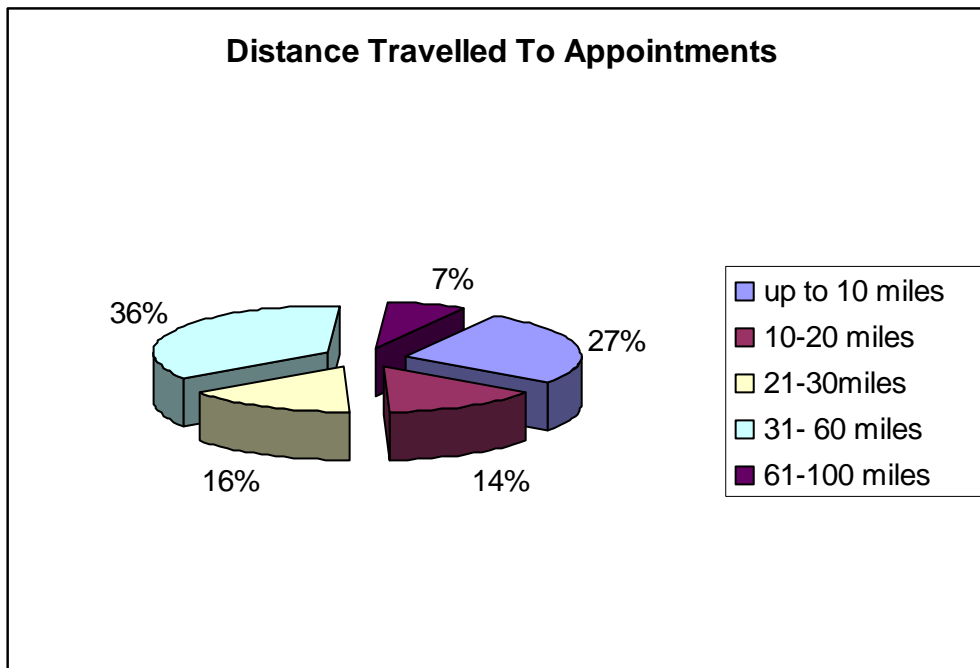


Figure 3 – Distance Travelled to Appointments (as a percentage of the total number of families)

This does not reflect the occasional journeys undertaken by some families to The Royal Hospital for Sick Children (Yorkhill) or The Royal Hospital for Sick Children (Edinburgh). It was decided not to count these as the majority of families reported that they only had to visit these hospitals on an annual or occasional basis. It was felt that it was only the “regular” trips to clinics or hospitals that should be counted.

Many families were in Ninewells with children who had recently suffered acute problems, and they did not know what their travel commitments to clinics would be when the child was discharged as an in-patient and became an out patient. It should be noted that the after-care of the child does not affect the outcome of this information, only the number of miles a family would be expected to travel in order to attend clinics as the frequency of travel will clearly depend upon the nature of the condition. The distance travelled is shown for one return journey only, to the main place of treatment. It was decided not to measure the distances travelled over any specific period of time or to measure the distances in any other way due to the sheer combinations of circumstances and numbers of centres that families attend.

Nine families relied on public transport (two of these were from rural locations).

Thirty-seven used their own transport (or relied on family or friends) and a further five used both.

The remaining five did not specify however their responses revealed that they all reside in Dundee.

Many families reported that they had initially come to Ninewells using their own transport but were then staying with the children, and due to parking problems at the hospital were dependent on family coming to collect them when they were

discharged (either on a temporary or permanent basis). This was problematic for some families (as illustrated below in a mother's experience), particularly for those relying on other people who were working (partners, spouses or other family members).

A Mother's Experience

One parent who resided within a particularly rural area was discharged with her very young baby shortly after completing the questionnaire. She had no transport and no money and was told that she was not entitled to hospital transport. When she objected to going home with the baby on public transport as she did not feel the baby was fit enough for the journey on two buses and then a long walk, she was told that if the baby was not fit enough, then they would have to stay in hospital. Eventually, she reached a friend who could collect her and the child, but this resulted in a delayed discharge of over four hours.

Part Four – Education (Questions 28-49)⁶

Below school age: 15
Nursery: 8
Primary school: 21
Secondary school: 12

Therefore the total number of children included in the educational statistics amounts to 41

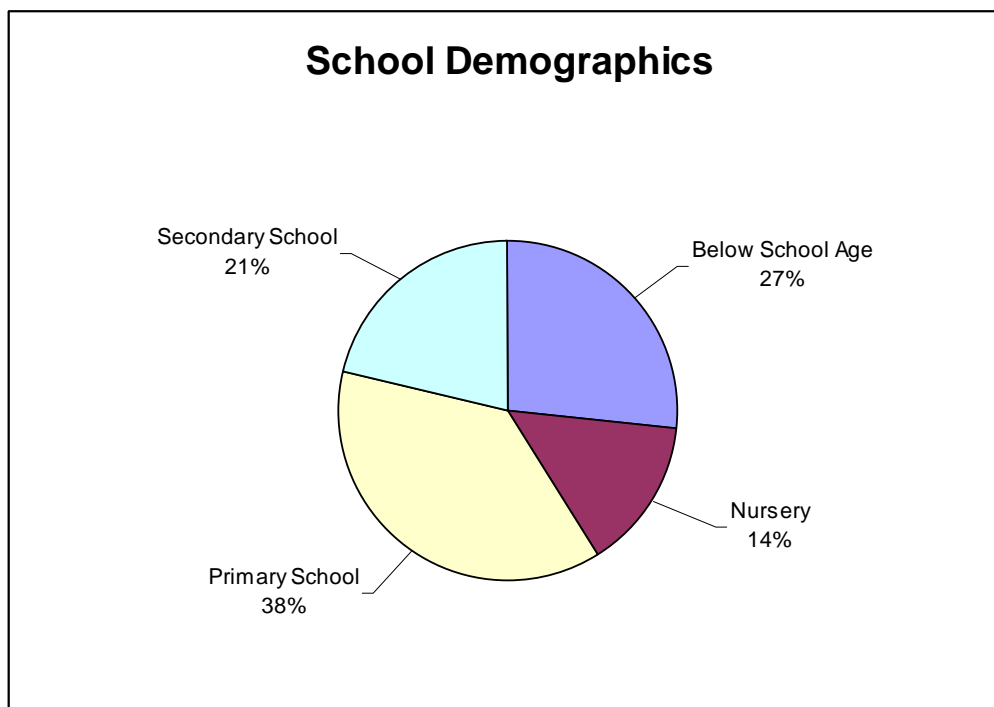


Figure 4 – School Demographics

⁶ Please refer to Appendix I – Questionnaire – Part 4 Education – P 4-6

Time Absent from School Due to Ill Health

	1-3 weeks	3-6 weeks	6 weeks+
urban	12	3	11
rural	7	2	4

- note that these figures include children who attend nursery/playgroup. Two children were not reported as having taken any time off due to illness.

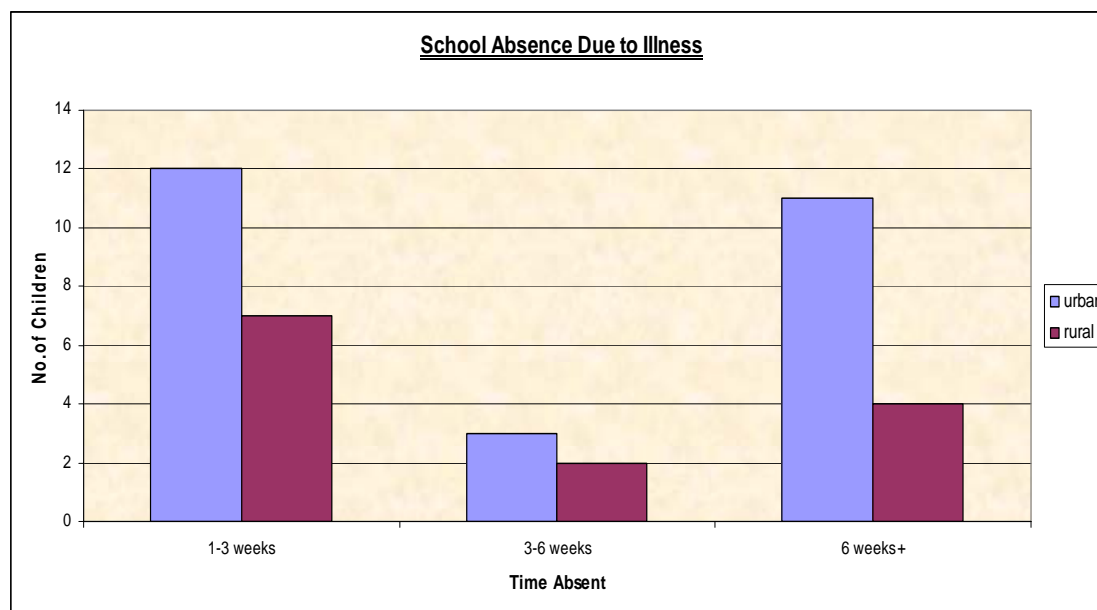


Figure 5 – School Absence Due to Illness

One child was home-educated on a full-time basis. This was a life-style choice and was not influenced by the child's health in any way. For the purposes of the chart depicting the school demographics/age ranges (see Figure 4), this child was counted as primary school age because the location of their education is immaterial.

The comments suggest that although many people responded that there was no homework or education provision whilst the child was ill, there were often "informal" arrangements in place. These seemed to extend mainly to primary school children.

Only two children had provision for education during their absence.

Only four people responded that they were aware of the existence of local guidelines in relation to education of children during times of illness/absence. A further two people were aware of the legislation relating to the same. Please note that most parents of nursery or below school age children did not complete the education section in its entirety so this may not be a wholly accurate reflection of parents' knowledge. However, the results would still suggest that the majority of parents are not aware of either the legislation or local education authority guidelines in relation to the education provision for children when they are unwell or absent from school.

It is encouraging to note that the majority of families felt that the schools were supportive of their children during times of illness/absence

Note that time off school should not be regarded as being indicative of whether a child is suffering from an acute or chronic condition and nor is it an indication of the “seriousness” of their illness.

Positive Feedback to Question 38

Thirty families felt that the school was supportive and understanding (20 – urban and 10 rural)

Nine felt that the school tries to keep the child up to date with class-work

Five were kept up to date with curriculum activities and topics covered and were provided with work

Two felt that the school were given sufficient advice about educating the child at home during times of illness

Nine believed the child was engaged and involved with school as much as was possible under the circumstances.

Only one child had work posted or sent to the school to be marked.

Negative Feedback to Question 38

Three felt the school could do more to help the child educationally

One marked the work themselves

Five families reported that the school felt that if the child is unwell they should not have to do work at home

Two felt that the child could do more educationally but was being “held back” by the lack of school support

Two felt the child was isolated educationally

On the whole families seemed to feel that the schools were generally supportive. The questionnaire did not break-down the analysis according to the schooling stage of the child since the survey did not set out to be an in-depth analysis of any one issue. Instead an over-view was sought and posing the question in this way satisfied this criterion. However, the data showed that there were more families of secondary school children who had concerns about the provision.

The families of secondary school children generally liaise with school Guidance Teachers and rely upon them to co-ordinate the staff, work provided and the marking of that work.

Discussions with individual young people revealed that they also had concerns about being able to “keep up.” One 14 year old had missed over six weeks of school in the past year and is expected to be off for at least another six weeks in the near future. His parents reported that he has not qualified for a home-school tutor as he has not had a continuous absence for a sufficient period of time to qualify for additional help (in the form of a Home-School Tutor). The parents had spoken to the school, but were told that no additional help was available and he now faces the possibility of having to repeat a year. A further two 12 and 13 year olds are in a similar position.

Discussions with parents suggest that they are unaware of how to ask for assistance and what the rights of the sick child are in relation to educational support. Parents are also unaware of who to ask for support.

Further information and guidance regarding the education of sick children is contained Appendix 2 – Advice and Further Information for Parents/Carers.

Part Five – Financial Impacts/Working and Caring (Questions 50-64)

Forty-five (36 urban / 8 rural) families have taken time off work during the last year to be with their children during their illness

Five people took no time off

Five people reported that they do not work and rely on benefits

One person did not complete this section.

Note that some respondents completed this section both for themselves and their spouse/partner for example, they indicated that they did not work themselves but their partner had taken two weeks off. A number of families reported that both parents had taken time off to be with their child. In order to accurately collate the data, the occupation and time off of one person only have been accounted.

Nine people have given up work to become carers. Three people had given up work temporarily and a further six permanently to become carers for their children.

	Up to 1 week	2-4 weeks	4-8 weeks	8 weeks+
urban	15	4	8	9
rural	7	2	0	0

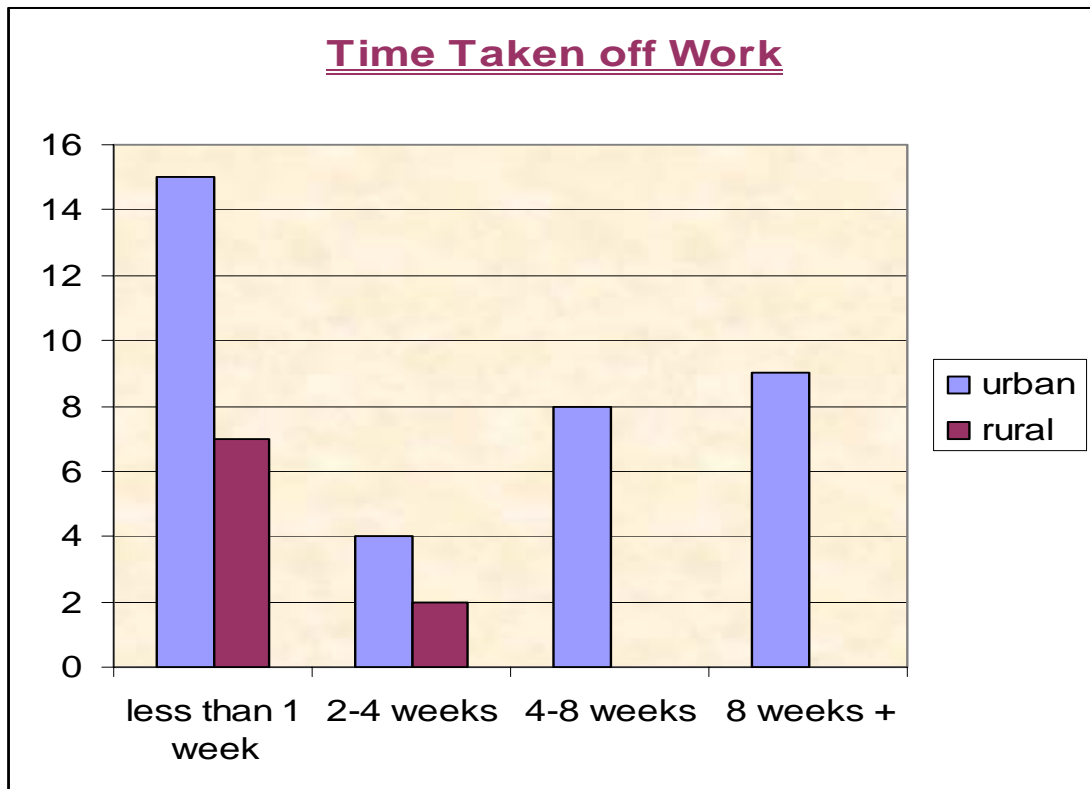


Figure 6 – Time Taken off Work

Employers' Attitudes

Positive

Twenty-four people felt that their employers were supportive

Eleven reported that their employers were supportive but within the constraints of the size of the organisation, number of employees etc.

Twenty believed their colleagues were understanding

Seventeen stated that their colleagues actively supported them.

Negative

Four stated that their employers were obstructive

Three stated that their employers were not supportive and were uninterested.

Fifteen people had had to take unpaid leave

Three felt that their colleagues were either unhelpful or lacked understanding

Two believed that their colleagues objected to the time off they had taken for their child

Six people stated that they did not work and that they relied on benefits.

Discussions with families revealed that there was confusion about what some people regarded as paid/unpaid leave. It should be noted that some families stated that they were given annual leave (and that the majority of participants generally regarded this as paid leave), or that they would have to “work the time back” so also regarded it as paid. This did not apply to those who are self employed. Others were given as much time as was needed. Due to the sheer combinations of circumstances (employed, self employed and the fact that some families gave details of both partners), it was decided not to analyse this data in any greater depth.

Disability Living Allowance

Fifteen families receive DLA at the present time in respect of their children. However, there were a number of parents of babies who thought they would need to submit a claim in the future. Three people had previously had claims rejected, but had been successful on appeal. One further family had received DLA for their son from birth to five years but when he started full-time education, the DLA ceased despite the condition still being present (and problematic) and DLA is still not currently awarded. The mother of this child stated that she had received help completing the form at the time of the child’s birth, but had not challenged the decision to withdraw the benefit. She had concerns about her ability to complete it as a fresh application.

Travel Costs

Only three people had claimed for travel expenses but conversations suggest that families are usually unaware that they may be eligible to claim or do not know how to claim. Of the 56 people surveyed only three people claimed for their travel costs and seven claimed for the alterations they had made to their homes.

Home Adaptations

Just as with travel costs, lack of information also applies to home improvement alterations. Discussions with families suggests that they are either unaware that they may be eligible or how to submit a claim. Only seven people surveyed have applied for a home improvement grant or for the purchase of specialist equipment.

The costs to alterations in one case amounted to £42,000 and £22,000 in another, although most were around £4,000 (where reported). Others had applications pending, mostly for bathroom/toilet adaptations. One family reported paying approximately £7,000 for alterations themselves “*as the council refused to make the necessary alterations.*” It is not known whether this family tried to claim from other sources. Discussions with families suggest that families seem to be unclear about how to claim or to whom they should submit their applications.

As already mentioned on page nine, one family reported purchasing their own wheelchair for their child. The cost of this wheelchair was not disclosed.

Childcare Costs

It was appreciated that childcare costs is another item that would fluctuate from time to time according to circumstances.

Only one family reported additional expenditure in respect of childcare for siblings. All other families stated that they were being assisted by other family members or friends. It was felt that the accurate collation of estimated childcare costs, particularly of estimates, would not be possible as families would have to have based estimates using the same hourly rate and add in variables such as over-night stays in order to allow for accurate comparison.

Impacts on Siblings

Families were asked to comment upon the impacts on siblings. Several people reported being aware of feelings of jealousy by the siblings of unwell children due to the attention being given to the sick child. The parents/carers also admitted to feeling guilty about the way that they manage their time with other children and having to pass their children to other family members and childminders in order to be at the hospital with their sick child.

One mother stated, *"I know my other children often feel left out and they sometimes resent days out and holidays being cancelled at the last minute."*

Another mother stated, *"Sister has been pushed aside as most of the focus is on the sick child and family life is very restricted."*

A number of parents expressed concerns about siblings whilst they are at the bedside of their unwell child, one mother said, *"Other children have not had me as a mum due to time spent at hospital."*

Part Six – Other Information

Eight people had heard of Action for Sick Children (Scotland), 46 had not.

Thirty wanted to receive more information about us, 21 did not want to receive more (but some of these respondents were given information at the time which was judged as sufficient).

Forty-three asked to receive the results of the survey. 12 did not wish to receive the results.

CONCLUSION

The results of the survey suggest that there are no obvious variations in the level of services provided by hospitals, education departments or local authorities, that would disadvantage families with a sick child, living in a rural location compared to a family in a similar circumstance, residing in an urban area.

However, in discussion, families from the rural localities report that attending specialist clinics can pose a problem from time to time. They report that this is mostly due to travel constraints but that these issues are generally accepted as being part of the price that is paid for living in rural areas. Indeed, one family specifically commented that they felt that they knew their GP and Health Visitor and local hospital staff better because they lived in the country and so saw their location as a benefit for them and their child.

The main impacts on families are centred around the:

- education of their child,
- the work and financial implications for the parents/carer, (securing time off being a major concern for many)
- managing childcare of other children.

The majority of people only managed care of their other children thanks to the intervention and support of other family members and friends. In face to face meetings, many commented that they were only able to spend time at the hospital with their sick child thanks to the support of family and friends.

Travel Costs

Travel and car parking is frequently mentioned by families as being problematic. Cars are often left at home and parents rely on other people, or public transport, to get home, simply because the charges are so restrictive over a prolonged hospital visit. Families are unaware of how to claim or to whom they should submit their application. This information is not widely publicised or made available to patients. Telephone enquiries to Ninewells about this issue revealed that there is also confusion among hospital staff; several calls were required before gaining the correct information. Some advice about how to obtain assistance or further advice about claiming should be made more accessible, for example through hospital admission literature/leaflets, posters or on the Health Board website.

Employment / Time off for Parents

Discussions with parents/carers revealed that there is considerable confusion as to their employment rights when their child is ill, in particular, their rights to time off. As stated, the results suggest that there is an inconsistent approach to arrangements around working and caring as some employers give paid time off, whereas others simply refused any time off at all, paid or otherwise. Employers should set out the employees' rights in this area, in the employees' Terms and Conditions of Employment.

Parents/Carers are therefore advised to consult the Terms and Conditions in their Contract of Employment as this can vary from employer to employer. However, S.57A of the Employment Rights Act 1996 as amended by the Employment Relations Act 1999, states that parents may take “reasonable time off to care for a sick dependant” but does not specify what is considered “reasonable.” Note that this does not grant an automatic right to that time off being paid. Therefore, an employee may have to take unpaid or annual leave, depending upon the terms specified in their contract.

Disability Living Allowance

Disability Living Allowance claims continue to concern families partly due to the complexity of information required and the rules governing entitlement. Families find the application process confusing and are even discouraged from actually applying. Ideally, there should be an application form specifically for children and their carers. This would allow for the issues relating to children to be addressed in their own right. An application form for children and young people would also reduce the stresses faced by families and allow for stream-lining of entitlements. In the meantime, families are advised to seek the support of persons involved in the health of their child, such as Occupational Health Therapists, MacMillan nurses, or other specialist nurses, when completing a Disability Living Allowance application form.⁷

Incontinence Issues

Families are clearly concerned about the issue of waste disposal, particularly when their area has fortnightly bin collections. This is an issue that is of concern for families as their child progresses from using nappies to incontinence pads since their disposal becomes more problematic. When considering the implementation of fortnightly bin collections, local authorities should take this issue into account. Ideally, local authorities should offer some flexibility on this issue and be willing to negotiate alternative or special arrangements.

Education of Unwell Children

It is encouraging to note that the majority of families felt that schools were supportive of their children during times of illness/absence. Thirty families felt that the school was supportive and understanding (20 – urban and 10 rural), only three families felt that the school could do more to support their sick child.

Only four people responded that they were aware of the existence of local guidelines in relation to education of children during times of illness/absence. A further two people were aware of the legislation relating to the same. Forty children were of school age (including nursery) but this question was asked of all respondents, so six people out of 55 were aware of local authority guidelines for the education of sick children and/or the legislation. The education of unwell children is governed by The Standards in Scotland's Schools etc. Act 2000. The Act states that the local authority must “make special arrangements for the pupil to receive

⁷ Please refer to Appendix 2 for further information and comment.

education elsewhere than at an educational establishment” and furthermore, that this should be put in place “without undue delay.”⁸

There was considerable difficulty in establishing the local authority guidelines for the education of unwell children, for Dundee City, Angus Council and Perth & Kinross District Council. It took some time to establish contact with the correct person who could identify the criterion for a Home School Tutor and how to access such a service if it was in place. All Education Authorities in Scotland are governed by the 2001 Guidelines on Education of Children Absent from School Through Ill-Health, issued by the Scottish Government. These guidelines stipulate that a child is entitled to additional support if they are absent from school for 15 continuous working days or 20 intermittent days.

The Education Departments of Perth & Kinross District Council, Dundee City Council and Arbroath Council, all advise that parents should speak to the Guidance Teacher or the Head Teacher of the child’s school. The school should be informed about the child’s absence and any future expected absence (for a planned surgical procedure for example). The Guidance Teacher is generally responsible for liaising with other teachers, co-ordinating homework and its marking. The results of the survey suggest that this process is not always effective. The main problems seem to centre on children whose attendance/absence is spasmodic and unpredictable, making the planning and management for staff and parents more difficult. However, this makes it even more distressing for the young person who is at the centre of this issue.

Each case should be judged according to its own merits in terms of the needs of the child - after all a child may be off for more than three weeks but be too incapacitated to complete any work. On the other hand a secondary school child may be sitting in a hospital bed, yet still be perfectly capable of completing homework.

Families are understandably finding clear guidance relating to the education of the sick child, difficult to access and establish. In general terms the educational care of younger children in Primary School is regarded as being well managed as it is straight-forward and the process of liaison between the parent/carer and one teacher tends to work satisfactorily. However, the educational care of older children and young people of secondary school age is entirely different.

Parents need to be made more aware of how to access help and who to approach for support. The information needs to be more publicly accessible through Local Authority websites and consideration should be given to including this in school handbooks and websites.

The Scottish Government website (www.scotland.gov.uk), provides more in-depth information and comment on the current legislation and local authority guidelines.

Impacts on Siblings

Parents consistently reported being concerned about the impact on other children in the home, particularly when the circumstances mean that the sick child is in hospital

⁸ For further information, please refer to Appendix 2.

and the siblings are being cared for out-with the home. This causes anxiety for both the other children as well as the parents who feel guilty and “torn” between the needs of their individual children. Of course, there is no ideal answer to this but it should be pointed out that in order to accurately assess the true impact on siblings, it would be necessary to conduct a separate survey soliciting the opinions of the siblings themselves. Interestingly, only one parent mentioned that she felt there was some jealousy and resentment by her other children in respect of the attention given to the sick child.

The outcomes of the survey have highlighted the fact that families face significant practical problems when their child is unwell, including childcare management of other children in the family – particularly when the sick child is in hospital. As stated, most families rely extensively on friends and family for childcare provision, but this becomes more problematic when there is an absence of other people to assist. On an emotional level, parents reported feeling guilty and torn between the needs of their sick child and the needs of other children in the family.

Practical problems can rebound to become emotional issues, such as access to transport or securing time off work or accessing educational support for the sick child or finding the money to pay for adaptations to the home environment or applying for financial support, such as DLA. These impacts and many more besides, can all add to the stress that families feel when their child is unwell and particularly if the child is in hospital. Many of these practical problems can be reduced by efficient “sign-posting” of the families in the direction of the appropriate support, by healthcare professionals, local authorities, education authorities, schools, benefits officers, etc.

It should be noted that this exercise was only ever intended to be a small survey, to gain a sample picture of the wider needs and issues faced by families in Tayside. By consulting families in the planning stages of the survey, we believe the survey outcomes give a representative indication and perspective of the problems faced by families when their child is unwell.

The principal aim of the survey was to assess how families are affected when sick children need hospital care. In order to do this it was felt that a “holistic” view of the impacts faced by families should be considered, hence the reason why issues such as education, finance and waste disposal have been included rather than solely focusing upon health matters. It is hoped this may give local authorities, employers, health professionals and others, the opportunity to consider the wider implications for families when there is a sick child in the home.

The participating families have come from the more urban localities than the rural areas of Tayside and it is felt that if a larger research study were to be conducted in the future, that the views of more families from the rural areas could be secured. Ideally, the number of respondents would have been equally divided 50/50 between urban and rural, but, the split was 42 Urban / 14 rural, 25.45% of the total were from rural areas despite considerable publicity in the rural areas of Perthshire and Angus appealing for participants. If this study is repeated in the future, it is hoped that the survey could be taken into surgeries in these areas. Requests for access were made of a number of GP surgeries but these did not elicit any response.

APPENDIX I

QUESTIONNAIRE – GUIDELINES & INFORMATION

This questionnaire has been specifically designed to include as many different circumstances as possible. This means that it is equally applicable to families who have a small baby who has a short term health problem as it is to a family who has a teenager with a long-term difficulty. Therefore, we would like to hear from you and receive your opinions irrespective of how long the child is likely to have a medical problem, and regardless of the seriousness of the illness. In other words, Action for Sick Children (Scotland) would still like you to complete the questionnaire, even if you do not consider the illness to be a particularly serious or long-term problem. We regard the illness of every child to be equally as important and we understand how traumatic it can be to have a poorly child in the family and how this impacts on the other members of the family. It is these impacts we wish to hear about and record.

Please note the following BEFORE completing the questionnaire

- All information will be treated in the strictest confidence.
- Your details will not be shared with any other organisation or person.
- The front sheet (containing your personal contact details) will be detached as soon as it is received.
- All or part of the questionnaire may be completed.
- The Tayside Area Coordinator (Fiona Bartley-Jones) can complete this with you or for you on a one-to-one basis if you wish. She will meet with you at a time/date mutually convenient.
- Where a question has a number of options given as an answer, please circle the appropriate choice. For example, questions 16 is a “Yes” “No” or “Don’t Know” option question – please circle the one that is most appropriate to your child’s illness.
- Questions 38 and 53 have a number of different options – please tick all that apply, i.e., you may tick more than one option in each question.
- Please do not worry about using technical jargon or spelling of medical conditions – please just use the terms you most frequently use yourselves. An example of this may be in question 23 – incontinence issues – if you feel more comfortable saying that your child wees himself or poos herself – then that is absolutely fine. After all, we all understand those terms.
- We would like this questionnaire to be as quick and simple as possible for you to complete, as we also understand that having a sick child, can sometimes result in you being required to complete lots of forms at different time , therefore, please feel free to keep your answers as brief as possible.
- However, if you wish to add further information in answer to any question please do so on the back of page 8 but indicate which question it is that you are referring to.
- The results of the survey will be made available to you if you wish but please ensure that you indicate that you would like to receive the results by completing page 8.
- If you have any difficulty in completing this questionnaire, please contact Fiona Bartley-Jones by email: asc.eastscot@dsl.pipex.com or mobile: 07810 238 663, or Action for Sick Children (Scotland) Head Office: 0131 553 6553

Thank you for your time

QUESTIONNAIRE

REF: _____
For Office Use Only



This questionnaire forms an important part of a small survey that is being conducted in order to assess some of the wider implications for families when there is a child in the family who has a health problem. These implications include: education, quality health care and equipment provision and financial impacts.

It is hoped this study will also establish if there are any significant differences between the issues faced by families in a rural location in comparison to those in an urban setting.

Please note that a specific time scale is not being applied to the illness or condition of the child. It is hoped that this study will capture as many different circumstances as possible.

ALL INFORMATION WILL BE TREATED IN STRICTEST CONFIDENCE.

Names and details will not be divulged to any third party whatsoever.

Participants may remain anonymous if they wish .

All or part of the questionnaire may be completed.

The results of the study will be made available to you if you wish (please leave details on the last page of the questionnaire).

PART 1 – Personal Details

1. Name of responsible adult _____

2. Relationship (parent / carer / etc) _ _____

3. Address

_____ Postcode _____

Telephone _____ day) _____ (evening) _____
(mobile)

4. Do you reside with the child Yes / No / other Please specify

5. Name of child

6. Address if different from above

7. Age _____ School / Nursery _____

8. Siblings & ages

9. Do they reside with the child?

PART 2 – medical details

10. Name or nature of condition (brief details)

11. When diagnosed

12. Where treated _____

13. How often

14. Health visitor / Community Nurse / Occupational Therapist / Social Worker, etc (please state giving name if known)

15. Is this a chronic or acute illness?

16. Is this anticipated to be a long-term illness? YES NO
DON'T KNOW

17. Is the expected duration likely to be:

> 3 months months+	3-6 months	6-12 months	12
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18. Any other medical information:

PART 3 - SPECIFIC PRACTICAL MEDICAL ISSUES / INFORMATION

19. Is specialist medical equipment required at home? (e.g Bathing or feeding equipment, visual aids, ventilator, etc)

20. Wheelchair or mobility aids - Wheelchair Splints Crutch(es)
Frame

21. Where assessed & how often

22. Outstanding needs / issues:

23. Are there any incontinence issues: YES NO N/A
(please state what they are)

24. Clinical waste (syringes, incontinence pads, nappies, etc) – what arrangements are in place for their removal?

Local authority removal Private contractor local auth other (please give brief details)

25. Who supplies the above: Purchased privately Health centre
Hospital Other

26. Have you ever been offered telemedicine facilities YES NO
N/A

27. If yes, please give brief details (by whom, did you accept, etc)

<u>PART 4 - EDUCATION</u>

28. Estimated time off school in past year (directly relating to child's medical problems)

1-3 weeks 3-6 weeks 6weeks+

Comment:

29. Is there education provision / arrangements in place for when the child is absent from school for medical reasons YES NO

N/A

30. Persons involved in child's educational decisions (other than teaching staff):

Learning Support Tutor Educational Welfare officer School Nurse

Social Worker Parent/Carer Other

31. Individual or Personal Learning Plan or Agreement: YES
NO DON'T KNOW

32. Does school supply homework when child is off school for medical reasons:
YES NO
Who arranged this: Teaching staff Social Worker Educational
Welfare
Parent/Carer Hospital Staff other (specify)

33. How often is this marked: Weekly Fortnightly Other
(specify)

34. Is any specialist support or equipment provided to assist the child
educationally: YES NO

What is the equipment:

35. Who provides it: School Hospital Occupational Therapist
Health Visitor
Educational Welfare Dyslexia Association Self / Family
Other (specify)

36. Is transport provided to / from school: YES NO
If provided is this a BUS or TAXI

37. Are these transport arrangements only in place at times of illness?
YES NO

38. Which of the following statements apply:
1. The school is supportive & understanding
 2. The school tries to help with keeping the child up to date with class-work
 3. I am kept informed of curriculum activities and topics being covered and work is provided
 4. The school have given me sufficient advice about educating the child at home
 5. The school relies on me/us to educate the child
 6. The school could do more to support the child educationally
 7. School work is posted or sent to school to be marked
 8. I have to mark the work myself
 9. The overall attitude is that if the child is unwell, they should not be expected to do schoolwork
 10. I feel that the child could do more educationally but is being “held back” by the lack of school support
 11. The child is isolated educationally
 12. The child is involved and engaged with school as much as is possible under the circumstances

PART 4A - EXAMS – *only complete if this applies (i.e., secondary school children)*

39. Have exams been sat during the last academic year? YES NO

40. STANDARD GRADE HIGHERS

41. Are they scheduled to be sat during the next academic year? YES
NO

42. STANDARD GRADE HIGHERS

43. Are any special measures in place to support the child in preparation?
YES NO

Scribe	Transcribe	Computer	Large print papers
Alternative seating or desk submission		Toilet access	Sticker marked

44. Do you have: A Personal invigilator Invigilation arrangements Other
(specify):

45. If any of the above are not currently in place, do you think they may be beneficial to the child – please specify

46. Have you asked for any of these and been refused? YES NO
Please give brief details:

47. Do you feel special measures are necessary YES NO

48. Are you aware of local education authority guidelines or policies in relation to the education of sick children? YES NO

49. Are you aware of current legislation relating to the rights of sick children?

YES NO

Please specify those you are aware of:

PART 5 - FINANCIAL IMPACTS

50. Occupation of parents / carers & Employers

51. Time taken off work in past year to attend to needs of child

> 1 week 2-4 weeks 4-8 weeks 8 weeks+

52. Have you (or your partner) had to give up work – Temporarily

Permanently N/A

53. Which of the following statements apply:

1. My employers are very supportive
2. My employers are supportive but are limited due to other constraints (size of organisation, staffing etc)
3. My employers are uninterested & not supportive
4. My employers are obstructive about time off

- 5. I have had to take unpaid leave to be with the child
- 6. My colleagues are understanding
- 7. My colleagues actively support me
- 8. My colleagues are unhelpful
- 9. My colleagues resent the time off I have for my child
- 10. I do not work and rely on benefits (or other source of income)

54. If you are self employed or have had to take unpaid leave, can you estimate the cost to you over the last year?

(may show this in numbers of weeks wages)

55. What are the distances you must travel to / from hospital or clinics? *(round trip)*
 > 10 miles 10-20 miles 20-30 miles 30-60 miles 60-100 miles
 100 miles +

56. How frequently?
 Weekly Fortnightly Monthly 6 monthly Annually

57. Do you travel to appointments or hospital visits by:
 Public transport Own transport (incl. friends & family) Both

58. Approximate costs incurred in providing specialist equipment or home alterations:

59. Do you receive any benefits in respect of your child's medical condition or illness, e.g., Disability Living Allowance? YES NO N/A

60. Have you tried to claim but have been refused? YES NO
 N/A

(please give brief details – grounds for refusal and approximate dates)

61. Have you tried to claim (from any other source), for any travel costs?
 YES NO N/A

62. Have you tried to claim for any equipment or home alterations?
 YES NO N/A

63. Have you tried to claim for additional childcare costs for the sick child or other children in order to attend hospital appointments, or hospital visits?
 YES NO N/A

63a Have you incurred additional costs for other children in the home, resulting from taking your sick child to hospital or visiting your sick child? YES NO N/A

63b Who provides this childcare (for the sick child or for other children in the family)?

Childminder Carer Relative/ Friend Out of School Club
Other (please state)

63c How frequently does this occur? Daily Weekly Monthly
Less Regularly

63d Please estimate how much childcare costs you for other children in the home, that are directly related to providing care whilst you attend hospital visits or appointments?

please state if weekly or monthly

63e Are there any other ways that you believe that siblings are affected by having a sick child in the family? (e.g. do the children act as carers, are holidays affected, etc)

64. Do you receive support from any other agency, charity or department?
YES NO N/A *Please give brief details:*

PART 6 – OTHER INFORMATION

65. Have you heard of Action for Sick Children? YES NO

66. Would you like to receive more information? YES NO

67. Would you like to receive information about the outcomes of this study?
YES NO

68. Contact details of the person who would like to receive the results:

Email:

THANK YOU VERY MUCH FOR YOUR TIME, HELP AND CO-OPERATION IN THIS STUDY.

Fiona Bartley-Jones
Tayside Area Coordinator
Action for Sick Children (Scotland)
Tel: 07810 238 663

asc.eastscot@dsl.pipex.com

Website for more information about Action for Sick Children (Scotland) -
www.ascscotland.org.uk

Please feel to leave any comments:

(please continue on an additional sheet if necessary)



Action for Sick Children (Scotland)

Data Protection Policy Statement

The Data Protection Act 1998 establishes rights for individuals in relation to what information is held about them and how it may be used. Action for Sick Children (Scotland) is a national charitable voluntary organisation which helps sick children and young people meet their healthcare needs in partnership with parents, carers and professionals.

ASC(S) is committed to providing the best possible service to those we work with. This includes a commitment to ensure that all personal information is handled fairly and lawfully with due regard to confidentiality and in accordance with the principles of the Data Protection Act 1998. We hold statistical information on those who contact us for support and assistance. This information is held to assist us:

To monitor, evaluate and provide the best possible service to sick children, young people and their families
In our work campaigning for improved standards in healthcare

ASC(S) also holds personal information about other individuals, for example staff, volunteers, supporters and business contacts. ASC(S) is committed to ensure that all personal information held on these individuals is relevant, up-to-date and accurate. All personal information is treated with due regard to confidentiality in accordance with the principles of the Data Protection Act 1998. Information we have on individuals will not be passed on to any other agencies without their consent.

The Data Protection Act 1998 also gives individuals rights to access information held about them, upon payment of an appropriate fee.

If you would like to know more, contact Action for Sick Children (Scotland)
22 Laurie Street, Edinburgh, EH6 7AB or telephone 0131 553 6553

APPENDIX 2

Sources of Help for Parents and Carers

EMPLOYMENT RIGHTS

As stated in the conclusion of the main text (pages 17 – 18) parents do not have an automatic right to **paid** time off when their child is unwell. Parents/carers should consult the Terms and Conditions of Employment of their Employment Contract.

Anyone who has any concerns regarding their rights to time off when their child is ill, should consult their Union Representative, Citizens Advice Bureau or their solicitor for specific guidance. Additional information can also be found at the end of this appendix under “Useful Links for Families, Parents and Carers.”

EDUCATION OF A SICK CHILD

The following information was given by local education authorities:

Dundee City Council

Parents can also access this help via the Home School Support Service. Further advice and assistance can be obtained from Alison Siddons (Co-ordinator for Additional Support Needs) at Dundee City Councils Education Department. If they feel unhappy with the service being offered by the school, they may also speak to the Advice & Conciliation Officer who is based in Tayside House, on 01382 433477.

Angus Council

Families are advised to contact the school in the first instance regarding support for an unwell child. However, applications can also be made to the Principal Officer for Additional Support Needs via the school.

Perth & Kinross District Council

As stated in the report, parents should speak to the child’s school, but further advice can be obtained from the Balhousie Support Centre, 79 Dunkeld Rd, Perth PH1 5DH Tel: 01738 636940.

EXPENSES, FINANCE AND FUNDING

Travel Costs

Travel and car park expenses can be claimed back if the claimant is in receipt of benefits. Eligibility also depends upon whether the carer is accompanying a child to an appointment or visiting a child in hospital as the procedures do differ according to the circumstances. A Community Care Grant is awarded if the person is visiting a child or young person, but a refund is awarded in respect of travel expenses incurred if you are accompanying a child or young person to appointments. The Community Care Grant is applied for through local Job Centre Plus offices, but the Health Cost Centres (where you can apply for travel refunds) are administered through your local hospital and anyone who wishes to claim can do so via the Social Work

Department at Ninewells (ask for directions at reception). However, claimants must be able to produce all receipts, record of exact mileage and proof of being in receipt of relevant benefits

Home Improvement Grants/Specialist Equipment

The same applies for any alterations to the home and any expenses relating to mobility aids or other specialist equipment. These can be claimed via the local social work department and again, receipts must be kept and the needs of your child will probably be assessed. For further advice claimants are advised to speak to their local Job Centre Plus, Carers Centre, local Community Nurse or Occupational Therapist.

Other Childcare Costs

In some instances additional childcare costs may be met through Working Families Tax Credits, but claimants are advised to discuss this with their local Tax Office or the Tax Credits Helpline before proceeding as there may be additional qualifying criteria involved according to individual circumstances. However, where additional costs have been incurred, prior to making any claim, persons are advised to retain all receipts.

For families in Scotland, more detailed information can be found within the guide '*Housing Grants - An applicant's guide to improvement and repair grants for private housing*' available from the Scottish Government, Housing Division 2, Victoria Quay, Edinburgh EH6 6QQ. This can also be downloaded from Web: <http://www.scotland.gov.uk/Publications/2003/09/18303/27475>

DISABILITY LIVING ALLOWANCE

The rules governing applications are extremely complex and families are advised that they should seek assistance from someone directly involved with their child's healthcare, ideally that person should have specialist knowledge of their child's condition and experience of completing DLA applications. However, if this is not possible, then they should speak to one of the agencies or bodies who do have this expertise – **prior** to completing the form.

Please refer to the Useful Contacts List below for a list of agencies and organisations who can assist you in completing a DLA Application Form.

Useful Links for Families, Parents and Carers

Action for Sick Children (Scotland) - *Action for Sick Children is the only charity in Scotland dedicated to representing, promoting and safeguarding the interests of all sick children, young people and their families.* Action for Sick Children (Scotland) Office: 22 Laurie Street, Edinburgh, EH6 7AB Tel: 0131 553 6553
email: enquiries@ascscotland.org.uk www.ascscotland.org.uk

Contact a Family – *Provides advice and information to the parents of all disabled children. Contact a Family produces a range of factsheets and publications on a range of illnesses and conditions as well as advice and information on rights, finance and services.* Contact a Family, Craigmiller Social Enterprises & Arts Centre, 11/9 Harewood Rd, Edinburgh EH6 4NT Freephone Helpline – 0808 808 3555
www.cafamily.org.uk/factsheets.html

Parent-To-Parent – *Supports parents of children with special needs across Tayside, on a one-to-one basis in the parent's own home. Also gives advice on rights and services.* Parent-To-Parent, Wallacetown Health Centre, Lyon Street, Dundee DD4 6RB
Tel: 01382 455200

Children in Scotland – *National agency for voluntary, statutory and professional organisations and individuals working with children and their families in Scotland. Children in Scotland makes connections between research and policy, and practitioners' everyday experiences, to influence policy and to develop best practice in working with and for children and young people.* Princes House, 5 Shandwick Place, Edinburgh EH2 4RG
Tel: 0131 228 8484 www.childreninscotland.org.uk

Enquire – *The Scottish Advice Service for additional Support for Learning. For additional information on the Education (Additional Support for Learning) (Scotland) Act 2005 and to download a leaflet:* Tel: 0845 123 2303 www.enquire.org.uk/pcp/news.php and follow link

Family Fund – *provides timely grants to families with severely disabled children, based on families' views and needs.* Tel: 0845 130 4542 www.familyfund.org.uk
e-mail: info@familyfund.org.uk

Capability Scotland – *supports children, young people and adults with a range of disabilities. Provides a diverse range of services, including community living, day and residential services, employment, respite/short breaks, therapy and family support.* ASCS (Advice Service Capability Scotland), 11 Ellersly Road, Edinburgh EH12 6HY. Tel: 0131 313 5510 email: ascscapability-scotland.org.uk

Open Minds - *a family support centre based in Perth for children, young people and adults with autistic spectrum disorder.* Real Change Family Support Centre, 50 Princes Street, Perth PH2 8LJ Tel: 01738 449347

Sleep Scotland – *supports parents/carers of children with additional support needs and sleep problems using tried and tested behavioural and cognitive techniques to adapt their child's night-time behaviour.* Sleep Scotland 8 Hope Park Square, Edinburgh EH8 9NW
Tel: 0131 651 1392 www.sleepscotland.org

Care Coordination Network – works with disabled children and their families to ensure that they have access to high quality care co-ordination or key-worker services.
Princes House, 5 Shandwick Place, Edinburgh EH2 4RG Tel: 0131 229 8575
email: scotland@ccnuk.org.uk www.ccnuk.org.uk

The Dundee Voluntary Action at 10 Constitution Rd, Dundee DD1 1LL
Tel: 01382 305732

Perth and Kinross Advice and Volunteer Centre at The Gateway, North Methven Street, Perth PH1 5PP Tel: 01738 567076

The Angus Independent Advocacy Centre - can give advice to individuals on a range of benefits, entitlements and specialist agencies that may be able to support you with a particular issue. 62 High Street, Arbroath DD11 1AW Tel: 01241 434 413

Barnardo's – provides a range of individual, family, or group support on a range of issues, for families of children up to age 19. Referrals welcome for any source. Tel: 01382 224924
www.barnardos.org.uk email: dundee.familysupport@barnardos.org.uk

Advisory Conciliation & Arbitration Service (ACAS) – provides advice relating to all employment issues including employee's rights and resolving disputes.
Helpline: 08457 47 47 47 (Mon-Fri 08.00 – 18.00)

Home Start – Angus – offers regular support, friendship and practical help to young families under stress. 10a Millgate Loan, Arbroath DD1 1PQ Tel: 01241 431131
www.homestartangus.org.uk

Strathmore Centre – provides respite care for children with profound and complex disabilities. Strathmore Centre, Strathmore Avenue, Forfar Tel: 01307 461767

Princess Royal Trust - gives advice on welfare rights **Note – you must book an appointment.** Provides information and a range of support services for carers and people who are disabled, ill and frail in Dundee.
Princess Royal Trust Dundee Carers Centre, Telephone House, 21 Ward Road, Dundee DD1 1ND Tel: 01382 200422 email: centre@dundeecarerscentre.org.uk

Specific benefits advice can also be obtained via the following websites:
www.direct.gov.uk
www.dwp.gov.uk
www.benefitsandwork.co.uk