



County Carers' Group
LEARNING DISABILITIES
LINCOLNSHIRE

Lincolnshire Hospitals Carers' Satisfaction Survey Report



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Preface

This survey was carried out on behalf of the County Carers Group, and with their help and support, by Mike Ormian and John Gurney.

Mike, a previous chair of the group, has had, with his wife, considerable and mixed experiences of hospital visits supporting their daughter who has profound intellectual and multiple disabilities. He provided the motivation and enthusiasm to initiate the survey in the first instance and has been involved in the analysis and reporting process.

John, the current chair of the group, has also had mixed experiences, with his wife, supporting their learning disabled son, whose behaviour can be very challenging, during hospital visits and stays. He has considerable experience in survey design and analysis within a professional role in quality management in a service industry.

Much appreciation goes to Reference Point Ltd for the kind donation of the use of their specialist questionnaire design and analysis software package "Easi-Quest".

Special thanks also goes to Mike's and John's wives for the constant checking and rechecking as the survey and this report developed.

Finally, and most importantly, thanks goes to all of those carers who were so willing to share their experiences, taking time to complete the questionnaire.

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EXECUTIVE SUMMARY

This survey has been undertaken by the County Carers Group (Learning Disabilities) Lincolnshire, a group of carers working for carers in the quest for improvements. It is partly in response to the numerous published reports, such as 'Death by Indifference', 'Six Lives' and 'Raising Our Sights' that have put hospitals and health care under intense scrutiny and partly in response to members own concerns. It is hoped that the findings reported here will assist hospitals in their quest for improvement.

The survey was based on a questionnaire which gathered the levels of satisfaction of 113 Lincolnshire family carers supporting people with learning disabilities on 163 separate hospital visits, including day visits, hospital stays and A&E visits. 137 of these visits were to United Lincolnshire Hospital Trust (ULHT) hospitals; 100 being in the last 4 years.

A scoring system has been applied to the Carer's Satisfaction questions to provide a convenient way to make comparisons over time and between hospitals, etc. This scoring system, explained more fully in section 1.3, provides a percentage score where 50% represents a balance of positive and negative feeling towards 10 positive statements covering: the needs of the carer; the admissions process; staff awareness and response to special needs; appropriateness of consultation with carer and the person with the learning disability, recognition of the carer's expertise; follow-up action. Responses to each of the 10 statements have been analysed and reported on separately in this report and underlying patterns/trends have been identified. This summary includes the main threads of the analysis but is no substitute for the full report.

An analysis of time trends showed that in all but one satisfaction question, the score was at its highest, around 70% - 80%, in 2006 or 2007 and reduced to a low of around 55% to 65% in 2009 before increasing slightly in 2010. The Trust must decide what an acceptable level of satisfaction is, but it is reminded that a 50% score represents a balance of negative and positive feedback, 0% and 100% being the negative and positive extremes respectively. Greater detail for each question is given in the body of the report. The final satisfaction question, relating to the timely and appropriateness of any agreed follow-up action, showed increasing satisfaction up to about 80% but then falling sharply in 2009 and remaining low in 2010.

There was clear evidence to show that carer satisfaction was greatest, although not always good, at the smaller hospitals. Carer satisfaction scores for visits to Grantham and Louth Hospitals were significantly higher than for Boston and Lincoln Hospitals across all 10 statements. The number of respondents for Gainsborough, Grimsby and Skegness Hospitals were too few to be included in this analysis. It came as no surprise therefore that only 49% and 64% of carers would recommend Boston and Lincoln Hospitals, respectively, compared to 96% and 91% for Grantham and Louth Hospitals respectively. It also emerged that carer satisfaction was much reduced where the patient was either below 19 years of age or over 60.

Probably the most concerning outcome from the analysis of satisfaction scores was the overwhelming evidence that the more severe or more complex the disabilities the lower the level of satisfaction. Where the disability seriously compromised the ability of the patient to communicate, thus putting greater reliance on the carer to maintain the link between patient and medical professionals, the level of satisfaction dropped considerably, compared to that where the patient had '*normal speech*'.

Documented information relating to the special needs of the patient, only accompanied 29% of patients, but where this was the case carer satisfaction was reduced, suggesting that the documents are often not sufficiently referred to. One issue here is that such documents can take many different titles and forms, from simple 'grab sheets' to more complex and detailed documents named Hospital Passports or Hospital Admissions Documents, sometimes based around traffic light coding.

The County Carers Group have made a number of recommendations which it is hoped the Trust will consider within an action planning process aimed at improving standards for the most vulnerable, those patients with learning disabilities. The conclusions and recommendations are presented under part 3 of this report, page 19.

1. INTRODUCTION

1.1 Purpose of the survey

There have been surveys and reports about people with learning disabilities and their experiences in hospitals in the past but these neglect to reveal the thoughts and opinions of those people, be they family members or paid or unpaid carers, who support an individual during a hospital visit.

There have been numerous official reports, such as 'Death by Indifference', 'Six Lives' and 'Raising Our Sights' that have put hospitals and health care under intense scrutiny. Parents and caring organisations have been greatly alarmed by these shortcomings and improvements to services cannot be delayed. Additionally, Hospital 'Charters' seem not to recognise the valuable role that family and carers play in supporting people with learning disabilities through what can often be a traumatic and frightening experience.

The County Carers Group committee spend a lot of time talking to family carers, both individually or in group meetings, and there is always a constant underlying disquiet concerning healthcare provided to their learning disabled family members. It is hoped that this initial survey will establish a local healthcare 'benchmark' against which future health developments can be measured. As family carers we need to see that healthcare is constantly improving and the role and value of carers is recognised across the health service.

The County Carers Group will publish the results of our survey and, in the spirit of co-operative involvement, will ensure that all relevant health organisations in Lincolnshire receive a copy, together with our recommendations for service quality improvement.

1.2 The Questionnaire

The questionnaire (see Appendix A) comprised five sections, as follows:

1. **Where and When:** This identified information about which hospital was visited and in which year.
- 2 & 3. **Carer's Satisfaction:** These sections presented 10 positive statements and asked carers to indicate their level of agreement or disagreement with each. There were 4 possible answers to select from, as indicated in the scoring strategy below.
4. **Overall Opinion and Additional Comments:** An overall impression was asked for in terms of whether they would or would not recommend the hospital. It also provides an opportunity to record details of any good or bad experiences in a 'Relevant Comments' section.
5. **About the Person with the Learning Disability.** In addition to age and sex, this section identifies the nature of the learning disability and any communication difficulties. It also asks about the information accompanying the patient on admission, such as Hospital Admission Documents, Communication Passports or 'Traffic Light' Information.

1.3 Scoring strategy

To provide a convenient way to make comparisons, a scoring system has been applied to the Carer's Satisfaction section. For each of the possible responses to the 10 positive statements the following points were allocated:

Strongly agree	4	The allocation of points is designed to give greater difference between 'Agree' and 'Disagree' than between 'Strongly agree' and 'Agree' or 'Strongly disagree' and 'Disagree'.
Agree	3	
Disagree	1	
Strongly disagree	0	

If the carer could neither agree nor disagree, the option of a nil response was made available.

An overall score of 50% (i.e. an average score of 2 out of 4) represents a balance of positive and negative feeling. It should be noted however that, whilst this percentage score provides a useful method of comparison, it should not replace the consideration of the actual number of positive and negative responses. Clearly a balance of positive and negative responses cannot be considered to be a satisfactory outcome.

1.4 Survey process

Approximately 600 questionnaires were distributed by post with a covering letter (see Appendix A) and sent to members of the County Carers Group (family carers of adults with learning disabilities). The Parent Carers Council (family carers of children with learning disabilities) was also asked to distribute

questionnaires to their members. Carers were asked to complete the questionnaire, focusing on one recent visit/stay in hospital, but were invited to make separate responses for up to 3 visits/stays. It is not known what proportion of those receiving a questionnaire had not had any hospital visits during recent years, so a meaningful response rate could not be identified.

1.5 Analysis strategy

In all there were 113 respondents providing feedback on 163 separate hospital visits/stays. One additional response was in respect of private treatment which was outside the remit of this survey, and has therefore been excluded. Where the visit was as an inpatient following a visit to A&E, this was recorded as “inpatient” to avoid double counting. For the same reason, if more than one year was ticked, the latest was used in the analysis, unless the comments related to more than one visit and the responses were clearly relevant to both.

Initial analysis has been undertaken for the full set of data. More detailed analysis has then been undertaken by drilling down to individual hospitals and to identify time trends and satisfaction by the patients’ gender, disability and communication difficulties.

1.6 Reporting strategy

The general method of reporting has been to consider each question in turn, reporting the overall findings and any significant¹ issues resulting from the more in-depth analysis. Extracts from the ‘relevant comments’ responses have been used to illustrate issues with good and bad experiences. Care has been taken in this to ensure comments are not taken out of context. The full set of comments are listed in Appendix C

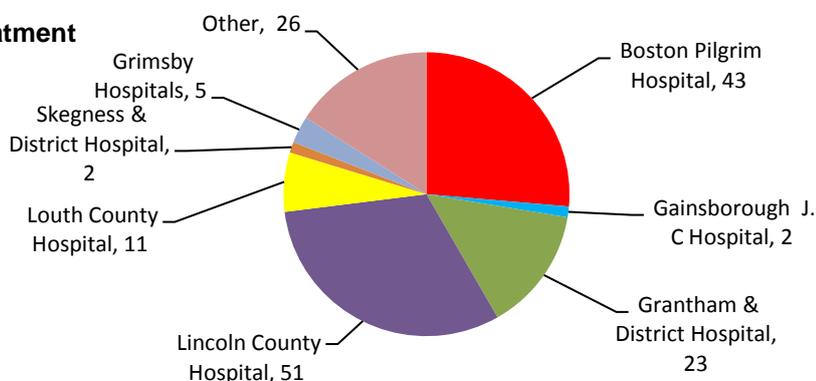
2 FINDINGS BY QUESTION

The full set of responses is summarised in Appendix B.

Section 1: Where and When

Q1.1 In which hospital was the treatment received?

Graph 1. Where treatment was received



The “Other” Hospitals attended were recorded as follows:

Hull Royal Infirmary	1	Nottingham City Hospital	1
Leeds General Infirmary	1	Papworth Hospital, Cambridge	1
Leicester Royal	1	QMC, Nottingham	4
Long Leys Assessment Unit, Lincoln	3	Queen Elizabeth, Kings Lynn	1
Kings Lynn & Addenbrooks	1	Richmond Primary Care, Birmingham	1
Newark	1	Royal Hallamshire Hospital, Sheffield	1
Peterborough District Hospital / Peterborough Edith Cavell Hospital	8	Scunthorpe	1

For the remainder of the report the data set excluding the “Other Hospitals” will be referred to as United Lincolnshire Hospitals Trust (ULHT) Hospitals. Long Leys Assessment Unit has been left in the “Others” since it is not strictly a hospital.

Footnote 1: Throughout the report the term ‘significant’ is used for its dictionary meaning ‘extensive or important enough to merit attention’ rather than any statistical measure of significance. The absence of any benchmark data or control data prevented a full statistical analysis being undertaken, but this does not detract from the findings.

Q1.2 The person visited hospital for treatment as an: (ULHT Hospitals only in parenthesis).

Outpatient (not staying in overnight)	76 (64)	Inpatient (staying in overnight, e.g. for surgery or observation)	58 (47)	Accident & Emergency	28 (25)
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Q1.3 In which year was this treatment undertaken (if it involved a stay spanning two years select the latter year (ULHT Hospitals only in parenthesis)).

2010	63 (48)	2009	34 (31)	2008	14 (12)
2007	9 (9)	2006	13 (11)	2005 or before	26 (22)

Sections 2 & 3 Carers' Satisfaction:

The overall scores for each of the statements in the Carers' Satisfaction sections can be seen in Appendix B. However, when this is broken down to "ULHT Hospitals" and "Other", significant differences can be seen in the bar chart below. In every case "ULHT Hospitals" falls several percentage points below that for "Other", the biggest differences being for the statements:

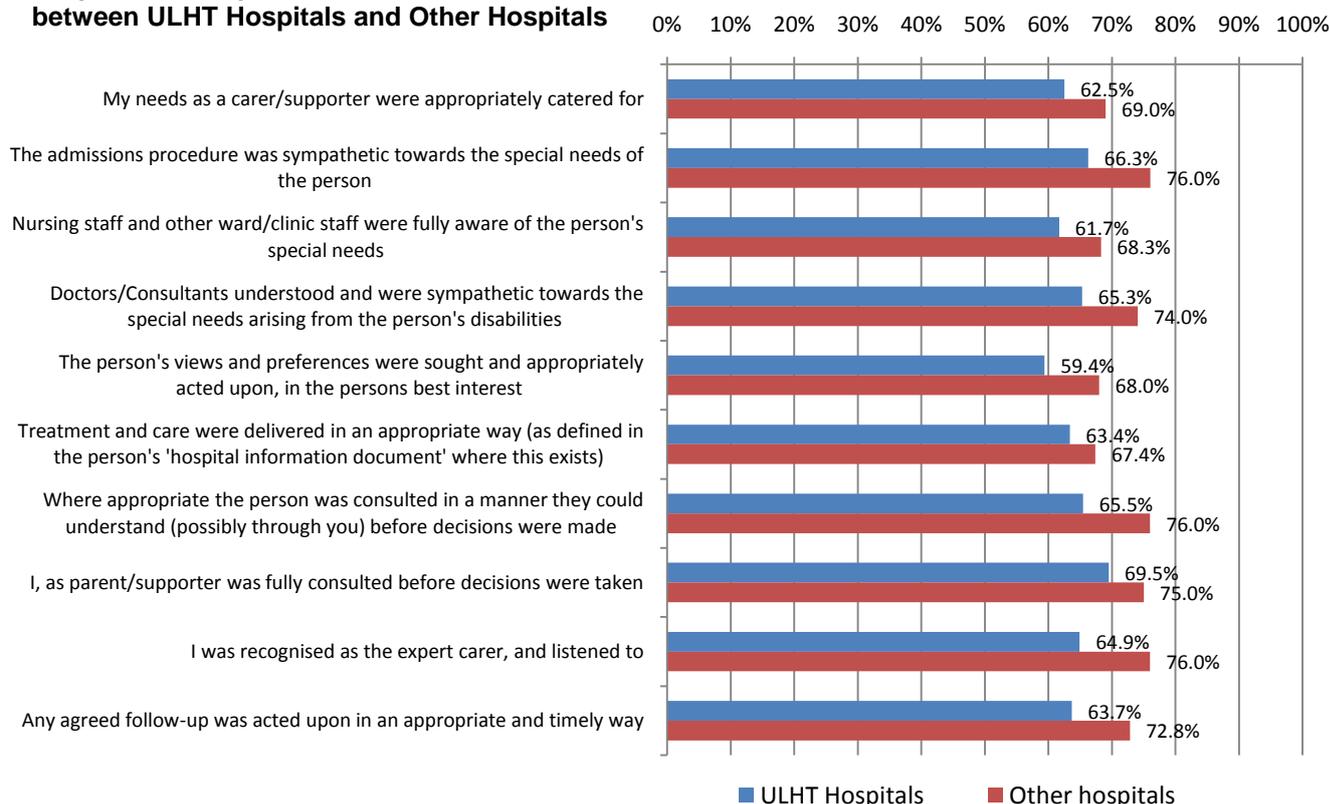
- 3.5 I was recognised as the expert carer, and listened to 11.1% points below
- 3.3 Where appropriate the person was consulted in a manner they could understand (possibly through you) before decisions were made 10.5% points below
- 3.1 The person's views and preferences were sought and appropriately acted upon, in the persons best interest 10.5% points below
- 2.2 The admissions procedure was sympathetic towards the special needs of the person 9.7% points below
- 3.6 Any agreed follow-up was acted upon in an appropriate and timely way 9.1% points below

and the least difference being:

- 3.2 Treatment and care were delivered in an appropriate way (as defined in the person's 'hospital information document' where this exists) 4% points below

The full results are illustrated in Graph 2, below:

Graph 2. A comparison of satisfaction scores between ULHT Hospitals and Other Hospitals

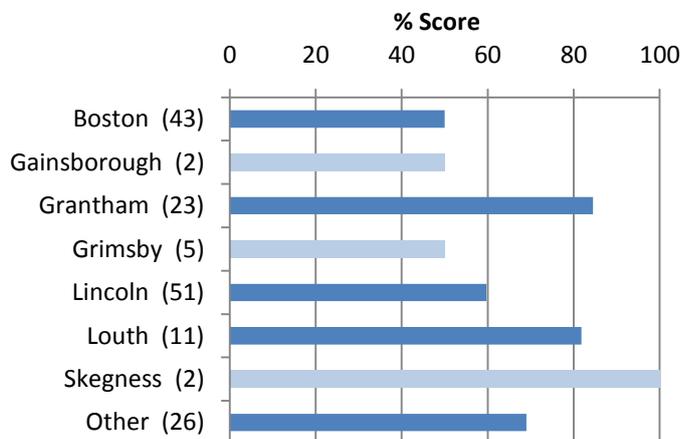
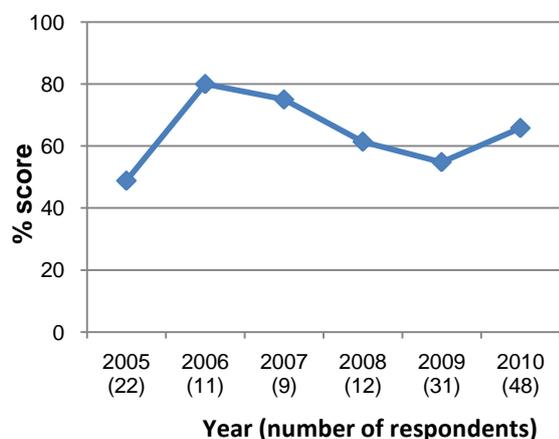


Q2.1 My needs as a carer/supporter were appropriately catered for.

Year on year trends for ULHT Hospitals is shown in Graph 3.²

This would suggest that the decline in satisfaction score from 80% in 2006 down to 55% in 2009 may have been halted, showing a rise to 66% in 2010. The question still remains whether 66% can be considered as satisfactory. The 66% represents 33 Agree or Strongly agree and 13 Disagree or Strongly disagree responses.

The overall score of 63% for Lincolnshire NHS Hospitals is broken down by Hospital, Graph 4.



Graph 3. Satisfaction scores for Question 2.1 by year.

Graph 4. Satisfaction scores for Question 2.1 by hospital

With the very low number of responses for Gainsborough, Skegness and Grimsby these results may be unreliable and have been shown in the lighter colour in the graphs throughout the report. Otherwise, in this comparison, Grantham & District and Louth County Hospitals have clearly outperformed the other ULHT Hospitals and the “Other” group of hospitals. In both of these hospitals there was only 1 *Disagree* and equal numbers of *Strongly Agree* and *Agree*. For Boston Hospital, the 50% score representing a balance of positive and negative perception, there were 23 *Agree* or *Strongly agree* but 20 *Disagree* or *Strongly disagree* (11 of these being *Strongly disagree*). The full set of responses for this question is shown in Table 1 below.

Table 1. Responses to Question 2.1 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	50.0	8	15	9	11
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	84.5	10	10	1	
Grimsby (5)	50.0		2	2	
Lincoln County (51)	59.7	13	18	11	7
Louth County (11)	81.8	5	5	1	
Skegness & District (2)	100	2			
Other (26)	69.0	8	11	4	2

In the comments section there were 6 comments illustrating where carers needs had not been met.

One example:

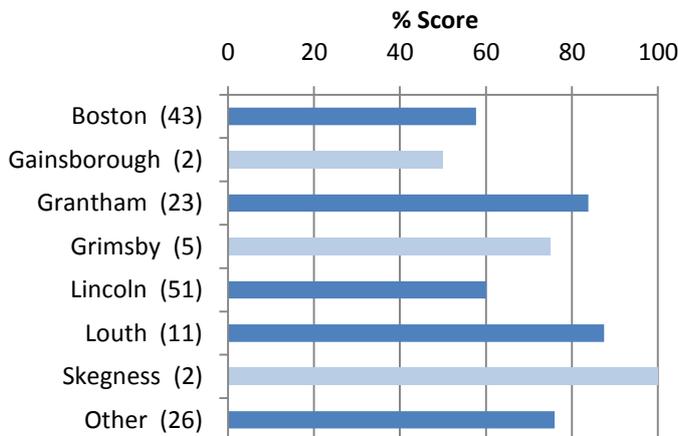
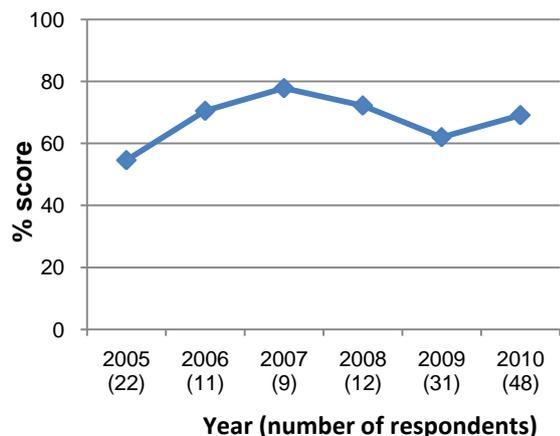
The patient stayed overnight in a side ward. I was not offered anywhere to sleep. I had to sleep in an armchair. I was given a sandwich and drink in the early hours of the morning as I had nothing to eat for around 20 hours.

Boston Hospital, 2010

Footnote 2: It should be noted here that the “2005 or before” response has been plotted as 2005, hence the apparent rapid change between 2005 and 2006 may be more gradual or more varied. Comments about these graphs therefore tend to omit the 2005 plotted point.

Q2.2 The admissions procedure was sympathetic towards the special needs of the person.

The year on year trend for ULHT Hospitals is shown in Graph 5. This shows a varying score between 54% at its lowest in 2005 or before to 78% at its highest in 2007. The 69% for 2010 represents 32 Agree or Strongly agree and 10 Disagree or Strongly disagree.



Graph 5. Satisfaction scores for Question 2.2 by year.

Graph 6. Satisfaction scores for Question 2.2 by hospital

The overall score of 66% for ULHT Hospitals broken down by Hospital is shown in Graph 6, above.

Louth County and Grantham & District Hospitals again outperformed the other Lincolnshire NHS Hospitals and the “Other” group of hospitals, with the exception of Skegness & District Hospital that again had just 2 responses, both *Strongly agree*. Grimsby Hospital, although having only 3 responses, did better in this question than the previous question, all *Agreeing* to the statement. The full set of responses for this question is shown in table 2 below.

Table 2. Responses to Question 2.2 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	50.0	8	17	7	7
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	84.5	9	10	1	
Grimsby (5)	50.0		3		
Lincoln County (51)	59.7	13	18	7	9
Louth County (11)	81.8	5	5		
Skegness & District (2)	100	2			
Other (26)	69.0	11	9	2	2

One example:

As his dad, I would recommend Skegness Hospital. I took him to see the ENT specialist on Friday 22/10/2010. I was greeted with a warm smile from the receptionist, and kindly shown to the waiting room. We were treated like VIP people. He was very tense but the nurse tried to put him at ease and the appointment went along very smoothly. Thank you for all concerned, in helping to make our visit run so well.

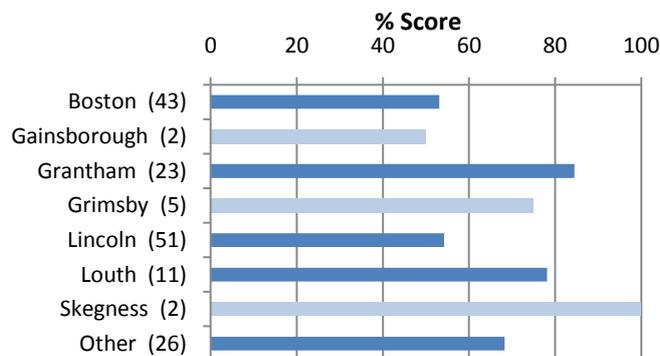
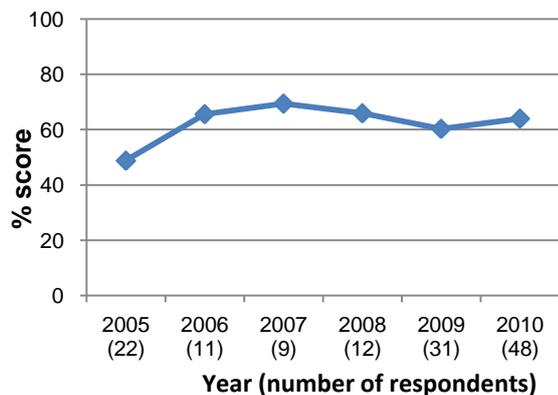
Skegness 2010

Q2.3 Nursing staff and other ward/clinic staff were fully aware of the person's special needs.

The year on year scores for ULHT Hospitals are less variable for this question, shown in Graph 7, below. This shows a score between 49% at its lowest in 2005 or before to 69% at its highest in 2007. The 64% for 2010 represents 29 Agree or Strongly agree and 14 Disagree or Strongly disagree.

The overall score of 62% for ULHT Hospitals broken down by Hospital is shown in Graph 8.

Again, Grantham and Louth Hospitals lead the way, ignoring those with 5 or less respondents, shown in the lighter colour in the graph. Boston and Lincoln Hospitals scores are very close to a balance between positive and negative perceptions.



Graph 7. Satisfaction scores for Question 2.3 by year.

Graph 8. Satisfaction scores for Question 2.3 by hospital.

The full set of responses for this question is shown in table 3, below.

Table 3. Responses to Question 2.3 by Hospital

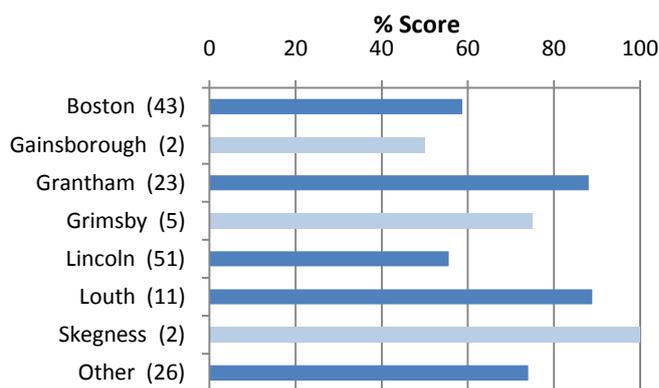
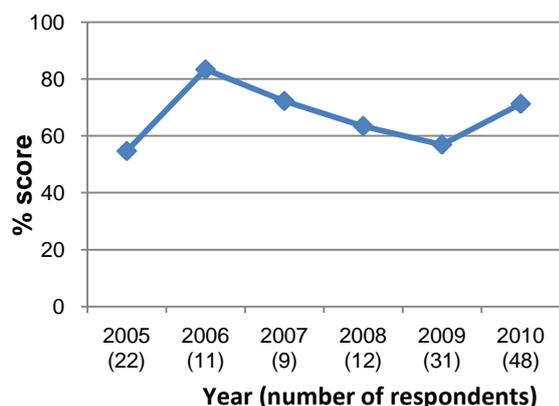
HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	53.1	10	12	9	9
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	84.5	10	10	1	
Grimsby (5)	75.0		3		
Lincoln County (51)	54.2	9	19	11	9
Louth County (11)	78.1	3	4	1	
Skegness & District (2)	100	2			
Other (26)	68.3	10	9	4	3

The patient was accused of being drunk as she was unable to communicate properly and had slurred speech. The medical staff did not want to speak to me on her behalf as they were suggesting that I had something to hide and had perhaps caused the injury to my sister (the person with learning difficulties). They twice took her away on her own to question her. Obviously she was terrified, already shaken by her injuries. Lincoln County Hospital, 2010

The person spent a day on the ward having dental treatment. She was given a general anaesthetic as she gets panicky when needing hospital treatment. She was allowed to walk down to the anti-room to the theatre and was frightened to lie down on the trolley so the staff sat her on a chair and gently put the anaesthetic mask on her face until she fell asleep and then transferred her to the trolley. I stayed with her until then. I was very touched by their kindness and patience. She looks back on the experience with no fear, and for that I am very grateful. Louth Hospital, 2007

Q2.4 Doctors/Consultants understood and were sympathetic towards the special needs arising from the person's disabilities.

There is a marked 3-year decline in carers' satisfaction from 2006 to 2009 with an apparent upturn for 2010, shown in Graph 9, below.



Graph 9. Satisfaction scores for Question 2.4 by year.

Graph 10. Satisfaction scores for Question 2.4 by hospital.

Of the 11 responses in 2006 there were 6 *Agrees*, 3 *Strongly agrees* and no *Disagrees* or *Strongly disagrees*. In comparison, in 2009 11 out of 29 were dissatisfied and in 2010, 34 carers *Agreed* or *Strongly agreed* and 12 *Disagreed* or *Strongly disagreed*.

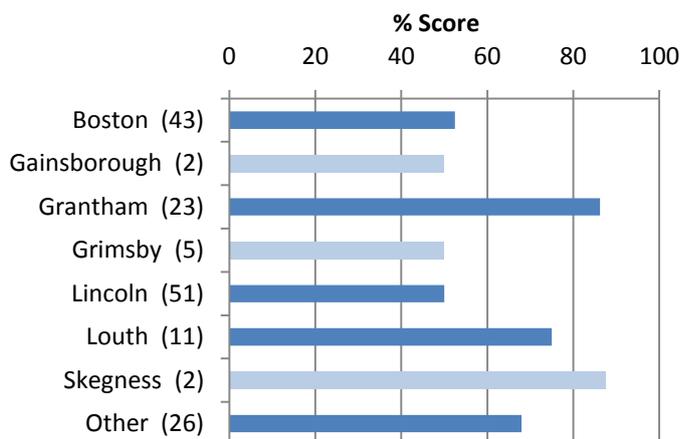
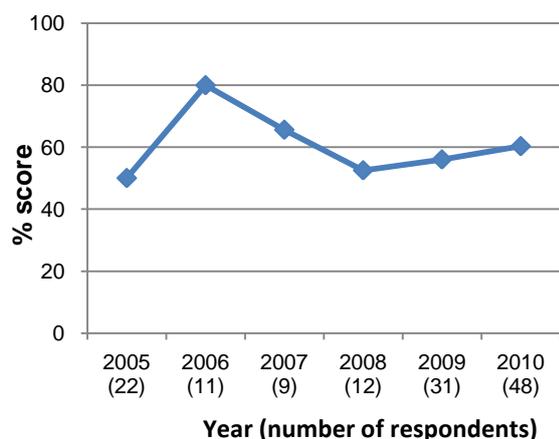
When broken down to hospitals the same pattern as with previous questions is seen, Graph 10 above, Grantham and Louth heading the field with Boston and Lincoln trailing behind by a considerable degree. Again, those with 5 or fewer respondents have not been included in this consideration. The full set of responses for this question is shown in the table 4, below.

Table 4. Responses to Question 2.4 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	58.7	12	15	8	8
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	88.1	13	7	1	
Grimsby (5)	75.0		3		
Lincoln County (51)	55.6	15	13	10	11
Louth County (11)	88.9	5	4		
Skegness & District (2)	100	2			
Other (26)	74.0	11	10	3	2

Q3.1 The person's views and preferences were sought and appropriately acted upon, in the person's best interest.

This question had the lowest overall score at 59.4% for ULHT Hospitals. For 2010 the score of 60.3% represents 29 positive responses (*Agree* or *Strongly agree*) and 17 negative responses (*Disagree* or *Strongly disagree*).



Graph 11. Satisfaction scores for Question 3.1 by year. Graph 12. Satisfaction scores for Question 3.1 by hospital.

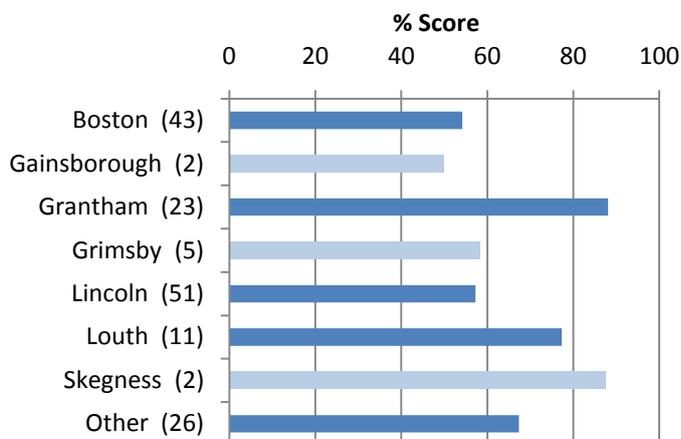
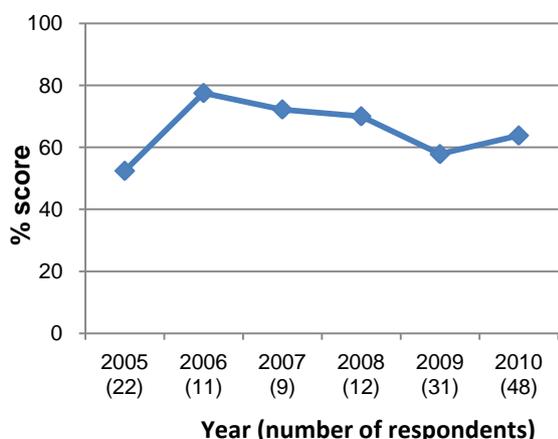
There was just 1 negative response for Grantham Hospital over the entire period and 2 for Louth, with 19 and 9 positive responses respectively. In comparison, Lincoln County Hospital had more negative responses than positive, 24 and 22 respectively. This result for Lincoln County Hospital was the only question in the entire survey where the number of negative responses outweighed the number of positive responses. The full set of responses for this question is shown in the table 5, below.

Table 5. Responses to Question 3.1 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	52.5	9	14	6	11
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	86.3	11	8	1	
Grimsby (5)	50.0		2	2	
Lincoln County (51)	50.0	11	11	15	9
Louth County (11)	75.0	4	5	2	
Skegness & District (2)	87.5	1	1		
Other (26)	68.0	7	12	4	2

Q3.2 Treatment and care were delivered in an appropriate way (as defined in the person's 'hospital information document' where this exists).

Year on year trends follow more or less the same pattern as for the previous questions, 2006 providing the highest score and dipping to 2009 and then showing a small upturn. The 2010 score of 63.8% represents 33 positive and 14 negative responses.



Graph 13. Satisfaction scores for Question 3.2 by year. Graph 14. Satisfaction scores for Question 3.2 by hospital.

A similar pattern to that obtained for previous questions is also obtained when drilled down to Hospital level, Grantham emerging as the clear leader with just one negative response again, (Graph 14 above).

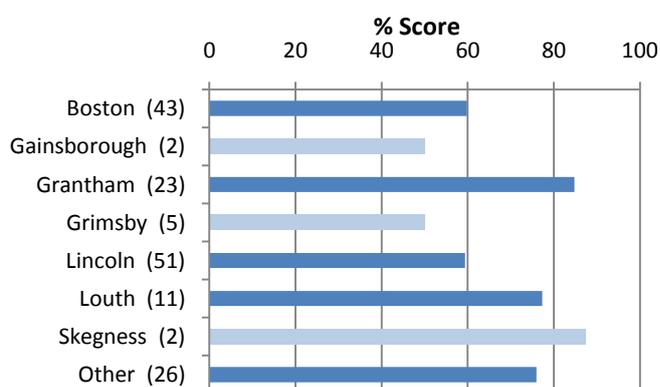
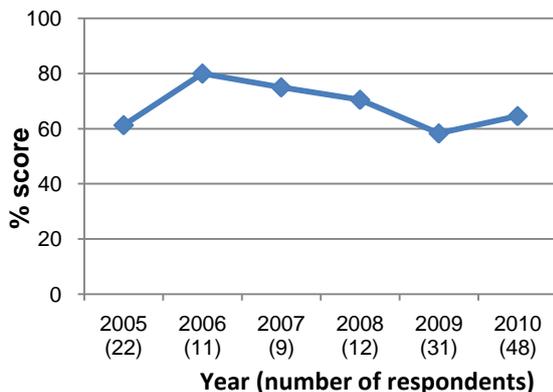
The full set of responses for this question is shown in the table 6, below.

Table 6. Responses to Question 3.2 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	54.2	9	16	7	10
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	88.1	11	10		
Grimsby (5)	58.3		2	1	
Lincoln County (51)	57.3	10	19	13	6
Louth County (11)	77.3	5	4	2	
Skegness & District (2)	87.5	1	1		
Other (26)	67.4	6	12	2	3

Q3.3 Where appropriate, the person was consulted in a manner they could understand (possibly through you) before decisions were made.

The familiar pattern for year on year trends is shown in Graph 15 for this question, 2006 giving the highest score and dipping to 2009 and then showing a small upturn. The 2010 score of 64.6% represents 34 positive and 14 negative responses.



Graph 15. Satisfaction scores for Question 3.3 by year. Graph 16. Satisfaction scores for Question 3.3 by hospital.

Again Grantham & District Hospital leads the field with Skegness (2 respondents), closely followed by Louth. Between these three there were only 3 negative responses compared to Boston and Lincoln where there were 13 and 17 negative responses respectively. Gainsborough and Grimsby Hospitals both had equal numbers of positive and negative responses.

The full set of responses for this question is shown in the table 7, below.

Table 7. Responses to Question 3.3 by Hospital

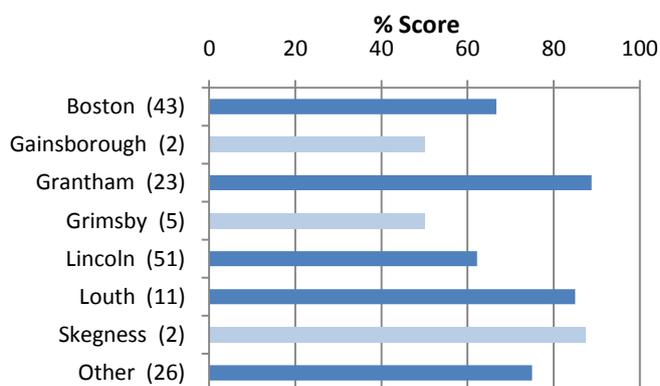
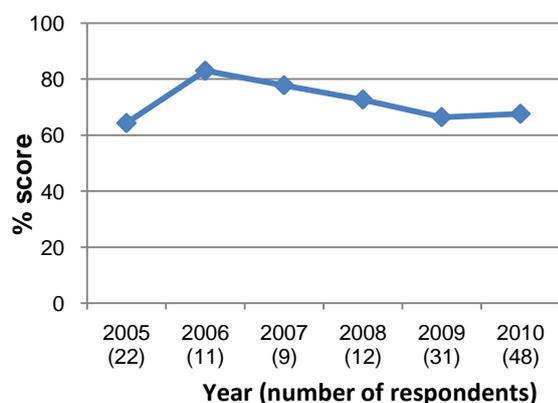
HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	59.8	11	17	3	10
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	84.8	12	10		1
Grimsby (5)	50.0		2	2	
Lincoln County (51)	59.4	10	21	11	6
Louth County (11)	77.27	5	4	2	
Skegness & District (2)	87.5	1	1		
Other (26)	76.0	10	12		3

..... During a so called sight test to check "all was well" the consultant/medical doctor held up words asking her to call them out - she would call out anything to try and read. To be told "no the word is wrong, try again, what is wrong with you?" I told them she had learning difficulties and couldn't read, but was told not to interfere, again I was trying to speak for her and I must have something to hide. He then proceeded to show her numbers which she could not read. Again seemingly to grunt disapproval at her attempts to say something - not the right thing. A nightmare of a visit. The only people sympathetic and helpful were the reception staff.

Lincoln County Hospital, 2010

Q3.4 I, as parent/supporter, was fully consulted before decisions were taken.

The time trend graph is a little flatter than for many questions indicating slightly less variation. On drilling down to Hospital level the usual pattern is again repeated, although Boston Hospital has closed the gap a little scoring above 60% for the first time.



Graph 17. Satisfaction scores for Question 3.4 by year. Graph 18. Satisfaction scores for Question 3.4 by hospital.

The full set of responses for this question is shown in the table 8, below.

Table 8. Responses to Question 3.4 by Hospital

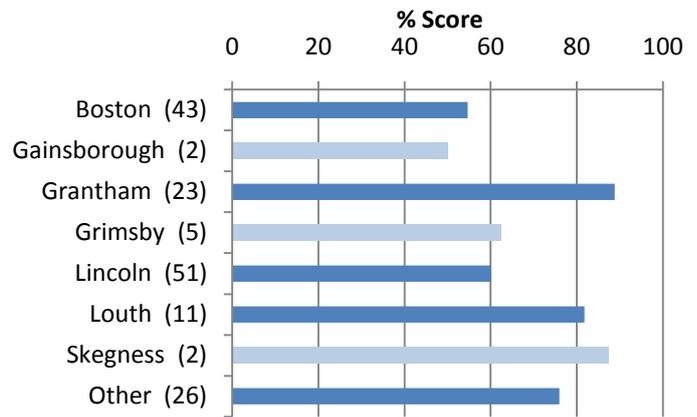
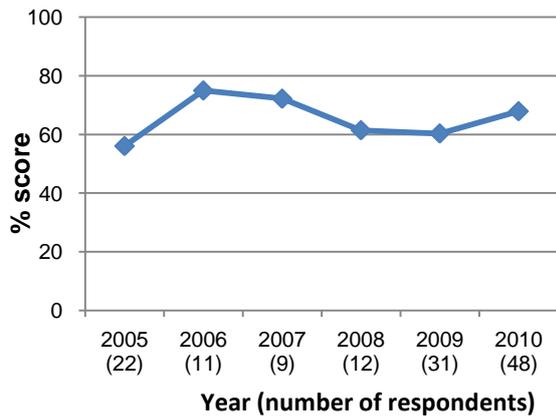
HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	66.7	10	23	3	6
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	88.8	11	9		
Grimsby (5)	50.0		2	2	
Lincoln County (51)	62.2	12	20	9	6
Louth County (11)	77.3	5	4	2	
Skegness & District (2)	87.5	1	1		
Other (26)	75.0	11	11	1	3

Appalled at OPD treatment. Would not listen to me, not interested in the patient as I believe was because of having a learning disability. Rude at times. Did not explain procedures. Did not communicate with patient, therefore I went to GP and asked for a second opinion - we were referred to Lincoln County where it was 100% better.

Boston Hospital, 2009

Q3.5 I was recognised as the expert carer, and listened to.

The familiar time trend and Hospital comparison is again seen in Graphs 19 and 20 for this question. In 2010 The responses for Boston Pilgrim Hospital included 18 negative responses, 10 of which were *Strongly Disagree*.



Graph 19. Satisfaction scores for Question 3.5 by year. Graph 20. Satisfaction scores for Question 3.5 by hospital.

The full set of responses for this question is shown in the table 9, below.

Table 8. Responses to Question 3.5 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	54.7	11	14	8	10
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	88.8	11	9		
Grimsby (5)	62.5		3	1	
Lincoln County (51)	60.1	13	17	10	7
Louth County (11)	81.8	5	5	1	
Skegness & District (2)	87.5	1	1		
Other (26)	76.0	11	10	2	2

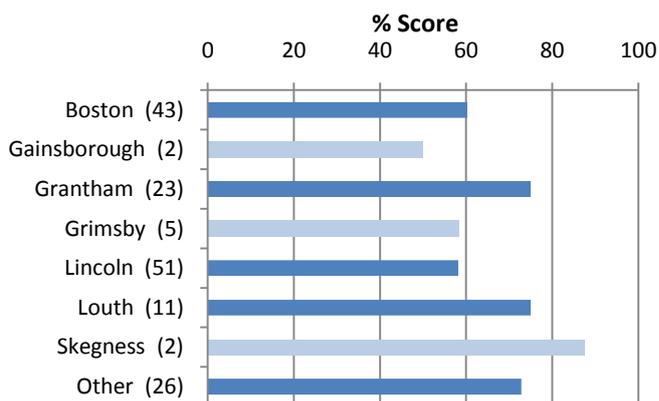
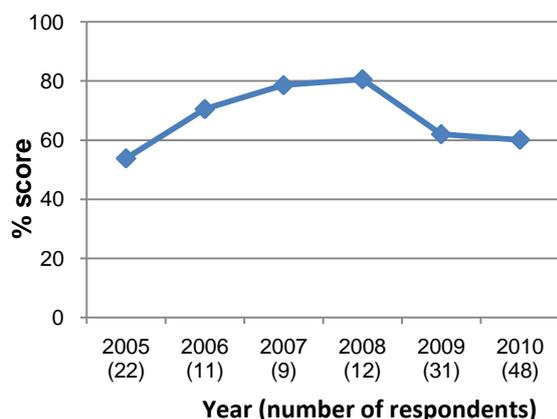
Our son was admitted for an operation. I had contacted the hospital before admission and explained that he was autistic and his current obsession was with switches and that he would need to be away from any machines with switches. They placed us in a room with a child connected to a machine with switches. I could not stop my son darting towards the machine and touching the switches. Alarms went off, all hell broke loose and we were transferred to a single room! The staff showed no understanding of autism whatsoever.

Boston Hospital, 2005

Q3.6 Any agreed follow-up was acted upon in an appropriate and timely way.

The year of year trend for this question shows that following a 4 year upward trend there was a marked decline in 2009, with a similar poor score in 2010, Graph 21.

Drilling down to Hospital level, Graph 22, suggests that Grantham and District Hospital and to a lesser extent Louth Hospital may have played the largest contributory part in this, it being the first question in which both had a score of much less than 80%, although still leading the field, apart from Skegness which maintained its 2 positive scores position.



Graph 21. Satisfaction scores for Question 3.6 by year. Graph 22. Satisfaction scores for Question 3.6 by hospital.

Closer inspection of the Grantham scores reveals a total of 3 negative scores but 2 of these, which were both *Strongly disagree*, out of 9 responses, were in 2010.

The full set of responses for this question is shown in the table 10, below.

Table 10. Responses to Question 3.6 by Hospital

HOSPITAL	% Score	Strongly Agree	Agree	Disagree	Strongly Disagree
Boston Pilgrim (43)	60.3	9	14	4	7
Gainsborough J. C (2)	50.0	1			1
Grantham & District (23)	75.0	8	10	1	2
Grimsby (5)	58.3		2	1	
Lincoln County (51)	58.2	13	14	13	6
Louth County (11)	75.0	4	5	2	
Skegness & District (2)	87.5	1	1		
Other (26)	72.8	8	11	2	2

Following a thorough examination by the ENT consultant it was recommended that a CT scan was needed to identify the possible cause of pain We have since spent almost 6 months trying to get this referral made. We were passed from pillar to post, until a chance conversation with a private osteopath practitioner identified a possible route through a TMJ specialist. It has however taken 6 months of chasing to get there; presumably anyone with less persistent parent/carers would not have got there.

Grantham & District, 2010

Section 4 Overall opinion

Q4.1 Would you recommend the hospital?

Looking down the percentages of those recommending the hospital they visited over the years, it will come of no surprise that a similar year on year trend is returned. 2006 was the best year with 91% being satisfied overall and only 9% not wishing to recommend the hospital, (see Table 11).

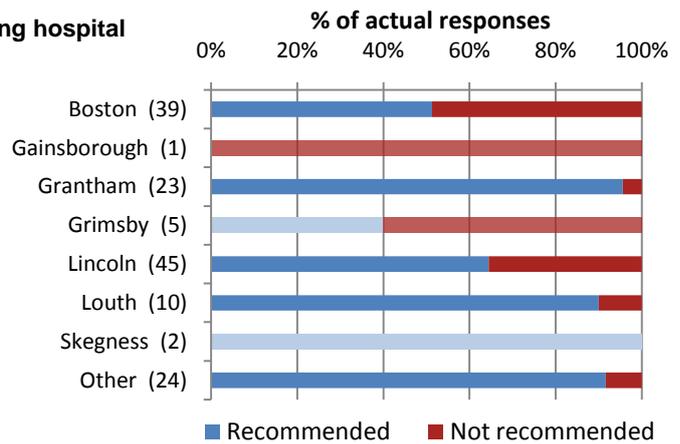
Drilling down to Hospital level, Graph 24: Of the 23 who responded to this question for Grantham, only 1 failed to recommend the hospital. This was the only ULHT Hospital which exceeded that for the *Other* group for which 2 out of 24 respondents failed to recommend the hospital. Louth Hospital was close behind with 1 out of 10 failing to recommend. For Boston only 20 out of 39 respondents would recommend the hospital.

Table 11. Percentage responses by year for Question 4.1

	Recommended		Suggest other	
	Number	%	Number	%
2005 (22)	9	41	11	50
2006 (11)	10	91	1	9
2007 (9)	7	78	1	11
2008 (12)	7	58	4	33
2009 (31)	19	61	11	35
2010 (48)	29	60	13	27

Graph 24
% Responses recommending hospital

Although having very few respondents, it is worth noting that for Skegness, both would recommend the hospital, while Gainsborough and Grimsby fared less well with 0 out of 1 and 2 out of 5 respectively.



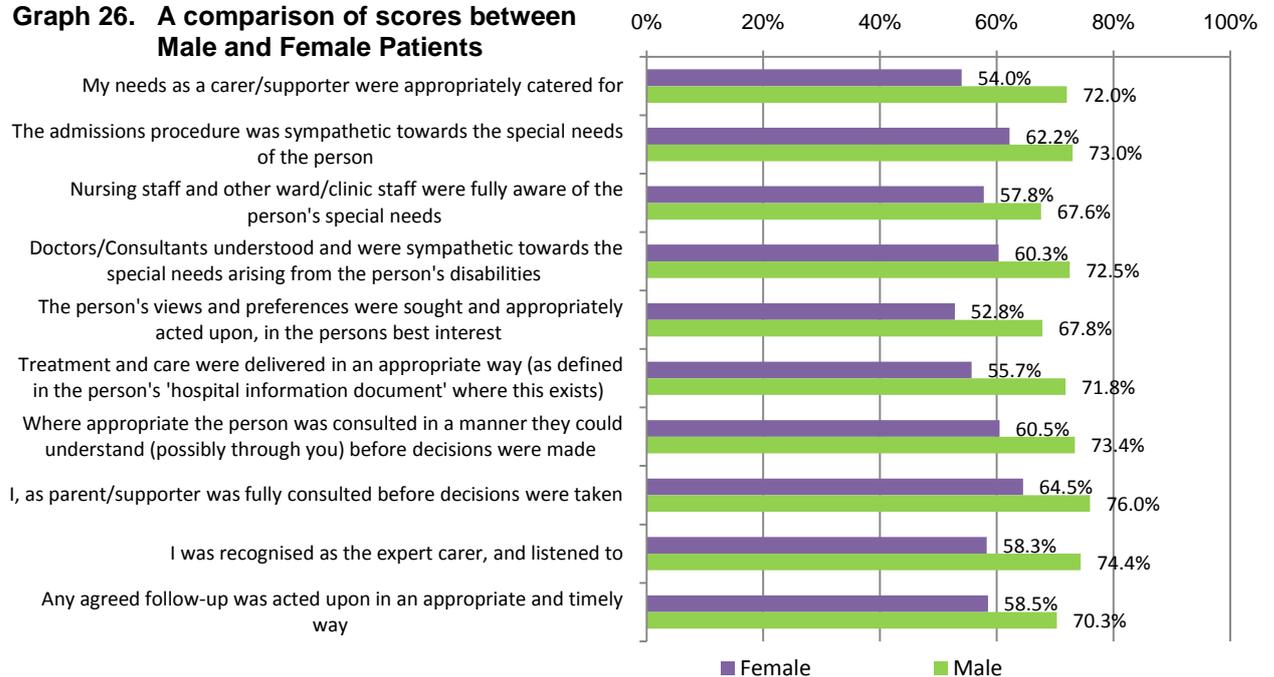
Q4.2 Additional comments are recorded verbatim, by hospital and year in Appendix C. Names have been omitted, in line with standard practice. Some snippets have been used as illustrations in the body of the report.

Section 5 About the person with the disability

Q5.1 Male or Female?

The patients with the learning disabilities being supported during their hospital visits comprised 83 males and 78 females, 2 respondents opted not to say. An interesting male/female split is identified when considering the overall score for each carer satisfaction question, (see Graph 26 below). Carer satisfaction is significantly lower when the person being cared for is female than if they are male. This may be to do with carer expectation but, whilst the data may be consistent with this, it is just speculation.

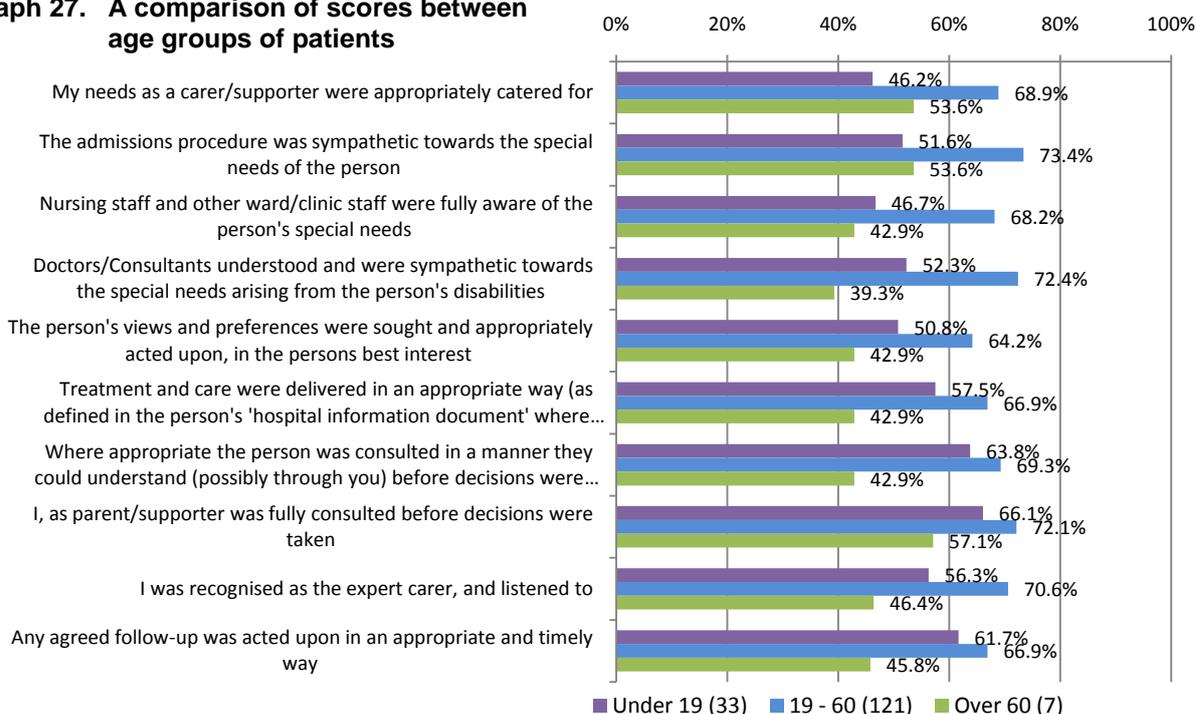
Graph 26. A comparison of scores between Male and Female Patients



Q5.2 Age group:

There were 33, 121 and 7 responses for the age groups *less than 19*, *19 to 60* and *more than 60*, respectively. Graph 27, below, clearly shows that carer satisfaction was significantly reduced for the lower and high age groups than for the *19 to 60* group. It should be noted however that there were very few respondents in the higher age group.

Graph 27. A comparison of scores between age groups of patients

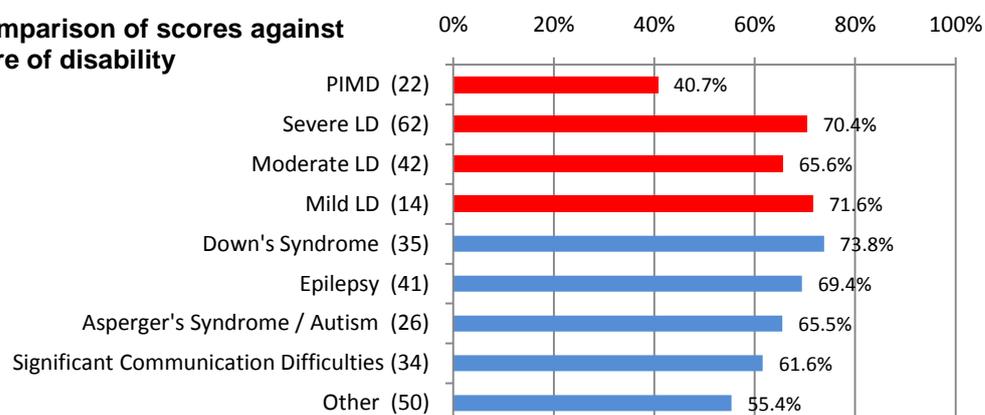


These large differences raise the question as to whether this contributes towards the differences in satisfaction scores between hospitals. Further investigation reveals that for Boston and Lincoln hospitals, those with the worst satisfaction scores, 33% and 29%, respectively, were in the lower or higher age groups, whilst for Louth and Grantham hospitals, those with the highest satisfaction scores (ignoring those with 5 or fewer respondents), it was only 18% and 4% respectively. It follows therefore that a major factor in carer satisfaction is to do with the age group to which the patient belongs. This is not an overriding factor however, since if these age groups are removed from the analysis the overall satisfaction scores for Boston and Lincoln hospitals increases to 57.1% and 63.9% respectively, compared to 84.8% and 78.6% for Grantham and Louth hospitals respectively.

Q5.3 The patients' main disabilities:

This was a multiple response question, in which 86% of respondents selected one of the first 4 answers many selecting additional answers which best described the disabilities. The 50 other responses, relating to 36 different patients, are listed in Appendix D. Considering the first 4 answers, which identify the level of disability, it is clear that overall satisfaction for the most disabled, those with profound intellectual and multiple disabilities (PIMD), was very low compared to the other 3 levels of disability. Again, drilling down to hospital level, there are differences in the proportions of those with PIMD but this is not as great as for the age group differences, above. For Boston and Lincoln hospitals, those with the worst satisfaction scores, 14% and 17% respectively were in the PIMD category, whilst for Louth and Grantham hospitals, those with the highest satisfaction scores (again ignoring those with 5 or fewer respondents), it was only 9% each. It follows therefore that this is a lesser contributory factor in carer satisfaction.

Graph 28. A comparison of scores against nature of disability

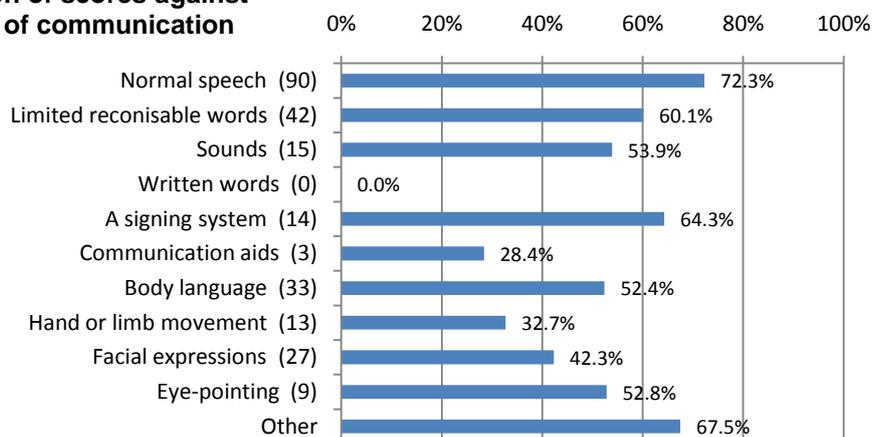


The low scores for those with *Significant Communication Difficulties, Syndrome / Autism* and *Other* would also suggest that the more complex the nature of the disabilities the lower the carer satisfaction.

Q5.4 The patients' main methods of communication:

Again this was a multiple response question, although of the 90 who selected *normal speech* only 8 selected additional responses. The carer overall satisfaction scores by main communication method are shown in Graph 28 below.

Graph 28. A comparison of scores against main means of communication



This clearly shows for that those patients for whose communication is most reliant of the carers help, carer satisfaction is particularly low. For example; *Hand or limb movement, Facial expressions, body language* and *Eye-pointing* will only be understood by the parent or carer supporting the person and these have the lowest carer satisfaction scores. This ignores the *Communication aids* response because there were only three respondents.

Q5.5 Hospital information document:

Only 44 out of 154 (29%) respondents to this question said that an information document, identifying such things as medication and any special needs, accompanied the patient to hospital. The percentage was about the same for those attending ULHT Hospitals: 38 out of 130 (29%). Interestingly, and unexpectedly, the overall carer satisfaction score for those where such a document was provided was significantly lower than for those without: 56.8% and 66.0% respectively for ULHT Hospitals. This is matched by the scores for question 3.2, which asked about the appropriateness of treatment and care in respect of the persons special needs (as defined in the persons 'hospital document' where this exists). The score was over 10 percentage points lower for those accompanied by such a document. The comments below would support a concern that these document are not always referred to by those who need the information.

Comment in respect of 'Hospital information Document: Very explicit detailed information. I always take to hospital and make everyone aware. Have had praise for this document from several medical personnel.

General comment for the same hospital visit: As carer I was told to only visit at visiting hours, yet staff didn't attend to patient's personal care needs, left him in a mixed ward inappropriately dressed, sitting on toilet with door open. Some treatments/procedures not done because patient couldn't give D.O.B. when I wasn't in attendance.

Boston, 2007

3 CONCLUSIONS AND RECOMMENDATIONS

Clearly carers are often dissatisfied with the standard of care and consideration received during hospital visits supporting their learning disabled family members. This is particularly the case where the nature of the disability is severe and complex and where the carers support is vital in providing the communication link between health professional and patient. This seems to be further compounded if the patient is young or older. It is hoped that the findings in this report are used by the Trust to bring about improvements and to avoid any serious outcomes such as those reported in publications such as 'Death by Indifference' and 'Six Lives'. The County Carers Group would support any initiative to work cooperatively with the Trust or individual hospitals to bring about improvements. It is recommended that action planning is undertaken to address the main issues identified through this survey. The following recommendations are aimed at bringing about such improvements:

Recommendation 1:	Include a statement in the Carers Charter which ensures the needs of the carer/supporter are appropriately catered for, thus maximising the effectiveness of their support.
Recommendation 2:	Introduce mandatory annual training, delivered by Acute Liaison Nurses and carers, to improve understanding of learning disabilities (including communication problems and autism/asperger's syndrome) amongst health professionals, and to raise awareness of the value of carers' expertise.
Recommendation 3:	Develop a single model information document that will be recognised by all as being important in meeting care needs. This should include the 'Passport' and Assessment & Care Planning and must be used by all.
Recommendation 4:	Include the satisfaction statements from this one-off survey within a rolling carer satisfaction survey process.
Recommendation 5:	Develop and adopt carers' performance indicators as part of a quality improvement process.



County Carers' Group
LEARNING DISABILITIES
LINCOLNSHIRE



Hospitals – How was your experience as a carer for someone with a learning disability?

The need for improvement in hospitals for people with learning disabilities is well known and has been highlighted in the Mencap report ‘Death by Indifference’ and their new ‘Getting it Right’ campaign. We cannot expect improvements to be made unless we tell them what is good and what is not good.

With this aim County Carers' Group are gathering information about carers' good and bad experiences to present to the NHS and Learning Disability Partnership Board. Whilst we recognise that progress is being made and that events like the “Big Health Day” held earlier in the year and other activities play a part, as far as we are aware, carers' views are seldom sought in a way that provides analytical evidence. As the “expert carers” with greatest knowledge of those we support, we feel our views are important. The resulting report will only have impact if it includes findings from a large number of carers, so please take a few minutes to complete the questionnaire. This asks you to focus on a particular hospital visit and indicate the level of agreement or disagreement with a number of positive statements. There is ample opportunity to elaborate on your responses or comment further if you wish. Two continuation sheets are included so that you can tell us about up to 3 separate hospital visits or stays if you wish.

You will see that we have not asked for your name and address so as to ensure your anonymity remains intact.

Our intended time scale will see a report published by Spring next year at the latest. It is planned that this will be accessible through the internet or can be e-mailed or sent to you by post, on request. Future mailings will give further information about this at the time.

Please return your completed survey in the prepaid envelope by:

Friday 3rd December 2010

With your help, we can make things better

If you have any queries please contact either:

Contact details were provided

Hospital Satisfaction Survey (Parents/Carers)

Please tell us about your experience as a carer/supporter of a person with a learning disability during a hospital visit (preferably within the last few years). Focus on one particular visit (good or bad) and tell us about that. If you wish to tell us about other visits, please use the continuation sheets, which just include those questions relevant to the visit/stay itself.

General information (please read this before completing the questions):

(a) This questionnaire is about YOUR feelings as a parent/carer supporting a person with a learning disability during their visit to, or stay in, hospital. This information is rarely sought and seldom used, so please make the most of this opportunity to make your voice heard.

(b) The term 'The Person' means the person with the learning disability for whom you care/support.

(c) The term 'Hospital' includes local and general hospitals, regional specialist hospitals, Assessment and Treatment Units and Accident & Emergency departments. Outpatients departments, clinics, X-ray departments etc., are also included. Treatment in private hospitals is not included unless it is paid for by the NHS. GP surgeries are not included.

(d) The term 'Hospital Information Document' refers to anything owned by the person that gives comprehensive details of medical conditions, medications and how the person should be treated. Sometimes these documents are called 'Traffic Light Assessments', 'Hospital Passports' or 'Hospital Admissions Documents'.

Where and When

For this particular hospital visit, please tell us when and where it took place.

1.1 In which hospital was the treatment received?

- | | | |
|--|---|---|
| a <input type="checkbox"/> Boston Pilgrim Hospital | b <input type="checkbox"/> Gainsborough J. C Hospital | c <input type="checkbox"/> Grantham & District Hospital |
| d <input type="checkbox"/> Lincoln County Hospital | e <input type="checkbox"/> Louth County Hospital | f <input type="checkbox"/> Skegness & District Hospital |
| g <input type="checkbox"/> Spalding Johnson Hospital | h <input type="checkbox"/> Grimsby Hospitals | i <input type="checkbox"/> Other (please specify below) |

Other Hospital

1.2 The person visited hospital for treatment as an:

- | | | |
|--|--|---|
| a <input type="checkbox"/> outpatient (not staying in overnight) | b <input type="checkbox"/> inpatient (staying in overnight, e.g. for surgery or observation) | c <input type="checkbox"/> Accident & Emergency patient |
|--|--|---|

1.3 In which year was this treatment undertaken (if it involved a stay spanning two years select the latter year)

- | | | |
|---------------------------------|---------------------------------|---|
| a <input type="checkbox"/> 2010 | b <input type="checkbox"/> 2009 | c <input type="checkbox"/> 2008 |
| d <input type="checkbox"/> 2007 | e <input type="checkbox"/> 2006 | f <input type="checkbox"/> 2005 or before |

This section is about how you and the person were supported during the person's hospital visit.

Please indicate the level to which you agree or disagree with each of the following positive statements. If you feel the statement is not applicable or if you can neither agree nor disagree then please leave that one blank and go on to the next statement.

	a.	b.	c.	d.
	Strongly agree	Agree	Disagree	Strongly disagree
2.1 My needs as a carer/supporter were appropriately catered for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.2 The admissions procedure was sympathetic towards the special needs of the person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.3 Nursing staff and other ward/clinic staff were fully aware of the person's special needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.4 Doctors/Consultants understood and were sympathetic towards the special needs arising from the person's disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.1 The person's views and preferences were sought and appropriately acted upon, in the persons best interest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.2 Treatment and care were delivered in an appropriate way (as defined in the person's 'hospital information document' where this exists)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.3 Where appropriate the person was consulted in a manner they could understand (possibly through you) before decisions were made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 3.4 I, as parent/supporter was fully consulted before decisions were taken
- 3.5 I was recognised as the expert carer, and listened to
- 3.6 Any agreed follow-up was acted upon in an appropriate and timely way

Overall opinion and additional comments

- 4.1 If I had a friend in a similar situation I would
 a Recommend the hospital b Suggest they tried a different hospital
- 4.2 Any other relevant comment in respect of this hospital visit/stay. Please include details of any good or bad experiences during the visit. Continue on a separate sheet if required.

About the person

- 5.1 The person is:
 a Male b Female
- 5.2 At the time of the visit the person's age was:
 a less than 19 b 19 to 60 c more than 60
- 5.3 The person's main learning disabilities and health issues are: (tick all applicable boxes)
- | | |
|--|---|
| a <input type="checkbox"/> Profound intellectual & multiple disabilities | b <input type="checkbox"/> Down's syndrome |
| c <input type="checkbox"/> Severe learning disabilities | d <input type="checkbox"/> Epilepsy |
| e <input type="checkbox"/> Moderate learning disabilities | f <input type="checkbox"/> Asperger's syndrome/Autism |
| g <input type="checkbox"/> Mild learning disabilities | h <input type="checkbox"/> Significant communication difficulties |
| i <input type="checkbox"/> Other (please specify below) | |

Other conditions (please specify)

- 5.4 The person's main method of communication is: (tick only those that are considered to be their main communication methods)
- | | |
|--|--|
| a <input type="checkbox"/> Normal speech | b <input type="checkbox"/> Communication aids |
| c <input type="checkbox"/> Limited recognisable words | d <input type="checkbox"/> Body language |
| e <input type="checkbox"/> Sounds | f <input type="checkbox"/> Hand or limb movement |
| g <input type="checkbox"/> Written words | h <input type="checkbox"/> Facial expressions |
| i <input type="checkbox"/> A signing system | j <input type="checkbox"/> Eye-pointing |
| k <input type="checkbox"/> Other method (please specify below) | |

- 5.5 Does the person have any sort of hospital information document which identifies such things as medication and any special needs?
 a yes b no

Details:

Thank you for your participation

The first two pages are duplicated so that you can comment on up to 2 other hospital visits/stays. You are limited to a total of three visits/stays so as to keep a balanced view in the analysis.

Appendix B

Hospital Satisfaction Survey (Parents/Carers)

by Report/Questionnaire/Section/Question/Answer

No Filter Set

Respondents Selected: 163

1. Where and When	Points	Response Count	Actual Score	% Score
1.1 In which hospital was the treatment received?				
Boston Pilgrim Hospital		43		
Gainsborough J. C Hospital		2		
Grantham & District Hospital		23		
Lincoln County Hospital		51		
Louth County Hospital		11		
Skegness & District Hospital		2		
Spalding Johnson Hospital				
Grimsby Hospitals		5		
Other (please specify below)		26		
1.2 The person visited hospital for treatment as an:				
outpatient (not staying in overnight)		76		
inpatient (staying in overnight, e.g. for surgery or observation)		58		
Accident & Emergency patient		28		
1.3 In which year was this treatment undertaken (if it involved a stay spanning two years select the latter year)				
2010		63		
2009		34		
2008		14		
2007		9		
2006		13		
2005 or before		26		
<hr/>				
2. This section is about how you and the person were supported during the person's hospital visit.				
2.1 My needs as a carer/supporter were appropriately catered for			399/628	63.54%
Strongly agree	4	47		
Agree	3	61		
Disagree	1	28		
Strongly disagree	0	21		
2.2 The admissions procedure was sympathetic towards the special needs of the person			399/588	67.86%
Strongly agree	4	49		
Agree	3	62		
Disagree	1	17		
Strongly disagree	0	19		
2.3 Nursing staff and other ward/clinic staff were fully aware of the person's special needs			377/600	62.83%
Strongly agree	4	45		
Agree	3	57		
Disagree	1	26		
Strongly disagree	0	22		
2.4 Doctors/Consultants understood and were sympathetic towards the special needs arising from the person's disabilities			414/620	66.77%
Strongly agree	4	59		
Agree	3	52		
Disagree	1	22		
Strongly disagree	0	22		

	Points	Response Count	Actual Score	% Score
3. How you and the person were supported (continued).			2385/3628	65.74%
3.1 The person's views and preferences were sought and appropriately acted upon, in the persons best interest			365/600	60.83%
Strongly agree	4	44		
Agree	3	53		
Disagree	1	30		
Strongly disagree	0	23		
3.2 Treatment and care were delivered in an appropriate way (as defined in the person's 'hospital information document' where this exists)			389/608	63.98%
Strongly agree	4	43		
Agree	3	64		
Disagree	1	25		
Strongly disagree	0	20		
3.3 Where appropriate the person was consulted in a manner they could understand (possibly through you) before decisions were made			419/624	67.15%
Strongly agree	4	50		
Agree	3	67		
Disagree	1	18		
Strongly disagree	0	21		
3.4 I, as parent/supporter was fully consulted before decisions were taken			431/612	70.42%
Strongly agree	4	52		
Agree	3	69		
Disagree	1	16		
Strongly disagree	0	16		
3.5 I was recognised as the expert carer, and listened to			411/616	66.72%
Strongly agree	4	53		
Agree	3	59		
Disagree	1	22		
Strongly disagree	0	20		
3.6 Any agreed follow-up was acted upon in an appropriate and timely way			370/568	65.14%
Strongly agree	4	44		
Agree	3	57		
Disagree	1	23		
Strongly disagree	0	18		
4. Overall opinion and additional comments				
4.1 If I had a friend in a similar situation I would			411/616	66.72%
Recommend the hospital		106		
Suggest they tried a different hospital		43		
4.2 Any other relevant comment in respect of this hospital visit/stay.			Reported in Appendix C	
5. About the person				
5.1 The person is:				
Male		83		
Female		78		
5.2 At the time of the visit the person's age was:				
less than 19		33		
19 to 60		121		
more than 60		7		

	Points	Response Count	Actual Score	% Score
5.3 The person's main learning disabilities and health issues are: (tick all applicable boxes)				
Profound intellectual & multiple disabilities			22	
Severe learning disabilities			62	
Moderate learning disabilities			42	
Mild learning disabilities			14	
Down's syndrome			35	
Epilepsy			41	
Asperger's syndrome/Autism			26	
Significant communication difficulties			34	
Other (please specify below)			50	
5.4 The person's main method of communication is: (tick only those that are considered to be their main communication methods)				
Normal speech			90	
Limited recognisable words			42	
Sounds			15	
Written words				
A signing system			14	
Communication aids			3	
Body language			33	
Hand or limb movement			13	
Facial expressions			27	
Eye-pointing			9	
Other method (please specify below)			6	
5.5 Does the person have any sort of hospital information document which identifies such things as medication and any special needs?				
yes			44	
no			110	

Boston Hospital**2010**

- [30] Couldn't get rid of my daughter fast enough. Very impatient with her and snappy. Doctor did not speak English well which made it impossible for my daughter to understand.
- [32] My son visits every 6 months to monitor his condition to review his medication.
- [71] If she had been treated quickly and properly, as in given the medication she was used to and needed and also sedated/ventilated sooner she may have been here today still!!!
- [72] I wouldn't want to be treated in that hospital again or any family or friend that I know.
- [73] The hospital doesn't cater for learning disabilities full stop.
- [84] He had hurt his foot which necessitated an x-ray. The radiologist was kind and considerate towards him. Waiting for the results was less efficient as I had to seek the doctor. No recommendations or treatment suggested - I suspect because they were unsure of how to deal with a non-fracture situation!
- [109] The patient stayed overnight in a side ward. I was not offered anywhere to sleep. I had to sleep in an armchair. I was given a sandwich and drink in the early hours of the morning, as I had nothing to eat for around 20 hours.
- [156] Despite warnings and a full telephone briefing re the reluctance of the patient, no account was taken of any likelihood of failure to perform procedure due to patient's aversion to it. Staffing consisted only of a locum doctor who had no knowledge of the patient either by consulting her notes or by awareness of our telephone briefing. There was a TOTAL lack of nursing staff available to support the locum.
- [157] The treatment was arranged and supervised by the Health Liaison Nurse who we consulted after the occasion indentified in (156). Her intervention, preparation and sympathetic understanding helped to complete a thoroughly distasteful procedure for our daughter.
N.B. Until our daughter (who is employed at a London hospital) informed us of the existence of Health Liaison Nurses, we were at our wits end.

2009

- [15] Some nurses were not very good with the person's handicap, but most nurses were very good.
- [47] Adult intensive care: Although young person was 18, child doses on medication (i.e. morphine) was a struggle, could have sought guidance from children's ward but didn't. Staff were good but didn't understand, weren't sensitive enough dealing with family, child/adult with complex needs & no communication. Children's ward: Staff nurses and nurses, very good. Have known child for several years. Happily haven't been in very often.
- [49] Insufficient Health Care Support Workers to provide adequate support.
- [65] When my son had to be admitted for an overnight stay from the A&E Dept. staff ensured that he would go to the same ward as his father (both injured in a car accident) and I stayed on the ward until my son had gone to sleep and was settled for the night.
- [75] Appalled at OPD treatment. Would not listen to me, not interested in the patient as I believe was because of having a learning disability. Rude at times. Did not explain procedures. Did not communicate with patient, therefore I went to GP and asked for a second opinion - we were referred to Lincoln County where it was 100% better.
- [91] If the ward could not manage my daughter she kept getting moved. There was no offer to sit with her so I could get something to eat. Staff did not come into the room, all her care and administration of medication was felt to me. It took a lot of requests to try and get her moved into a side room so her dignity was preserved. The domestic staff never came into her room to clean it or remove the dirty food pots and the bins were never emptied, so asked for a black bag to put rubbish in. I have lost all faith that the hospitals in Lincolnshire will ever treat my daughter with the respect she deserves so her care is now being managed by Addenbrooke's who treated her with respect and put her as a human being first.
- [93] Orthotics/Surgical support were brilliant and he listened to my daughter and explained in a way that she could understand.
- [128] The patient on admission to A&E was accompanied by his support worker and subsequently supported by parents. At all opportunities it was possible to explain to staff of the learning disability. Also the patient was able to do this for himself on occasions. I have a slight concern that if he had been admitted alone, and parents were not able to support him fully throughout the 8 day stay in hospital, how adequately would the extent of his learning disability been communicated to various individual members of staff in the hospital. Since the operation he has limited movement in his left arm.
- [131] On the whole I was very satisfied with the treatment my son received in I.C.U. and ward 7, but very dissatisfied with the physiotherapy department. My son spent 5 weeks unconscious in the I.C.U. When the Physios came to him to offer their support they let him fall on his backside and after that they refused to support him, saying he was being uncooperative - could you blame him? He spent 2.5 months in hospital with pneumonia and one lung collapsed completely and I believe he also had a stroke, although this was never confirmed. He left hospital on Christmas eve and from there went to residential care for a further 4 months until he regained mobility.

2008

- [147] My daughter broke her leg behind the knee very badly. The A&E Department were very good with her. The first ward that she was admitted to was good because it was a gyney ward and there were younger people that spoke to her and helped her as I was not allowed to stay. After her operation she was put in a ward with old ladies that were very difficult and noisy which made her frightened. She could not walk because the leg had to be elevated, so she

just sat in her chair in the corner. The buzzer for the nurse was always put out of reach so of course she had little accidents and they said she was incontinent and treated her that way instead of helping her now and then to the toilet. When it came to physiotherapy the woman in charge of her did not seem to have any patience with her. If she says she can't do something the woman just left it like that, she didn't even try to talk her into doing things or show her how to do it. My husband tried to help but the woman just refused help.

- [151] My son was knocked off his bike and air lifted to hospital. I was in Scotland at the time and travelled back the next day. He was still in his blood stained clothing and had slept in them all night despite my older son taking PJs and explaining he had learning difficulties. No one had told him to change or helped to bath or shower him. Very disappointed in hospital.

2007

- [20] As carer I was told to only visit at visiting hours, yet staff didn't attend to patient's personal care needs, left him in a mixed ward inappropriately dressed, sitting on toilet with door open. Some treatments/procedures not done because patient couldn't give D.O.B. when I wasn't in attendance.
- [37] My son had his gall bladder out and he had a big bleed during the operation which I was not told about. Someone that was in the theatre told my daughter about it. There was not enough staff on the ward, he was sick, I pressed the buzzer for some assistance, it took 20 mins for someone to come. The room was never cleaned. Medicine never on time and sometimes it just never came. When we went to outpatients for his check up we walked in and the doctor just said he was discharged. I asked him to check that he had healed OK and reluctantly he checked him and told me I had been told everything at the hospital but I did not know he had over 100 gallstones. He also got a very bad chest infection in hospital and instead of an overnight stay we were there for 6 days.

2006

- [95] In patient for tonsillectomy. The bathroom closest was not clean. It was difficult to get information on timings and routines. Some of the staff appeared rushed when dealing with us and my daughter panicked every time I left her for food or drink which was not provided.

2005 or before

- [6] Our son was admitted for an operation. I had contacted the hospital before admission and explained that he was autistic and his current obsession was with switches and that he would need to be away from any machines with switches. They placed us in a room with a child connected to a machine with switches. I could not stop my son darting towards the machine and touching the switches. Alarms went off, all hell broke loose and we were transferred to a single room! The staff showed no understanding of autism whatsoever.
- [18] We have also had good experience with pre-planned admissions but this night in A&E was appalling. My son was admitted after his first epileptic seizure. It was the middle of the night, we had a long stay in A&E while a bed was found. No one seemed to know that his challenging behaviour meant he could not be left alone (by then just in a pad as he had vomited on his cloths) so that I could go to the loo/get a drink. I was furious because I could hear two staff members chatting about their new house/mortgage/car. It Another comment from a surgeon, before eye surgery, explaining why he would only correct a squint in one eye because it would mean a second general anaesthetic, "every time you have a GA, you lose a few grey cells - and let's face it, your son needs as many as he can get!" I can laugh now --- or can I?!
- [45] Although my daughter, who has cerebral palsy, had suffered a broken arm we were kept waiting for 4 hours. At one stage I had to go find someone to let us know what was going on (leaving her on her own - very frightened). We were treated with suspicion over the bike ride accident which is OK if when the situation was explained we weren't questioned again. This was the first accident in 8 years! The visit should have been shorter, needs understood and better communication would have made things more acceptable.
- [69] As mother/carer I was left to deal with my son, as I stopped in hospital for the duration of stay. No help was offered. Had I not been there I wonder who would have bothered with my son's needs. I was not even offered a drink, although my services were fully utilised and I felt taken for granted.
- [82] First treatment was NHS - for dental work to be carried out as daughter refused to have work done - had a great fear of dentists. Second occasion was to have a wisdom tooth removed. As there was a 6 month waiting period for this to be done, we paid for my daughter to see a consultant at the Bostonian as she was in constant pain and was done almost immediately. Treatment and care, from consultant to staff, could not be faulted. This was a situation that should not have been. Not every parent can afford to go down the road of paying for private treatment.
- [146] My brother has had a few visits for procedures as an outpatient, mostly planned, once as an emergency. He has always been supported by myself and a member of the house staff (safety in numbers!), only problem is they seem to not always refer to his notes as he always needs a premed before cannulisation - which has in the past held things up and moved him to a later slot in the day. Also on one occasion a serious hand wound required surgery - hospital staff 'assumed' he would keep an ordinary dressing on..... I suggested a 'pot' would be needed. 3 hours later they agreed after watching him yank every scrap of dressing off and about to chew the wound... he got the 'pot'. Why has funding been withdrawn from Pilgrim Hospital for Dental treatment under General Anaesthetic? He now has to travel to Lincoln.

Undated

- [50] Stay overnight was on CDU and was a mixed ward (male/female)! Doctor had already seen person when I returned as I was not allowed opportunity to be present from early am.

Grantham Hospital

2010

- [70] My needs as a carer/supporter were not catered for because the Department we wanted was not adequately marked so it made it difficult to find.
- [76] He had been recommended by the dentist who had found a suspicious growth on his tongue. We were seen immediately by the hospital who found it to be harmless. We were seen quickly and efficiently. His learning difficulty was never a consideration, he was treated as any other patient.
- [140] Had we as carers not been at the hospital all the time we feel the staff didn't have the time or knowledge to care for him. A nursing role is much different than that of a carer. A couple of doctors told us we were lucky he had lived to the age of thirty and we think they thought we should let him go (but he thought differently) and we are still trying to resolve his problems.
- [159] Following a thorough examination by the ENT consultant it was recommended that a CT scan was needed to identify the possible cause of pain since it was not an ENT problem. He said that he would write to our GP asking him to make the required referral. He didn't; after some chasing he simply wrote to him saying he had been signed off the ENT clinic. We have since spent almost 6 months trying to get this referral made. Our GP says he can't make it; the ENT doctor won't, suggesting that our dentist might, it being a possible jaw problem; the dentist can't or won't. We were passed from pillar to post, until a chance conversation with a private osteopath practitioner identified a possible route through a TMJ specialist. Our GP could make that referral and we await the appointment with fingers crossed. It has however taken 6 months of chasing to get there; presumably anyone with less persistent parent/carers would not have got there.

2009

- [88] I was not consulted or understood. I did not understand what was being said to me.
- [98] The nurses and doctors were very patient and explained things to us and K.....

2005 or before

- [52] My son was treated very well by all departments. The only comment I got was from X-ray department was "He wants to know everything that was being done" OK.
- [63] I could not speak too highly of her treatment (gynaecological). An Indian lady (registrar) became her friend and we were very distressed to hear after her stay that she had passed away. Whenever we have visited Grantham Hospital the care has been excellent.
- [133] I found the nursing staff very helpful and considerate.

Grimsby Hospital

2010

- [116] Everyone treated my daughter with respect & kindness, but I felt that they didn't quite know what to do with her as she is so severely disabled. Everything they did, in my opinion, took far too long to implement and I do wonder if we had not taken her home - what the consequences would have been.

2009

- [77] The person is in residential care and her carers supported her by visiting daily, helping with feeding, washing, etc. Without such help, her stay in hospital would have given us, as parents, a great deal of concern. She was later admitted as an inpatient in Louth Hospital and these comments also apply to that hospital. The devotion shown by her carers cannot be praised too highly

2008

- [59] My daughter did not stay in hospital but over a period of almost 3 years was an outpatient visitor, who was suffering with severe headaches and in the end back pain when at times she could not walk. I felt the consultant doctors were fed up of us complaining about the same thing all the times we saw them, often insisting on head and back scans which they said were OK. She finally went blind - my daughter is hydrocephalus and pressure had built up so bad she went blind. They never referred her to a neurosurgeon which would have avoided her going blind, this is now a life sentence for her and me. Why do we have to shout out to be heard? Why don't they listen to us instead of treating us like idiots?
- [148] The person was admitted to hospital as an emergency as she had developed diabetes and needed immediate treatment. I was able to stay with her to help with interpreting her needs to the staff and vice versa. On the whole the staff were very patient as the person tends to panic at the mention of any treatment. I was allowed to stay at night (she was in hospital for 6 days) and I slept in a chair beside her bed as there were no facilities for persons sleeping the night to help with the patient. The staff were pleasant and understanding and joked with the person (luckily she has a good sense of humour!) to keep her spirits up. The treatment required the use of many needles which can be unpleasant, but the staff handled the situation very well, with positive results. She now has no fear of needles which helps enormously as she has insulin injections every day.

Lincoln Hospital

2010

- [5] The person with special needs attended Lincoln County Hospital for a bone density scan. We were kept waiting for a very short time before going through for the scan. The lady doing the scan calmed and reassured our son throughout the procedure while also explaining fully to me what was happening.
- [24] Special needs person would have been unable to understand nurses, doctors or procedures unless I had explained and been with him!! Had to ask if I could accompany him to see doctors, nurses etc and explain special needs and persons condition, e.g. special needs. Anyone unable to speak for themselves would have struggled. Person's special needs and condition should be on medical records clearly. On another occasion when person with special needs was offered counselling by local GP, counsellor hadn't been informed of special needs!!
- [46] The person's visit, was totally unexpected and therefore unprepared for, to A&E following a 1st seizure. The person was not safe to be left unattended and therefore I was required throughout once admitted, I was asked to leave at meal times (even though she could not feed herself) and she was upset and unsafe to be left. I tried to explain politely but in the end had to refuse to leave in a very firm manner. It was impossible for me to leave to visit the shop for food or drink and was refused a cup of tea by the ward staff. After a few complaints we were dealt with in a more efficient way and finally I was accepted as the person's carer and guardian. Throughout, not a pleasant experience. Information was hard to come by.
- [53] The patient was accused of being drunk as she was unable to communicate properly and had slurred speech. The medical staff did not want to speak to me on her behalf as they were suggesting that I had something to hide and had perhaps caused the injury to my sister (the person with learning difficulties). They twice took her away on her own to question her. Obviously she was terrified, already shaken by her injuries. During a so called sight test to check "all was well" the consultant/medical doctor held up words asking her to call them out - she would call out anything to try and read. To be told "no the word is wrong, try again, what is wrong with you?". I told them she had learning difficulties and couldn't read, but was told not to interfere, again I was trying to speak for her and I must have something to hide. He then proceeded to show her numbers which she could not read. Again seemingly to grunt disapproval at her attempts to say something - not the right thing. A nightmare of a visit. The only people sympathetic and helpful were the reception staff.
- [61] Department was not aware of LD and stopped the procedure because paperwork had not been processed as per health & safety! Power of Attorney came into the discussion that followed.! Lack of communication about LD and ability of understanding between departments. Outcome of this was that procedure was eventually cancelled altogether and discharged from the hospital but still had the same problems.
- [66] I supported a visually impaired gentleman with a learning disability. The support he was given was appalling. He was not consulted at all and the communication of staff team was appalling. We spent hours explaining how the gentleman needed supporting but this was not communicated between staff team and so the support he needed was not given. Also when we went to support him no-one could give us the appropriate information regarding decisions made. It took 4 weeks for it to be discovered that the gentleman had a fractured hip.
- [67] Came to bring a gentleman to orthopaedics clinic. The consultant that was seeing him for his fractured hip spoke to the gentleman I supported. He spoke appropriately to him and involved him in the conversation. I was pleased at how he interacted with him.
- [74] Brilliant care. One OPD appt. plus operation. All staff brilliant. Made patient feel at ease. Laughed and joked. All needs met. Well done Lincoln County.
- [79] My daughter had to wait over 10 months to finally get treated for her teeth. The hospital staff and dentist were very good. But we were sent for and waited for treatment only to be sent home after being up at 6am to be ready for transport and then a 1 hour drive to Lincoln only to be told that my daughters notes were not at the hospital because she had been to Pilgrim the day before and the notes had not arrived. My daughter was seen about 2 weeks later and the service at the hospital was fine, As a result my daughter lost over 2 stone in weight, she had three loose teeth and one tooth had an exposed nerve. She lost 6 teeth, no wonder she could not eat. This was all due to administration, going back and forth just because she is disabled and needs a general anaesthetic which she has to have to do anything what so ever. Also there are facilities to hoist her at a hospital for the toilet.
- [85] There was nothing in place regarding 1 to 1 nursing. My daughter needed someone with her 24 hours and I had to stay the 4 days she was in hospital due to nothing being in place for a patient with not only severe learning difficulties but physical as well. The staff were very supportive and tried very hard to help me in every way. Unfortunately there was a shortage in staff. The ward was full and none of the staff had had any training to deal with a situation like this. I will say once again the staff were brilliant.
- [87] The waiting period was too long. Patient was not able to understand what the doctors were saying.
- [102] Sadly I feel it was 2 weeks wasted time in hospital. I wrote a letter of complaint to Dr P..... which was acted upon appropriately.
- [141] Although a full support plan, and support staff available for nursing staff information, this was not acted upon. The supported person was de-skilled as a result of this situation, and was discharged from hospital with bedsores (which she did not have on admission), eating with her fingers (she had previously eaten with a knife and fork and had excellent table manners). She had been 'padded up' with incontinence pads when she was able to use the commode and as a result had not had the opportunity to mobilise, resulting in weakness and inability to walk safely. She was discharged still unwell and with no follow up plan to get to the bottom of her illness. It is as a result of care staff's insistence that the G.P. and other medical professionals support this lady (district nurse, etc) and the dedication of support staff that this lady made a full recovery (this took 6 months to achieve). I feel strongly that the hospital contributed to this lady's illness becoming worse and she came out of Lincoln County Hospital worse than

she went in.

- [158] This was a routine appointment for epilepsy in the neurology Department. The doctor is always helpful and understanding.
- [163] My son had a RTA and refused to go to hospital. He appeared OK but 5 weeks later he suffered with a knee injury. They x-rayed and thought he had broken his knee. My son doesn't deal with plaster casts very well and I tried to explain this to "deaf ears". They casted him from the top of his thigh to his ankle. 2 days later we were back at A&E for a replacement cast. They x-rayed again and discovered it was not broken just twisted and cartilage damage problem. The first doctor he saw was unsympathetic whilst the 2nd was very supportive and understanding

2009

- [11] The hospital would have to be informed first that you have a special needs person. I suggest the referring GP to let the hospital know beforehand and it would help if the Doctor you were seeing read the letter first.
- [41] Admitted for overnight observation via A&E. Hospital admission document totally ignored. Taken to X-ray without giving due attention to a specific danger warning in document. Ignored a specific request from us to bandage our daughters arm to a splint board to prevent her from pulling her cannula out. She did tear cannula out causing damage to her hand.
- [43] This response relates to the wheelchair service at Lincoln Hospital. The service was so poor we were forced to purchase a wheelchair privately in order to meet our daughter's specific requirements.
- [83] I could not fault the hospital for the treatment, I knew she needed some teeth extractions and a blood test and asked that while she was sedated for the removal of a cyst on his neck while they do the other two. They said "no problem" so it saved us another trip. The main problem I had was with the overnight stay. There was no reclining chair. We were in a men's day ward and despite there being a spare bed, I had to sleep across three chairs. I had to go home to get sleeping equipment and cloths for myself and and return to hospital.
- [113] The questionnaire was based on a 7 week stay in intensive care. Sadly, when moved into another ward, the level of care and attention was very greatly reduced and only got a visit from the nurse when medication was needed or he had a visit from the doctor. I was left to see to him when I was there for everything else. Also there was one nurse on ITU who thought that because he had special needs she didn't have to tell him what she was about to do because he wouldn't understand. Children's ward are not too bad but now he is 20 yrs old he is classed as an adult and they are not as sympathetic to his needs.
- [162] They did not understand why my son was fitting and passing out. The hand incident: He was seen originally at Grantham Hospital for a hand injury. He was released with no further action. 2 weeks later we were away at the time and apparently they had missed a broken bone. We were informed we had to go to the local hospital via A&E. We were at Burton visiting family. On sitting there for many hours and more prodding and poking, x-rays again, it was discovered there were no broken bones. We had to go to A&E at Lincoln on our return and again sit for hours waiting to be seen to be told there had been a mix up.

2006

- [106] Stayed overnight in A&E amongst drunks etc., very noisy and frightening for my son. I sat beside him all night, no help or even a cup of tea. Had to keep reminding staff to try to get my son something to eat as they kept moving us from ward to ward. In the end my husband had to bring us something to eat from home (Mablethorpe to Lincoln). No firm diagnosis of what happened to my son, lots of suggestions but nothing else. Was advised to take him home and look for any more symptoms. Never heard from them again!

2005 or before

- [28] 1. 1999: Aged 5 months. Meningitis Not allowed to leave room and no one cared for my child while I went to toilet or for drinks etc. (We were in an isolation room). Had to beg staff to have him while I did those things. He was there for two days! I am a qualified nurse. Told nurse I could care for him at home after I found it was not meningitis. Nurse stated "she says she is a qualified nurse." I qualified 1990! (as if she did not believe me) I am more than an expert carer.
2. 2002: Grommet operation. Left me to give premeds, put him straight next to a TV on full blast (relative was watching it) I told them about this, they were not interested, only in needs of relative who was NOT the patient.
- [51] He was admitted to hospital in December 1999 with double pneumonia and remained there for six weeks during which time we were told on three occasions he would not survive. Although he already had difficulty in swallowing and choked constantly on food. This was not acknowledged for at least a month except in depriving him of any food during this time. Eventually it was of necessity to insert a PEG appliance. Here again, as parents, we knew this operation would be impossible to achieve without a full anaesthetic (as in a normal person) but both staff and consultant refused to accept this - until they tried! The result was indeed a full anaesthetic, after my husband added his protest and help in theatre. He had lost 1.5 stones when he left hospital. Another great problem was the difficulty in finding veins for cannulas to be inserted. In the six weeks in hospital this had to be resited 14 times. His screams could be heard right down the corridor. His arms, in turn became infected as cannulas leaked into the tissues (I don't know what the answer to this could have been). Luckily my husband and I were able to stay at his bedside most of the time and we were also well supported by staff from his home. Otherwise I dread to think what might have become of him.
- [54] The carers had to take it in turns to stay at the hospital so that all needs were fulfilled otherwise probably the experience would have been diabolical as even food choices were left to the patient to make despite the fact that she couldn't read. No follow up treatment or physiotherapy were given despite everyone else recovering from the same op receiving 10 days physio in hospital.
- [90] Other patients on the ward were very supportive of needs

- [105] My son had cataracts removed from both eyes in one operation. The ward staff and especially the theatre staff were absolutely wonderful. My son has Downs Syndrome and autistic tendencies. We thought the anaesthetist was just leaning over him to talk to him, but he was secretly waving gas to his face and my son fell asleep smiling!! No injections or anything, marvellous!! Aftercare was equally good, being taken into the theatre to be with him when he awoke.

Undated

- [19] Day surgery - dental work under general anaesthetic. My son unable to tolerate/accept cannula for pre-anaesthetic. Anaesthetist refused to deal with him. Finally, after hours of unnecessary 'nil by mouth' it was revealed that he could use a liquid oral version. Out like a light.... Just not thinking 'outside the box'. Challenging behaviour just not understood.

Louth Hospital

2009

- [42] The selected visit was to the X-ray department. Previous visits for ultra sound and dentistry have been equally successful. Each visit has been made as stress free as it can be for us as parents and also for our daughter by the excellent support provided by all Louth Hospital staff. We particularly appreciate the willingness of staff to adapt their normal procedures to suit our daughter's particular needs.
- [78] Comments for [77] 'Grimsby Hospital' are also relevant to this visit.

2007

- [149] The person spent a day on the ward having dental treatment. She was given a general anaesthetic as she gets panicky when needing hospital treatment. She was allowed to walk down to the anti-room to the theatre and was frightened to lie down on the trolley so the staff sat her on a chair and gently put the anaesthetic mask on her face until she fell asleep and then transferred her to the trolley. I stayed with her until then. I was very touched by their kindness and patience. She looks back on the experience with no fear, and for that I am very grateful.

2005 or before

- [138] Staff training for dealing with a person/people with special needs could be improved upon. e.g. nurse saying "don't let him drink through a straw" when it is the only way the person will drink when away from home. Getting liquid into the person is more important than not drinking through a straw in this case.

Skegness Hospital

2010

- [40] As his dad, I would recommend Skegness Hospital. I took him to see the ENT specialist on Friday 22/10/2010. I was greeted with a warm smile from the receptionist, and kindly shown to the waiting room. We were treated like VIP people. He was very tense but the nurse tried to put him at ease and the appointment went along very smoothly. Thank you for all concerned, in helping to make our visit run so well.

2008

- [132] His eye appointment was cancelled several times

Question 5.3: The patients' main disabilities:

Appendix D

The following responses were recorded as *other* conditions

[15]	Asthma
[21]	DiGeorge Syndrome, Heart, Tetralogy of Fallot, Obsessive Compulsive Disorder
[24]	Dyspraxic condition; has difficulty sequencing; motor skills limited; doesn't understand letters or instructions fully. needs to be explained slowly and methodically.
[25]	Deaf/Blind
[30]	Movement disorder
[36]	ADHD
[38]	Mental health problems with anxiety and panic attacks. Doctor/Hospital phobic. Some physical ailments
[40]	Bed wetting. Has to be dressed each day, bathed each day, meals cut into manageable portions. Very agitated, won't stand still.
[45]	Cerebral Palsy
[46]	Alzheimer's
[47]	P.E.H.O syndrome: Life limiting genetic disorder.
[51]	Profoundly deaf
[59]	Hydrocephalus (water on the brain) has a shunt in her head.
[65]	Heart condition
[67]	Visual impairment
[68]	Dementia
[69]	Cannot sleep. All personal care to be done for him.
[70]	Retts syndrome
[79]	Rubinstein-Taybi Syndrome
[80]	Fragile X syndrome
[81]	Eisenmenger's syndrome
[85]	Also has hypotonia and chronic hip displacement.
[86]	Dystonic cerebral palsy. Quadriplegic.
[91]	She has a rare genetic condition life limiting Mucopolysaccharide Disease type 3A
[92]	Mucopolysaccharide disease type 3A
[103]	Hydrocephalus, Cerebral Palsy, Chronic Lung Disease, Nystagmus
[113]	ADHA, Autistic Spectrum Disorder, Sleep Apnea
[121]	Cerebral Palsy
[128]	Controlled asthma
[129]	Asthma
[132]	Cholesterol, Border line diabetes, Blood pressure
[137]	Undiagnosed neurological problems with no prognosis
[142]	Asthma and eczema
[148]	Diabetic (type 1)
[155]	Vaccine damaged
[162]	ADHA, Dyspraxia
